

Title	Communication partners' experiences of using augmentative and alternative communication with persons with severe/profound intellectual disability
Authors	Hanley, Edina
Publication date	2024
Original Citation	Hanley, E. 2024. Communication partners' experiences of using augmentative and alternative communication with persons with severe/profound intellectual disability. PhD Thesis, University College Cork.
Type of publication	Doctoral thesis
Rights	© 2024, Edina Hanley. - https://creativecommons.org/licenses/by-sa/4.0/
Download date	2026-11-01 12:11:50
Item downloaded from	https://hdl.handle.net/10468/16453

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork



**Communication Partners' Experiences of Using
Augmentative and Alternative Communication with
Persons with Severe/Profound Intellectual Disability**

Thesis presented by
Edina Hanley, BSc, RNID
ORCID ID: 0000-0001-7453-3668

for the degree of
Doctor of Philosophy

University College Cork
National University of Ireland, University College Cork
School of Nursing and Midwifery

Head of School: Prof. Patricia Leahy-Warren

Supervisor(s): Dr Elaine Lehane, Dr Anne-Marie Martin and
Dr Caroline Dalton

This PhD was supported by a studentship granted by the Catherine
McAuley School of Nursing and Midwifery, University College Cork

2024

Table of Contents

List of Tables	vi
List of Figures	vii
List of Appendices.....	viii
Glossary of Abbreviations.....	ix
Author's Declaration	x
Dedication	xi
Acknowledgements	xii
Abstract	xv
Introduction	1
Aim.....	2
Sequential Overview of the Thesis	4
Chapter 1. Background	6
1.1 Realising the Right to Communicate.....	6
1.1.1 Evolution of the Disability Policy and Legislation Landscape	9
1.1.2 International Strategies and Agendas	10
1.1.3 National Legislative Landscape	11
1.1.4 National Policy	13
1.2 Intellectual Disability	14
1.2.1 Definition and Prevalence of Intellectual Disability	15
1.2.2 Severe/Profound Intellectual Disability	18
1.3 Communication and Severe/Profound Intellectual Disability	19
1.4 Severe/Profound Intellectual Disability, Quality of Life and Communication.	22
1.5 Augmentative and Alternative Communication	25
1.6 Communication Partners' Engagement	28
1.6.1 Communication Partners and Augmentative and Alternative Communication.....	29
1.7 Conclusion.....	31
Chapter 2. Communication Partners' Experiences of Communicating with Adults with Severe/Profound Intellectual Disability through Augmentative and Alternative Communication: A Mixed Methods Systematic Review	33
2.1 Introduction	35
2.2 Methods	41
2.2.1 Protocol and Registration.....	41
2.2.2 Design	41
2.2.3 Search strategy	41
2.2.4 Study Selection	43

2.2.5	Data Extraction.....	46
2.2.6	Data Transformation	58
2.2.7	Data Synthesis.....	58
2.2.8	Research Integrity	58
2.3	Results	59
2.3.1	Background of Included Studies	59
2.3.2	Synthesis	60
2.3.3	Theme 2: Attitudes and AAC Use.....	62
2.3.4	Theme 3: Shared Commitment to Communication Partnership	64
2.3.5	Theme 4: Suitability of AAC	67
2.4	Discussion	69
2.4.1	Strengths and Limitations of the Review	74
2.5	Conclusion and Implications	75
Chapter 3. Communication Partners' Perceptions of their Roles and Responsibilities in the Design, Planning and Use of Augmentative and Alternative Communication with Persons with Severe or Profound Intellectual Disability: A Qualitative Descriptive Study		
3.1	Introduction	78
3.2	Methods	79
3.2.1	Study Design	79
3.2.2	Participant Recruitment.....	80
3.2.3	Data Collection.....	80
3.2.4	Data Analysis	81
3.2.5	Trustworthiness	82
3.3	Results	83
3.3.1	Sample Characteristics	83
3.3.2	Maximising Communication through AAC	87
3.3.3	Theme One: Developing a Communicative Environment.....	88
3.3.4	Theme Two: The Act of Communicating: Attempting to Realise the Individuals' Ability	96
3.3.5	Theme Three: Living with Uncertainty.....	98
3.4	Discussion	99
3.4.1	Strengths and Limitations	102
3.5	Conclusion and Implications	102
Chapter 4. Factors Influencing Communication Partners of Persons with Severe/Profound Intellectual Disability Use of Augmentative and Alternative Communication: An Integrative Review.....		
4.1	Introduction	109

4.2	Methods	112
4.2.1	Protocol and Registration	112
4.2.2	Design	113
4.2.3	Data Sources and Search Strategy.....	113
4.2.4	Study Selection	114
4.2.5	Quality Appraisal	116
4.2.6	Data Extraction.....	117
4.2.7	Data Synthesis.....	137
4.3	Results	137
4.3.1	Background of Included Studies	137
4.3.2	Theme 1: Achieving Meaningful Communication.....	139
4.3.3	Theme 2 Communication Partners' Preparedness.....	144
4.3.4	Conceptual and Theoretical Frameworks Identified	151
4.4	Discussion	153
4.4.1	Strengths and Limitations	157
4.5	Conclusion and Implications	158
Chapter 5. Examining the Intention of Communication Partners of Persons with Severe/Profound Intellectual Disability to Use Augmentative and Alternative Communication.....		160
5.1	Introduction	162
5.2	Theoretical Underpinnings and Hypothesis Development.....	164
5.2.1	The Theory of Planned Behaviour	164
5.2.2	The Technology Acceptance Model	166
5.2.3	The Combined Technology Acceptance Model and Theory of Planned Behaviour.....	167
5.3	Research Questions and Study Hypotheses.....	168
5.4	Methods	170
5.4.1	Study Design	170
5.4.2	Research Participants and Sampling	170
5.4.3	Measurement and Piloting.....	171
5.4.4	Data Collection Procedures.....	175
5.4.5	Ethical Considerations and Research Integrity	176
5.4.6	Data Analysis	177
5.5	Results	178
5.5.1	Participants.....	178
5.5.2	Statistical Analyses	181
5.6	Discussion	186
5.6.1	Strengths and Limitations	191

5.7	Conclusion and Implications	192
Chapter 6.	Discussion	195
6.1	Communication Partners' Shared Goal	195
6.2	Factors that Enable the Realisation of the Shared Goal	197
6.2.1	Implementing an Individualised Approach to AAC Strategies and Associated Goals.....	197
6.3	Strengthening Communication Partners' Ability to Use AAC	199
6.4	Strengths and Limitations.....	202
6.4.1	Strengths.....	202
6.4.2	Limitations	203
6.5	Recommendations	204
6.5.1	For Practice	204
6.5.2	For Policy	204
6.5.3	For Education	205
6.5.4	For Research.....	206
6.6	Conclusion.....	207
References		210

List of Tables

Table 1.1 ICD-11 Definition of Severe and Profound Intellectual Disability.....	16
Table 2.1 Inclusion and Exclusion Criteria	44
Table 2.2 Summary of Data Extraction.....	47
Table 3.1 Example of Analysis.....	82
Table 3.2 Summary of Sub-Categories, Categories and Themes.....	85
Table 4.1 Inclusion and Exclusion Criteria	115
Table 4.2 Data Extraction of 15 Studies.....	118
Table 4.3 Descriptive and Analytical Themes.....	139
Table 5.1 Eligibility Criteria	170
Table 5.2 C-TAM-TPB Constructs and Corresponding Measurement Items	173
Table 5.3 Demographic and AAC Usage Information of the Participants (n=152) .	180
Table 5.4 Correlation between Scores of Constructs	183
Table 5.5 Results of the Regression Model.....	186

List of Figures

Figure 1. 1 A Visual Representation of the Overall Methodological Approach.....	xix
Figure 2.1 PRISMA Flow Diagram.....	45
Figure 3.1 Visual Representation of the Themes and Sub-themes.....	84
Figure 4.1 PRISMA Flow Diagram	116
Figure 5.1 The TPB.....	166
Figure 5.2 The TAM.....	167
Figure 5.3 The C-TAM-TPB	168

List of Appendices

Appendix 1 PhD Achievements	255
Appendix 2 Communication partners' experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review	258
Appendix 3 Communication partners' experience of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review protocol.....	289
Appendix 4 PRISMA Reporting Guidelines for the MMSR	294
Appendix 5 Search Strategy for the MMSR	297
Appendix 6 Quality Appraisal using the MMAT	298
Appendix 7 Analytical and Descriptive Themes in the MMSR.....	306
Appendix 8 Ethical Approval from the Social Research Ethics Committee 1.....	307
Appendix 9 Ethical Approval from the Service Provider	308
Appendix 10 Standards for Reporting Qualitative Research Checklist	309
Appendix 11 Information Sheet 1	313
Appendix 12 Consent Form 1	316
Appendix 13 Interview Schedule	317
Appendix 14 Debrief Form	318
Appendix 15 Sample Coding Sheet	319
Appendix 16 Sample Critical Reflection	320
Appendix 17 Sample Memo	322
Appendix 18 PRISMA Reporting Guidelines for the Integrative Review	326
Appendix 19 Integrative Review Protocol	329
Appendix 20 PICo Framework	337
Appendix 21 Database Search: Academic Search Complete undertaken in August 2022 and May2023.....	338
Appendix 22 Theoretical Development	340
Appendix 23 Unpacking the Constructs of the C-TAM-TPB.....	345
Appendix 24 Ethical Approval from the Social Research Ethics Committee 2.....	348
Appendix 25 Sample Size Calculation.....	349
Appendix 26 Approval to Use the C-TAM-TPB Instrument from the Author.....	350
Appendix 27 Approval to Use the C-TAM-TPB Instrument from the Journal.....	351
Appendix 28 Invitation Flyer Posted to Social Media	352
Appendix 29 Information Sheet 2	354
Appendix 30 Screening Items	357
Appendix 31 Consent Form 2	358
Appendix 32 Thank You Message Displayed to Participants on Completion of the Survey	359

Glossary of Abbreviations

AAC Augmentative and Alternative Communication
AAIDD American Association on Intellectual and Developmental Disabilities
APA American Psychiatric Association
ASHA American Speech Language Hearing Association
ATT Attitude
BI Behavioural Intention
BLN Blended Learning Network
CNS Clinical Nurse Specialist
C-TAM-TPB Combined Technology Acceptance Model and Theory of Planned Behaviour
DSM Diagnostic and Statistical Manual of Mental Disorders
EBP Evidence Based Practice
EU European Union
ERIC Education Resource Information Centre
HCA Healthcare Assistant
HSE Health Service Executive
ICD International Classification of Disease
ICF International Classification of Functioning, Disability and Health
JB Joanna Briggs Institute
KWS Key Word Signing
MMAT Mixed Methods Appraisal Tool
MMSR Mixed Methods Systematic Review
MMST Multisensory Story Telling
NIDD National Intellectual Disability Database
PBC Perceived Behavioural Control
PECS Picture Exchange Communication System
PEU Perceived Ease of Use
PICo Population, Interest, Context
PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines
PU Perceived Usefulness
QoL Quality of Life
RAA Reasoned Action Approach
SGD Speech Generating Device
SLT Speech and Language Therapist
SN Subjective Norm
SRQR Standards for Reporting Qualitative Research
TAM Technology Acceptance Model
TPB Theory of Planned Behaviour
TRA Theory of Reasoned Action
UN United Nations
UNCRPD United Nations Convention on the Rights of Persons with Disabilities
UTAUT Unified Theory of Acceptance and Use of Technology
VOCA Voice Output Communication Aids
WHO World Health Organisation

Author's Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism and intellectual property.

Name: Edina Hanley

Student ID: 114437122

Signature: Edina Hanley

Date: 30/01/2024

Dedication

To Mam and Dad. Thank you for always encouraging me to follow my dreams. Your advice has always been to find and follow a path that I was passionate about, and to always do my best in whatever path I take whilst believing in myself on the way. This dedication is for you, your unconditional love, support and moments of fun and laughter guided me through my journey. This thesis would not have been possible without you.

Acknowledgements

I feel extremely grateful to have so many people to thank for their time, support, guidance and encouragement throughout my time undertaking this research.

My supervisory team, Dr. Elaine Lehane, Dr. Anne-Marie Martin and Dr. Caroline Dalton, whose commitment to excellence in both research and practice, expertise, unwavering support, and reassurance made this PhD possible. Dr. Elaine Lehane, thank you for sharing your expertise in research. Your questions and discussions enabled me to develop my critical thinking at each stage of the research, which helped me to acquire the necessary skills to engage in quantitative research. Thank you for your flexibility at the times it was needed. For the teams calls following an email I sent where you recognised the questions I needed to discuss. As lead supervisor, Dr. Lehane ensured the diverse expertise of each supervisor was heard, valued and respected, cultivating a team approach. From the outset you encouraged me to disseminate my work through peer review publication and conference papers. Dr. Lehane has been so open to discussions on the topic, your keen interest added to the team's expertise. Dr. Anne-Marie Martin and Dr. Caroline Dalton, your commitment to the field of intellectual disability research and practice shone through during my undergraduate journey and inevitable had a large impact on me. Dr. Anne-Marie Martin, this journey began in 2018, during our discussions about areas of practice that I felt passionate about and wanted to delve into deeper. Thank you for igniting that curiosity and spark in me and making this journey a reality. Your expertise in this topic area and clear passion for advancing the research and support for persons with severe/profound intellectual disability enabled me to continuously develop my thinking and apply it to my research. Dr. Martin

encouraged me to network with other researchers in this field, and I joined the International Association of the Scientific Study for People with Intellectual and Developmental Disability, providing me with a network of international researchers in the field. Dr. Caroline Dalton, thank you for sharing your wealth of knowledge and expertise in both intellectual disability and research. Your reminders to look at the work I had done and acknowledge the progress made were welcome and always helped me to persevere. Thank you for your guidance and listening ear when I was making the decision to transfer from a MSc by Research track to a full time PhD. To my supervisory team, thank you for your complete professionalism and your kindness throughout my journey as a PhD student. Your positive approach to discussions, feedback and questions led to me develop my thoughts, knowledge, confidence, and competence as a researcher.

Prof. Eileen Savage, Head of the School at the time I applied for a MSc by Research in 2019, thank you for interviewing me for that role, for your insightful questions and supporting me in undertaking a MSc by research. Prof. Josephine Hegarty, Head of the School at the time that I transferred from a MSc by Research to a full time PhD, thank you for supporting this transition and making it possible. Prof. Patricia Leahy Warren, your recommendation to transfer from the MSc by Research to a PhD track in 2021 made this PhD a possibility, thank you. This provided me with the opportunity to develop my research. Thank you for your support in your role as Head of the School at present. I would also like to thank the Catherine McAuley School of Nursing and Midwifery at University College Cork for funding this PhD.

To my parents, Eileen and Christopher, I could not have done this PhD without you.

To my partner Pierce, thank you for encouraging and supporting me in my decision to pursue this path during our many changing plans. And for continuously supporting me.

To my dear friend Gemma, thank you for your support and words of encouragement.

Most importantly, thank you to the Service Provider, gatekeeper and participants in this study. This research would not exist without you, I am forever grateful for your time and openness.

Abstract

Aim To obtain an in-depth understanding of communication partners' experiences of communicating with people with severe/profound intellectual disability through augmentative and alternative communication (AAC).

Background Individuals with severe/profound intellectual disability experience significant communication challenges. They require additional support to ensure their potential is recognised and realised and communication needs are met. AAC offers people with complex communication needs, including those with severe/profound intellectual disability, more opportunities, and ways to communicate. The success of AAC relies upon the individual and their communication partners using AAC. However, communication with people with severe/profound intellectual disability through AAC is not straightforward. Many challenges can arise and become barriers to optimising AAC interventions. Given their fundamental role in interacting with and supporting individuals with severe/profound intellectual disability to communicate, understanding communication partners' experience is essential to promote effective and efficient use of AAC. Therefore, this study explores communication partners' experiences of using AAC with persons with severe/profound intellectual disability to contribute to knowledge, evidence and to inform practice in this area.

Method A multimethod approach was adopted, where various research methods were used to answer associated research questions at each stage of the research, to address the overall aim (Anguero et al., 2018). A mixed methods systematic review (MMSR) explored communication partners' experiences of communicating with adults with severe/profound intellectual disability through

AAC. A qualitative descriptive approach was utilised to address the gap identified in the MMSR and explored communication partners' perceptions of their roles and responsibilities in the design, planning and use of AAC with persons with severe/profound intellectual disability. The findings of the qualitative descriptive study indicated that multiple factors influenced communication partners' use of AAC and identified the need for an integrative review. The integrative review aimed to identify and understand the factors affecting communication partners' use of AAC. The findings from the qualitative descriptive study and integrative review indicated that the factors influencing use of AAC were interconnected. However, the nature and extent of their interconnections remained unclear. Therefore, a cross-sectional, descriptive, correlational study was developed and undertaken to gain a more nuanced understanding of the factors influencing the intention of communication partners to use AAC with this population. The study was underpinned by a theoretical framework; the Combined Technology Acceptance Model and Theory of Planned Behaviour (C-TAM-TPB), which brought the factors influencing the use of AAC together to test specific hypotheses related to the interconnections between these factors. Survey methods were used to collect data, the survey items tested the constructs of the C-TAM-TPB.

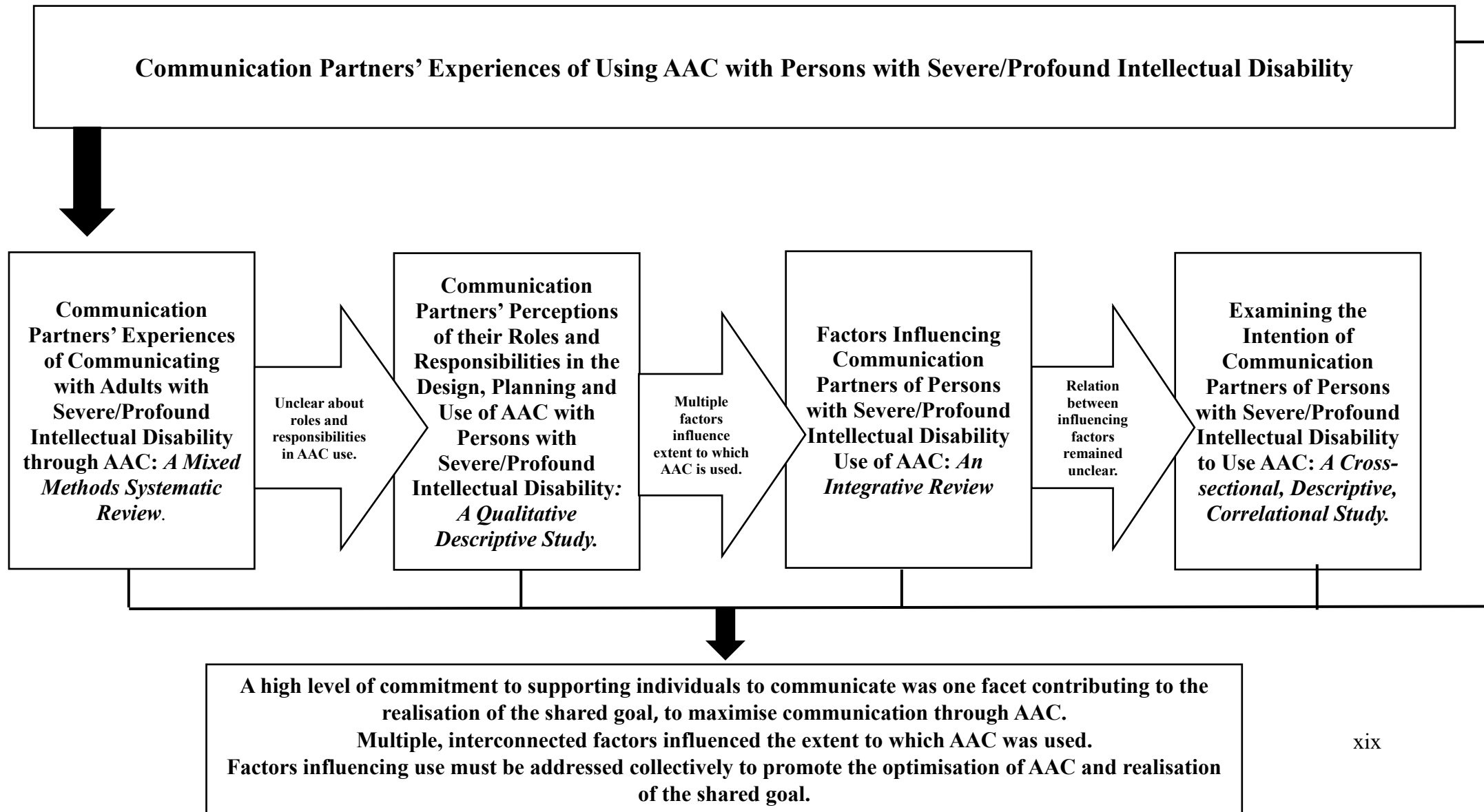
Findings The results of the MMSR and the qualitative descriptive study highlighted the importance of a shared commitment to the communication partnership to support the use of AAC. However, the results of the MMSR indicated that there was a disconnect between communication partners' perceptions of their roles and responsibilities in the design, planning and use of

AAC, which posed as a barrier to effective and efficient use. Participants in the qualitative descriptive study took ownership of their roles and responsibilities and respected the roles and responsibilities of other communication partners of the individual they supported. They established a reciprocal relationship to work together and share their expertise to achieve a shared goal, maximise communication through AAC. Despite such commitment, AAC was not optimised to maximise the ability of the individual to communicate. Multiple factors influenced the extent to which AAC was used. Some factors were recurring in each stage of the research and appeared to be interconnected. The integrative review established potential interconnections between the factors influencing the use of AAC, adding to the complexity of factors influencing the optimisation of AAC. The quantitative study identified the nature and extent of the interconnections between the factors influencing communication partners' intention to use AAC. The findings confirmed those of the literature, where positive relationships existed between the constructs of the C-TAM-TPB. Moreover, some factors carried greater influence than others. Perceived usefulness (p value=0.000 and β =0.253, Wald's Chi-square χ^2 =27.5) and perceived ease of use both had a significant impact (p =0.007, β =0.145, Wald's χ^2 =7.2) on attitude towards using AAC. Attitude (p value=0.000 and β =0.528, Wald's χ^2 =20.8) and perceived behavioural control (p value=0.000 and β =0.332, Wald's χ^2 =16.8) had a significant impact on behavioural intention.

Conclusion The study findings indicate that communication partners were committed to communicating with the individual they supported. This commitment was evidenced through attempts to realise their shared goal, maximising communication. Their commitment fuelled their perseverance.

However, AAC was not always optimised, and communication partners attempted to reach and realise their shared goal in the context of uncertainty. The extent to which AAC was used by communication partners was impacted by multiple, interconnected factors that must be considered collectively. Factors were both internal to communication partners, such as attitudes and beliefs, while others were environmental. They experienced competing demands that posed as an impediment to their use of AAC.

Figure 1. 1 A Visual Representation of the Overall Methodological Approach



Introduction

Communication is a human need and right (Brady, 2016; United Nations; UN, 1948; UN, 2006). Communication allows people to engage with one another, express their wants and feelings, and thus, supports self-determination and enhances quality of life (QoL) (Goldbart, 2023).

Goldbart (2023) states that the definition of communication is an important consideration when interacting with persons with severe/profound intellectual disability to ensure they are included. Their communicative behaviours tend to be subtle and idiosyncratic (Grove et al., 1999) adding to the complexity of interactions. Although significant challenges in communicating are experienced, individuals with severe/profound intellectual disability can and do communicate. They require extensive support to ensure their potential is recognised, opportunities for communication are optimised and their communication needs are supported.

Communication partners have a fundamental role supporting individuals with severe/profound intellectual disability to communicate. Moreover, familiar, willing and skilled (Hostyn & Maes, 2009; Wilder et al., 2015) communication partners are fundamental to ensure their subtle communication attempts are recognised, received and understood. Interpreting these subtle communication signals can be challenging and requires extensive time and effort.

AAC is a recognised means of supporting communication with persons with severe/profound intellectual disability and complex communication needs (Beukelman & Light, 2020). It can increase opportunities for communication and subsequently, social participation (Beukelman & Light, 2020). It may help individuals to realise their right to communicate. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; UN, 2006) advocates for the

acceptance and use of AAC. However, people with severe/profound intellectual disability continue to have unmet communication support needs (Brady et al., 2016), with AAC not being used, not being used optimally, and/or abandoned (Bircanin et al., 2019; Chung et al., 2012; Johnson et al., 2006).

Multiple factors may contribute to this, for example, communication partners' knowledge (Beukelman et al., 2008; Moorcroft et al., 2019), attitudes regarding the ability of individuals with complex communication needs to learn to use AAC (Sigafoos, et al., 2021), time (Koski et al., 2010), access to professionals with AAC expertise (Sutherland et al., 2014) and collaboration between those supporting the individual (Binger et al., 2012; Lund & Light, 2007; Uthoff et al., 2021). In addition, it can be challenging to provide effective AAC interventions due to the combination of intellectual, sensory, physical and health impairments that they can experience (Sigafoos et al., 2021).

Communication is central to our lives, well-being and QoL. Indeed, it is something often taken for granted by each of us. The catalyst for this research was to improve the effective and efficient use of AAC with persons with severe/profound intellectual disability by obtaining an in-depth understanding of their communication partners' experience of using AAC with them. Without communication partners' involvement, engagement, and commitment an individual's opportunity to use AAC may be limited.

Aim

The overall aim of this research is to gain a more nuanced understanding of communication partners' experiences of using AAC to communicate with persons with severe/profound intellectual disability. Communication partners may find it challenging to recognise and understand individuals with severe/profound

intellectual disability communication attempts. AAC may offer additional opportunities to interact. The overall goal of AAC is '*to enable individuals to efficiently and effectively engage in a variety of interactions and participate in activities of their choice*' (Beukelman et al., 2012, p.8). It has the potential to support individuals to communicate and interact. However, the involvement of both the individual who uses AAC to communicate and their communication partners are pivotal for the success of AAC. Communication partners are foundational to providing opportunities for individuals to communicate using AAC. Therefore, understanding communication partners' experiences may aid in designing implementation plans and promote the use of AAC with persons with severe/profound intellectual disability. It may, as a consequence of improved implementation and use of AAC, contribute to improving individuals' QoL.

Sequential Overview of the Thesis

To note: Chapter 2 is published as a peer review paper; Chapter 4 has been accepted for publication in a peer-reviewed journal, and Chapter 3 and Chapter 5 are being prepared for submission in peer-reviewed journals. PhD achievements can be found in Appendix 1 and outline detailed dissemination of the research thus far.

The thesis chapters are as follows:

Chapter 1 offers a contextual background to this study. An overview of international and national policy and legislation that set out the right to communicate is provided. This is followed by an overview of intellectual disability, with a particular emphasis on communication with individuals with severe/profound intellectual disability. The intersection between communication and QoL is discussed, followed by an overview of appropriate communicative supports including the role of AAC in realising the right to communicate. Finally, the fundamental roles of communication partners in supporting AAC success is discussed.

Chapter 2 details a mixed method systematic review of the empirical literature aimed at exploring communication partners' experiences of communicating with adults with severe/profound intellectual disability through AAC.¹

Chapter 3 presents a qualitative descriptive study which explored communication partners' perceptions of their roles and responsibilities in the design, planning and use of AAC with persons with severe/profound intellectual disability.²

¹ Hanley, E., Martin, M., Dalton, C. & Lehane, E. (2022). Communication partners' experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review. *Journal of Intellectual Disabilities*. Advance Online Publication. <https://doi.org/10.1177/17446295221115914> The paper can be found in Appendix 2

² Hanley, E., Dalton, C., Lehane, E. & Martin, AMM. (2023a). Communication partners' perceptions of their roles and responsibilities in the design, planning and use of AAC with persons with severe or profound intellectual disability: A qualitative descriptive study. Manuscript in preparation for publication.

Chapter 4 sets forth an integrative review of the empirical literature examining the factors influencing communication partners' use of AAC with this population, the intersection between these factors and theoretical and conceptual frameworks that have guided research focused on the factors influencing communication partners' use of AAC.³ An overview of potential theoretical frameworks to use as a lens to examine the factors influencing communication partners' intention to use AAC is also provided in Chapter 4.

Chapter 5 presents a cross-sectional, descriptive, correlational study using survey methods to examine the factors influencing the intention of communication partners to use AAC with persons with severe/profound intellectual disability using the C-TAM-TPB.⁴

Chapter 6 discusses the key findings from this thesis, strengths and limitations, and recommendations for future research, practice and policy followed by final concluding thoughts.

³ Hanley, E., Lehan, E., Martin, AMM. & Dalton, C. (2023b). Factors influencing communication partners of persons with severe/profound intellectual disability use of augmentative and alternative communication: An integrative review. Manuscript accepted for publication.

⁴ A manuscript titled: "Examining the factors that influence the intention of communication partners of persons with severe/profound intellectual disability to use augmentative and alternative communication using the combined technology acceptance model and theory of planned behaviour" is currently in preparation for submission.

Chapter 1. Background

Chapter 1 begins with an overview of the right to communicate, intellectual disability, and more specifically, communication and severe/profound intellectual disability. The importance of supporting communication to improve one's QoL and cognisance of a rights-based agenda, is outlined. Finally, an overview of the potential of AAC to support individuals with severe/profound intellectual disability to communicate and the fundamental role of their communication partners is provided.

Communication is a fundamental human need and right (Sen, 2015; UN, 2006). It is central to one's ability to develop and maintain relationships, influence one's environment and participate in society (Elmqvist et al., 2023). Relationships (Cummins, 2018; Nieuwenhuijse et al., 2023a) and the ability to influence the environment were proposed to be two important aspects of QoL for individuals with profound intellectual and multiple disabilities (Nieuwenhuijse et al., 2022; Nieuwenhuijse et al., 2023a). Additionally, interactions are fundamental in achieving QoL domains (Mansell & Beadle-Brown, 2012).

Individuals with severe/profound intellectual disability experience significant communication challenges that limit all aspects of life, including one's ability to relate to and interact with others, understand, achieve and maintain good physical and mental health (International Communication Project, 2014). They require additional and extensive support to ensure their potential is recognised and right to communicate is realised.

1.1 Realising the Right to Communicate

The right to communicate is advocated for in both international and national strategies and legislation. Article 19 of the Universal Declaration of Human Rights (UN, 1948) states that: *“Everyone has the right to freedom of opinion and*

expression; this right includes freedom to hold opinions without inference and to seek, receive and impart information and ideas through any media and regardless of frontiers”.

Many other human rights depend on the realisation of the right to communicate (Lundy, 2007; McCormack et al., 2018). Lundy (2007) described the significance of realising the right to communicate ‘...since, when it is implemented effectively, other rights fall into place naturally’ (p.940). The implications of this for individuals with severe/profound intellectual disability are significant in the context of their complex communication needs and is recognised by the UNCRPD (UN, 2006).

The UNCRPD provides the framework to promote, protect and ensure equal rights of all people with disabilities. The UNCRPD applies principles from the UN Declaration on Human Rights (1948) to the circumstances of persons with disabilities (National Disability Authority; NDA, 2022). The UNCRPD (Article 12) grants people with disabilities legal capacity and recognition as people before the law (Carey et al., 2023; Lundy, 2007). In the context of the right to communicate, Article 21 states that: *“Persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice”.*

Article 21 refers to all forms of communication as per Article 2, which states that communication includes languages, display of text, Braille, large print, tactile communication, accessible multimedia, written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication,

including accessible information and communication technology (UN, 2006; NDA, 2022). Article 26 highlights the right to assistive devices and technologies designed for individuals with disabilities as they relate to habilitation and rehabilitation (UN, 2006). Article 9 of the UNCRPD states that:

To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

The UNCRPD considers the environment, supports and the individual's needs (Verdugo et al., 2012). It was adopted on 13 December 2006 and opened for signature on 30 March 2007. The Irish Government signed the Convention on the 30 March 2007 and on 20 March 2018 the Convention was ratified. Once ratified, member states commit to immediately realising these rights (NDA, 2022). However, Ireland is one of three European Union (EU) member states who have not ratified the Optional Protocol. The Optional Protocol provides strategies to strengthen the implementation and monitoring of the UNCRPD. Consequently, individuals with disability in Ireland cannot take a complaint to the UN Committee if they feel that their rights have not been met. Therefore, their capacity to take action in situations where their rights are not fulfilled is restricted.

All human rights apply to all humans. However, additional support is required to ensure that these rights are realised for those with disabilities (Flynn, 2009). Everyone has the responsibility to search for, listen and pursue the voices of those who are at risk of not being heard (McCormack et al., 2018). In addition, everyone has the right to be provided with a means to communicate that is suitable to

their individual needs. The UNCRPD was the catalyst for international and national reform in disability policy and legislation, to ensure individuals' rights are protected, promoted and realised. All other national and organisational policy is judged against the standard of the articles within the UNCRPD (Brown, 2020). The following section offers an overview of the rights-based agenda on an international and national level, discussing the reforms to date whilst considering the fulfilment of this agenda through policy and legislation.

1.1.1 Evolution of the Disability Policy and Legislation Landscape

The philosophy underpinning disability policy and legislation has evolved from segregation to inclusion. The development of international conventions and guiding policy represents the change in societal views towards people with intellectual disability (Verdugo et al., 2012). This paradigm shift is evident in the move from a medical model of disability to a social model (Flynn, 2009; NDA, 2020). The medical model and associated definition of disability assumed that a disability was a personal, medical issue requiring medical treatment (Barnes & Mercer, 2010). Conversely, the social model recognises the societal barriers posed (Flynn, 2009), viewing disability as a source of oppression (Barnes & Mercer, 2010). More work is required to ensure people with severe/profound intellectual disability live their lives equally (Carey et al., 2023) as people with intellectual disability are more likely to experience denial of their fundamental rights (Garcia Iriarte et al., 2016). The rights-based model respects each person's right to decide how they wish to live their lives. The disability policy and legislation landscape has been shaped by the rights-based approach and agenda internationally and nationally.

1.1.2 International Strategies and Agendas

The rights of persons with intellectual disability to lead lives equal to others and of their choosing is recognised in international and national strategies. They strive to improve health and well-being, participation and inclusion and address barriers that impact on the lives of individuals with intellectual disability. They are underpinned by principles of respect, inclusion, autonomy, QoL and person-centredness.

Internationally, the UNCRPD is a driving force to ensure the realisation of individuals with disabilities' fundamental human rights (Brown, 2020). A number of key initiatives were developed to support the implementation of the UNCRPD. The UN Disability Inclusion Strategy (2019) calls for active disability inclusion to be brought to the forefront of all pillars of the UN's work (UN, 2019; World Health Organisation; WHO, 2023a). The strategy includes a policy and accountability framework to ensure a commitment to implementation. In the context of communication and inclusion, indicator 6 of the strategy relates to accessibility, calling for accessible information and communication technologies and systems (UN, 2019).

The European Commission Strategy for the Rights of Persons with Disabilities 2021-2030 promotes social participation and community inclusion. It builds on the 2010-2020 European Disability Strategy (Friscic, 2021). Progress was made between 2010-2020, however individuals with disabilities continue to experience substantial barriers accessing healthcare, employment, education, leisure activities and participation in political life (Friscic, 2021). The 2021-2030 strategy can be achieved with a strong commitment from member states to meet the actions of the Commission (Friscic, 2021). It considers the UNCRPD and the UN agenda for sustainable development (UN, 2015) whilst contributing to the implementation of the

European Pillar of Social Rights (Friscic, 2021). Principle 17 of the European Pillar of Social Rights relates specifically to the inclusion of people with disability.

The UN Agenda for Sustainable Development strives to achieve a sustainable and improved future for all by addressing challenges faced, such as inequality and justice (UN, 2015). It includes 17 interconnected goals, each with their own set of targets. It is important that researchers align their work with the goals and/or targets. This research topic aligns with the second target of the tenth sustainable development goal: *“By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status.”*

The international landscape informs national plans. National legislation and policy were developed and/or changed to meet the actions set out by the international strategies. These changes and developments are discussed below, with a focus on the right to communicate.

1.1.3 National Legislative Landscape

The UNCRPD was a catalyst for change. National legislation has been introduced to ensure individuals' human rights are placed into law. One such evolution was the change from a medical to social model of disability. The move from the medical to social model of disability was marked in Ireland by the 1996 Report on the Status of People with Disabilities- A Strategy for Equality (NDA, 2020). The strategy made recommendations to overcome barriers to equality, with two being the establishment of the NDA and specific disability legislation (NDA, 2020). The NDA is the independent statutory body that provides information about disability policy and practice to the Government in Ireland. The NDA's work is guided by the UNCRPD (NDA, 2023). The establishment of the NDA reflects a

commitment to the rights-based movement (NDA, 2020), to enable individuals with disability to exercise choice and control and promote inclusion.

A number of legislative reforms were evident in Ireland (Flynn, 2009) in response to the UNCRPD. Such reforms included The Disability Act, 2005 (Flynn, 2009; Murphy & Bantry White, 2021). The Disability Act (2005) states that communication must be accessible with part three, section 28 stating that: “*as far as practicable, the contents of the communication are communicated in a form that is accessible to the person concerned*”.

The Assisted Decision-Making (Capacity) Act, 2015 is also relevant in terms of communication and intellectual disability. The Assisted Decision-Making (Capacity) Act 2015 reformed the capacity legislation in Ireland and replaced The Lunacy Act 1871. The purpose of this legislation is to support and maximise people’s capacity to make decisions (Health Service Executive; HSE, 2015) by ensuring people have the necessary legal and healthcare structures in place to do so (Kelly, 2017). The guiding principles include the presumption of capacity, provision of support to make decisions and respect of each person’s will and preferences (HSE, 2015; Kelly, 2017). It assists in complying with the human rights obligations in the Irish Constitution, the European Commission of Human Rights and the UNCRPD (HSE, 2015). A common theme across disability legislation is the need to support individuals to choose how they wish to live their lives. National legislation is in place to ensure that individuals have access to information in a format they understand, to ensure they can make informed decisions and receive support when required to ensure their voices are heard. This cannot be achieved through legislation alone (Flynn, 2009). The contribution of policy in making these rights a reality is outlined below.

1.1.4 National Policy

Several national policies have been developed to assist in meeting the obligations and implementing the actions to have a meaningful impact on individuals' lives.

The National Disability Strategy (2004) provided a framework for consistent planning and implementation of disability policy (NDA, 2020). The most current version of the National Disability Strategy is the National Disability Inclusion Strategy 2017-2022, which outlines actions to facilitate national realisation of the UNCRPD (Department of Justice and Equality, 2017).

Transforming Lives aims to support people to live the lives they choose within the community (NDA, 2020). It sets out a number of actions, with examples including, but not limited to, the provision of tailored supports that the individual decides on and the transition from institutional living to community living (NDA, 2020). *Time to Move on from Congregated Settings* (HSE, 2011) is a national strategy to support the relocation of people from congregated settings (i.e., 10 or more people with a disability who live together in a single living unit or placed in campus-based accommodation) to community-based housing or their own homes in the community with the supports they need (HSE, 2011). The 2019 Report on *Time to Move on from Congregated Settings* detailed that fewer than 2,000 people were living in congregated settings, compared to 4,000 people in 2012. Those living in congregated settings at the end of 2019 included 1,075 people (over 54%) with severe or profound intellectual disability. In total, 456 individuals with severe/profound intellectual disability had completed their transition (HSE, 2019). *New Directions* (2012-2016) relates to the provision of day services, and is underpinned by principles of person-centredness, independence, choice and community inclusion. *New Directions* (2012-2016) advocates for the participation of

people with disabilities in communities, to ensure they have the choice about how they wish to live their lives and spend their time (Gadd & Cronin, 2019). The New Directions Benchmarking Report (2016) indicates that further progress is required to ensure individuals have access to information that is accessible to their communication needs. Of the 70 organisations included, 46 responded to a question on access to information in a format accessible to individuals' communication needs, 11 cited individual aids or technology, inclusive of AAC (HSE, 2016).

The international and national policies and legislation driving the rights-based agenda are underpinned by principles of person-centredness, autonomy, self-determination, respect and inclusion. Much progress has been made; however, these rights are not always realised for those with intellectual disability (Brown, 2020; Murphy & Bantry White, 2021). Further progress is required to ensure the commitment to, and enactment of human rights for people with disability. Particular efforts must be made for those with severe/profound intellectual disability, who require substantial support. One way of doing this is to support their communication, and thus, support them to influence their environment, express their emotions, make choices, develop relationships, friendships and to take part in their communities.

To contextualise the issues faced by people with intellectual disability and more specifically people with severe/profound intellectual disability, the nature of this type of disability is now discussed.

1.2 Intellectual Disability

There are varying definitions of intellectual disability including the: (a) American Association on Intellectual and Developmental Disabilities (AAIDD); (b) American Psychiatric Association (APA); publishers of the Diagnostic and Statistical Manual of Mental Disorders (DSM; 2013); and (c) the International Classification of

Diseases (ICD) by the WHO (Brady et al, 2016). These classifications are used to inform service planning and support systems. Support systems aim to enhance individual's functioning and wellbeing by promoting their development and interests (Schalock et al., 2021a). Thus, recognising that the application of individualised supports can enhance human functioning (Schalock et al, 2021b).

1.2.1 Definition and Prevalence of Intellectual Disability

The ICD-11 definitions of severe intellectual disability and profound intellectual disability are outlined in Table 1.1.

Table 1.1 ICD-11 Definition of Severe and Profound Intellectual Disability

Severe Intellectual Disability	Profound Intellectual Disability
<p><i>“A severe disorder of intellectual development is a condition originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behaviour that are approximately four or more standard deviations below the mean (less than approximately the 0.003rd percentile), based on appropriately normed, individually administered standardized tests or by comparable behavioural indicators when standardized testing is unavailable. Affected persons exhibit very limited language and capacity for acquisition of academic skills. They may also have motor impairments and typically require daily support in a supervised environment for adequate care but may acquire basic self-care skills with intensive training.” (ICD-11)</i></p>	<p><i>“A profound disorder of intellectual development is a condition originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behaviour that are approximately four or more standard deviations below the mean (approximately less than the 0.003rd percentile), based on individually administered appropriately normed, standardized tests or by comparable behavioural indicators when standardized testing is unavailable. Affected persons possess very limited communication abilities and capacity for acquisition of academic skills is restricted to basic concrete skills. They may also have co-occurring motor and sensory impairments and typically require daily support in a supervised environment for adequate care.” (ICD-11)</i></p>

Standardised tests of intelligence cannot reliably or validly differentiate among individuals with intellectual functioning below the 0.003rd percentile, therefore severe and profound intellectual disability are differentiated on the basis of adaptive behaviour differences (WHO, 2022).

It is challenging to establish the prevalence of intellectual disability. Figures may vary as different definitions are used (Carnaby, 2007). There is consensus that there is an increase in the population of adults with intellectual disability (Oullette-Kuntz et al., 2016), with individuals with severe/profound intellectual disability having improved life expectancy (Hourigan et al., 2018). This increase is expected to impact the future service demand and supports required (Oullette-Kuntz et al, 2016).

Globally, approximately one percent of the population experience intellectual disability (APA, 2021). In Ireland 109,288 people (representing 2% of the population) had an intellectual disability in 2022 (Central Statistics Office, 2023) compared to 66,611 people (1.4% of the population) in 2016 (Central Statistics Office, 2016). The Census data does not capture the different classifications of intellectual disability. The National Intellectual Disability Database (NIDD) gathers data about service use among people with intellectual disability in Ireland. In 2011 there were 26,044 individuals with intellectual disability registered on the NIDD. This figure increased to 27,474 in 2016 and to 28,388 in 2017. Of those registered in 2017, 4,846 (17%) had severe/profound intellectual disability (Hourigan et al., 2018). It is important to note that the reports capture service provider data. Therefore, those who do not attend a service may not be captured.

With this increasing population of people with intellectual disability, there will be a greater demand for services that respond to and meet each person's

individual needs. The next section outlines the characteristics of individuals with severe/profound intellectual disability.

1.2.2 Severe/Profound Intellectual Disability

This research is focused on those who communicate at the earlier stages of communication development. The ICD-11 classifies intellectual disability in four categories: mild, moderate, severe and profound. It offers a specific description regarding communication ability in relation to people with severe or profound intellectual disability. This description is in keeping with the communication ability of the people with intellectual disability this research relates to.

Individuals with severe/profound intellectual disability exhibit limited intellectual and communicative abilities (Hermsen et al., 2022) as well as multi-morbidities (Doody & Bailey, 2017) and may have motor impairments (WHO, 2022). Many also have co-existing motor and sensory impairments (WHO, 2022) and complex health conditions, such as epilepsy (Arvio & Sillanpää, 2003), seizures, scoliosis, respiratory issues (Gulati & Sondhi, 2018; Sigafos et al., 2021) and heart disease (McCarron et al., 2013). They are dependent on others in all aspects of daily life (Nieuwenhuijse et al., 2022). Of relevance to this study, they experience great difficulty in communicating, relying greatly or entirely on non-verbal behaviours to communicate their messages (Mansell, 2010). Efforts must be taken to ensure an individual's communication potential and thus, attempts are recognised and understood.

The differing terminologies and definitions of this target group is a recognised challenge faced by researchers in this field (Maes et al., 2020). There is a need for greater consensus regarding the terminology used for this population (Nakken & Vlaskamp, 2007) to ensure the research undertaken informs

individualised supports tailored to each person's needs. When the same terms are applied to this heterogeneous group, misunderstandings in interpreting data can arise (Maes et al., 2020). Therefore, researchers should provide a detailed description of individuals' characteristics (Maes et al., 2020). Some researchers are hesitant to describe individuals by their degree of intellectual disability, conforming to the medical model of disability (Danker et al., 2023). However, it is important to be specific about the population of interest to create more information that can outline and advocate for their needs (Danker et al., 2023).

A variety of terms are used relating to individuals with severe/profound intellectual disability, for example 'severe', 'profound', 'pervasive', 'multiple' and 'intellectual disability', 'learning disability', or 'developmental disability'. The focus of this study is on individuals who communicate at the earlier communication developmental stages, which includes persons with severe/profound intellectual and/or multiple disability. For accuracy, when referencing the work of others, the terminology used by the referenced authors is used. Otherwise, the term severe/profound intellectual disability is used throughout. Communication, and more specifically individuals with severe/profound intellectual disability communication attempts and needs are outlined in the following section.

1.3 Communication and Severe/Profound Intellectual Disability

Friedman and Ellyn (2018, p.111) describe communication as "*a series of complex and fluid interactions that include but are not limited to using and understanding facial expressions, body language and gestures, reading, writing, speaking, and listening*". The way in which communication is defined is of key importance to ensure individuals with severe/profound intellectual disability are included and therefore, supported to communicate and interact (Goldbart, 2023).

Their subtle, idiosyncratic and individual communication behaviours must be considered. As discussed by Goldbart (2023), the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities is deemed a suitable definition to ensure the inclusion of persons with severe/profound intellectual disability; “*Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or non-linguistic forms, and may occur through spoken or other modes*” (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992, p.2). Recognising that communication can be both intentional and unintentional, conventional and unconventional, verbal and non-verbal (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992) may help to ensure that individuals are recognised as capable communicators and thus, supported to communicate.

People with severe/profound intellectual disability require the people around them to recognise and draw meaning from their idiosyncratic expressive methods and try to understand their messages. It is the role of their communication partners to draw meaning from such idiosyncrasies, to ensure the individuals’ communication attempts are recognised and needs met and hence the underlying motivation for this research in gaining a better understanding from the perspective of communication partners.

Individuals with severe/profound intellectual and/or multiple disability tend to function at pre-intentional communication stage (Coupe O’Kane & Goldbart, 1998; Erickson & Quick, 2017; Maes et al., 2007; Sigafoos et al., 2021; van Splunder et al., 2006). Their expressive communication involves a range of subtle and idiosyncratic behaviours that may be individual to the person or context (Brady

et al., 2016; Stillman & Siegel-Causey, 1989) such as eye gaze, body language and movements, changes in muscle tone, facial expressions and vocalisation (Brady et al., 2016; Coupe O’Kane & Goldbart, 1998; Petry & Maes, 2006). In addition, they may have limited social skills (Sigafoos et al., 2010). The communication challenges experienced by individuals pose as a barrier to social participation (Smith et al., 2020).

Individuals with severe/profound intellectual disability require high levels of support in communicating and interacting with others (Ogletree et al. 2012). However, those around them may find it challenging to interpret and support their needs. It is not surprising then, that communication breakdowns are common (Keen, 2014; Sigafoos et al., 2021). Efforts must be taken to ensure an individual’s communication attempts are recognised, understood and responded to.

An appropriate starting point may be to promote the recognition of individuals as capable communicators and respect their individual methods used to communicate. Fisher et al. (2022) discusses the importance of recognising all behaviour as communication. Similarly, Sigafoos et al. (2000) argue that individuals who may appear to demonstrate unintentional communication can be perceived as potential communicators because those listening recognise, interpret and respond to their behaviour as communicative (Sigafoos et al., 2000). Everyone communicates, the effectiveness of communication differs due to individual and environmental factors (Brady et al., 2016; National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992). The onus is therefore, on each of us interacting with individuals to recognise, respect and thus, adapt to their capabilities.

Effective and efficient communication affects our daily lives, the impact we have on our environment, our relationships with others and contributes to our overall

QoL. QoL is a key principle of the rights-based agenda. It is the outcome people strive to achieve. The following section discusses QoL and moreover, the intersection between QoL and communication.

1.4 Severe/Profound Intellectual Disability, Quality of Life and Communication

Promoting QoL is central to the policy and legislation surrounding the rights-based agenda. Policies that set out rights, entitlements and support systems create an environment that strives for an improved life for people with disabilities (Brown, 2020). The WHO (1995, p.1405) defines QoL as an *“individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”*. QoL is a broad concept, including individuals' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships with aspects of their environments (WHO,1995). QoL is objective as well as subjective. Objective QoL is tangible, for example the extent of their friendship networks (Cummins, 2018). Subjective QoL, also referred to as subjective wellbeing, is individual to that person, for example, the level of satisfaction with friends (Cummins, 2018). Therefore, QoL may mean different things to different people.

The QoL construct aims to support persons with profound intellectual and multiple disabilities (Neerinckx & Maes, 2016; Nieuwenhuijse et al., 2022). Their QoL may differ from others. Their intellectual disability combined with motor and/or sensory disabilities, means they are highly dependent on other people to realise an optimal QoL (Nakken & Vlaskamp, 2007; Neerinckx & Maes, 2016; Petry et al.2007). Considerable efforts must be made to ensure individuals are supported to attain a good QoL. To facilitate this, it is important to assess and therefore, understand their lived experience.

Different approaches are adopted to assess individuals' QoL. Verdugo et al (2005) suggest that individuals should be involved in the measurement of their own QoL. For people who are unable to complete QoL instruments independently, proxy reporting by people who are familiar with them is often used (Stancliffe 1995; Verdugo et al., 2005). However, it is argued that proxy reporting lacks validity when measuring subjective variables (Cummins, 2018). Vos et al. (2013) state that it is necessary to have a good measure of subjective wellbeing of individuals with severe/profound intellectual disability to get an accurate view of QoL. For individuals with severe/profound intellectual disability, it is challenging to measure how satisfied they really are as they experience challenges in expressing their satisfaction with life (Hughes et al., 2018). Lyons (2005) developed the Life Satisfaction Matrix (LSM), to assess the subjective component of QoL "satisfaction with life" in people with profound and multiple intellectual disability using observations and proxies. Petry and Maes (2006) developed a procedure to assess individual's subjective well-being using behavioural observations. Nieuwenhuijse et al. (2023a) state that the interpretation of signals and signs by proxy reporters should be accepted as part of the QoL assessment for individuals with profound intellectual and multiple disability. People who are familiar with them, in particular their parents and professional caregivers are fundamental to gaining a deeper understanding of their QoL, by interpreting their subtle signals to gain a closer insight to their lived experiences (Nieuwenhuijse et al., 2023b).

Although it is challenging to measure individuals with severe/profound intellectual disability QoL, individuals with more complex needs, including those with severe/profound intellectual disability who have multiple physical or sensory disabilities may experience poorer outcomes (Mansell & Beadle-Brown, 2012). It is

essential to search for ways to improve their subjective well-being and overall QoL. Communication is an essential subdomain of QoL for people with profound multiple disabilities (Petry et al., 2005). Hewitt et al. (2019, p. 10) argue that the ‘good life’ for everyone is underpinned by the ability to participate socially, to interact, connect and give and receive human contact. Supporting communication and social interaction may reduce individuals' level of dependency and improve connectedness, independence and overall QoL (Dammeyer & K ppe, 2013).

It is clear that the quality of interpersonal interactions greatly contributes to the LS and overall QoL of individuals with intellectual disability. Individuals with severe/profound intellectual disability can attain a good QoL. However, their communication partners are fundamental in helping them to do so (Wilder & Granlund 2003). They require skilled communication partners (Wilder et al., 2015) who are sensitive to and can ‘read’ their individual signals and communication attempts and thus, enable them to influence their environment (Kruithof et al., 2020; Nieuwenhuijse et al., 2022). Moreover, those supporting the person must ensure that they develop effective communication with them (Doukas et al., 2017) as appropriate communicative methods are essential for individuals’ QoL (Martin, 2020).

Despite communication and interactions being recognised as fundamental to achieve QoL domains, individuals with severe/profound intellectual disability are reported to spend a large amount of time disengaged and isolated (Netten et al., 2010) with little contact from others (Beadle-Brown et al., 2016). The opportunity to interact, participate socially, connect and develop social relationships with others may be compromised. The QoL construct acts as a link between the human rights of persons with disabilities (Verdugo et al., 2012). These rights are internationally

recognised (Article 21, UN, 2006), and therefore considerable efforts must be made to ensure they become a reality.

AAC has the potential to support individuals with severe/profound intellectual disability to communicate, and therefore has potential to contribute to their QoL. The potential of AAC in supporting individuals to communicate and realise their right to communicate is discussed below.

1.5 Augmentative and Alternative Communication

AAC is defined as “*an area of clinical practice that addresses the needs of individuals with significant and complex communication disorders characterised by impairments in speech-language production and/or comprehension, including spoken and written modes of communication*” (ASHA, 2019). Typically, it is divided into unaided and aided forms of communication. Unaided forms consist of natural, nonverbal means of communication, including gestures, body movements and facial expressions as well as manual signs such as Lámh (a key word signing system in Ireland), Key Word Signing and Makaton. Unaided forms of AAC may require adequate motor control and communication partners who can interpret the message (Sigafos et al., 2014). Aided forms of communication require some form of external support (Hourcade et al., 2004). Aided forms are broken down further to low-tech and high-tech options. Low tech AAC consists of non-electronic or paper-based approaches such as communication boards, communication books, Picture Exchange Communication Systems (PECS). High tech AAC consists of electronic aids, such as computers, handheld devices, or tablet devices with symbols, words, letters, or icons (Beukelman & Light, 2020). Aided modes of AAC may be suggested for those who do not have sufficient motor control for using gestures and manual signs or when those they communicate with do not understand such modes (Sigafos et al., 2014).

Multimodal AAC is recommended to ensure individuals have ample opportunities and indeed, various means to communicate across multiple contexts with multiple people (Beukelman & Light, 2020; Light et al., 2021).

1.5.1 Augmentative and Alternative Communication and Severe/Profound Intellectual Disability

Substantial progress has been made in the field of AAC since it emerged in the 1950s (Hourcade et al., 2004). AAC assessment was once underpinned by a candidacy model where potential AAC users were required to have certain prerequisite skills. Individuals with severe/profound intellectual disability did not usually receive AAC services as they do not meet the minimum developmental criteria (Hourcade et al., 2004). It was not until the 1980s that widespread use of AAC systems were extended to include them (Beukelman et al., 2012). In contrast to the previously used candidacy model, the contemporary universal model is underpinned by the assumption that everyone can communicate, benefit from (Hourcade et al., 2004) and use AAC (Ronski & Sevcik, 2005).

The potential benefits of AAC for this population are recognised in the literature (Danker et al., 2023; Marshall & Goldbart, 2008; Mirenda, 2014, Sigafoos et al., 2021). AAC aims to provide people with a means to communicate and promote participation (Beukelman & Light, 2020), thus contributing to QoL. Specifically, in the context of individuals with severe/profound intellectual disability, Sigafoos and Couzens (1995) taught a child with severe intellectual disability to use an eye gaze communication board to request headphones, a cassette player, and tapes to listen to music (Sigafoos & Couzens, 1995). Danker et al. (2023) undertook a recent scoping review to explore the range of communication resources individuals with severe/profound intellectual disability used for functional communication. AAC systems were reported to enable individuals to make choices and requests (Danker et

al., 2023). However, many challenges arise in the adoption and use of AAC (Bircanin et al., 2019). Learning to use AAC takes extensive time and effort (Bircanin et al., 2019). Individuals may experience difficulties physically operating AAC devices (Hodge, 2007). Individuals with complex communication needs can become competent communicators using AAC (Beukelman & Light, 2020). This is influenced by a number of intrinsic factors (related to the individual), as well as extrinsic factors relating to the environment, their communication partners and the actual AAC system (Light & McNaughton, 2014). Therefore, when implementing AAC both the individual and their communication partners need to be considered (Light et al., 2019a).

Despite the potential of AAC to support individuals' complex communication needs, individuals' communication support needs are not always met (Brady et al., 2016). Individuals' AAC systems have been found to be out of reach (Bircanin et al., 2019) and not readily available (Chung et al., 2012). Thus, there is an apparent need to understand the adoption and use of AAC with this population.

It can be challenging to provide effective AAC interventions to individuals with severe/profound intellectual disability because of their individual communication needs (Rensfeldt Flink et al., 2022a) and the sensory, physical and health impairments that they can experience (Sigafos et al., 2021). They are a heterogeneous group (Griffiths & Smith, 2016) and their individuality must be recognised when implementing AAC. The best communication approach is determined by the needs of the individual and their communication partners (ASHA, 2019), recognising the individual's strengths and needs (Newby et al., 2019) to promote individually tailored support (Light et al., 2021). To ensure an individualised approach is adopted, the individual's developmental skills in

communication, cognition, motor skills and sensory perception need to be applied when choosing an AAC system and outcomes, to ensure AAC supports their current needs and enhances further development of skills (O'Neill & Wilkinson, 2019).

AAC has the potential to support individuals to communicate, however multiple factors impact AAC adoption and implementation. A fundamental factor is the support from their communication partners. Communication partners input in supporting individuals with severe/profound intellectual disability to communicate and more specifically, their fundamental role in contributing to AAC success is discussed in the next section.

1.6 Communication Partners' Engagement

Communication partners are the companion in the interaction and include those with social roles such as family members and those with professional roles (Kent-Walsh & McNaughton, 2005) such as support workers (Johnson et al., 2009). Familiar communication partners who try to understand and draw meaning from the individual's messages are crucial (Hostyn & Maes, 2009; Lyons, 2005) to ensure their subtle behaviours are recognised and understood.

Communication partners need to adapt their communication to within the individual's ability. However, communication partners have been reported to underestimate their own use of verbal communication and overestimate their use of non-verbal communication (Bradshaw, 2001). They may fail to adapt their communication to the understanding skills of the individual they support (Bradshaw, 2001). In addition, their practices such as not waiting for the individual to respond and making assumptions about their intended message may pose as a barrier to facilitating communication (Dennis, 2002).

Communication partners reported that they needed to spend time with the person and undertake activities together to get to know them, to become familiar with and to them (Penninga et al., 2022). However, time alone may not mean that they will get to know the individual and recognise their communicative behaviours. In addition to time, communication partners have linked their own attitudes, mind-set, and characteristics, such as patience and ‘taking time’ to their ability to recognise the subtle behaviours of a person with profound intellectual disability (Penninga et al., 2022). Communication partners need to understand the importance of prioritising time for communication (Koski et al., 2010) amongst the multiple daily tasks they must undertake. It is recognised that communication partners may lack such time (Martin, 2020) with multiple tasks to be implemented (Rombouts et al., 2017a) resulting in competing demands. Their limited time and competing demands must be considered by professionals implementing communication supports.

There are multiple factors to consider when supporting interactions between individuals with severe/profound intellectual disability and their communication partners. It is not a straightforward process, with many influences at play. It is understood that individuals with profound intellectual and multiple disability and their communication partners are at risk of experiencing “*non-optimal and non-mutually rewarding interactions*” (Hostyn & Maes, 2009, p. 297). Therefore, additional support is required to optimise their interactions and ensure individuals with severe/profound intellectual and/or multiple disabilities right to communicate is realised.

1.6.1 Communication Partners and Augmentative and Alternative Communication

More specifically in the context of AAC, it is recognised that successful communication through AAC depends on both the individual and their

communication partners (Bircanin et al., 2019; Kent-Walsh et al., 2015; Light et al., 2019a). Communication partners' approach to communication is a fundamental factor impacting upon effective and efficient use of AAC (Hanley et al., 2022). It is not surprising then that the importance of including communication partners in interventions for persons with severe/profound intellectual and/or multiple disabilities is well documented in the literature (Bruce & Bashinski, 2017; Ogletree, 2021; Rensfeldt Flink et al., 2022a).

AAC may support interactions between communications partners and those they support. Aided AAC modes may help enhance communication partners' understanding (Chung et al., 2012) of the individuals' idiosyncratic communicative methods (Hustad, 2007). Despite the potential of AAC in supporting individuals to communicate, communication partners may not, for different reasons, fully commit to the time required to engage with AAC strategies (Forster & Iacono, 2007) and at times have been reported to use AAC inconsistently (Rombouts et al., 2017a). An important consideration is the existing interaction approaches of communication partners and people with intellectual disability (Rensfeldt Flink, 2022).

Communication partners may have a unique way of interacting with the individual (Wilder & Granlund, 2003). Rensfeldt Flink (2022) argues the introduction of new communication supports such as AAC in these contexts may be experienced as disruptive.

This highlights the importance of including communication partners in the AAC intervention, to ensure they are considered and AAC is adapted to support them to engage with it (Marshall & Goldbart, 2008). Given the potential of AAC to support individuals to communicate, the multiple factors impacting the optimisation of AAC and the fundamental role of communication partners in supporting the

adoption and use of AAC, gaining a deeper understanding of communication partners' experiences may be of value when planning and implementing AAC support.

1.7 Conclusion

Both nationally and internationally, the rights-based agenda strives to improve individuals' QoL. Policy and legislation underpin the rights of persons with intellectual disability to inclusion, participation, respect, autonomy and choice. Given their complex communication needs, individuals with severe/profound intellectual disability face challenges realising these rights. Supporting their communication may help them to realise their human rights. It is also a requirement in meeting the obligations set out in policy and legislation. AAC has potential to contribute to the meaningful actualisation of this right for persons with severe/profound intellectual disability. Despite this, individuals are reported to spend significant amounts of time disengaged, do not always have access to AAC and a high rate of AAC abandonment is reported.

The literature on the implementation of AAC for people with severe/profound intellectual disability is limited (Danker et al., 2021; Mirenda, 2014; Light et al. 2019b) but growing and thus, there is a need to contribute to the evidence-base and resulting policy and practice guidelines. It is clear that both the AAC user and their communication partners contribute to the success of AAC, and therefore, both parties' perspectives must be considered and included (Light et al., 2019a). Understanding communication partners' experiences of using AAC may contribute to the evidence informing policy and practice to aid in successful adoption and use of AAC with individuals and thus, improve their overall well-being and QoL.

A mixed methods systematic review was undertaken to explore communication partners' experiences of communicating with adults with severe/profound intellectual disability through AAC. The mixed methods systematic review is presented in the upcoming chapter (Chapter 2).

Chapter 2. Communication Partners' Experiences of Communicating with Adults with Severe/Profound Intellectual Disability through Augmentative and Alternative Communication: A Mixed Methods Systematic Review

Abstract

Background

People with severe/profound intellectual disability experience challenges in communicating and require their communication partners to adapt to their means of communication. AAC is recognised as a potential means to meet their communication needs. Interventions need to be aimed at both the individual and their communication partners.

Methods

We conducted a mixed methods systematic review of the literature to synthesise evidence on communication partners' experience of communicating with adults with severe/profound intellectual disability through AAC. Eight publications met the inclusion criteria, they underwent thematic synthesis where four themes emerged.

Results

A shared commitment to communication partnership is fundamental for the effective and efficient use of AAC. However, there was a disconnect between communication partners' perceptions of their roles and responsibilities.

Conclusion

This review⁵ prompts further research to explore communication partners' perceptions of their roles and responsibilities in the use of AAC with people with severe/profound intellectual disability.

Keywords: augmentative and alternative communication; communication; communication partners; severe or profound intellectual disability

⁵ This systematic review was published in the Journal of Intellectual Disabilities; the paper can be found in Appendix 2

2.1 Introduction

Communication is a basic human need and human right (UN, 2006; Williams, 2000). Communicating effectively is a fundamental life skill (Sen, 2015) central to most life activities and impacts the QoL of individuals (Bennett et al., 2016). Powell (2008) describes communication as a complex process that involves the interaction of the cognitive-linguistic and motor systems. Similarly, Friedman and McNamara (2018) describe communication as “*a series of complex and fluid interactions*” (p.111) inclusive of, but not limited to the use and understanding of facial expressions, body language, gestures, writing, reading, speaking and listening.

The terminology and definition of intellectual disability has evolved over time (Brady et al, 2016). These changes represent the move from a medical oriented approach to disability, to a more person-centred perspective, focusing on the individual and their interaction with their environment (Brady et al., 2016). There is agreement that intellectual disability is characterised by substantial limitations in intellectual functioning and adaptive behaviour originating during the developmental stage (ICD-11, 2022; Schalock et al., 2021a). The 11th edition of the ICD definition of intellectual disability was used and should be taken to include all individuals with severe/profound intellectual disability, including those with profound intellectual and multiple disability, which is a term used to describe persons with severe to profound intellectual disability as well as substantial physical impairment (Lyle, 2019; Nakken & Vlaskamp, 2007; Sigafoos et al., 2021). Individuals with severe/profound intellectual disability experience significant communication difficulties (van der Gaag, 1998) which can impact their wellbeing and QoL. Therefore, strategies must be provided to ensure their communication needs are met. The focus of this review is on individuals who communicate at earlier stages of communication developmental. Therefore, persons with severe/profound intellectual disability and persons with

profound intellectual and multiple disability were included. Terms such as profound intellectual and multiple disabilities, severe/profound intellectual and multiple disabilities and complex disabilities are used in the literature. For accuracy and to remain true to the original work, the terminology of cited authors is being used in this review.

Individuals with severe/profound intellectual and/or multiple disability tend to function at pre-intentional communication stage and may experience sensory and physical disabilities and health issues (Coupe O'Kane & Goldbart, 1998; Erickson & Quick, 2017; Sigafoos et al., 2021; van Splunder et al., 2006). Expressive communication tends to involve a range of subtle and idiosyncratic behaviours that may be individual to the person or context (Stillman & Siegel-Causey, 1989) such as eye gaze, body language and movements, changes in muscle tone, facial expressions and vocalisation (Brady et al., 2016; Coupe O'Kane & Goldbart, 1998; Petry & Maes, 2006). Their communication attempts can go unnoticed (Munde & Vlaskamp, 2015; Wilder & Granlund, 2003) or may be misunderstood (Grove et al., 1999). It is difficult to place meaning on an individual's communicative behaviour, especially when these are idiosyncratic and therefore, communication breakdowns are common (Keen, 2014; Sigafoos et al., 2021). Efforts must be taken to ensure an individual's communication attempts are recognised and understood.

Communication partners need to be sensitive to individuals with severe/profound intellectual disability subtle behaviours to interpret these behaviours and respond, thus facilitating a two-way process of communicating (Coupe O'Kane & Goldbart, 1998). In the context of this review, communication partners include persons who have social relationships with AAC users (e.g., parents, siblings) and educational or care relationships with AAC users (e.g., teachers, health care

professionals, residential staff members) (Kent-Walsh & McNaughton, 2005).

Communication partners have a fundamental role in assessing adults with severe/profound intellectual disability. They observe and interact with the person over an extended time and across different environments. Such experiences enable them to share their knowledge of the person's abilities (Cascella, 2004).

Acknowledgement that all people can communicate creates a sense of responsibility for everyone who interacts with persons with severe/profound intellectual disability to recognise and enhance the individual's communication methods and opportunities (Brady et al., 2016).

The right of people with intellectual disability to have a means to communicate is recognised internationally (UN, 2006). AAC is recognised as one method of facilitating and supporting communication with persons with complex communication needs (Beukelman & Light, 2020). AAC is defined as *“an area of clinical practice that addresses the needs of individuals with significant and complex communication disorders characterised by impairments in speech-language production and/or comprehension, including spoken and written modes of communication”* (ASHA, 2019). Typically, forms of AAC are divided into unaided and aided forms of communication. Unaided communication includes gestures, facial expression, eye gaze, body postures and signs (Pino, 2014). Aided forms of communication include approaches which require some form of external support including physical objects or equipment such as symbol charts or books; it also refers to computer-based systems or Voice Output Communication Aids (VOCAs) (Pino, 2014). The goal of AAC intervention is to empower individuals to engage and participate in a variety of interactions and activities of their choice (Beukelman et al., 2012). However, learning to communicate through AAC is a complex process for

both the AAC user (Bailey et al., 2006; Rackensperger et al., 2005) and their communication partners.

Given the complex communication needs of individuals with profound intellectual and multiple disability, it can be challenging to provide effective AAC interventions (Sigafoos et al., 2021). The four components of communicative competence for AAC users include linguistic, operational, social and strategic competence (Light, 1989; Light et al., 2003). Individuals who require AAC need support from their communication partners for successful communication as communication competence relies on both the AAC user and factors related to their communication partners and environment (Blackstone et al., 2007). Individuals are likely to interact with a range of communication partners, who have various roles in their lives (Kent-Walsh & McNaughton, 2005). Therefore, successful communication through AAC depends on both the individual and their communication partners using the AAC (Kent-Walsh et al., 2015). However, communication partners' approach to communication may negatively impact upon AAC use. For example, communication partners have been found to control interactions, ask close ended questions, provide little opportunities for AAC users to start conversations or to respond and often interrupt the AAC users' utterances (Blackstone, 1999; Light et al., 1985). In addition, and more generally, Bradshaw (2001) discusses how communication partners may overestimate their use of nonverbal communication and underestimate their use of verbal communication. Therefore, they may not adapt their communication to the individual's understanding (Bradshaw, 2001). Attitudinal barriers where people presume individuals with complex communication needs cannot learn to use AAC also pose as challenges to successful AAC provision and use (Sigafoos et al., 2021). In addition, several studies

have reported unmet needs of persons with intellectual disability and complex communication in relation to AAC provision (Siu et al., 2010; Sutherland et al., 2005; Sutherland et al., 2014). The absence of AAC for this population may be due to a possible lack of awareness or training (Sigafos et al., 2021) and lack of access to professionals with expertise in AAC (Siu et al., 2010; Sutherland et al., 2005; 2014).

Professionals must be mindful of the impact of AAC on both the user and their communication partners. The introduction of AAC impacts both the AAC user and their family (Angelo, 1997; Parette & Angelo, 1996; 1998). Therefore, professionals need to understand the effect AAC has on the family members (Angelo, 2000). More than half of families in a study by Angelo (2000) reported improvements in their child's QoL, communication and independence. Communication partners have expressed frustration towards AAC device malfunctions (McCord & Soto, 2004; Kulkarni & Parmar, 2017) and difficulty understanding the AAC system (McCall et al., 1997). Despite these findings, it has been found that AAC has the potential to support individuals' complex communication needs (Beukelman & Mirenda, 2005; Beukelman & Light, 2020). With encouragement, support, instruction and practice AAC users can transition from AAC novices to competent AAC communicators (Beukelman & Light, 2020; Beukelman et al., 2012). Similarly, individuals with profound intellectual and multiple disability may develop intentional or functional communication skills when an AAC mode is suitably developed with a systematic instructional program that is well designed (Reichle et al., 1991).

Internationally, the UNCRPD (UN, 2006) provides a framework to promote, protect and ensure the rights of all people with a disability and encourages equal

rights in all parts of life. The UNCRPD advocates accepting and facilitating the use of AAC. However, people with severe/profound intellectual disability continue to have unmet communication support needs (Brady et al., 2016). Changes in policy, legislation and regulation have transformed the approach to services for individuals with intellectual disability. People with severe/profound intellectual disability are more present today than they were ever before (Brady et al., 2016) and the increase in the population of adults with intellectual disability is expected to have an impact on the need for services and supports (Oulette-Kuntz et al., 2016). In addition, individuals with complex communication needs and their families have greater expectations to take part in a range of environments (Light et al., 2019). Increased expectations have led to a greater demand for access to AAC. To meet individuals' variety of needs, service providers must consider new AAC supports, improved skill instruction and partner supports (Light & McNaughton, 2014; Light et al., 2019b).

Given the potential of AAC to meet individuals with severe/profound intellectual disability complex communication needs, the challenges to successful AAC use and the significant role of communication partners in successful AAC provision and use, there is a need to explore communication partners' experiences of using AAC with adults with severe/profound intellectual disability. The aim of this review was to explore communication partners' experience of communicating with adults with severe/profound intellectual disability through AAC with a view to identifying potential barriers and facilitators to successful AAC use. Such knowledge may be of value when planning AAC support for persons with severe/profound intellectual disability and implementing AAC with them and their communication partners.

2.2 Methods

2.2.1 Protocol and Registration

A review protocol was developed by the researchers. The protocol can be found in Appendix 3.

2.2.2 Design

The Joanna Briggs Institute (JBI) guidelines for mixed methods systematic reviews (MMSR) were followed. MMSR combine the findings of effectiveness from quantitative research and participants' experiences from qualitative research to increase the helpfulness of findings for decision makers (Bressan et al., 2016). Both perspectives are increasingly required to inform clinical, policy or organisational decisions (Lizarondo et al., 2020). The universal steps of undertaking a systematic review apply to MMSR (Lizarondo et al., 2020). However, there are differences in combining and integrating data. This MMSR followed a convergent integrated approach in keeping with the JBI methodology for MMSR. Specifically, this approach is a process of combining the data that was extracted from quantitative, qualitative and mixed methods studies. Data transformation was required to allow for the integration of qualitative and quantitative data.

2.2.3 Search strategy

A preliminary scoping search was undertaken with a specialist health sciences librarian. Databases were then selected based on the 'fit' with the topic area and return of relevant results.

In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009, see Appendix 4), a literature search of seven databases was conducted including CINAHL, Scopus, Academic Search Complete, PubMed, ERIC, Cochrane, and Linguistics Collection

in January 2020 and reviewed again in January 2021. No new literature was identified. These databases are comprehensive for health, social care and education, areas of practice commonly supporting people with intellectual disability. English language was the only database filter applied. As per PRISMA (2009) guidelines one full electronic search strategy has been presented in this review (Appendix 5).

The following key concepts were searched and combined: search terms referring to severe/profound intellectual disability (i.e. “severe intellectual disability*” OR “severe learning disability*” OR “severe mental retard*” OR “severe developmental disability*” OR “profound intellectual disability*” or “profound mental retard*” or “profound developmental disability*” OR “profound learning disability*” OR “pervasive intellectual disability*” OR “pervasive mental retard*” OR “pervasive developmental disability*” OR “pervasive learning disability*”) were combined with search terms referring to AAC (i.e. “Augmentative and alternative communication” OR “AAC”) which were combined with search terms referring to communication partners (i.e. caregivers OR “communication partners” OR “family members” OR friends OR “support staff” OR teachers). The PICO (Population, Interest, Context) framework was used to refine the search concepts and parameters - “What are communication partners’ (Population) experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication (Interest) in community settings, day services, acute care settings, school, home settings in all countries (Context)?”.

The inclusion of the key concept relating to caregivers resulted in a limited number of hits in CINAHL and Academic Search Complete. Therefore, a second search was completed in these databases without that search string to identify potential literature relevant to this topic.

2.2.4 Study Selection

Through database searching, 474 records were identified. A further 13 relevant records were identified through searching reference lists of included studies. All identified citations were transferred into EndNote and duplicates removed (n=12). Titles and abstracts of 475 records were screened by two independent reviewers for assessment against the inclusion and exclusion criteria (Table 2.1) with 376 records excluded.

Table 2.1 Inclusion and Exclusion Criteria

Inclusion Criteria:

Population:

Communication partners of adults who have severe/profound intellectual disability.

Communication partners must be 18 years or older.

Communication partners included either paid or unpaid partners.

Individuals with severe/profound intellectual disability may also have multiple disability. Therefore, adults with profound/multiple intellectual disability were also included.

No restrictions were placed on ethnicity or gender.

Phenomenon of Interest:

Studies that explored communication partners' experiences of communicating with adults with severe/profound intellectual disability through AAC.

Context:

Studies that investigated communication partners of adults with severe/profound intellectual disability using AAC in community services, school, home settings, acute care settings, day services, during their day-to-day lives.

Types of Studies:

Quantitative, qualitative and mixed methods studies.

Studies were only considered when the data relating to communication partners of adults with severe/profound intellectual disability could be clearly extracted.

Exclusion Criteria:

The person with whom the communication partner is communicating with does not have severe/profound intellectual disability.

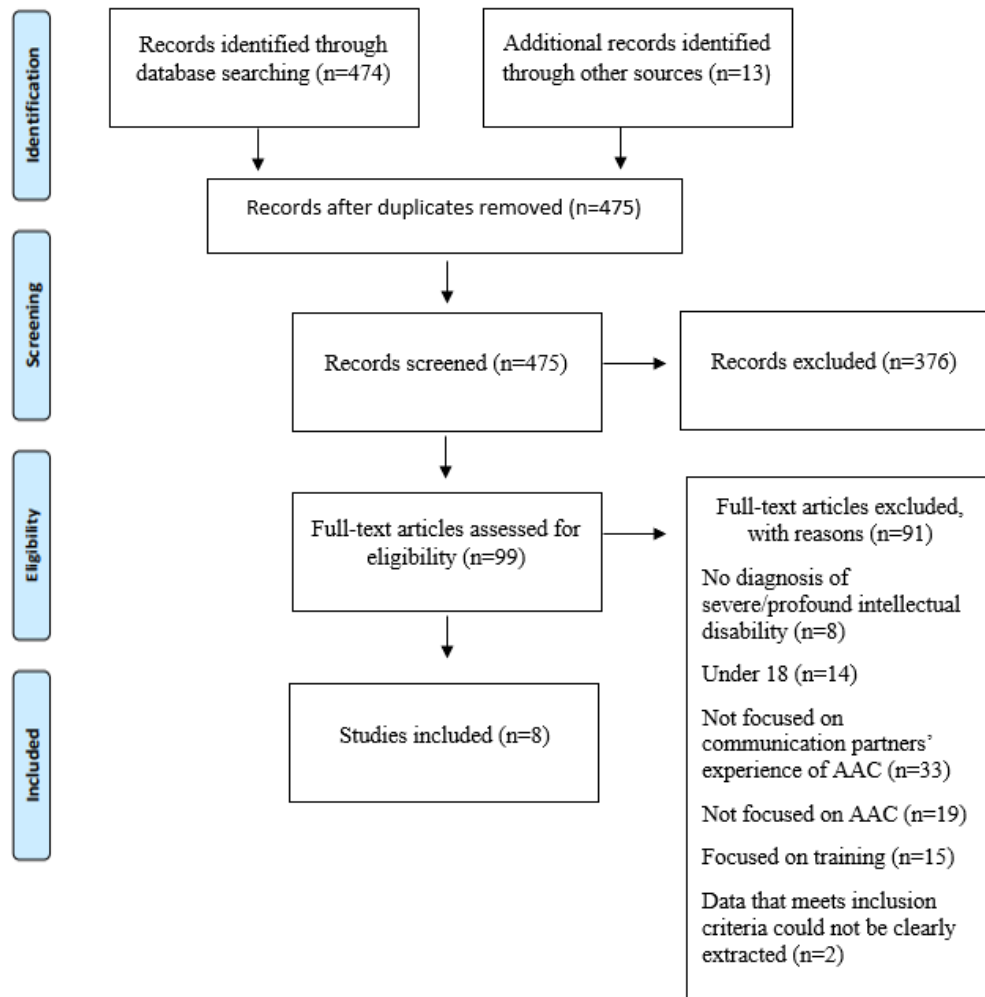
The person with severe/profound intellectual disability or profound/multiple intellectual disability is not over the age of 18.

Communication is not supported by AAC.

*Abbreviations: AAC, Augmentative and Alternative Communication.

The full text of the remaining 99 articles were assessed for eligibility. Eight of these 99 articles met the inclusion criteria. The rationale for excluding 91 full-text records is detailed in the PRISMA Flow Diagram (Figure 2.1). Any disagreements that arose between the researchers were settled through discussion.

Figure 2.1 PRISMA Flow Diagram



(Moher et al., 2009)

*Abbreviations: AAC, Augmentative and Alternative Communication

The studies that met the inclusion criteria were assessed for methodological quality using the Mixed Methods Appraisal Tool version 2018 (MMAT; Hong et al., 2018). The MMAT includes a total of 25 criteria and 2 screening questions. The MMAT was developed to appraise qualitative research, randomised control trials, non-randomised control trials, quantitative descriptive studies and mixed methods studies. The scoring system was removed from the 2018 version of the MMAT as it is advised to provide a more detailed presentation of the ratings of each criterion (Hong et al., 2018). Exclusion of papers with low methodological quality is not

encouraged. Therefore, before screening, the researchers' agreed that all studies regardless of the results of their methodological quality would undergo extraction and synthesis. The MMAT was applied by the researchers (EH, AMM, CD, EL). Any disagreements were discussed as a group. To improve the transparency in reporting the appraisal process, a summary of the MMAT results is included (Appendix 6).

2.2.5 Data Extraction

Data were extracted by the researcher (EH) and thesis supervisors (AMM, CD, EL). The data extraction was reviewed at a meeting with any disagreements discussed until they were resolved. The following information was extracted from all studies and documented in the data extraction form which included: (i) author, year, country (ii) research aim (iii) research approach and design (iv) sample approach, size, eligibility and setting (v) data collection methods (vi) data analyses (vii) key findings and conclusions (Table 2.2). Where studies collected data from communication partners of both adults and children, only data from the communication partners of adults were extracted.

Table 2.2 Summary of Data Extraction

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
1. Rombouts, Maes & Zink 2017 Belgium	Compare the views of direct support staff and SLTs who work with adults with intellectual disability of AAC	1. Qualitative 2. Descriptive study	1. Non-probability, Convenience 2. n=25 (9 SLTs, 1 OT, 15 direct support staff) 3. All professionals were supporting at least one adult with mild-severe intellectual disability who used AAC to communicate 4. Residential and day-care services	One-to-one interviews with a flexible question sequence	Thematic analysis	1. SLTs' believed that most clients would benefit from consistent use of KWS, direct support staff decided on AAC usage in the moment. 2. Both SLTs and direct support staff believed staff should encourage clients to use AAC, support staffs' responsibility to maintain their clients' KWS skills. There was a contrast in these values and the AAC use. 3. Support staff used AAC less when they knew

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
						the client well. Restricted AAC use led to communication partners making assumptions about the message the client was communicating. 4. Time as a barrier. 5. SLTs and support staff have expertise in supporting individuals' communication.
2. Rombouts, Maes & Zink 2016 Belgium	To examine the relation between key word signing attitudes and usage in support staff	1.Quantitative 2.Comparative, Correlational Design	1.Nonprobability, Convenience 2. n=24 (SLT or special educationalist and direct support staff) 3.12 adults with an intellectual disability were recruited with two communication partners. A SLT or special educationalist who had completed the official KWS training program and a direct	Each service user was filmed during a dyadic interaction with their communication partners A survey to measure professionals' attitude	Conversational analysis To determine which items scores could be added to find a scaled score, the interitem relations were explored using PCA on 234 pilot surveys Welch t tests to compare the three	1. All communication partners from 1HT and 2HT scored higher than four on all three scales (performance scale, effort scale, intention scale), suggesting that

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
			support staff with second hand KWS training 4.Group homes	towards KWS along with a single category Implicit Association Test (IAT)	scaled scores between 1HT and 2HT Independent samples t test analysed the between-group difference in implicit attitude scores Difference in proportion of signed utterances an ANCOVA was conducted Correlational measures investigated the relation between attitude and sign production	each communication partner had positive explicit attitudes. 2. Those with a more positive implicit attitude produced more signed utterances. There was no relation between explicit attitude and the number of signed utterances. 3. Training did not have a significant effect on signed utterances and KWS experience. Communication partners from 1HT did produce more KWS because they knew more signs.

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
3. Meuris, Maes & Zink 2014 Belgium	How many Residential Programs and Day Care Programs for adults with intellectual disability in Flanders use KWS with one or more clients? How many clients in these programs use KWS? How many signs do clients using KWS comprehend and produce? What is the relationship between different characteristics of support staff, clients and service providers and the sign knowledge of the	1.Quantitative 2.Descriptive, comparative, correlation design	1.Non-probability, Convenience 2. n=93 3.Provide services for adults with an intellectual disability 4.Residential and day care programs for adults with intellectual disability in Flanders (Dutch speaking part of Belgium)	A telephone survey and written questionnaire	Descriptive statistics Mann-Whitney U tests used for categorical predictors; Kruskal- Wallis H tests used to assess group differences with a continued outcome variable Chi-square tests used for categorical outcome variables FET was used if expected cell counts in a 2x2 table were fewer than 5 Spearman's correlation (rs) for continuous predictors with a continuous or binary categorical outcome variable	1. Support staff were estimated to understand and produce fewer signs when their clients had a more severe intellectual disability. The more severe their intellectual disability the fewer signs the clients understood and produced. 2. Support staff produced more signs when a SLT taught them KWS as opposed to a support worker. 3. 0.0% of participants had a negative attitude towards KWS. 5. Staff attitude was more likely

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
	support staff and their clients?					to be positive when KWS taught by a support worker over a SLT.
4. Wilder, Magnusson & Hanson 2015 Sweden	To discover professionals and parents' views and experiences who took part in online BLNs related to communication and AAC for persons with severe disability. Explore the role of BLNs as a way of facilitating participation, exchanging knowledge and learning between parents and professionals of persons with severe disability.	1.Qualitative 2.Educational intervention study and evaluation	1.Non-probability, Purposive 2. n=36 (15 parents; 13 mothers and 2 fathers of children/adolescents with profound and multiple intellectual disability, 21 professionals comprised of 20 females and 1 male) 3.Working as a professional was a requirement Parents of a child or adolescent with profound multiple intellectual disability 4.Swedish Family Care Competence Centre	Four groups participated in four discussion sessions and an evaluation session	Thematic analysis	1. Parents and professionals involved with these individuals' viewed communication and interaction with persons with severe disability from an “interactional approach”. 2. Important that person with intellectual disability is surrounded by supportive people and environment. 3. They recognise that individuals with severe disability

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
						are always communicating and interacting, and communication is a human right. 4. There was a focus on new technology, mainly iPads and apps. An iPad is easy to use, and portable, universal design discussed by all groups.
5. Patel, Roche, Coward, Meek & Harding 2018 UK	An evaluation of a training programme provided to staff to encourage supported communication environments for people with intellectual disability The STARS project was introduced with the aim to	1.Quantitative 2.A service evaluation	1.Non-probability, Purposive 2. n=4 (Provision A: 4 service users with severe and profound disability, aged between 55-79 and their support staff, 2 service users communicated non-verbally, 2 had very limited verbal skills) 3. Support staff of adults with intellectual disability 4.Residential homes	Observations of service users and staff were completed before, mid-way through and at the end of the programme. Staff were asked to informally comment on their confidence	Descriptive analysis	1. Staff had low confidence in using Makaton, both before the intervention started, and throughout the duration of the STARS project. Some staff had not used Makaton in previous roles or were unsure of

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
	support staff in implementing communication interventions, including AAC			with using AAC		specific Makaton signs. 2. Staff increased their use of objects of references. 3. Training and ongoing support offered to staff during the STARS project did not result in a regular communication environment.
6. Goldbart, Chadwick & Buell 2014 UK	What communication intervention approaches are most commonly used by SLTs working with children and adults with profound multiple intellectual disability? What rationales do SLTs give for selection and use	1.Quantitative 2.Explorative, Descriptive Investigation	1.Non-probability, Purposive and snowball 2 n=55 3.SLTs working with children and/or adults with profound multiple intellectual disability in the UK 4.Represented all apart from two of the Higher education institutions in the UK with qualifying programs	Surveys via email or post Was piloted by 3 SLTs in Manchester Metropolitan University	Simple descriptive and comparative statistics used to analyse quantitative data Conceptual content analysis for qualitative data collected from open ended questions Rationales identified from the content analysis were reviewed and grouped using thematic analysis	1. 77.1% (27) of respondents used objects of references with adults. 2. 14.3% (5) of respondents used switches with adults. 3. 42.9% (15) used communication passports with adults 4. 22.9% (8) used symbolic

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
	of these intervention approaches? To what extent do the rationales given by SLTs for decision making around intervention selection equate to the EBP framework?					interventions with adults. 5.The SLTs main rationale for using these interventions were the empowerment, development and behavioural preference of the client.
7. Johnson, Douglas, Bigby & Iacono 2010 Australia	What does social interaction look like for an adult with severe intellectual disability? Who comprises her social network? How are social relationships experienced by her social network members?	1.Qualitative 2.Constructivist Grounded Theory Case Study	1.Non- probability, Purposive 2.n=15 (1 central person with severe intellectual disability, 4 family members, 3 home support workers, 5-day support workers, 2 peers with an intellectual disability) 3.People Sandra could name when not in her presence, people with whom interactions were positive, people with whom an interaction lasted more than 15mins, people who were familiar/shared a special bond with Sandra 4.A family home setting and a day centre in Australia	Observations of Sandra over five months with field notes. Members of Sandra's social network were interviewed	Followed Charmaz's (2006) grounded theory guidelines Textual analysis Qualitative coding, line-by-line and examined for in vivo codes Questions applied to the data Focused coding as the data from each interview were compared and contrasted Metaphors developed	1. Communication varies across roles and domains, and this impacted on communication in different ways. 2. Social network was dense and knew each other to varying extents. 3. Relationship with social network was reported to be positive as

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
						members' experience enjoying the individual's company. 4. Love, personal satisfaction, feeling fortunate.
8. Wormnaes & Abdel Malek 2004 Egypt	To explore speech therapist knowledge and experiences of AAC. To identify training needs of speech therapists who work with persons with complex communication needs in Egypt	1.Quantitative 2.Descriptive, correlational study	1.Non-probability, Purposive 2.n=30 SLTs 3. Licensed speech therapists in Cairo, university graduated and working with people with intellectual disability and complex communication needs 4.The two main Cairo hospital clinics that provided medical assessment and treatment services as well as speech-language therapy Mostly privately owned special schools/centres offering programs for persons with intellectual disability and complex communication	52 item Likert type questionnaire with additional open-ended questions	Spearman p coefficients were used to determine any associations between respondent's evaluation of their own knowledge/importance of learning about AAC and when they graduated and duration /experience as a SLT A Mann-Whitney U test carried out to determine differences between work settings on the results of knowledge/importance of AAC	1.Only one respondent reported AAC worked very well for a person with mild intellectual disability. 2.Blissymbols were introduced in two cases where AAC was not being used, to young adults with severe intellectual disability as well as physical, visual and hearing impairments with the aim to increase

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
						<p>communication. Teachers and parents of these students/clients reported that AAC didn't work well.</p> <p>3. No respondents said that AAC was not important.</p> <p>4. Nine respondents felt that SLTs should not be involved in providing therapy to persons with certain types of disability that were associated with complex communication needs.</p> <p>5. SLTs who had received some information about AAC during undergraduate education</p>

Author, Year, Country	Research question or study aim	1.Research Approach 2.Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key Findings and conclusions
						believed their knowledge to be better than those who did not.

*Abbreviations: AAC, Augmentative and Alternative Communication; BLN, Blended Learning Network; EBP, Evidence Based Practice; KWS, Key Word Signing; SLT, Speech and Language Therapist; UK, United Kingdom

2.2.6 Data Transformation

Following the JBI convergent integrated approach for MMSR, the quantitative data were 'qualitised.' The quantitative data were 'qualitised' as codifying the quantitative data has a lower risk of errors compared to applying numerical values to the qualitative data (The JBI, 2014). 'Qualitising' the quantitative data was achieved by extracting data from quantitative studies and translating quantities into textual descriptions (Lizarondo et al., 2020). Once extracted, the quantities were translated into individual sentences to answer the research question. This was then pooled with the data that were directly extracted from qualitative studies (Stern et al., 2020). This allowed the quantitative and qualitative data to be combined (Hong et al., 2017).

2.2.7 Data Synthesis

Thematic synthesis was undertaken manually (Thomas & Harden, 2008). The synthesis of the results was carried out in three stages; (1) free line by line coding of the extracted data followed by (2) grouping of these codes into related areas to develop descriptive themes, then (3) developing analytical themes (Thomas & Harden, 2008). The assembled data were categorized and pooled together based on similar meanings to produce a set of integrated findings to answer the review question.

2.2.8 Research Integrity

Each researcher has the responsibility to make ethical decisions at each stage of the review process. Wager and Wiffen (2011) outline practical and ethical issues that need to be considered when planning and publishing a MMSR. These include avoiding plagiarism, providing transparency and ensuring accuracy.

In this review other people's words are indicated using double quotation marks and citation. It is acceptable to describe a person's work in your own words. To ensure transparency, those who worked on the review are acknowledged and statements regarding information about funding and competing interests are provided (Higgins & Green, 2008). Each researcher has the responsibility to ensure accuracy in data extraction. The results are presented without bias and review limitations outlined. Data extraction was clearly planned, disagreements were resolved through discussion and all researchers agreed on which data were to be included (Wager & Wiffen, 2011). This MMSR followed the JBI convergent integrated approach according to the JBI methodology for MMSR.

2.3 Results

2.3.1 Background of Included Studies

Eight studies met the inclusion criteria. Three of these were qualitative (Johnson et al., 2010; Rombouts et al., 2017a; Wilder et al., 2015) and five quantitative (Goldbart et al., 2014; Meuris et al., 2014; Patel et al., 2018; Rombouts et al., 2016; Wormnaes & Abdel Malek, 2004). Three studies were conducted in Belgium (Meuris et al., 2014; Rombouts et al., 2016; Rombouts et al., 2017a), two in the United Kingdom (Goldbart et al., 2014; Patel et al., 2018) and the remainder were conducted in Australia, Sweden and Egypt (Johnson et al., 2010; Wilder et al., 2015; Wormnaes & Abdel Malek, 2004).

All studies considered the experiences of either support staff (i.e., support workers, teachers, personal assistants) or facilitators who supported communication partners and AAC users (i.e., Speech and Language Therapists (SLT) and Occupational Therapists) with a total of 256 professionals participating in seven of the eight studies selected. One study did not specify how many staff were included

(Patel et al., 2018). Two (Johnson et al., 2010; Wilder et al., 2015) of the eight studies included both support staff and family members' (n = 19) views and one study (Johnson et al., 2010) included two peers as communication partners. Three studies used surveys and two studies used questionnaires as the data collection method. Meuris et al. (2014) used both written questionnaires and telephone surveys. Interviews were utilised by two studies. Observations were undertaken by two studies. Johnson et al. (2010) used both observations and interviews. Discussion sessions were held in one study (Wilder et al., 2015). Sample sizes ranged from 8 to 93 respondents.

2.3.2 Synthesis

Four major themes were identified relating to communication partners' experiences of communicating with adults with severe/profound intellectual disability through AAC: (1) Knowledge of AAC, (2) Attitudes and AAC Use, (3) Shared Commitment to Communication Partnership, and (4) Suitability of AAC (Appendix 7).

2.3.2.1 Theme 1: Knowledge of AAC

Theme one captures the sources from which communication partners acquired information and knowledge about AAC, the impact of training on their knowledge and the value of having knowledge in AAC. Four articles reported on knowledge of communication and AAC (Meuris et al., 2014; Rombouts et al., 2016; Wilder et al., 2015; Wormnaes & Abdel Malek, 2004)

2.3.2.2 Acquiring Knowledge about AAC

Communication partners acquired their information and knowledge about AAC through several resources.

Training provided by SLTs to support workers increased knowledge and use. Support staff knew and produced more signs when trained by a SLT (Meuris et al., 2014; Rombouts et al., 2016) or at an official training program (Rombouts et al., 2016) rather than a support worker. However, there were mixed reports about SLTs' preparedness to provide such training, where SLTs wanted more knowledge and training in AAC. Wormnaes and Abdel Malek (2004) reported that SLTs within their study wanted further training and education in AAC to support persons with complex communication needs. Thirty per cent (9/30) of their respondents suggested a need for training about signs or symbols (Blissymbols, sign language, Makaton, pictures, tangible symbols) for SLTs who wanted to support people with little or no functional speech. SLTs within this study introduced Blissymbols to individuals with sensory impairments, which were reported to be unsuccessful. Introducing abstract symbols to such individuals highlights a lack of expertise (Wormnaes & Abdel Malek, 2004) as those who have significant cognitive and language limitations may find abstract symbols challenging to use. This suggests that SLTs within this study required further training and education in the selection of suitable AAC methods for persons with severe/profound intellectual disability.

Providing AAC information to SLTs during their education was beneficial to their knowledge level. SLTs received information about AAC through undergraduate education, postgraduate training, colleagues, books, journal articles, conferences, seminars, courses, workshops or television (Wormnaes & Abdel Malek, 2004). The value of providing information to professionals during their undergraduate education was highlighted, where SLTs who had received this information evaluated their knowledge as greater than those who did not receive such information about AAC during their undergraduate education (Wormnaes & Abdel Malek, 2004). This

suggests that more in-depth, extensive training may improve knowledge of AAC and result in professionals who feel knowledgeable in the field.

2.3.2.3 Knowledge and AAC Use

The relationship between knowledge and AAC use was captured by two studies. Communication partners' knowledge about AAC could enhance or hinder AAC use (Rombouts et al., 2016; Wilder et al., 2015). A lower level of knowledge was considered a limiting factor to AAC use (Wilder et al., 2015). An enhanced knowledge of AAC led to increased use of AAC by communication partners (Rombouts et al., 2016).

To summarise, gaps in communication partners' knowledge of AAC may result in unmet communication needs of persons with severe/profound intellectual disability. The importance of training and education around AAC use with persons with severe/profound intellectual disability to enhance the communication partners' skillset is highlighted by the findings in this theme. SLTs have a fundamental role in facilitating AAC training. Therefore, they need to have sufficient training in and knowledge about AAC. Previous education about AAC may improve communication partners' ability to communicate with persons with severe/profound intellectual disability who use AAC, potentially increasing the likelihood of meeting the individual's communication needs.

2.3.3 Theme 2: Attitudes and AAC Use

This theme captures the interplay between communication partners' attitudes towards AAC, their personal characteristics and the relationship between attitude and AAC use. This theme includes findings from six studies (Johnson et al., 2010; Meuris et al., 2014; Rombouts et al., 2016; Rombouts et al., 2017a; Wilder et al., 2015; Wormnaes & Abdel Malek, 2004).

Available evidence indicates that communication partners' attitudes towards AAC was positive overall or at least they did not have a negative attitude towards AAC (Meuris et al., 2014; Rombouts et al., 2016; Wormnaes & Abdel Malek, 2004). Those who had a more positive implicit attitude produced more signed utterances. However, there was no relation between explicit attitude and the number of signed utterances (Rombouts et al., 2016). Wilder et al. (2015) highlighted communication partners' willingness to communicate as an important component in facilitating communication. Therefore, the available evidence would indicate that communication partners' attitudes towards and willingness to use AAC may improve AAC usage.

2.3.3.1 Communication Partners' Assumptions

While Johnson et al. (2010) found that knowing the individual with severe/profound intellectual disability was important to facilitate communication (Johnson et al., 2010), Rombouts et al. (2017a) identified that it could be a potential barrier to communication when communication partners make assumptions about what the individual is communicating (Rombouts et al., 2017a). When such assumptions were incorrect, the AAC user may not clarify their intended message resulting in misunderstanding (Rombouts et al., 2017a). In addition, when support staff knew the AAC user well, they felt there was less of a need for communication support. Consequently, the perceived need to use AAC was lowered and AAC use was less frequent. Direct support staff mainly used KWS when there was an acute need for communication support depending on each person's individual needs (Rombouts et al., 2017a). This could result in limiting AAC use (Rombouts et al., 2017a).

To summarise, communication partners' attitude may enhance or hinder AAC usage with adults with severe/profound intellectual disability. Communication partners' personal characteristics may promote AAC use with individuals that they support. Knowing the individual well was cited as an important factor in AAC use. However, this may also hinder AAC use should communication partners make assumptions about the intended message on the premise that they know what they are communicating. Such assumptions could pose as a potential barrier to communication opportunities for individuals with severe/profound intellectual disability.

2.3.4 Theme 3: Shared Commitment to Communication Partnership

The shared commitment to communication partnership is fundamental for effective and efficient use of AAC with adults with severe/profound intellectual disability. There are various factors that can enhance or hinder this commitment, including uncertain ownership of AAC roles and responsibilities, time constraints and the inclusion of communication partners in intervention planning.

2.3.4.1 Perceptions about Roles and Responsibilities

Communication partners have various roles and responsibilities in supporting persons with severe/profound intellectual disability communication through AAC (Rombouts et al., 2017a; Wormnaes & Abdel Malek, 2004). Skilled communication partners were acknowledged as having additional responsibility within the individual's environment (Wilder et al., 2015).

Uncertain ownership of responsibilities was cited as a limiting factor to effective communication for AAC users (Wilder et al. 2015). Communication partners' uncertain ownership could limit the individual's communication goals and overall progress of these goals (Wilder et al., 2015; Wormnaes & Abdel Malek,

2004). There was a disconnect between SLTs' perceptions of their roles, where some SLTs saw their role as supporting persons with severe/profound intellectual disability and complex communication needs while others did not (Wormnaes & Abdel Malek, 2004). More than half (52% n=15.6) of the SLTs provided speech therapy to people with severe intellectual disability and complex communication needs. However, 30% (9/30) of SLTs did not see the provision of therapy to persons with disabilities associated with complex communication needs as part of the SLT role (Wormnaes & Abdel Malek, 2004). The SLTs' believed psychiatrists should be responsible for working with people with severe or multiple disabilities and that AAC specialists should be responsible for working with those who do not gain from speech training (Wormnaes & Abdel Malek, 2004). Therefore, to ensure individuals with severe/profound intellectual disability communication needs are met, there needs to be a clear outline of each communication partner's roles and responsibilities in AAC use. From a professional perspective, a decision needs to be made regarding roles and responsibilities for training and knowledge about AAC and its use.

2.3.4.2 Professional and Family Members Input

Communication partners have different areas of expertise that contribute to the AAC intervention (Rombouts et al., 2017a). Support staff shared their expertise with SLTs and SLTs viewed this contribution as crucial for AAC implementation (Rombouts et al., 2017a). However, a gap in the inclusion of other communication partners was noted in two studies. SLTs worked with professionals and family carers but did not mention the views of these partners as often as expected when choosing an intervention (Goldbart et al., 2014) or co-operate with them to gather information as regularly as expected when developing supportive communication environments (Wormnaes & Abdel Malek, 2004).

2.3.4.3 Time

The importance of communication partners spending time with individuals with severe intellectual disability to learn how to interact with them was cited (Johnson et al., 2010). Therefore, partners need to have sufficient time to support individuals to communicate. However, time constraints were recognised to be a potentially limiting factor for effective AAC use with persons with severe/profound intellectual disability (Rombouts et al., 2017a; Wilder et al. 2015).

Time constraints were related to communication partners' workload, such as completing a range of tasks implemented by multiple stakeholders (Rombouts et al., 2017a). They led to difficulty in detecting subtle communication signs, resulting in missed opportunities for communication (Patel et al., 2018). Patel et al. (2018) stated that the difficulty in detecting subtle communication signs may be due to the higher demands of providing physical care. Skilled interpretation was needed to understand the individual's communication (Johnson et al., 2010) and it was a challenge to be persistent when communicating with individuals with delayed or subtle communication attempts (Wilder et al., 2015). Therefore, communication partners need sufficient time to recognise and interpret individuals' communication.

While SLTs understood that support staff had a high workload, they felt that their assessment of KWS and training as time demanding was unfair (Rombouts et al., 2017a). Investing time into consistently using AAC would result in less deliberation in the future resulting in time efficient supports (Rombouts et al., 2017a). In addition, the perceived time constraints were somewhat determined by the educational background of the staff. Support staff who had received care orientated education were not as involved in service users' communication needs, where a participant stated that carers' viewed care as their primary responsibility. Therefore, pre-service education may provide support staff with guidance for their role as

‘aided language stimulator’ (Rombouts et al., 2017a, p. 109) which may help to further enhance their understanding of the continued and consistent use of AAC.

Communication partners hold different roles and responsibilities in meeting the communication needs of a person with severe/profound intellectual disability through AAC. However, lack of ownership of such roles and responsibilities may result in limited communication for persons with severe/profound intellectual disability. The inclusion of all communication partners in deciding on an intervention may lead to increased understanding and ownership of roles and responsibilities in AAC use. To strengthen the shared commitment to communication partnership it is important that each person is aware of their individual roles and responsibilities in the design, planning and use of AAC.

2.3.5 Theme 4: Suitability of AAC

Certain methods of AAC were deemed more suitable in meeting the complex communication needs of adults with severe/profound intellectual disability than others.

2.3.5.1 Promoting Acceptance

Two studies found that certain methods of AAC use were reported to encourage inclusion and participation (Goldbart et al., 2014; Wilder et al., 2015). For most respondents, switch use was a route to intentional communication for persons with severe/profound intellectual disability or increased participation and interaction (Goldbart et al., 2014). Similarly, iPads were discussed as being able to overcome boundaries as they are well known and can improve acceptance and encourage inclusion (Wilder et al., 2015). Introducing a method of AAC that improves acceptance could increase the use of AAC with the person with severe/profound intellectual disability in different environments.

One study highlighted the suitability of objects of references for supporting individuals (Goldbart et al., 2014). Objects of reference were the most used method of AAC with adults with profound and multiple intellectual disability within one study (Goldbart et al., 2014). They were deemed important to support service users' understanding and encourage choice making (Goldbart et al., 2014). The importance of objects of reference for people with sensory impairment, specifically visual impairment was mentioned by 25% (9/36) of SLTs (Goldbart et al., 2014).

2.3.5.2 Individuals' Communication Needs

The importance of recognising individuals' communication needs emerged from five studies. The ability and needs of individuals with severe/profound intellectual disability need to be considered when introducing AAC. This was evident where SLTs main rationale for the introduction of AAC was the 'empowerment, development and behavioural preferences' of the service user (Goldbart et al., 2014).

The more severe the level of intellectual disability, the fewer KWS the person with intellectual disability were estimated to understand and produce (Meuris et al., 2014). Despite this, signing systems were used with people with severe/profound intellectual disability in five studies (Goldbart et al., 2014; Meuris et al., 2014; Patel et al., 2018; Rombouts et al., 2017a; Rombouts et al., 2016). In addition, support staff produced less signs when the service users had severe intellectual disability (Meuris et al., 2014). This impacts on the communication opportunities of persons with severe/profound intellectual disability who communicate through signs.

Symbolic approaches were reported as having the potential to be very motivating for persons with sufficient vision (Goldbart et al., 2014). However, Blissymbols were introduced to adults with severe intellectual disability and sensory

impairments including visual impairments, teachers and parents reported AAC did not work well in these cases (Wormnaes & Abdel Malek, 2004).

The AAC chosen and used must be tailored and suitable to each person's individual need.

2.4 Discussion

This review aimed to explore communication partners' experiences of communicating with adults with severe/profound intellectual disability through AAC.

Findings suggest that increased use of AAC could be aligned with communication partners' increasing knowledge. Limited knowledge indicated lower usage. This finding is similar to Beukelman et al. (2008) where AAC success or failure was somewhat dependent on communication partners' knowledge. In addition, in their Egyptian study, Wormnaes and Abdel Malek (2004) found that SLTs who received training during their undergraduate education felt more confident using AAC and those who believed they were more qualified in AAC supported more service users to use AAC (Wormnaes & Abdel Malek, 2004). In the hope of improving professionals' knowledge of AAC, training other professionals, such as teachers and healthcare professionals in AAC during their undergraduate education may further improve the provision and use of AAC with this population. The requirement for pre-service and in-service education in AAC has been repeatedly advocated in the literature (Balandin & Iacono, 1998; King, 1998; Simpson et al., 1998; Sutherland et al., 2005; Wormnaes & Abdel Malek, 2004). In addition, Lund and Light (2007) stated that knowledge barriers could be reduced by ensuring service providers are trained in AAC. By reducing knowledge barriers of service providers,

persons with complex communication needs will have better access to experienced professionals (Lund & Light, 2007).

Similarly, communication partners need to have knowledge of AAC systems, services and a skillset in interaction strategies to provide suitable support (Kent-Walsh et al., 2010). A need for training relating to suitable methods of AAC for adults with severe/profound intellectual disability and complex communication needs was identified. This is reflected in SLTs introduction of Blissymbols to individuals with sensory support needs (Wormnaes & Abdel Malek, 2004). This highlighted a potential knowledge gap as some individuals who have significant cognitive and language limitations have difficulty using abstract symbols (Wormnaes & Abdel Malek, 2004). They benefit from expressing themselves using fewer abstract representations such as objects (Light et al., 2019b). Objects of reference were reported to be successful when used (Goldbart et al., 2014). In addition, signing systems were used in five studies (Goldbart et al., 2014; Meuris et al., 2014; Patel et al., 2018; Rombouts et al., 2017a; Rombouts et al., 2016). However, as severity of intellectual disability increased, communication partners estimated that fewer KWS were understood and produced by the individual (Meuris et al., 2014). This finding highlights the importance of having knowledge of AAC techniques that are individualised to each person and their needs. This concurs with the wider literature about feature matching, where team members work to match the individuals who require communication supports with the AAC (Ogletree, 2021). Having an awareness of an individual's complex communication needs may optimise the selection of suitable interventions that will offer each person the equal opportunity to communicate.

Individuals with severe/profound intellectual disability have complex and specific communication needs, therefore interventions should be specific to these needs. A person-centred and individualised approach to supporting communication is recommended. One way of achieving this is to develop personal support plans to maximise individual's human functioning dimensions (Schalock et al., 2021b). In addition, the Supports Model concentrates on the match between individuals and their environments, whereby disability is "*the expression of limitations in individual functioning within a social context*" (Schalock et al., 2021b, p382). In line with the Supports Model, strategies and resources need to promote individual's development and interests as well as enhance their well-being. Such support systems need to be person-centred, outcome oriented, co-ordinated, comprehensive, include choice, inclusive environments and both generic and specialised supports (Coulter, 2005; Schalock et al., 2019; Shogren et al., 2018; Stancliffe et al., 2016; Thompson et al., 2014). In addition, support plans should match an individual's needs (Schalock et al., 2018). It is recognised that it is challenging (Munde & Vlaskamp 2015) to develop interventions that match individuals' abilities and needs. Therefore, the form of AAC used should be reflective of communication and functional needs of the individual AAC user.

The role of the SLT in training communication partners in AAC and improving their skillset was highlighted. Both support staff and service users knew more signs when they were taught by a SLT compared to a support staff. This is important as the success of interactions of persons using AAC is dependent on their own skills and that of their communication partners (Kent-Walsh & McNaughton, 2005).

There is agreement in the literature that AAC is a team approach that includes multiple stakeholders (De Paepe & Wood, 2001; Beukelman et al., 2008; Ogletree, 2021). Everyone who uses AAC with the individual should be involved in the team (ASHA, 2002). In addition, collaboration between team members can result in positive outcomes for AAC users and their family members (Lund & Light, 2007) and facilitate AAC success and implementation (Uthoff et al., 2021). The uncertain ownership of AAC roles and responsibility is a key finding of this review (Wilder et al., 2015; Wormnaes & Abdel Malek, 2004). This can lead to limited provision and use of AAC with adults with severe/profound intellectual disability. Firstly, SLTs' uncertainty around providing support to persons with complex communication needs indicates that potentially, services may not be provided. This finding arose from an Egyptian study and therefore, should be considered within this cultural context. Furthermore, a participant in Lund and Light's (2007) qualitative study discussed encountering a number of SLTs who did not think AAC was part of their profession. This suggests that a lack of clarity around professional responsibility may lead to inconsistency in access to certain services, which could result in unmet communication needs for persons with severe/profound intellectual disability. Therefore, all team members need to be aware of their own and other team members roles and responsibilities when supporting individuals to communicate through AAC.

The findings of this review indicate that collaboration between stakeholders is sub-optimal to what is recommended. Family views and wishes did not inform the rationale for certain AAC methods used by SLTs (Goldbart et al., 2014) and SLTs did not gather information from parents within natural settings (Wormnaes & Abdel Malek, 2004). This concurs with the literature that family carers felt that they were

not included by professionals in decision-making about their family members lives (Chadwick et al., 2013; Goldbart & Canton, 2010). In line with the recommended use of a holistic approach, teams are required to ensure multiple perspectives are heard and included (Schalock et al., 2021b). In addition, the actions in the Supports Model outline the importance of working with the individual and their family to develop personal goals, support needs and strategies (Schalock et al. 2021b). Similarly, there is an increased recognition of the need to facilitate family centred care in the field of intellectual disability. The importance of collaborative, family centred AAC decision-making is repeatedly documented within the literature (Angelo, 2000; Bailey et al., 2006; Sonnenmeier et al., 2005; Soto et al., 2001).

A greater number of individuals are seeking and receiving AAC services than ever before due to more individuals presenting with complex communication needs and families and professionals recognising the positive impact of AAC (Light et al., 2019b). Therefore, it is important that family members and all other appropriate communication partners are involved in the design, planning and use of AAC with and for the person with severe/profound intellectual disability with the intention of increasing their awareness of its importance and their roles and responsibilities. Similarly, De Geeter et al. (2002) suggest that parents take on more responsibilities when they are actively involved in making decisions.

Including all appropriate communication partners in the decision-making process may further increase their understanding of their responsibilities, therefore leading to an increase in their ownership of such responsibilities and potentially facilitating a collaborative AAC approach. It is recognised that responsibilities of stakeholders can vary and be shared when a collaborative relationship is developed (Beukelman et al., 2008).

The findings of this MMSR indicate that clarity is required about the roles and responsibilities of all communication partners of individuals with severe/profound intellectual disability involved with AAC use. Given communication partners' fundamental role in supporting individuals with severe/profound intellectual disability AAC use, uncertain ownership of roles and responsibilities creates an impediment to meeting their communication needs. Further research is required to explore communication partners' perceptions of their roles and responsibilities and those of other communication partners when implementing AAC and supporting persons with severe/profound intellectual disability to communicate and interact. From a practical standpoint, understanding communication partners' perceptions of their roles and responsibilities and those of other partners involved could be valuable for facilitating collaboration between all stakeholders involved. Having knowledge of such perceptions could help to inform organisational policy and direct the future of AAC implementation with persons with severe/profound intellectual disability and their communication partners.

2.4.1 Strengths and Limitations of the Review

The findings of this MMSR should be considered in the context of its limitations. The risk of bias was increased by not publishing the review protocol. Language biases may have been introduced as the studies were only published in English, which may have led to relevant studies being missed. Psychology databases were not included. It is recognised that they can cover papers of interest on this topic. However, in consultation with the subject librarian seven databases were selected based on the 'fit' with the review topic and the return of relevant results.

The presence of strengths within this MMSR are also acknowledged. The researcher and a thesis supervisor screened the title and abstract of the articles and

assessed the full text articles for eligibility. Selection bias was not a feature of this MMSR as all studies were included regardless of their quality rating using the MMAT. The thematic synthesis process was robust. The translation process, through the development of descriptive and analytical themes was done in a rigorous way that ensured transparency in reporting the results (Thomas & Harden, 2008).

2.5 Conclusion and Implications

This review provides insight into the experiences of communication partners who communicate with adults with severe/profound intellectual disability through AAC. There is a disconnect between communication partners' perceptions of their roles and responsibilities in the use of AAC with adults with severe/profound intellectual disability. Clarity is required about the roles and responsibilities of each communication partner using AAC with adults with severe/profound intellectual disability to increase the likelihood of the individual's communication needs being met. Therefore, further research is required to explore communication partners' perceptions of their roles and responsibilities in AAC use with this population to advance understanding, improve communication partnerships and practice.

To address the research gap identified in this review, a qualitative descriptive study was undertaken to explore communication partners' perceptions of their roles and responsibilities in the design, planning and use of AAC. The qualitative descriptive study is presented in Chapter 3.

Chapter 3. Communication Partners' Perceptions of their Roles and Responsibilities in the Design, Planning and Use of Augmentative and Alternative Communication with Persons with Severe or Profound Intellectual Disability: A Qualitative Descriptive Study

Abstract

Background

This study explores communication partners' perceptions of their roles and responsibilities in the design, planning and use of AAC with persons with severe/profound intellectual disability.

Method

A qualitative descriptive approach was used. Purposive sampling, data collection and qualitative content analysis were undertaken simultaneously. Data were collected from nine participants, four parents and five professionals over four months through audio or video recorded, semi-structured, open-ended interviews.

Results

An overarching theme 'Maximising Communication through AAC' emerged, capturing participants unanimous agreement that their shared goal was to optimise the individuals' communication through AAC. This was influenced by three themes; 'Developing a Communicative Environment', 'The Act of Communicating; Attempting to Realise the Individuals' Ability' and 'Living with Uncertainty'.

Conclusion

These findings contribute to enhancing understanding of AAC use with individuals with severe/profound intellectual disability and their communication partners.

Keywords: augmentative and alternative communication; communication;
communication partners; qualitative research; severe or profound intellectual
disability

3.1 Introduction

Communication is a fundamental human right (Brady et al., 2016).

Individuals with severe/profound intellectual disability experience communication difficulties (van der Gaag, 1998) and therefore, face challenges securing this right. They tend to function at the earlier stages of communication development (Coupe O’Kane & Goldbart, 1998) demonstrating subtle communication behaviours such as eye gaze, body language and facial expression (Grove et al., 1999). These behaviours can be individual to the person and context (Stillman & Siegal-Causey, 1989). They require additional supports to enable them to secure their right to communication.

The focus of this study is on communication partners of individuals who communicate at the earlier stages of communication developmental. The 11th edition of the ICD (WHO, 2022) definition of intellectual disability was used to include persons with severe/profound intellectual and/or multiple disabilities.

This populations’ QoL may differ as they require support from others to help them meet their needs (Petry et al., 2005). Supporting communication and social interaction may help to increase participation and thus, improve their connectedness, independence and QoL (Dammeyer & K ppe, 2013). Social relationships are also recognised as a key element of QoL (Petry et al., 2005). Supporting peoples’ communication to promote both the development and maintenance of social relationships may help them to meet their needs and attain their rights (Brady et al., 2016). Strategies must be provided to support individuals with severe/profound intellectual disability to communicate.

AAC has potential to support communication for persons with severe/profound intellectual and multiple disabilities (Roche et al., 2015; Wood & Standen, 2021). AAC requires a collaborative approach including multiple stakeholders (Binger et al., 2012; Calculator et al., 2009; Uthoff et al., 2021) who

have different roles and responsibilities. Clearly defining roles may help team members to realise that responsibilities are shared (Binger et al., 2012).

Communication partners are the people who engage with the person in an interaction. They may be family, friends, and support workers (Johnson et al., 2009). AAC success is dependent on both the user and their communication partners (Kent-Walsh et al., 2015; Light et al., 2019a).

Despite their fundamental roles and responsibilities in supporting the success of AAC, the literature suggests there is a disconnect between communication partners' perceptions of their roles and responsibilities in supporting AAC implementation with persons with severe/profound intellectual disability (Hanley et al., 2022; Wormnaes & Abdel Malek, 2004). This creates an impediment to effective communication for AAC users (Wilder et al., 2015). Thus, this study explored communication partners' perceptions of their roles and responsibilities when implementing AAC with persons with severe/profound intellectual disability. The following questions were posed:

(1) What are communication partners' perceptions of their roles and responsibilities in the use of AAC when communicating with persons with severe/profound intellectual disability?

(2) Who do they believe should be involved in the design, planning and co-ordination of AAC with persons with severe/profound intellectual disability?

3.2 Methods

3.2.1 Study Design

Ethical approval was gained from the Social Research Ethics Committee, University College Cork (Log 2020-131, Appendix 8) and the Service-Providers Research Committee (Appendix 9). An interpretivist paradigm following naturalistic

methodology underpinned the study. Therefore, a qualitative descriptive approach was followed (Sandelowski, 2000; Sandelowski, 2010). The Standards for Reporting Qualitative Research (Appendix 10) were used to report the study (O'Brien et al., 2014).

3.2.2 Participant Recruitment

Purposive sampling, specifically typical case sampling was adopted to ensure communication partners of persons with severe/profound intellectual disability, communicating with AAC were represented in the final sample (Robinson, 2014). To be eligible, communication partners were required to be paid or familial partners, communicating with a person with severe/profound intellectual disability using AAC and knew the individual for at least six months.

The researcher liaised with the Service Provider's Gatekeeper to identify eligible participants. The service provides supports to persons with intellectual disability and autism and their family members. Potential participants were sent the information sheet (Appendix 11) and consent form (Appendix 12). Once the signed consent forms were received, interviews were scheduled.

3.2.3 Data Collection

Data were collected using semi-structured interviews with open ended questions between November 2020 to March 2021. The findings from a systematic review (Hanley et al., 2022) informed the topic guide (Appendix 13). Two pilot interviews were conducted, and one question was rephrased. Interviews were conducted online via Microsoft Teams due to public health guidelines around Covid-19. The interviews were recorded with the participants' consent to allow the interviewer to build rapport rather than being distracted with note taking (Edwards & Holland, 2013). Interviews lasted between 27-45 minutes. The sample included nine

participants. Two participants were interviewed together as they were more comfortable with this. Both participants were asked about their individual perspective. Supports were in place throughout the process and each participant was debriefed (Appendix 14).

3.2.4 Data Analysis

The interviews were transcribed verbatim and anonymised by the researcher. Data were analysed using inductive content analysis, including three phases: preparing, organising, and reporting (Elo & Kyngäs, 2008). During the preparation phase, it was decided that both manifest and latent data would be analysed to take note of silences, sighs etc. (Burns & Grove, 2005). The written material was read and re-read, the recordings were listened to and watched multiple times (Grove et al., 2013). The material was read through, listened to, and watched again during the organisation phase. During this process notes and headings were written down to describe the content (Hsieh & Shannon, 2005). Meaning units were generated and condensed further. Both the meaning units and their condensed versions were transferred to open coding sheets (Appendix 15).

Sub-categories and categories were generated. Categories were grouped under headings (McCain, 1988). Data were classified as 'belonging' to a certain group and comparisons made (Dey, 1993). In the reporting phase, results were described by the content of the categories describing the phenomenon (Elo et al., 2014). The analysis was undertaken by the researcher (EH). The researcher was in continuous dialogue with the supervisory team (AMM, CD, EL) to reach agreement on the labelling of the data (Graneheim & Lundman, 2004). An example of this process is represented in Table 3.1.

Table 3.1 Example of Analysis

Meaning Unit	Condensed Meaning Unit	Code	Sub-Category	Category	Sub-Theme	Theme	Overarching Theme
“So, I always try to look at what they have and then build on that.” (Interview 3)	Look at what they have and build on that	Build on the individuals’ communication	Building on the Individuals’ Existing Ability	Recognising Individuality	Enhancing the Individuals’ Potential for Success	Developing a Communicative Environment	Maximising Communication through AAC

*Abbreviation: AAC, Augmentative and Alternative Communication

3.2.5 Trustworthiness

The researcher, aimed to remain mindful of her influence as a registered nurse in intellectual disability on the research study. Continuous self-reflection and a reflexive approach helped to identify and articulate the researcher’s positionality (Holmes, 2020). The researcher wrote reflective entries (Appendix 16) (Connelly, 2016) and memos (Appendix 17). Credibility was enhanced by taking field notes after every interview (Elo et al., 2014). The supervisory team, (AMM, CD, EL) reviewed the codes and analysis to enhance credibility and confirmability (Cope, 2014). Confirmability was enhanced further by including quotes when reporting the results (Cope; 2014; Graneheim & Lundman, 2004). Dependability was enhanced by using audit trails (Bailey, 2018; Cope, 2014) and debriefings with the supervisory team (Connelly, 2016). Data collection was described in detail to enhance transferability (Graneheim & Lundman, 2004; Stahl & King, 2020) and information was provided about the participants and research context (Connelly, 2016; Cope, 2014).

3.3 Results

3.3.1 Sample Characteristics

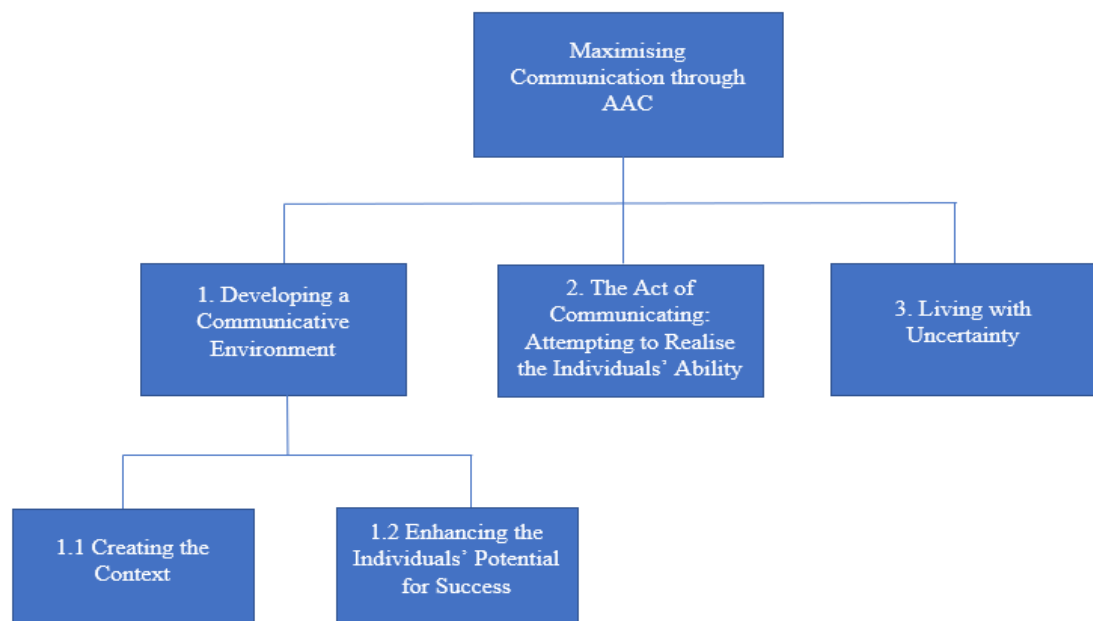
Participants included four familial partners whose children attended the service and five professional partners working in the service. Of the familial partners, three mothers and one father participated. Their children ranged between 8 to 20 years of age with two males and one female. Two children attended school and a young adult attended an educational day service for students transitioning from school within the service. The familial partners discussed multiple types of AAC that they used which differed at times for each child, examples include Lámh, PECS, eye-gaze devices, iPads, and pictures.

The professional partners included a teacher working in an educational day service for students transitioning from school, a healthcare assistant (HCA) who was an activity co-ordinator and a clinical nurse specialist (CNS) who were working in the intellectual disability service with adults. Two SLTs were included as they have a fundamental role in implementing AAC. The SLTs had experience in both early intervention and adult services. The teacher discussed his use of an eye-gaze device with a young adult with severe intellectual disability. The remainder of the professional partners discussed their use of AAC with multiple individuals with severe/profound intellectual disabilities that they supported. Some examples of AAC used include Lámh, visual supports, PECS, pictures of reference, board maker pictures and eye-gaze devices.

Following an in-depth analysis, the overarching theme; ‘Maximising Communication through AAC’ emerged and was influenced by; 1) ‘Developing a Communicative Environment’, 2) ‘The Act of Communicating: Attempting to Realise the Individuals’ Ability’ and 3) ‘Living with Uncertainty’.

Developing a Communicative Environment comprises two sub-themes: (i) ‘Creating the Context’ and (ii) ‘Enhancing the Individuals’ Potential for Success’ (Figure 3.1).

Figure 3.1 Visual Representation of the Themes and Sub-themes



*Abbreviation: AAC, Augmentative and Alternative Communication

Each theme is comprised of categories and sub-categories (Table 3.2).

Table 3.2 Summary of Sub-Categories, Categories and Themes

Sub-Category	Response Count		Category	Sub-Theme	Theme	Overarching Theme
	Prof. Partner	Fam. Partner				
Assessing the Environment and the Communication Partners within it	n=3	—	Creating Opportunities for Communication	Creating the Context	Developing a Communicative Environment	Maximising Communication through AAC
Training Communication Partners	n=5	n=2				
Availability of AAC	n=4	n=3				
Sharing Information about the Individuals’ Communication Methods	n=4	—				
Building a Relationship of Trust	n=2	n=1	Maximising Collaboration and Co-operation	Enhancing the Individuals’ Potential for Success		
Regular Communication is Required	n=2	n=4				
A Reciprocal Relationship	n=5	n=4				
Knowledge of the Individual	n=4	n=1	Recognising Individuality			
Selecting AAC Informed by Individuality	n=5	n=4				
Trialling AAC	n=2	n=1	Techniques to Facilitate Individuals’ Use of AAC			
Training the Individual to Use AAC	n=3	—				
Identifying the Individuals’ Progress	n=4	n=2				
Repetitive and Consistent Use	n=5	n=2	Facilitating Continuity of Communication			
Multiple Forms of AAC	n=3	n=2				
Consistency of Staff	n=1	—				

Sub-Category	Response Count		Category	Sub-Theme	Theme	Overarching Theme	
	Prof. Partner	Fam. Partner					
Offering Time and Space	n=5	—					
High Workloads	n=2	n=1					
Offering Choice	n=2	n=1					
Communication Partners' Investment	n=2	—	Communication Partners' Characteristics				
Communication Partners' Expectations	n=3	n=1					
Communication Partners' Assumptions	n=2	n=3					
Uncertainty of Individuals' Potential	—	n=1	Uncertainty is Common amongst Communication Partners		Living with Uncertainty		
Uncertainty around Funding	—	n=3					
Uncertain around Individual's Communication Technique in School	—	n=1					
Communication Partners may be Uncertain if they are Using AAC Correctly	—	n=1					

*Abbreviations: AAC, Augmentative and Alternative Communication; Prof., Professional; Fam., Familial

3.3.2 Maximising Communication through AAC

Participants' roles and responsibilities varied between the different types of communication partners and the nature of their relationship with the AAC user. Both SLTs and the CNS identified their roles and responsibilities primarily in the provision of training, assessment, selection of AAC and reviewing the system. The CNS discussed her role in running regular groups with individuals who used AAC. These groups were disrupted by the Covid-19 lockdown. A teacher, HCA and parents identified their roles and responsibilities in implementing AAC, ensuring it was used, reporting issues to the person who introduced the system and providing feedback. Although roles and responsibilities differed, there was unanimous agreement that they shared the role to support individuals to communicate to the best of their ability. Therefore, the shared goal, regardless of roles, was to maximise communication through AAC. Seven participants mentioned this as their role. *"Being a SLT it's communication, it's empowering that person and everyone around them so they can communicate..."* (SLT, I4).

My role is to give her the best opportunity that we can... that she can try to communicate in the best way that she can... So my role is to give her the best we can so that you know she feels like she can be heard... (Mother, I6)

Participants witnessed the potential of AAC to support individuals to communicate. Participants discussed the progress that individuals can and did make through AAC, where their voices were being heard. However, participants stated that their voices need to be heard more. Participants were hopeful that AAC would further support individuals with severe/profound intellectual disability to communicate. This hope was reflected in their attempts to realise the shared goal.

3.3.3 Theme One: Developing a Communicative Environment

This theme outlines a preparatory phase to develop an optimal communication environment, comprising two sub-themes: (i) ‘Creating the Context’ and (ii) ‘Enhancing the Individuals’ Potential for Success’.

3.3.3.1 Sub-theme One: Creating the Context

‘Creating the Context’ outlines the steps taken to create the context for a communicative environment, comprising of factors that were extrinsic to the AAC user. It relates to preparatory work involving creating opportunities for communication and maximising collaboration and co-operation.

3.3.3.1.1 Creating Opportunities for Communication

Both SLTs and the CNS identified assessment as part of their role. They assessed the environment to identify communication opportunities. They discussed the importance of assessing partners’ understanding of communication and AAC. The next step looked to creating more opportunities within the environment.

Both SLTs and the CNS discussed their role in training communication partners to ensure they were prepared to support the individual to communicate. They tried to increase partners’ awareness and understanding of persons with severe/profound intellectual disability communication attempts. They recognised that AAC may be difficult to use so partners needed to be trained to use it. Training was valued by a number of participants who received it from either the SLTs or the CNS. In addition, one SLT identified that all communication partners had the responsibility to be trained in AAC to support the individual.

Both SLTs and the CNS highlighted the importance of drawing communication partners’ attention to subtle, non-verbal communication cues to ensure that they recognise more subtle or nuanced non-verbal communication.

...they might not be speaking or using gestures to communicate but like kind of drawing their attention to those real subtle nonverbal cues that the client is using...showing them that even though they might seem absolutely tiny but that's really important to that person, that's them communicating what they want....

(SLT, I4)

Similarly, a HCA stated that there are different ways to communicate, outlining the importance of recognising communication techniques to provide support.

Communication partners' attitudes towards AAC and training were discussed by one participant. They discussed the importance of invested communication partners who were willing to learn. However, in the past the participant had met partners who had received training but did not apply it in practice, stating that sometimes people have a way of communicating that is difficult to change. In contrast, both SLTs stated that if there was an incidence where AAC was not being used it may be due to limited knowledge. Therefore, they would offer support or further training.

Communication partners having previous education and knowledge in communication and AAC facilitated teamwork, as there was recognition that the role was not just the SLTs. Government bodies and policy documents were recognised for such developments. One mother also believed that Lámh was easier to use due to her existing knowledge in Irish Sign Language.

Some participants stated that they were not aware of AAC before meeting with the SLTs, highlighting the value of training in increasing their awareness and knowledge of AAC.

The impact of knowledge gaps was indicated where communication supports were discarded as it was not understood that they could be updated. Additionally, one participant seemed unaware of the types of AAC they were using, stating that they were not currently using AAC. However, they were using Lámh and PECS.

A further knowledge gap was discussed by a HCA who identified the need for education for communication partners to increase their confidence and awareness of the time it takes to implement AAC with this population. She discussed other staff members who used AAC a few times and felt it did not work. This participant also highlighted the need for education on different syndromes to enable communication partners to provide more individualised support.

The provision of Lámh training by the service provider was discussed by six participants. Lámh training was provided to two mothers of individuals where one individual could not form signs independently and the second did not understand Lámh, therefore did not sign. Alternative AAC strategies were then implemented. Training communication partners in AAC that is not individualised to the users' needs may limit communication opportunities.

Two participants discussed the need to look at where individuals were networked, to ensure the network members were trained and had a suitable skill set. Staff transitions resulted in further monitoring of the network to ensure new members had a suitable skillset. Larger areas with more members resulted in a longer time to provide training.

Four participants identified the importance of sharing information about how the individual communicates. This is an extension of recognising communication. Similar to training, it acted as a strategy to increase communication partners' understanding of individuals' communication. Information was shared through

spoken word, communication passports and profiles. *“Yeah, that’s the problem, I might have all the information but if I retired it would be lost so the communication profiles are great then.”* (HCA, I5).

Availability of AAC was discussed by seven participants. AAC was more available in recent years. However, four participants discussed the challenges securing funding and investment in high-tech AAC. Insufficient funding hindered the availability of AAC at home for two individuals with severe intellectual disability. Further, although a device was physically available to an individual, software issues resulted in delays and interruptions which sometimes led to frustration for the user. A teacher discussed that he was able to fix these issues, but the individual may not be able to rectify them himself.

3.3.3.1.2 Maximising Collaboration and Co-Operation

A second category in this subtheme of ‘Creating the Context’ captures the role of collaboration and co-operation between communication through teamwork. Trust was considered foundational to facilitate collaboration and co-operation among communication partners.

Collaborative and co-operative work was demonstrated in a variety of ways, including regular communication between the individual's communication partners and communication partners’ reciprocal relationship to facilitate teamwork. Regular communication was important to ensure everyone was up to date and informed of the targets and plans. Teachers were seen to have a liaison role, which was valued by parents and a SLT.

During Covid-19 restrictions, one parent stated that she communicated with communication partners through email and WhatsApp. Another participant stated that the lockdown had a negative impact on communication with

SLTs. She discussed the need for more regular and structured communication to progress towards the AAC goals.

Participants held different expertise and experience both with the individual they supported and in AAC. They took ownership of their own roles and responsibilities and respected the roles and responsibilities of the other partners involved. They helped each other, whereby the SLTs and CNS shared their professional experience and expertise in AAC, and familiar partners shared their personal experience with the AAC user. This collaborative approach was highlighted by seven participants. *“Yeah, so like I was working with Paul for the device let’s say, but then Mom and Dad were working on the picture at home as well, so we’re kind of all working on the same goal together.”* (SLT, I4).

A teacher, HCA and parents acknowledged the SLTs and CNS expertise in communication and AAC. They acknowledged the SLTs’ role in the provision of training, selecting AAC, making it available and reviewing an issue. Conversely, the SLTs and the CNS acknowledged the role of partners such as teachers, nurses, HCAs, and parents in sending referrals for assessments, helping them to get to know the person, selecting pictures for the systems used, using AAC and providing feedback.

The CNS also identified her role in reviewing issues with AAC, however she stated that she would contact the SLT for advice with devices. Both SLTs and the CNS also discussed their positive relationship with the AAC providers (the company and their reps.) and their importance when implementing AAC and reviewing issues they could not rectify themselves.

Multidisciplinary team involvement was deemed important.

The behaviour support team, occupational therapists, physiotherapists, nurses,

special needs assistants, visiting teachers and dual sensory impairment practitioners were mentioned outside of the team members that were interviewed.

3.3.3.2 Sub-theme Two: Enhancing the Individuals' Potential for Success

The second sub-theme includes factors intrinsic to the AAC user, relating to engagement with the individual when developing a communicative environment.

Recognising Individuality

Each person's individuality was identified through gaining knowledge of the individual through assessment and gathering information from their familiar partners. Individuality related to their ability, needs, motivators and preferences. Participants discussed the importance of having knowledge of the individual when selecting, using, and reviewing AAC.

Applying this knowledge was beneficial when selecting AAC, where partners built on the individuals' existing ability, supported their understanding and selected AAC that matched their individual needs. AAC tailored to the users' individuality was reported to have been successful. For example, eye-gaze devices were selected for two individuals who had limited range of movement in their arms and could eye-point. The SLTs selected AAC that built on their existing ability. "*He has limited movement of his arms, so it gives him more freedom of choice which is good.*" (Teacher, I8).

Similarly, three participants discussed AAC use with older adults who preferred gestures and pictures as opposed to technology. This was due to previous exposure to these forms of AAC as opposed to technology. Objects of reference were introduced to an individual as he preferred to feel and touch items. His preference was included in the selection of AAC and was reported as successful.

Not considering each persons' individuality may potentially lead to introducing AAC that does not match their needs or abilities. Two mothers discussed the introduction of Lámh to their children. One mother stated that her son required physical assistance to use Lámh as he has abducted thumbs and found using Lámh difficult. Although, this mother continued to use Lámh, she displayed a level of uncertainty about her child's understanding of Lámh. This suggests that introducing AAC that the individual cannot use may have led to feelings of uncertainty. A second mother stated that her child did not understand Lámh and therefore, did not sign. A different type of AAC was then introduced. A SLT stated that Lámh was introduced to supplement individuals' understanding to promote total communication.

AAC was reported to support individuals' communication needs. It was stated that AAC helped to supplement users' understanding, as well as helping them to make choices, requests, and express themselves. However, three participants identified the need for further supports for individuals to express themselves and have their voices heard. There was a need to support both their receptive and expressive communication.

The inclusion of parents and familiar staff from the start is essential for the selection process. *"You have to have them involved...that's their field"* (SLT, I4). SLTs highlighted the need to manage expectations. They had worked with parents who sometimes wanted to start with supporting their children to speak as opposed to communicate. With time parents accepted using AAC that built on the individual's ability, which was to support communication as opposed to speech.

3.3.3.2.1 *Techniques to facilitate Individuals' use of AAC*

A number of techniques were discussed to prepare individuals with severe/profound intellectual disability to use AAC and facilitate their continued use of AAC. Techniques involved trialling AAC, training the individual to use it and documenting their progress.

Where the AAC strategy was trialled, participants felt the right AAC was selected. This suggests the value of trialling possible types of AAC before making a final decision.

Participants discussed the need to train the individual to use AAC. One participant stated that she trained the individual first so their partners could see the individuals' ability.

A number of participants discussed the AAC progress made by individuals' they supported. A SLT and teacher discussed documenting progress made by an individual who used an eye gaze device. The teacher documented the individual's daily progress to monitor his overall progression.

The SLT identified it as encouraging for communication partners to see progress. Four participants identified witnessing individuals' ability to communicate as positive. It was stated that people sometimes think persons with severe/profound intellectual disability do not make much progress. If their ability is not recognised, then it cannot be maximised. Therefore, documenting progress could act as a strategy for feedback. *"...when parents see okay, their son or daughter is actually able to use this device, they kind of get pulled in then and get a bit of knowledge about it and then everyone's able to use it together."* (SLT, I4).

3.3.4 Theme Two: The Act of Communicating: Attempting to Realise the Individuals' Ability

Theme two outlines' participants attempts to realise individuals' ability through the act of communicating.

3.3.4.1 Facilitating Continuity of Communication

Repetitive, consistent AAC use, using multiple forms of AAC, consistency of communication partners and providing the individual with sufficient time and space to communicate through AAC were important to facilitate continuity of communication through AAC.

Repetitive, consistent AAC use was important to ensure all partners implemented the same plan. The significance of using multiple forms of AAC was discussed during an interview with a mother of a child with severe intellectual disability. Her child had become more mobile and therefore, more independent. As she became more mobile, she was less interested in using PECS to communicate. They tried other types of AAC that were already introduced, which provided the AAC user with choice.

Consistency of communication partners was discussed by one participant who outlined a case where an individual's keyworker was transferred, but there didn't seem to be a reason for the move. This was thought to have negatively impacted the individual's communication. The need to move staff was recognised but the importance of discussing the communication partnership when making such decisions was highlighted.

Time and space were important to support individuals' communication needs. A HCA stated that when she had one to one time with an individual, she was better able to support their expressive communication.

High workloads were reported to have had a negative impact on the provision of time for assessment and AAC use. In addition, staffing levels limited time. Within a residential setting for adults with intellectual disability, there were individuals with various needs. Two participants spoke about the relationship between staffing levels and workload within this setting. The CNS highlighted the need to have sufficient staffing levels to support a variety of individual needs. *“Cause things do kind of slide when you have a hundred and one things to do, sadly.”* (Mother, I6).

3.3.4.2 Communication Partners’ Characteristics

Communication partners’ characteristics were deemed important to reach the shared goal. These characteristics included investment, attitudes, expectations, and assumptions based on presuming to know what the individual was communicating.

Participants discussed their experiences with other people who had a generic view of persons with severe/profound intellectual disability and their ability. The CNS outlined the importance of communication partners expecting that the individual has the ability to communicate, where low expectations could result in limitations for maximising individuals’ ability; *“...nobody believes that the person that has been referred is going to change, nobody has an expectation that this is going to get better...she is always doing this, she will never do that ...”* (CNS, I3). A second participant thought that the individual could not use AAC. *“... I don’t know like if he actually understands it or like is it...either he can’t do it or he won’t do it and I think it’s a case of he can’t”* (Mother, I1). However, this participant stated that she continued to try to use AAC. This highlights a sense of hope in AAC. The participant’s expectation stemmed from her uncertainty in AAC, thus posing as a limitation to maximising the individual's communication.

Individuals' right to choices and the importance of offering choices was highlighted. However, assumptions about what the individual was communicating were identified as a potential limitation for the provision of choice. Such assumptions were evident in discussions with three participants. The CNS discussed the need to work with the individual as well as their partners to ensure partners understood that environmental cues may supplement such understanding.

Such assumptions could limit continuity of communication with other people and environments. One mother discussed her awareness of the importance of using AAC more with her child, to ensure that her child could communicate with other people in different environments. To maximise individuals' ability to communicate with others, consistency and continuity of use is important.

3.3.5 Theme Three: Living with Uncertainty

The key finding represented in this theme relates to the overall feeling of uncertainty and living with this uncertainty.

A mother discussed her uncertainty around her son's ability to understand and use Lámh. The mother's uncertainty was related to her son having a severe intellectual disability and being unable to sign as he had abducted thumbs. This participants' uncertainty in her son's ability resulted in further uncertainty about reaching the shared goal. *"I keep trying but I don't know if it will happen."* (Mother, I1).

Three participants discussed uncertainty around funding. Furthermore, they discussed their uncertainty of accessing AAC at home which stemmed from the cost of the device and the funding available.

A mother was uncertain as to how her child communicated in school. She expressed her feelings of needing to do more and felt this was a characteristic of

mothers. She stated that she plans to speak to the class teacher in the future to find out how her child communicates in school. This suggests that there is potential to reduce such uncertainty through communication between partners in different settings.

Furthermore, a HCA spoke about communication partners' uncertainty in their own use of AAC. Such uncertainties may hinder the ability to reach the shared goal of maximising communication through AAC.

3.4 Discussion

This study provides nuanced insights into communication partners' perceptions of their roles and responsibilities in supporting individuals with severe/profound intellectual disability.

The overarching theme, Maximising Communication through AAC, captures participants agreement that their shared goal was to maximise the individuals' communication, where they were hopeful that AAC would help them to realise their goal. Three factors influencing this shared goal included (1) 'Developing a Communicative Environment', (2) 'The Act of Communicating: Attempting to Realise the Individuals' Ability' and (3) 'Living with Uncertainty'.

AAC helped to support individuals' communication needs. The positive impacts of AAC are echoed by other studies (Roche et al., 2015, Wood & Standen, 2021). However, individuals' voices need to be heard more. Participants' hope in AAC was reflected in their attempts to reach and realise this shared goal. However, such attempts were made within a context of uncertainty.

The shared goal encouraged teamwork. AAC is a collaborative approach requiring teamwork amongst stakeholders for successful use (Uthoff et al., 2021). Effective and efficient teamwork must be developed (Lund & Light, 2007). The

importance of establishing trust to facilitate collaboration is reiterated by Jansen et al. (2015). Trust was established in the present study by listening to communication partners, including them in the assessment and intervention and having knowledge of both the AAC user and AAC.

Communication partners must work together to maximise the individuals' communication and establish a person-centred approach. A collaborative approach involving communication partners increases the likelihood of positive outcomes for individuals (Lund & Light, 2007). Each partner's unique contributions were respected and shared in the current study. Communication partners' responsibilities can vary and be shared when a collaborative relationship has been developed (Beukelman et al., 2008). The importance of collaborative, family centred AAC decision-making is repeatedly documented within the literature (Ogletree, 2021; Sonnenmeier et al., 2005) as not considering families perspectives could result in the abandonment of AAC (Johnson et al., 2006).

The impact of effective and efficient teamwork on maximising individuals' communication and providing individualised support was highlighted. Gathering information about the AAC user from familiar partners and selecting AAC informed by the users' individuality resulted in a better 'fit' (Johnson et al., 2006) of the AAC with the user. This led to more consistent AAC use by communication partners in the current study. Communication partners may be hesitant to use AAC as they may think it does not match the individual's needs and when AAC enables communication successes they are more likely to consistently implement it (Johnson et al., 2006). AAC must be individualised for each person's needs (Williams et al., 2008) and team members must ensure that the chosen support represents all facets of

the user (Ogletree, 2021). Therefore, each person's individuality needs to be identified collaboratively and the selected AAC tailored accordingly.

In addition to the impact of the 'fit' between the users' individuality and selected AAC on consistent use, expectations and attitudes were deemed key factors. Communication partners' attitudes can impact the provision and use of AAC (Moorcroft et al., 2019). Attitude barriers can result in reduced expectations of individuals with disabilities which can limit opportunities for participation (Beukelman et al., 2012). There were differing expectations and attitudes between partners, towards both individuals with severe/profound intellectual disability and AAC. A participant in this study discussed working with communication partners who had negative attitudes. Despite having received AAC training they did not implement AAC, thus limiting opportunities (Beukelman & Mirenda, 2005). Both SLTs discussed the need for further training if such a situation arose, although additional training may not necessarily alter communication partners' attitudes. These findings raise the question of how to positively affect partners' beliefs and attitudes towards AAC and individuals with severe/profound intellectual disability. Light and McNaughton (2015) state that *"the persistent focus on deficits alone may cloud recognition of the unique characteristics of the individual and important strengths that may be leveraged to maximise outcomes"* (p.90). Therefore, steps need to be taken to ensure individuals' abilities are recognised and potential fulfilled. Documenting individuals AAC progress could further highlight their small improvements and their ability to their communication partners.

Optimal AAC use was also influenced by factors outside of the communication partners' control. The findings from this study and others (Rombouts et al., 2017a) indicate that communication partners may need to choose between

tasks. Therefore, one task was prioritised over the other. However, communication is fundamental for individuals' wellbeing. There needs to be time to incorporate AAC into the daily lives and activities of AAC users.

3.4.1 Strengths and Limitations

Member checking was not undertaken and is recognised as a potential limitation; however, the interviewer verified the participants' answers during the interviews through feedback. The interviewer's experience as an intellectual disability nurse was acknowledged. Continuous reflection was undertaken by the researcher to enhance credibility (Connelly, 2016). Moreover, a reflexive approach helped to articulate her positionality (Holmes, 2020). The interview schedule was followed with the use of probing questions when required. Therefore, participants discussed their experiences openly. The research team reviewed, discussed, and verified the analysed data. Transferability was attempted by recruiting a sample that included both paid and familial communication partners.

The current study outlines communication partners' perceptions of their roles and responsibilities in the design, planning and use of AAC with this population. Such knowledge could be beneficial when planning and implementing AAC support. Secondly, it identifies the potential barriers and facilitators to maximising this populations' communication through AAC.

3.5 Conclusion and Implications

Participants' roles and responsibilities differed depending on the type of partner that they were and the nature of their relationship with the individual. Both SLTs and the CNS identified their roles and responsibilities primarily in the provision of training, assessment, selecting AAC and reviewing the system. Familiar partners included both familial and professional partners. Professional partners who

spent regular time with the individual were considered familiar partners, i.e., a teacher and HCA. These two partners along with parents identified their roles and responsibilities in sharing the information and experience they had with the individual with professionals, using AAC, reporting issues to the person who introduced the system and providing feedback. Although roles and responsibilities varied, participants believed that multiple partners should be involved in the design planning and use of AAC, with each partner having distinct yet important roles and responsibilities to optimise the outcomes for the individual. Roles and responsibilities can and do vary. The key finding is the importance of respecting the roles and responsibilities of each partner and working together to optimise the outcomes.

The findings highlight the importance of employing strategies both intrinsic and extrinsic to the AAC user to optimise their communication. Teamwork is essential for AAC success (Uthoff et al., 2021) and must be developed (Lund & Light, 2007). Trust is an underlying principle of teamwork and was developed through multi-way communication and participation in decision-making.

Communication partners have different expertise and experience in AAC and with the individual, the recognition and respect of the various contributions of each partner aided teamwork. Therefore, it is recommended that teamwork is developed and fostered by including diverse team members with distinct roles and responsibilities, fostering open communication, listening to each partner involved and sharing decision-making where the individual AAC user is central to those decisions.

Introducing AAC that is not compatible with the individual's current ability poses as a barrier to optimising the individual's communication. Each

communication partner has a fundamental role in identifying the person's individuality. Therefore, collaboration must be promoted to ensure a thorough assessment is undertaken that aids in selecting AAC that is individual to each user.

Communication partners must provide communication opportunities that promote participation. Training communication partners in methods of AAC not tailored to the individual may limit such opportunities. It is recommended to train partners in AAC that supports the user's individuality, explicitly inform them of their roles and responsibility and prepare them for what to expect in terms of progress and timelines.

There were differing expectations and attitudes, both towards individuals with severe/profound intellectual disability and AAC. It was deemed encouraging for partners to see individuals' ability and progress in AAC. It is recommended that intervention plans include a method of objectively recording progress with regular feedback and updates to the individual's network.

Uncertainty was common amongst participants. It is recommended to acknowledge such uncertainty and encourage partners to share their own experiences.

The findings demonstrate the intersection between availability of AAC, funding, teamwork, time, workload, consistent use, attitudes towards AAC, the expectations that partners have about individuals with severe/profound intellectual disability and the capability of AAC to match the individual's ability. However, it is unclear as to how they are linked. Further research to explore the intersection between the factors and their influence on maximising individuals with severe/profound intellectual disability communication is required. Therefore, an integrative review was undertaken to explore the intersection between these factors

and their influence on communication partners' use of AAC. The integrative review is presented in Chapter 4.

Chapter 4. Factors Influencing Communication Partners of Persons with Severe/Profound Intellectual Disability Use of Augmentative and Alternative Communication: An Integrative Review

Abstract

Purpose

To present a synthesis of evidence related to the factors influencing communication partners' use of AAC with persons with severe/profound intellectual disability.

Methods

An integrative review guided by five steps; problem identification, literature search, data evaluation, data analysis and presentation was undertaken. In accordance with the PRISMA statement, nine databases were searched, 1,342 studies were screened against the eligibility criteria, and 15 studies underwent thematic analysis.

Results

Two themes emerged; (1) Achieving Meaningful Communication and (2) Communication Partners' Preparedness to Use AAC. Achieving meaningful communication was central to communication partners' use of AAC and was two-fold. It involved identifying the persons' communication methods and encouraging them to communicate. Communication partners' preparedness also influenced their use of AAC. This preparedness was impacted by communication partners' preconceived thoughts about and knowledge of AAC, nurturing their belief in AAC, and the interpersonal dynamic between network members.

Conclusion

Communication partners' use of AAC is influenced by multiple and complex factors. The findings contribute to the knowledge of the potential factors to be considered to prepare communication partners to use AAC.

Keywords: augmentative and alternative communication; communication; communication partners; severe intellectual disability; profound intellectual disability; profound intellectual and multiple disability; integrative review

IMPLICATIONS FOR REHABILITATION

- Multiple, complex factors influence communication partners of persons with severe/profound intellectual disability use of AAC, which include communication partners' beliefs, attitudes, expectations, knowledge and resources such as training, support and time.
- To offer individuals with severe/profound intellectual disability opportunities to communicate, communication partners need to recognise their attempts and thus, their ability. Continuously being sensitive to individuals' communication methods, whilst being cognisant that these methods can change, may enhance communication partners' awareness and understanding of the individuals' communication attempts.
- Communication partners' need to feel prepared to use AAC. To feel prepared, they need to be aware of the potential benefits that AAC can offer the interaction and the long-term outcomes, develop their knowledge and be surrounded by a supportive team dynamic.

4.1 Introduction

Communication is a basic human right (UN, 2006) that impacts individuals' QoL (Bennett et al., 2016; Goldbart, 2023). Individuals with severe/profound intellectual disability have complex communication needs (Wilder et al., 2015). Their communication is often at the pre-intentional communication stage (Sigafos et al., 2021). Their subtle and idiosyncratic forms of expressive communication include eye gaze, body language and movements, changes in muscle tone, facial expressions and vocalisation (Brady et al., 2016; Coupe O'Kane & Goldbart, 1998; Petry & Maes, 2006) which tend to be individual to the person (Stillman & Siegel-Causey, 1989). Therefore, their individual communicative behaviours may go unnoticed (Munde & Vlaskamp, 2015; Wilder & Granlund, 2003) or be misunderstood (Grove et al., 1999). They require additional support to ensure their communication abilities are supported and needs met.

Communication partners play a fundamental role in supporting individuals with severe/profound intellectual disability to communicate. Communication partners are those with whom interactions arise (Biggs et al., 2019; Johnson et al., 2009). In the context of this review, communication partners include those who have social roles (e.g., parents, siblings) and educational or care relationships with the individual (e.g., teachers, healthcare professionals) (Kent-Walsh & McNaughton, 2005). SLTs are also important given their role supporting both the individual and their communication partners (Hanley et al., 2022).

There are multiple factors that can influence the communication process. The communication process can be influenced bi-directionally, where each partner's contributions affect the other partner involved (Bunning, 2018). Therefore, communication partners must change and adapt their communication to the ability of the individual with an intellectual disability to strive for a “*more balanced*

interactional relationship” (Bunning, 2018, p.202). However, communication partners may not always adapt to the individual's level of understanding (Bradshaw, 2001). In such circumstances the individual may not have the opportunity to be an equal communication partner in the interaction (Dalton & Sweeney, 2010). Individuals with severe/profound intellectual disability are a heterogenous group (Griffiths & Smith, 2016), their individuality must be recognised to support their communication and the implementation of communication supports. Additional environmental factors can impact the communication process, including limited resources, knowledge (Dalton & Sweeney, 2013), time (Wilder et al., 2015) and lack of appropriately trained communication partners (Dalton & Sweeney, 2013). Such factors should be addressed to support optimal contributions to the communication process.

AAC is a recognised means of support that can positively impact individuals with severe/profound intellectual disability (Roche et al., 2015). The focus of this integrative review is on individuals who communicate at the earlier stages of communication development, in particular, individuals with severe or profound intellectual and/or multiple disability. Examples of AAC reported to be used with individuals with severe/profound intellectual disability include objects of reference (Goldbart et al., 2014; Rensfeld Flink et al., 2022a), PECS (Danker et al., 2023), SGD's (Danker et al., 2023; Rensfeld Flink et al., 2022a) and manual signs (Goldbart et al., 2014; Rensfeld Flink et al., 2022a). A multimodal approach is recommended (Beukelman & Light, 2020). AAC systems have been reported to support individuals to make choices (Danker et al., 2023; Goldbart et al., 2014) requests (Danker et al., 2023) and support understanding (Goldbart et al., 2014). AAC is not a one size fits all approach (Stoner et al., 2006). Therefore, a person-centred approach should be

adopted when selecting an AAC system, ensuring that the persons individual needs, abilities and preferences are identified and the AAC is tailored accordingly (Hanley et al., 2023a).

Communication partners' strategies can support AAC users to succeed in communication and affect their personal development and QoL (Midtlin et al., 2015). However, AAC use may be impacted by communication partners' attitudes (Hanley et al., 2023a; Lund & Light, 2007; Moorcroft et al., 2019), expectations towards individuals (Calculator, 1999; Hanley et al., 2023a), knowledge (Hanley et al., 2022; Hanley et al., 2023a; Wilder et al., 2015; Wormnaes & Abdel Malek, 2004), selecting AAC that applies to each person's individuality, availability of AAC, teamwork amongst network members (Hanley et al., 2023a) time (Danker et al., 2023; Hanley et al., 2022; Hanley et al., 2023a; Wilder et al., 2015), workload (Hanley et al., 2023a; Rombouts et al., 2017a) and uncertainty amongst communication partners (Hanley et al., 2023a). Therefore, AAC research and practice must be cognisant of communication partners (Midtlin et al., 2015) and their important roles within various types of interactions (Blackstone et al., 2007).

Existing reviews have focused on communication partners of persons with severe/profound intellectual disability experiences of using AAC (Hanley et al., 2022), the barriers and facilitators to the provision and use of low-tech and unaided AAC systems for various people with complex communication needs, not individuals with intellectual disability specifically (Moorcroft et al., 2019) and the attitudes toward individuals who use AAC (McCarthy & Light, 2005). This review aimed to bring the empirical research together to better understand the factors influencing communication partners of persons with severe/profound intellectual disability use of AAC and identify how the factors relate to affect their use of AAC.

In the context of this review, the use of AAC means when communication partners' use it as a direct support to interact and engage with the individual. Previous research indicates that multiple factors influence communication partners' use of AAC (Hanley et al., 2023a; Moorcroft et al., 2019; Rombouts et al., 2016; Rombouts et al., 2017a; Rombouts et al., 2017b). It is unclear how these factors interconnect to optimise AAC use (Hanley et al., 2023a). There is a need to better understand the intersection between these factors and their overall impact on maximising the individual with severe/profound intellectual disability communication. This review also aimed to identify theoretical and conceptual frameworks used to explain, describe, or predict the factors influencing communication partners' use of AAC. To the researcher's knowledge, an integrative review has not been conducted on this topic to date. The review is reported in accordance with the PRISMA guidelines (Moher et al., 2009, Appendix 18).

The research questions that guided this integrative review were: (1) What are the factors influencing communication partners' use of AAC? (2) Is there an intersection between the factors influencing communication partners' use of AAC? (3) What theories or conceptual frameworks have been used to examine the factors influencing communication partners' use of AAC?

4.2 Methods

4.2.1 Protocol and Registration

An integrative review protocol was developed and published on Prospero in October 2022 which can be seen in Appendix 19 (crd.york.ac.uk/PROSPERO/display_record.php?RecordID=361886).

4.2.2 Design

This review aimed to compare the diverse explanations (Cronin & George, 2020) for communication partners' use of AAC. Integrative reviews offer the opportunity to develop a holistic understanding of a topic (Dhollande et al., 2021). They offer the broadest review methods, which allow for the inclusion of diverse experimental and non-experimental studies and theoretical and empirical literature (Whittemore & Knafl, 2005). Therefore, Whittemore and Knafl's five steps: problem identification, literature search, data evaluation, data analysis and presentation guided this integrative review (Whittemore & Knafl, 2005).

4.2.3 Data Sources and Search Strategy

To identify studies on communication partners' use of AAC, PsycINFO, PsycARTICLES, CINAHL, PUBMED, ERIC, Cochrane, Academic Search Complete, Linguistics Collection and Scopus were searched between August to September 2022 and reviewed in May 2023 with one new study identified. These databases are comprehensive for health, psychology, social care and education, areas of practice commonly supporting people with intellectual disability.

The PICO framework was used to refine the search concepts and parameters (Appendix 20). The search strategy was adapted in accordance with each database and was restricted to the English language. No date restrictions were applied. The following key concepts were searched and combined: search terms referring to severe/profound intellectual disability (i.e. "severe intellectual disabilit*" OR "severe learning disabilit*" OR "severe mental retard*" OR "severe developmental disabilit*" OR "profound intellectual disabilit*" OR "profound mental retard*" OR "profound developmental disabilit*" OR "profound learning disabilit*" OR "pervasive intellectual disabilit*" OR "pervasive mental retard*" OR "pervasive

developmental disabilit*" OR "pervasive learning disabilit*" OR “Multiple and Complex Disabilities”) were combined with search terms referring to AAC (i.e. “Augmentative and alternative communication” OR “AAC”) which were combined with search terms referring to communication partners (i.e. Caregivers OR carer OR “communication partners” OR families OR parents OR mother OR father OR siblings OR friends OR “support staff” OR “support worker” OR teachers OR educator OR “speech and language therapists” OR “speech therapist” OR “speech pathologists” OR “speech language pathologist” OR assistant). Subject headings were searched alongside keywords when available in the databases. One full search has been provided as per the PRISMA guidelines and can be seen in Appendix 21 (Moher et al., 2009).

4.2.4 Study Selection

Through database searching, 1,342 records were identified. A further 14 potential records were identified through searching reference lists of included studies. Identified studies were exported into EndNote and duplicates removed (n=26). Covidence was used to screen the titles, abstracts, and full texts against the eligibility criteria (Table 4.1). To minimise bias, the researcher and a thesis supervisor (EH, CD) independently screened the titles and abstracts of 1,330 records for assessment against the eligibility criteria with 1,193 records excluded. A second thesis supervisor (AMM) was consulted where disagreement arose. The full text of the remaining 137 articles were assessed independently by the researcher and a thesis supervisor (EH, AMM) and 15 articles met the inclusion criteria.

Table 4.1 Inclusion and Exclusion Criteria

Inclusion Criteria

Population:

Communication partners of persons with severe/profound intellectual disability or profound intellectual and multiple disabilities using AAC to communicate.

Communication partners with a professional and social role.

Interest:

Studies that empirically explored or examined communication partners' use of AAC with persons with severe/profound intellectual disability and the factors influencing communication partners use of AAC.

Context:

The context of the review focused on persons who communicate at the earlier developmental stages which includes persons with severe/profound intellectual disability and persons with profound intellectual and multiple disability.

This review aimed to explore the context in which they communicate by examining factors that influence communication partners' use of AAC regardless of age, in any geographic area in all contexts (i.e., community settings, day services, residential services, schools, home settings).

Types of Studies:

Qualitative, quantitative and mixed methods studies.

Exclusion Criteria:

Studies that included communication partners of individuals with mild, moderate or no intellectual disability.

Studies that did not focus on AAC.

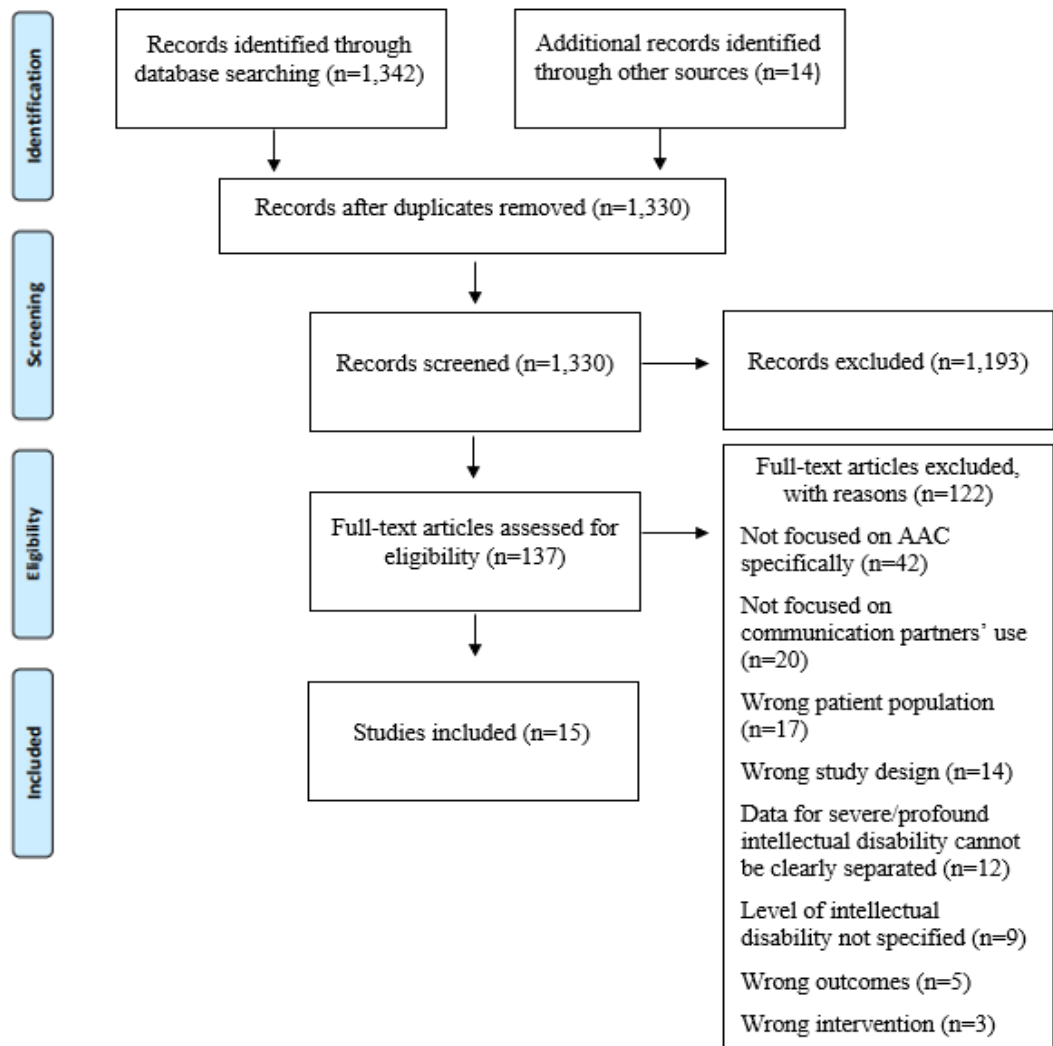
Studies evaluating the most suitable or effective types of AAC to support persons with severe/profound intellectual disability and that focused on assistive technology.

Systematic reviews, integrative reviews, meta-analyses, meta-syntheses, books, book reviews, editorials, and purely theoretical papers

*Abbreviations: AAC, Augmentative and Alternative Communication.

The selection of studies is presented in a PRISMA flow chart (Figure 4.1).

Figure 4.1 PRISMA Flow Diagram



(Moher et al., 2009)

*Abbreviations: AAC, Augmentative and Alternative Communication

4.2.5 Quality Appraisal

There is no standardised way to appraise the quality of the identified literature during the integrative review search process, although quality should be addressed in a meaningful way (Whittemore & Knafl, 2005). Hutchinson and Bodicoat's approach was used, whereby studies were not excluded based on quality (Hutchinson & Bodicoat, 2015). Hutchinson and Bodicoat state that when there is limited literature available it is more beneficial to critique the identified papers and *"use the deficits in quality to inform future research"* (Hutchinson & Bodicoat, 2015,

p.439). Considered in the context of the eight-level evidence hierarchy (Polit & Beck, 2021), the majority of the studies are in level seven (n=8), followed by level five (n=4) and level three (n=1). Although the majority of the studies were at the lower level of evidence, the designs used were appropriate in the context of the research questions and aims outlined (Polit & Beck, 2021).

4.2.6 Data Extraction

Data were extracted by the researcher and checked by a member of the supervisory team (EL) for accuracy. The data extraction was reviewed by the team with any disagreements discussed until they were resolved. The following data were extracted for each study; authors, year, country, study aim, methodology, sample approach, size, eligibility, setting, instruments/measures, variables, or phenomenon of interest, conceptual or theoretical frameworks and key findings (Table 4.2). The findings were extracted with particular emphasis on the factors that influence communication partners' use of AAC and the intersection between these factors.

Table 4.2 Data Extraction of 15 Studies

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
1.Rombouts et al. 2017 Belgium	Compare the views of direct support staff and SLTs who work with adults with intellectual disability of the factors influencing the use of AAC	1.Qualitative 2.Descriptive	1.Non- probability, convenience 2.n=25 (9 SLTs, 1 OT, 15 direct support staff. Ten services in total) 3.All professionals were supporting at least one adult with a mild-severe intellectual disability who used AAC to communicate 4.Residential and day-care services	One-to-one semi- structured interviews	Staff-client interactions, AAC benefits and purpose, AAC implementation and use, staff training and skills and staff support	The Reasoned Action Approach	(1) SLTs' believed that most clients would benefit from consistent use of KWS, direct support staff inconsistently used it despite believing that consistent use was important for implementation, they decided on KWS use in the moment. (2) Support staff's responsibility to maintain clients' KWS skills. (3) Support staff used AAC less when they knew the client well. (4) Some support staff knew less signs than their clients. (5) Time posed as a barrier to communication partners' use of AAC. (6) Staff support towards AAC influenced others implementation of it.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
							(7) SLTs and support staff have expertise in supporting individuals' communication.
2. Meuris et al. 2014 Belgium	To provide an account of the prevalence of KWS and the sign knowledge of adults with intellectual disability and their support staff in Flemish residential programs and day care programs	1.Quantitative 2.Descriptive, comparative, correlation design	1.Non-probability, convenience 2.n=93 support staff, psychologist, SLTs, other 3.Provide services for adults with intellectual disability 4.Residential and day care programs for adults with intellectual disability in Flanders (Dutch speaking part of Belgium)	(1)A telephone survey to obtain information about the prevalence of KWS use in residential and day care programs (2) Written questionnaire to obtain information on everyday use of KWS	Questionnaire ; Part 1 : contact and organisational information Part 2: use of KWS by adults with intellectual disability Part 3: Use of KWS by support staff. Categorical Variable: KWS taught to support staff, profession of person teaching KWS, estimated number of	Not reported	(1) Support staff were estimated to understand and produce fewer signs when their clients had a more severe intellectual disability. (2) The estimated sign comprehension and production of staff were significantly related to each other. (3) Support staff produced more signs when an SLT taught them KWS as opposed to a support worker. (4) Staff attitude was related significantly to their sign comprehension (but not to sign production).

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
					signs comprehended/ produced, Estimated attitude toward KWS		
3. Rensfeldt Flink et al. 2020 Sweden	To examine participants’ perceptions of a communicati on course as held for parents of children with profound intellectual and multiple disabilities	1.Qualitative 2.Exploratory	1.Non-probability, purposive 2.n=22 parents of children with profound intellectual and multiple disabilities Men; n=5 Women; n=17 3.Had previously completed a ComAlong program and evaluation form 4.Child and youth rehabilitation services	ComAlong Course; parent-mediated, which aims to promote caregiver-child communication and AAC-supported communication within the context of everyday activities and routines, included eight sessions which were two hours each, each session focuses on a theme, and include lectures, discussions, and collaborative analysis of videos of parent-child interactions as well as a coffee break to socialise. Participants were given homework to increase	Parents of children with profound intellectual and multiple disability experiences of the ComAlong Course with a focus on parental responsivity and AAC	ComAlong Course; guided by theory that proposes children’s understanding of communicative intentionality as a cornerstone in their acquisition of language	(1) Conflicting views about AAC, deemed useful or not useful. (2) AAC was useful; Several participants increased their use of AAC after the course. Half (n=11) had positive remarks about the AAC content and/or described different ways that they included AAC in communication with their child as a result of participating in the course. (3) AAC was not useful; Repeatedly mentioned as being difficult to apply with the child or that it was “too soon” to use AAC with the child. One participant perceived that AAC simply was not useful to their family,

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
				their learning, reflection and support their application of the knowledge to practice. An evaluation survey.			the others perceived that either they or their children were not ready for AAC yet. (4) Increased awareness about communication made them more confident in their child's communication capabilities. (5) Responded to their child using the same communication approaches that they used. (6) Gave their children more time to communicate.
4. Koski et al. 2010 Finland	To identify what key staff members perceived as important for their personal improvement as communication partners with persons with multiple	1. Qualitative 2. Explorative Descriptive	1. Non-probability, opportunistic and criterion 2. 6 key staff members (1 trained nurse; 3 had a degree in practical nursing; 2 had a bachelor's degree in social services) 3. (a) had participated in OIVA training from the beginning,	OIVA Training Semi-structured interviews conducted two months after the last training session	OIVA Training Program. Factors staff members deemed important for their personal improvement as communication partners of persons with multiple	Community Based Rehabilitation: Client-Oriented and Solution Focused	(1) Realised the importance of being patient. (2) Participants (n=6) repeatedly stated that they prioritised trying to understand clients' communication attempts, therefore they started to focus on their gestures and facial expressions. (3) Half (n=3) of the participants began to consider their own use of AAC strategies. They had learned the importance of finding out

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	intellectual disabilities after taking part in a communication training program. In addition, to present the OIVA training program		and (b) were still employed in the same department as they were employed in during that training. 4. Residential and day services		intellectual disabilities		if the clients had understood the AAC that has been used and noted that it is the staff's responsibility to try to find strategies that benefit the client. (4) Participants realised that using strategies similar to those of their clients helps to create contact. (5) Training helped them to realise the individual's communicative abilities. (6) Reported that they learned to give priority to communication.
5. Cheek et al. 2022 USA	Investigated the impact of a special education teacher's (researcher/practitioner's) use of interactive reading behaviours	1. Quantitative 2. Case Study AB design	1. Non-probability, convenience 2. n=4 (1 schoolteacher and 3 students with severe intellectual disability) 3. Students were identified in the researcher's	Shared storybooks from the Tar Heel Reader electronic bookshelf Observations: A Double Robot and charging station in the classroom collected data three days a week, each session was recorded via Panopto software for analysis Open-ended interviews	IV: Online professional development; shared reading module on the project core website, eCoaching DV and Measure:	Not reported	(1) The teacher felt that one-to-one communication was beneficial for the students as it enabled her to provide more intensive support. (2) She intended to continue using shared storybook reading.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	on communicati on interactions of students with severe intellectual disabilities who have complex communicati on needs		classroom where the teacher believed they were not communicating symbolically 4. Self-contained classroom for students with severe intellectual disability in a rural elementary school	Adult/Child Interactive Reading Inventory	Shared storybook reading interactive reading practices, fidelity of eCoaching, reliability of interaction coding, social validity		
6. Ogletree et al. 2016 USA	To determine the applicability of CPI with a small group of staff members at a state institutional setting for individuals with severe intellectual disabilities in	1. Quantitative 2. Single subject multiple baseline research design	1. Non-probability, convenience 2. n=5 (1 individual with severe intellectual disability along with 4 staff participants; 1 chaplain, 1 teacher, 2 staff trainers) 3. Staff were selected based on their willingness to engage in the training program and regular	CPI training program materials included objects needed for video probe sessions, an AAC book. Sessions were video recorded. Pre and post test questions and demonstrations used instructionally. A post-study survey including Likert scale	IV: CPI Training Model DV: Providing communication opportunities, modelling system use and assuring AAC system access	Not reported	(1) Provision of communication opportunities and modelling AAC supported the CPI training. However, no gains were maintained at significant levels after training. (2) Participants enjoyed the group nature of interventions that allowed partners to learn with others.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	North Carolina		contact with the client 4.Residential centre for individuals with intellectual disabilities	and open-ended questions.			
7. Blain Moraes et al. 2013 Canada	Investigated the effects of biomusic on caregiver perceptions of their interactions with persons with profound multiple disabilities	1.Qualitative 2.Descriptive, explorative study	1.Non-probability, purposive 2.n=10(3 parents and 7 staff members) and n=3(individuals with profound multiple disabilities) 3.Caregivers were required to: (a) routinely visit the participant at least once a week; and (b) to have normal or corrected to normal hearing. Individuals with profound multiple disabilities were required to: (a) have a Rancho Los Amigos	Biomusic sessions Semi-structured, open- ended interviews. The first interview occurred prior to all biomusic sessions, the second occurred after two sessions, and the third occurred after all four sessions. Data from second interviews were not analysed due to technical difficulties with the sensors.	Caregivers' perceptions of their interactions with persons with profound multiple disabilities while using biomusic	The social interactionist perspective of personhood	(1) Thomas: Caregivers were more aware of the individual's communicative behaviours, biomusic drew attention to subtle behavioural changes, that caregivers previously had not considered communicative. Created a sense of the individual's character, positive effect on caregivers' moods and created a sense of meaning. (2) Fred: died midway through the study. One participant completed all the sessions and viewed biomusic as helpful during interactions. They would have

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
			<p>Cognitive Level ranging from I – III and are unable to physically or verbally express themselves; (b) are an inpatient of the CCC Unit; (c) receive routine visits/care from a parent, volunteer, nurse, or therapeutic recreationist; (d) have fingers large enough to attach the physiological sensors (i.e., 7 years or older); (e) have had prior exposure to and neutral and/or positive reactions to music; and (f) have a parent or guardian who gives proxy consent</p> <p>4. Complex Continuing Care unit of a Canadian urban</p>				<p>used it in future interactions with Fred.</p> <p>(3) Joanne: For one caregiver, biomusic reinforced her interpretations of Joanne’s reactions to activities and events, her parent valued it as it allowed her to see her daughter’s responses to her, attributed to Joanne’s personhood.</p> <p>(4) Out of the 8 who completed a final interview, 6 were enthusiastic about having biomusic as part of their interaction.</p>

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
			paediatric rehabilitation hospital				
8.Rensfeldt Flink et al. 2022a Sweden	To address outcomes from the ComAlong communication course for parents of children with severe/profound intellectual and multiple disabilities	1.Convergent Mixed Methods 2.Case study; AB Design	1.Non-probability, purposive 2.n=4 (2 children and their mothers) 3.(a) The parents had to be on the waiting list to attend the AKKtiv ComAlong parental- communication course targeting parents of children with profound intellectual and multiple disabilities; (b) the children had to be diagnosed with a severe or profound intellectual disability and (c) the children had to have motor disabilities corresponding to level	Video recorded dyads of parent child communication. Semi-structured interviews at (1) baseline; (2) an eight- week intervention; and (3) follow-up immediately after the intervention phase as well as (qualitative) follow-up one year later	IV: AKKtivComAlong DV for parents; responsivity and AAC use DV for children; communicative attention and initiation	Guided by theory that proposes children's understanding of communicative intentionality as a cornerstone in their acquisition of language	(1) The analyses of video recorded data did not show any increase in the mothers' use of AAC. (2) No change in parental responsivity was seen in the coded video material. Qualitative Data: (3) Jenny; Development as a communication partner is a process. Reflection led to thinking and acted as a prerequisite for acting. Jenny identified Hanna's communicative needs and adapted to them. Viewing her child as a competent communicator led to the realisation that communication partners are responsible for providing quality interaction.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
			IV or V on the GMFCS 4.Public habilitation services				After the intervention she felt that AAC was something she chose to use and take charge of as opposed to something others expected her to use. (4) Sara; The course as a starting point, sparked her interest in AAC. Felt motivated to work on her child's communication and needed more knowledge and interventions. Held positive views of strategies on the course and trusted Sam would benefit if she used it.
9. Forster and Iacono 2007 Australia	To explore the meaning of a communication intervention and associated changes for an adult with severe	1.Qualitative 2.Case Study	1.Non-probability, purposive 2.n=7(Mark, a 22- year-old with an intellectual disability, his parents and 4 support workers) 3. The individual with intellectual disability was reported to have been chosen because	The Social Networks Inventory; a semi- structured interview assessment tool Time 1 (Before the interventions) and Time 2 (A year after) SLTs intervention delivered over 12 months; staff training,	SLTs Intervention The meaning of communication for the participant before and after the intervention, from the perspectives of	ICF and Participation Model discussed in Introduction	(1) Parents felt that after the intervention staff were taking more responsibility for Mark's communication. (2) Parents and support staff discussed strategies they already used and would continue to use, staff also discussed new strategies.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	intellectual disability from the perspective of key communication partners		the data collected during interviews with communication partners during the original quantitative study were deemed rich. 4. Group home and parents' home	individual meetings with keyworkers, and creating opportunities for learning or using new strategies, one SLT trialled and modelled strategies with Mark for partners to see, shared handouts of Mark's support needs and communication strengths	his communication partners'		(3) Support staff discussed strategies in the past that were abandoned before they worked. At Time 2, support staff seen a problem-solving opportunity when strategies were not working. (4) A more active approach was evident from support workers. (5) SLTs were sometimes faced with neutral responses from support staff.
10. Brug et al. 2013 The Netherlands	To analyse whether using MSST did lead to changes in teachers' knowledge about preferences and abilities of children with	1. Qualitative 2. Case Study	1. Non-probability, voluntary 2. n=6 (3 teachers, 3 children) 3. Teachers; (a) a degree in upper vocational education and training in a relevant discipline; (b) sufficient time to participate in the study; (c) worked at	1. An adapted version of the 'Inventory for attuning activities and situations to the abilities and preferences of persons with profound intellectual and multiple disabilities Completed before, after 10 sessions and after 20 sessions	Immediate available knowledge of the teacher: the knowledge they use on a day-to-day basis and the knowledge that is in their hands and minds	Not reported	(1) Findings indicate that teachers applied person-centred approaches when developing the story books. (2) Teachers tended to leave the book unchanged or make changes not in accordance with their new knowledge. (3) All teachers increased their knowledge.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	profound intellectual and multiple disabilities and whether this knowledge was applied in practice		least 3 days a week (or 6 half-day shifts) Children: (a) had profound intellectual and multiple disabilities; (b) visited the centre at least 3 days a week (or 6 half-day shifts); (c) the teacher expected the child to enjoy the storytelling activity; (d) written informed consent obtained by the parents for their child to participate. Additionally, the child and teacher should have known each other for at least a year; the child and the teacher should be in the same group for at least 2 days a week (or 4 half-day shifts)	Manual for making and reading an MSST book Reading an MSST book 20 times over 10 weeks	Expectations and Experiences		

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
			4. Centre for Special Education				
11. Goldbart et al. 2014 UK	Explore SLTs' decision making in communication interventions for people with profound multiple intellectual disability, in terms of the intervention approaches used, the factors informing the decisions to use specific	1. Quantitative 2. Explorative, Descriptive Survey Design	1. Non-probability, purposive and snowball 2. n=55 SLTs 3. SLTs working with children and/or adults with profound multiple intellectual disability 4. Higher education institutes in the UK	Survey via email or post	(1) The assessments SLTs' use (findings of this not included in this paper); (2) the interventions SLTs' use; (3) background information about the respondent SLT, their experience and the client group(s) they work with; and (4) the type of service and settings in	EBP Triad	(1) Main rationale for interventions were the empowerment, development, and behavioural preferences of the client. (2) The views and wishes of other partners and professionals and published evidence were not mentioned for AAC strategies.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	interventions and the extent to which the rationales underpinning these decisions related to the components of EBP				which they work		
12. Martin and Alborz 2014 England	Aimed to illustrate training areas that teaching assistants perceive to be important for their learning and development, so that they can proficiently support	1.Qualitative 2.Explorative, descriptive design	1.Non-probability, voluntary 2.n=23(17 teaching assistants; 5 teaching staff; 1 manager of the training department) 3.Not reported 4.A school	Semi-structured interviews Free text questionnaires	The training that teaching assistants received and whether they believed that the training available was sufficient in enabling them to support students with profound intellectual and multiple disabilities.	Not reported	(1) Thought the communication training gave helpful, but limited information. (2) Participants wanted more training to use appropriate AAC and gain understanding of the student's needs.

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	students with profound learning difficulties						
13. Wilder et al. 2015 Sweden	To examine how parents and professionals share learning about communication and AAC for persons with severe disabilities by participating in blended learning networks	1. Qualitative 2. Educational and evaluation	1. Non-probability, purposive 2. n=36 (15 parents; 13 mothers; 2 fathers and 21 professionals) 3. Parent of a child with profound multiple intellectual disability; Working as a professional 4. Swedish family care competence centre	Four groups participated in four discussion sessions online focused on: (1) communication in general, (2) communication/AAC in school, (3) communication/AAC and technology, (4) communication/AAC and a holistic perspective and an evaluation session using an online 27 item questionnaire	Parents and professionals shared learning about AAC and communication in BLNs	Categorical, Relational, and Interactional Perspectives	(1) Participants were aware that subtle behaviours were communication. (2) Importance of the people within the environment noted. (3) Communication forms; identified the ways individuals communicate. (4) Strategies such as responding using the same means the child had used to enhance and detect communication. (5) iPads were seen as a well-known item that could promote acceptance and inclusion. (6) Some participants were hesitant to use technology due to anxiety about learning to

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
							use it and a lack of knowledge of the benefits. (7) Positive personal traits were considered facilitative for communication, a lack of time, knowledge of AAC and uncertain ownership of responsibility were limiting factors.
14. Skotko et al. 2014 USA	To measure the level of interaction and communication that occurred between the children and their mothers during storybook reading	1. Quantitative 2. Multiple baseline design	1. Convenience 2. n=8 (4 girls with Rett syndrome and their mothers) 3. Not provided 4. Their homes	4-month storybook reading intervention at home. Included 4 phases, each phase involved mothers reading familiar (as many times as they wished) and unfamiliar books (twice a week) with their daughters. They video recorded the sessions where they read unfamiliar books. Hand splints were introduced in phase 2 to determine their effect for communication intervention and the child's involvement.	DV: successful switch use and labelling/communicating IV: parent codes: (a) requests for attention, (b) pointing to symbols, (c) pointing in books, (d) labelling, (e) describing, (f) relating scenes to the child's life, (g) directives, (h)	Not reported	(1) All mothers showed an increased percentage of successful pointing to symbols across phases (2) The mothers changed their use of some communication acts over time. (3) All mothers changed their responses to their child's attempts with more confirmation, praise, negation, and requests for clarification in two or more of the intervention phases. (4) As they directed their children more, they sought more confirmation or

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
				AAC devices and picture communication systems were introduced. Their impact on the intervention were studied in phase 3. Parents were later trained in assistive technologies. Trained to model, prompt and ask questions during storybook reading. The final phase was an evaluation.	action in the book, (i) prediction or inference comments and questions, (j) emphasizing print or sound concepts, (k) confirming or requesting clarification, (l) behaviour management, and assisting the girl with turning of the pages		clarification regarding their interpretations of their child's attempts.
15. Rensfeldt Flink et al. 2022 a Sweden	To explore SLTs' beliefs, clinical reasoning, and practices in relation to AAC implementati	1, Mixed Methods 2.A sequential, explanatory design	1.Non-probability, purposive 2.n=90 SLTs 3.SLTs working with children or youth with severe/profound intellectual and multiple disability (up to 18years of age) in	Phase one, online survey Phase two, online focus groups	Phase 1; Experienced value of AAC, intentions to implement AAC, perceived social norms, perceived	The Theory of Planned Behaviour	Phase 1; (1) Subjective norm; Rated highly on items relating to the importance or value of AAC. (2) Social norms; results indicate that they perceived other stakeholders to value AAC interventions, and to

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
	on with persons up to 18 years old with severe/profo und intellectual and multiple disability Looked at demographic information in relation to decision- making		habilitation services in Sweden 4.Habilitation services, Sweden		behaviour control relating to AAC implementation , AAC methods and tools included in interventions over the past two years Phase 2; 1) values and beliefs related to the variety of implemented AAC; 2) experienced challenges relating to AAC implementation ; 3) conceptual boundaries of AAC impleme ntation; 4) perceived social norm		expect the SLTs to implement AAC. (3) Perceived Behaviour Control; most participants reported having a low sense of control and experienced difficulties implementing AAC with this population. (4) Severe/profound intellectual and multiple disability experience correlated positively with perceptions about a strong evidence base of implementing AAC. (5) Habilitation Service experience correlated positively with perceived importance of AAC in relation to other interventions. Phase 2; (1) Overarching theme; clinical decision- making; leaning on experience to juggle complexity, comprising three sub-themes;

Authors, Year, Country	Study Aim	Methodology	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Instruments/Measures	Variables/ Phenomena of Interest	Theoretical/ Conceptual Frameworks	Key Findings
							Uncertainty regarding the child's ability and prognosis, Adjusting to the social network surrounding the child, The SLTs internal and external resources.

*Abbreviations: AAC, Augmentative and Alternative Communication; CPI, Communication Partner Instruction; DV, Dependent Variable; EBP, Evidence-Based Practice; GMFCS, Gross Motor Function Classification Scale; ICF, International Classification of Functional, Disability and Health; IV, Independent Variable; KWS, Key Word Signing; MSST, Multi-sensory storytelling; OIVA, Finnish acronym from the words participating through interaction; SLT, Speech and Language Therapist; UK, United Kingdom; USA, United States of America

4.2.7 Data Synthesis

The extracted data relating to the key findings and conceptual and theoretical frameworks were compared to allow for the grouping of similar data using thematic analysis (Thomas & Harden, 2008). This involved free line by line coding, grouping the codes into related areas to develop descriptive themes, followed by the development of analytical themes (Thomas & Harden, 2008). Thematic synthesis was undertaken manually by the researcher and reviewed regularly by the supervisory team. Discussions were ongoing to ensure agreement was reached on the coding, grouping and development of themes. The analysis focused on generating themes from the following areas to answer the research questions: (1) The factors influencing communication partners' use of AAC, both challenges and facilitators, where the similarities, differences and patterns were grouped accordingly (2) The intersection between the identified influencing factors and the effect on communication partners' use of AAC and (3) The theoretical and conceptual frameworks used in the studies were compared to identify how they guided research on this topic.

4.3 Results

4.3.1 Background of Included Studies

Of the 15 studies that met inclusion criteria, eight were qualitative (Blain-Moraes et al., 2013; Brug et al., 2013; Forster & Iacono, 2007; Koski et al., 2010; Martin & Alborz, 2014; Rensfeldt Flink et al., 2020; Rombouts et al., 2017a; Wilder et al., 2015), five were quantitative (Cheek et al., 2022; Goldbart et al., 2014; Meuris et al., 2014; Ogletree et al., 2016; Skotko et al., 2004) and two used a mixed methods approach (Rensfeldt Flink et al., 2022a; Rensfeldt Flink et al., 2022b). Three studies were conducted in the United States of America, four in Sweden, two in the United

Kingdom and two in Belgium. The remainder were conducted in Finland, Canada, Australia, and the Netherlands. A total of 380 communication partners across 15 studies were included. Nine of the 15 studies (Brug et al., 2013; Cheek et al., 2022; Goldbart et al., 2014; Koski et al., 2010; Martin & Alborz, 2014; Meuris et al., 2014; Ogletree et al., 2016; Rensfeldt Flink et al., 2022a; Rombouts et al., 2017a) included paid partners (n=300), three studies included parents (n=28) (Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b; Skotko et al., 2004) and three studies included both paid partners and parents (n=52) (Blain-Moraes et al., 2013; Forster & Iacono, 2007; Wilder et al., 2015). The total number of paid partners included across the studies was 332 and a total of 48 parents were included. Communication partners of children (Blain-Moraes et al., 2013; Brug et al., 2013; Cheek et al., 2022; Goldbart et al., 2014; Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022a; Rensfeldt Flink et al., 2022b; Skotko et al., 2004; Wilder et al., 2015) and adults (Blain-Moraes et al., 2013; Forster & Iacono, 2007; Goldbart et al., 2014; Meuris et al., 2014; Ogletree et al., 2016; Rombouts et al., 2017a; Wilder et al., 2015) were included in the studies. The age range reported was between 1.5 years (Rensfeld Flink et al., 2020) to 59 years old (Ogletree et al., 2016). Two studies did not specify if the individuals were children or adults (Koski et al., 2010; Martin & Alborz, 2014). AAC strategies in the studies included; vocalisations, gestures (Forster & Iacono, 2007; Koski et al., 2010; Ogletree et al., 2016; Wilder et al., 2015), facial expressions (Forster & Iacono, 2007; Koski et al., 2010), body language (Rombouts et al., 2017a), objects (Goldbart et al., 2014; Martin & Alborz, 2014; Rensfeldt Flink et al., 2022a; Rombouts et al., 2017a; Wilder et al., 2015), manual signs (Forster & Iacono, 2007; Goldbart et al., 2015; Meuris et al., 2014; Rensfeldt Flink et al., 2022a; Rombouts et al., 2017a), communication boards (Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b;

Rombouts et al., 2017a), communication books (Forster & Iacono, 2007; Ogletree et al., 2016), multi-sensory storytelling (MMST) (Brug et al., 2013), storybooks along with message AAC devices (Skotko et al., 2004), shared storybooks (Cheek et al., 2022), iPads, apps, flexiboard, pictures, signs, tactility, sounds, (Wilder et al., 2015), PECS (Goldbart et al., 2014; Martin & Alborz, 2014), switches (Goldbart et al., 2014), SGDs (Rensfeldt Flink et al., 2022a; Rombouts et al., 2017a), eye-gaze systems (Rombouts et al., 2017a) and biomusic (Blain-Moraes et al., 2013).

Two themes relating to factors influencing communication partners' use of AAC and the intersection between the influencing factors were identified; (1) Achieving Meaningful Communication and (2) Communication Partners' Preparedness to Use AAC (Table 4.3).

Table 4.3 Descriptive and Analytical Themes

Analytical Themes	Descriptive Themes
Achieving Meaningful Communication	Identifying the Individuals' Communication Methods
	Encouraging the Individual to Communicate
Communication Partners' Preparedness to Use AAC	Preconceived Thoughts about AAC
	Nurturing Communication Partners' Belief in AAC
	Developing Communication Partners' Knowledge
	The Team Interpersonal Dynamic

*Abbreviation: AAC, Augmentative and Alternative Communication

4.3.2 Theme 1: Achieving Meaningful Communication

This theme was central to communication partners' use of AAC. Meaningful communication is where the interaction goals of either or both communication partners are met such as to connect with each other or share a message. To achieve this, partners needed to identify and thus, be aware of individuals' communicative methods and become sensitive to their behaviours. Once this level of awareness was

established, communication partners adapted to individuals' communication to create opportunities to communicate.

4.3.2.1 Identifying the Individuals' Communication Methods

Communicative behaviours of individuals with severe/profound intellectual disability can be so subtle that it can be difficult for communication partners to attend to them (Wilder et al., 2015). Communication partners must be willing to communicate and try to understand individuals' communication methods (Wilder et al., 2015). However, being aware of the individuals' communication attempts and abilities is a pre-requisite to doing this. Findings indicate that communication partners were not always aware of individuals' full communication capabilities (Koski et al., 2010; Rensfeld Flink et al., 2020). Others believed those they supported were competent communicators (Rensfeldt Flink et al., 2022b) and recognised their subtle behaviours as communication methods (Wilder et al., 2015).

The findings highlight the importance of communication partners being sensitive to the individuals' communication methods, to detect their communication attempts and thus, try to understand what they have to say. Converting individuals' physiological signals into music, i.e., biomusic, at times helped communication partners to become more aware of individuals' reactions by drawing attention to subtle behaviour changes not previously perceived to be communication (Blain-Moraes et al., 2013). Educational interventions such as the OIVA (Finnish acronym from the words participating through interaction) training programme (Koski et al., 2010) and the ComAlong course (Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b) were found to increase partner sensitivity and subsequently, their interpretation attempts (Koski et al., 2010; Rensfeld Flink et al., 2020). Communication partners also became more confident in the individual's

communication capabilities (Koski et al., 2010; Rensfeld Flink et al., 2020). This confidence was in part, underpinned by their increased knowledge and awareness of their own communication as well as the individuals' communication ability (Rensfeld Flink et al., 2020) and better interpretation of the individuals' communication attempts (Koski et al., 2010). Increasing self-awareness and recognition of individuals' communication ability (Rensfeld Flink et al., 2020) is a necessity to communicate.

Communication partners wanted to hear the individual's voice and were proactive in using AAC to do so. SLTs introduced AAC to support individuals to express themselves, respond to their partners and develop their communication (Goldbart et al., 2014). Mothers asked more questions during storybook reading, increased their requests for clarification and confirmation, modelled possible responses to encourage their children to respond using AAC (Skotko et al., 2004), and some partners imitated the children to confirm their behaviours (Rensfeld Flink et al., 2020; Wilder et al., 2015). At times, biomusic (Blain-Maraes et al., 2013) and communication passports (Goldbart et al., 2014) strengthened communication partners' understanding of individuals' responses (Blain-Moraes et al., 2013; Goldbart et al., 2014). However, communication partners must not assume to know what the individual means based on knowing them (Rombouts et al., 2017a). This could hinder the intended message being received and subsequently, being understood (Rombouts et al., 2017a). Therefore, it is important to be continuously sensitive to the individuals' communication methods whilst acknowledging that these can change.

Communication partners' self-awareness, recognition of the individuals' communication ability and cognisance that this ability can change may improve

partner sensitivity and their readiness to attend to and interpret individuals' expressive behaviours.

4.3.2.2 Encouraging the Individual to Communicate

Communication partners engaged with the individual to encourage them to communicate. This involved adapting to the individuals' communication to provide them with opportunities to communicate.

While it is recognised that communication partners have the responsibility to support individuals with severe/profound intellectual disability communication (Forster & Iacono, 2007; Koski et al., 2010; Rensfeldt Flink et al., 2022b; Rombouts et al., 2017a; Wilder et al., 2015), uncertain ownership of responsibilities was identified as a limitation to AAC use (Wilder et al., 2015). Realising the individuals' communicative abilities may lead to a further realisation of their responsibilities as communication partners. When communication partners realised the individual's ability, they also realised the importance of providing the individual with opportunities to communicate (Koski et al., 2010) and their responsibility providing quality interactions (Rensfeldt Flink et al., 2022b).

Adapting to the individuals' ways of communicating is intertwined with identifying their communication methods. If communication partners do not identify individuals' communication methods, they cannot adapt to them. Participants identified the individual's needs and adapted their communication to them, which was an ongoing process (Rensfeldt Flink et al., 2022b). They simplified their communication (Koski et al., 2010) by communicating in clear and concrete ways (Rensfeldt Flink et al., 2022b) and using the same communication approaches as the individual (Koski et al., 2010; Rensfeldt Flink et al., 2020; Wilder et al., 2015).

Communication partners wanted to use strategies that suited the individual (Koski et al., 2010; Martin & Alborz, 2014; Rensfeldt Flink et al., 2020; Rensfeldt Flink et al., 2022b). This person-centred approach was evident in SLTs' decision-making (Goldbart et al., 2014; Rensfeldt Flink et al., 2022a) and communication partners' personalised approaches (Brug et al., 2013; Cheek et al., 2022; Skotko et al., 2004). Deciding on an AAC system that best suits each individual's ability was reported as a challenge, complicated further by uncertainty around the individual's abilities and cognitive process (Rensfeldt Flink et al., 2022a). Experience helped SLTs to manage such complexity, where they had learned to be flexible in their thinking, set reasonable goals and recognise the small progress made by the individual (Rensfeldt Flink et al., 2022a). At times, SLTs' implemented AAC that they were familiar with (Rensfeldt Flink et al., 2022a), while others seldom mentioned this as a rationale for implementing AAC (Goldbart et al., 2014). Introducing AAC based on experience with past users should be in conjunction with the current user's individuality.

Communication partners discussed using AAC that would support the individual to understand (Brug et al., 2013; Forster & Iacono, 2007; Goldbart et al., 2014; Koski et al., 2010) facilitating a mutual understanding in the interaction. However, communication partners did not always apply their knowledge of the individuals' ability to the AAC. For example, although teachers increased their knowledge of individuals' abilities through MSST, they tended to leave the book unchanged or made changes that were not based on this newfound knowledge (Brug et al., 2013). One teacher's (1/3) rationale for not changing the MSST was that they did not want to confuse the individual (Brug et al., 2013).

Communication partners require time to use AAC. Participants' experienced time constraints (Rensfeldt Flink et al., 2022a; Rombouts et al., 2017a; Wilder et al., 2015) caused by competing workloads involving multiple tasks (Rombouts et al., 2017a). In these circumstances AAC was sometimes abandoned (Rombouts et al., 2017a). Some time constraints were actual; however, others were reported to be perceptual (Rombouts et al., 2017a). OIVA training helped support staff to realise the need to prioritise time for communication (Koski et al., 2010). Others offered the individual time to communicate (Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b; Skotko et al., 2004). Increasing communication partners' awareness of the importance of prioritising time for communication may help them to incorporate the use of AAC into their daily activities and tasks.

Communication partners' use of AAC may be influenced by their identification of an individual's communication methods and ability. When communication partners recognise the individual's communication attempts, they may realise their full ability and/or potential. Steps need to be taken to recognise the individual's communication methods, thus, helping partners to engage with the individual using AAC that is unique to their needs.

4.3.3 Theme 2 Communication Partners' Preparedness

Communication partners need to feel prepared and ready to use AAC. This is influenced by their preconceived thoughts about and knowledge of AAC, nurturing their belief in AAC, and the interpersonal dynamic between network members, i.e., the people involved in supporting the individual to communicate.

4.3.3.1 Training Interventions to Prepare Communication Partners

Of the 15 studies, seven examined the use of training interventions on supporting communication partners' interaction and use of AAC (Cheek et al., 2022; Forster & Iacono, 2007; Koski et al., 2010; Ogletree et al., 2016; Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b; Skotko et al., 2004). Some interventions were found to be more successful than others. Participants provided opportunities and modelled the AAC system, a static communication book of approximately 100 symbols during the intervention (Ogletree et al., 2016), expanded their use of AAC (Forster & Iacono, 2007; Koski et al., 2010; Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b) and planned to continue using it (Cheek et al., 2022). However, some participants were hesitant to use AAC because they did not feel ready, or considered the AAC was not meaningful or hard to apply (Rensfeld Flink et al., 2020). For others, no significant gains were maintained after the training (Ogletree et al., 2016). Thus, the findings indicate that training alone does not prepare communication partners to use AAC.

Factors that underpin communication partners' use of AAC were evident in the training provided and changes identified. Some participants thinking towards communication and the individual developed during training (Koski et al., 2010; Rensfeldt Flink et al., 2022b). For example, they became more aware of individuals' communication needs and abilities and adapted to them (Koski et al., 2010; Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b). For others, storybook reading occurred in a more synchronous fashion (Skotko et al., 2004) and communication partners took a more active approach (Forster & Iacono, 2007; Rensfeld Flink et al., 2020; Rensfeldt Flink et al., 2022b). Thus, at times training prepared communication partners to identify the individuals' communication abilities, adapt, become aware of the benefits that AAC can offer to the interaction and develop their beliefs in AAC.

However, the findings indicate that further support is required to prepare communication partners to use AAC and maintain their use of it.

4.3.3.2 Preconceived Thoughts about AAC

Communication partners' preconceived thoughts around the likelihood of success influenced their preparedness to use AAC. These included, thinking it was too soon to use AAC (Rensfeld Flink et al., 2020), hesitancy towards using new technology (Wilder et al., 2015), thinking AAC was foreign and frightening (Rensfeldt Flink et al., 2022b) and feeling AAC was ineffective before they could use it (Forster & Iacono, 2007). Some believed that not everyone would benefit from AAC, or it did not offer interactional fluency (Rombouts et al., 2017a).

Communication partners need to be aware that AAC can benefit individuals with severe/profound intellectual disability. While some believed that AAC would be beneficial for individuals (Rensfeldt Flink et al., 2022a), others discussed the unexpected power of AAC (Wilder et al., 2015) and thought that not everyone needed it (Rombouts et al., 2017a).

Parents were hesitant about using AAC and felt that the individual and the family were not ready (Rensfeld Flink et al., 2020). Communication partners' readiness may impact ownership of responsibilities (Forster & Iacono, 2007). For one parent, this feeling of readiness stemmed from a belief that the pictures were too difficult for the individual (Rensfeld Flink et al., 2020). Similarly, a number of support staff displayed resistance towards using new technology due to their limited knowledge of the benefits and anxiety towards learning to use it (Wilder et al., 2015). When support staff were not aware that AAC could offer interactional fluency when consistently applied over time, they sometimes used alternative approaches to communicate with individuals they knew well (Rombouts et al., 2017a).

Communication partners should be aware of both the short and long-term benefits that AAC can offer to them, the individual and the overall interaction.

4.3.3.3 Nurturing Communication Partners' Belief in AAC

If communication partners do not believe in AAC they may not be fully prepared to use it. Participants' belief in AAC appeared to be stronger when they recognised the benefits AAC can offer to the individual and the interaction. For example, interventions were chosen by SLTs as they were deemed meaningful (Goldbart et al., 2014) and communication partners valued them when they allowed them to see the individual's reaction, responses, personality and created a sense of meaning during the interaction (Blain-Moraes et al., 2013). The findings capture the value placed on the status symbol of technology as it created a sense of normalcy (Rensfeldt Flink et al., 2022a) and iPads promoted acceptance (Wilder et al., 2015).

Experience and training may help communication partners to shape their beliefs around AAC. SLTs with more experience supporting persons with severe/profound intellectual disability had stronger perceptions about a strong evidence base for implementing AAC with them (Rensfeldt Flink et al., 2022a). Their experience in habilitation services was reported to be related to the perceived importance of AAC in relation to other interventions (Rensfeldt Flink et al., 2022a). In addition, communication partners' view towards AAC developed following training. Support staff who once viewed unsuccessful attempts as ineffective transitioned to view such attempts as opportunities for improvement (Forster & Iacono, 2007). A mother transitioned from viewing AAC as foreign and frightening and feeling that she was expected to use AAC, to taking control over her use of it (Rensfeldt Flink et al., 2022b). Thus, she concentrated on AAC that she believed in to support her daughter to communicate (Rensfeldt Flink et al., 2022b). Support

staffs' attitudes towards manual signs were related to their understanding of signs but not their production of them (Meuris et al., 2014). Communication partners need to believe in AAC to feel ready to use it.

4.3.3.4 Developing Communication Partners' Knowledge

Communication partners wanted to develop their knowledge to provide suitable support to individuals (Martin & Alborz, 2013; Rensfeldt Flink et al., 2022b). The importance of continuously developing their knowledge was highlighted, where SLTs' implementation of certain AAC methods was dependent on whether they were accredited in those methods, thus affecting the availability of AAC systems for those they support (Rensfeldt Flink et al., 2022a). Moreover, a low level of knowledge can hinder the use of AAC (Wilder et al., 2015) and, conversely, increased knowledge (Rensfeldt Flink et al., 2022b) and understanding (Meuris et al., 2014) can enhance communication partners' use of it (Meuris et al., 2014; Rensfeldt Flink et al., 2022b) and ease AAC implementation (Rensfeldt Flink et al., 2022a).

Communication partners' knowledge of AAC was influenced by the characteristics of the individual they supported and the training provider. Support staff knew less signs when they supported persons with more severe intellectual disabilities (Meuris et al., 2014). Their knowledge and production of signs was enhanced when they were taught by a SLT as opposed to a fellow support worker (Meuris et al., 2014) which suggests the importance of appropriate trainers to support communication partners to develop their knowledge and thus, prepare them to use AAC.

4.3.3.5 The Team Interpersonal Dynamic

A supportive and collaborative dynamic between communication partners was important to prepare them to use AAC. This dynamic was captured through the group nature of interventions that allowed communication partners to learn with others (Ogletree et al., 2016; Wilder et al., 2015), share their experiences (Rensfeldt Flink et al., 2020; Rensfeldt Flink et al., 2022a; Rensfeldt Flink et al., 2022b; Wilder et al., 2015) and reflect (Rensfeldt Flink et al., 2022b). Reflection should be encouraged as it may lead to change (Rensfeldt Flink et al., 2020; Rensfeldt Flink et al., 2022b). A supportive team dynamic needs to be established to prepare communication partners to work together towards a common goal.

Communication partners' support of AAC can filter through the team. SLTs believed that others valued AAC and expected SLTs to implement it (Rensfeldt Flink et al., 2022a) and support staff used AAC less when other partners did not support it (Rombouts et al., 2017a). Similarly, parents transitioned from viewing themselves as being primarily responsible for their son's communication to sharing responsibility with support workers who took greater ownership of their responsibilities to support the individual's communication (Forster & Iacono, 2007). These parents believed that the support workers were willing and interested (Forster & Iacono, 2007). Therefore, the supportive dynamic facilitated a collaborative approach in attempting to achieve a common goal.

To establish a supportive team dynamic, partners should be included (Rensfeldt Flink et al., 2022b) to increase sustainable communication practices (Goldbart et al., 2014). When a mother's input was sought, she felt trusted and supported (Rensfeldt Flink et al., 2022b). However, the findings indicate that communication partners were not always included, where the views and wishes of parents and staff did not inform SLTs' decision when introducing AAC supports

(Goldbart et al., 2014). SLTs' experience was reported to result in them being more inclined to listen to parents' opinions (Rensfeldt Flink et al., 2022a). Both paid and familial communication partners valued the unique input from the various team members (Forster & Iacono, 2007; Rensfeldt Flink et al., 2022a; Rensfeldt Flink et al., 2022b; Rombouts et al., 2017a). This was reflected in SLTs' adjustment of interventions around the individuals' communication partners to promote the success of AAC (Rensfeldt Flink et al., 2022a). However, such an approach may pose as a barrier to providing individually tailored AAC, where some SLTs reported that they introduced AAC systems already used in classrooms to promote functionality for teachers (Rensfeldt Flink et al., 2022a).

Although SLTs included support staff when implementing AAC, differing opinions between them and the support staff arose, attributed to their different experiences with AAC and the individual (Rombouts et al., 2017a). The dynamic between these partners was referred to as a balancing act by some SLTs (Rombouts et al., 2017a). Similarly, SLTs experienced differing expectations between partners (Rensfeldt Flink et al., 2022a). Others were unsure about support staffs' willingness to use AAC when they received neutral responses during implementation (Forster & Iacono, 2007). The findings highlight a potential disparity between communication partners' views and expectations towards AAC.

The findings indicate that collaboration and listening is central to a supportive team dynamic. However, partners sometimes held different views, which may be specific to their individual roles and experiences. Reflection can lead to different ways of thinking and allow communication partners to share their own views and experiences. Therefore, it may create a more balanced relationship

between them, encouraging communication partners to share their experiences and to work together to support the individual.

4.3.4 Conceptual and Theoretical Frameworks Identified

To address the third review question, theoretical and conceptual frameworks guided seven of the 15 studies. The theory of planned behaviour (TPB, Ajzen, 1991) guided the development of the survey examining SLTs' decision-making around AAC implementation (Rensfeldt Flink et al., 2022a). The reasoned action approach (RAA, Fishbein & Ajzen, 2010) stemmed from the TPB and guided the discussion in Rombouts et al. (2017a) study to address the discrepancy between support staffs' values and practice. From communication to language, a psychological approach (Bruner, 1974; Tomasello, 2001) guided the Akktiv project where the ComAlong Course was developed (Rensfeldt Flink et al., 2020; Rensfeldt Flink et al., 2022b); the concept of personhood from social interactionist theory (Cooley, 1972; Kitwood, 1997; Mead, 1970) guided Blain-Moraes et al. (2013) study; OIVA training was guided by Community-Based Rehabilitation (CBR) and Client-Oriented principles and it was Solution Focused (Koski et al., 2010); the categorical, relational (Persson, 2003) and interactional perspectives (Tangen, 2008) of disability guided the study by Wilder et al. (2015).

Although there were similarities between constructs used, no framework was used more than once. Behavioural theories were present in two studies, the TPB (Rensfeldt Flink et al., 2022a) and the RAA (Rombouts et al., 2017a). The dialogical perspective of disability (Wilder et al., 2015) also emerged in the definition of communication that underpinned the ComAlong Course (Rensfeldt Flink et al., 2020; Rensfeldt Flink et al., 2022b). Communication was defined as co-regulated and co-constructed where meaning is created dialogically, dynamically, and continuously

(Bruner, 1974). The OIVA training intervention was guided by CBR and Client-Oriented and Solution Focused principles (Koski et al., 2010). In Finland, CBR has been used to describe services that influence important social networks of individuals, aiming to create communities that support the individual (Koski et al., 2010). This is similar to the relational perspective, where the environment should be adjusted to the individual (Wilder et al., 2015). The concept of personhood (Blain-Moraes et al., 2013) derived from the social interactionist theory, states that the existence of the human self is based on successful interaction with others (Cooley, 1972; Kitwood, 1997; Mead, 1970). This concept is similar to the interactionism perspective (Tangen, 2008) where both within child and environmental factors of interactions are recognised (Wilder et al., 2015). The categorical perspective was evident in one study (Wilder et al., 2015).

The factors influencing communication partners' use of AAC are complex and seem related. However, there is a need to better understand the nature and extent to which they relate to affect the use of AAC. Such understanding would provide insight into how to encourage and optimise communication partners' use of AAC with persons with severe/profound intellectual disability. Therefore, to gain a nuanced understanding of the relationships between these factors and test specific hypotheses, use of a theoretical model is recommended. It appears that the conceptual and theoretical frameworks used in the studies identified aimed to co-construct communication by supporting the individual and/or developing the environment around them. The frameworks used in the included studies were sufficient in the context of those studies. However, the findings of this review now point to communication partners' preparedness to use AAC and the effect that this preparedness has on their use of it. Their preparedness was influenced by complex

factors including their belief in AAC and the benefits it could offer the interaction and individual as well as resources such as training, knowledge, time, and support. Of the frameworks identified in this review, the TPB or RAA would best explain the factors influencing communication partners' use of AAC.

4.4 Discussion

This review aimed to provide a synthesis of the factors influencing communication partners' use of AAC.

Achieving meaningful communication involved identifying the individuals' communication methods and encouraging them to communicate. The latter was dependent on the former. Persons who use AAC require those around them to listen (McCormack et al., 2018) and interpret their communication (Dennis, 2002). To do so, communication partners need to observe the individual to detect changes and recognise communication attempts that may be idiosyncratic (Bunning, 2018). Becoming more sensitive to individuals' communicative attempts may help communication partners to identify individuals' communication methods. The findings of this review indicate that once partners identified communication methods, they were better positioned to adapt their communication to the individual and better prepared to achieve a more balanced interactional relationship (Bunning, 2018).

The findings of this review capture the importance of communication partners believing and expecting that the individual can and does communicate to provide opportunities for communication. Communication partners' expectations of (Lund & Light, 2007; Moorcroft et al., 2019) and belief in individuals with severe/profound intellectual disability ability (Dennis, 2002; Soto, 1997) are key factors when optimising their communication attempts. Participants were not always

aware of individuals' communicative ability. The findings indicate that this lower level of awareness may be due to a combination of their expectations, awareness, understanding and knowledge. However, enhancing their knowledge of communication (Rensfeldt Flink et al., 2022b) and becoming sensitive to individuals' attempts to interpret their meaning (Koski et al., 2010) helped partners to realise that the individuals were communicating (Koski et al., 2010; Rensfeldt Flink et al., 2022b). This led to more opportunities to communicate (Koski et al., 2010; Rensfeldt Flink et al., 2020) and reduced the chances of reaching the cycle of devaluation. The cycle of devaluation can occur when communication partners do not recognise and therefore, do not respond to the communication skills of the person (Bunning, 2018). The individual may have "*few meaningful opportunities to participate, which effectively hides their true competence*" (Bunning, 2018, p.202). To strive to offer opportunities, communication partners should become aware of the individuals' attempts and thus, their ability. Following such a process over time could heighten communication partners' awareness of each individual's competence to communicate and furthermore, to use AAC to support their communication.

Communication partners' preparedness influenced their use of AAC. AAC required a team approach with a supportive interpersonal team dynamic. However, at times a disparity in the dynamic between certain team members emerged. An AAC user centred approach should be implemented, whereby all communication partners are considered, in order to uphold the communication rights of the individual (Norburn et al., 2016). Communication partners have a common goal to support the individual to communicate, but achievement of this requires the involvement of all partners (Hanley et al., 2023a). Communication partners' views may differ; however, they must not allow differing views interrupt the interpersonal team dynamic.

Communication partners' confidence, knowledge, resources and training can impact the use of AAC (Moorcroft et al., 2019; Norburn et al., 2016; Rombouts et al., 2017b). The findings indicate that communication partners feel the need for more training that is specific to the individual with severe/profound intellectual disability (Martin & Alborz, 2014). An enhanced knowledge can help communication partners to feel prepared to use AAC. In addition, it helped them develop their thoughts about communication and the individual (Koski et al., 2010; Rensfeldt Flink et al., 2022b). Communication partners may need to be supported to undergo such a cognitive process (Rensfeldt Flink et al., 2022b) as their preconceived thoughts may negatively influence their use of AAC.

The review highlights the importance of nurturing communication partners' beliefs to feel prepared to use AAC. Their belief in AAC may be dependent on the perceived benefits to the interaction and individual they support. However, some communication partners held preconceived thoughts around the low likelihood of success. Similarly, when communication partners did not understand the purpose of AAC they used it less (Moorcroft et al., 2019). Conversely, AAC systems were reported to be facilitated by partners who viewed them as beneficial (Moorcroft et al., 2019). Communication partners need to be aware of the benefits that AAC can offer to individuals with severe/profound intellectual disability. One potential way to raise the awareness of the need for and benefit of AAC is to introduce AAC tailored to each person's needs. In addition, encouraging the person to view the individual as a competent communicator may help with recognising the need for AAC for that individual. It is recognised in the literature that communication partners' belief in the individual's ability to learn to communicate more effectively influenced their intentions to use AAC systems (Soto, 1997).

The findings suggest that communication partners' beliefs influence their use of AAC. It would be helpful to identify a way that their beliefs and assumptions can be developed and adapted. However, there is an apparent need to first gain a nuanced understanding of the relationship between their beliefs and use of AAC. Therefore, the use of a theoretical model is recommended to test specific hypotheses related to these factors. Based on the review findings, the TPB and the RAA were explored.

The TPB and RAA postulate that three main factors, attitude towards the behaviour, subjective norm, and perceived behaviour control affect one's intention toward the actual behaviour (Ajzen, 1991). Both models offer the opportunity to examine the relationship between the independent constructs and intention to use AAC. However, the findings of this review indicate that factors influencing communication partners' use of AAC may be interconnected at times. The Combined Technology Acceptance Model and Theory of Planned Behaviour (C-TAM-TPB, Taylor & Todd, 1995a) combines the predictors of the Technology Acceptance Model (TAM, Davis, 1989) with the factors of the TPB (Ajzen, 1991). This hybrid model includes offers a mechanism to explain the formation of attitude by proposing that perceived usefulness and perceived ease of use predict attitude. The C-TAM-TPB includes the social and control factors captured by the TPB, similar to the constructs of the RAA.

The C-TAM-TPB offers the opportunity to examine the influence of communication partners' beliefs on their use of AAC as well as the influence of perceived usefulness and ease of use on their attitudes towards using AAC. Given the importance of communication partners' view towards AAC on their use of it, understanding the impact of perceived usefulness on attitude may help practitioners to promote positive attitudes towards using AAC. In addition, understanding the

impact of perceived ease of use on perceived usefulness, attitude and intention offers the potential to provide information to AAC developers.

This review included both paid and familial communication partners.

Although it was beyond the scope of this review to examine differences in the factors influencing the use of AAC between the different categories of communication partners, this topic merits further investigation.

4.4.1 Strengths and Limitations

The findings of this integrative review should be considered in the context of its limitations. Publication, location, and language biases may have been introduced during the search process, as grey literature was not considered, and the review only included studies published in English. As per Whitemore and Knafl (2005), two search strategies were undertaken, the database search and the reference list search of the included studies. The strengths are also acknowledged. A review protocol was published, thus reducing the risk of reporting bias. The researcher and a thesis supervisor independently screened the titles, abstracts, and full texts articles for eligibility. Data extraction was confirmed by a thesis supervisor. The research team was composed of members with different perspectives, allowing for several stances to be included and valued during discussions to reach agreement on research targets (Thomas et al., 2020). EH is a PhD student whose research is focused on AAC with people with severe/profound intellectual disability and is also a registered nurse in intellectual disability. CD, AMM, and EL are academic nurse lecturers, where CD and AMM are registered nurses in intellectual disability, and EL is a registered general nurse. The diversity of the research team ensured that sufficient methodological and content expertise were included to appropriately analyse the data (Thomas et al., 2020).

4.5 Conclusion and Implications

This review provides insight to the multiple factors that influence communication partners' use of AAC and the intersection between factors identified. Communication partners' use of AAC may be influenced by their recognition of individuals' communication ability and sensitivity to their expressive behaviour. Where they do not recognise their communication ability, strategies may not be used to provide opportunities for communication that are unique to the individual. Communication partners' use of AAC is influenced by their preparedness to use it. To be prepared they need to be aware of the benefits that AAC can offer the interaction, the long-term outcomes, develop their knowledge and be surrounded by a supportive dynamic. A key finding is the influence of communication partners' belief in AAC on their use of it. This belief was underpinned by the perceived benefits. However, preconceived thoughts affected their awareness of such benefits and thus, negatively influenced their use of AAC.

The factors influencing communication partners' use of AAC are complex, complexity may increase as factors interconnect. Therefore, further research is recommended to explain the determinants of communication partners' use of AAC with persons with severe/profound intellectual disability. Key variables identified in this review include their beliefs, attitudes, expectations, knowledge, and resources such as training, support, and time. The use of a theoretical model offers the opportunity to test the relationship between these variables and test specific hypotheses. Such variables are captured in the constructs of the C-TAM-TPB.

The next chapter (Chapter 5) outlines the empirical study that aimed to obtain an in-depth understanding of the nature and extent to which the factors influencing the intention of communication partners to use AAC interconnect by testing specific hypotheses underpinned by the C-TAM-TPB (Taylor & Todd, 1995a). Given the

importance of AAC benefiting the individual and the interaction, the C-TAM-TPB was adopted (Taylor & Todd, 1995a) to examine the influence of perceived usefulness on communication partners' attitude toward use, with attitude also being a determinant of intention to use technology. In addition, understanding more about how perceived ease of use, perceived usefulness, attitude, social norms, and perceived behaviour control contribute to communication partners' use of AAC will be of value to policy makers and professionals when designing and implementing AAC interventions.

Chapter 5. Examining the Intention of Communication Partners of Persons with Severe/Profound Intellectual Disability to Use Augmentative and Alternative Communication

Abstract

Background

AAC is a recognised means of support for persons with severe/profound intellectual disability. Communication partners have a fundamental role supporting the use of AAC. Multiple, complex factors influence communication partners' preparedness to use it. Understanding the factors that influence communication partners' intention to use AAC will be of value to policy makers and professionals when designing and implementing AAC interventions. This study aimed to obtain an in-depth understanding of the nature and extent to which the factors influencing the intention of communication partners to use AAC interconnect by testing specific hypotheses underpinned by the C-TAM-TPB.

Methods

In this cross-sectional, descriptive, correlational study, 152 communication partners of persons with severe/profound intellectual disability took part in an online survey. Survey items related to demographic information to characterise the sample and items corresponding to the constructs of the C-TAM-TPB.

Results

The results of this study indicate that perceived usefulness (p value=0.000 and β =0.253, Wald's Chi-square χ^2 =27.5) and perceived ease of use both had a significant impact (p =0.007, β =0.145, Wald's χ^2 =7.2) on attitude towards using AAC. Attitude (p value=0.000 and β =0.528, Wald's χ^2 =20.8) and perceived

behavioural control (p value=0.000 and β =0.332, Wald's χ^2 =16.8) had a significant impact on behavioural intention.

Conclusion

These findings contribute to the body of knowledge on the use of AAC with persons with severe/profound intellectual disability by providing a nuanced understanding of the nature and extent to which the factors influencing the intention to use AAC interconnect.

Keywords: augmentative and alternative communication, combined technology acceptance model and theory of planned behaviour, communication, communication partner, severe intellectual disability, profound intellectual disability, profound intellectual and multiple disability

5.1 Introduction

Individuals with severe/profound intellectual disability experience significant communication challenges. They tend to function at a pre-intentional communication stage (Sigafoos et al., 2021). Their expressive behaviour includes subtle signals such as body movements and changes in muscle tone (Petry & Maes, 2006). They require support from communication partners who are willing to understand and draw meaning from their messages (Hostyn & Maes, 2009; Lyons, 2005) and may use AAC (Beukelman & Light, 2020; Sigafoos et al., 2021).

Communication partners are the companion in the interaction, for example, family members, health, education and social care professionals. Successful communication depends on both the individual and their communication partners (Kent-Wash et al., 2015; Light et al., 2019a).

AAC is defined as “*an area of clinical practice that addresses the needs of individuals with significant and complex communication disorders characterised by impairments in speech-language production and/or comprehension, including spoken and written modes of communication*” (ASHA, 2019). Examples include unaided modes such as gestures and aided modes such as objects of reference and eye-gaze devices.

Supporting individuals to communicate with AAC is influenced by complex factors (Hanley et al., 2023b) related to the individual, the environment, their communication partners and the AAC strategy (Light & McNaughton, 2014). Therefore, both parties should be considered (Light et al., 2019a; Light et al., 2021).

AAC usage is not always optimised to maximise individuals’ ability to communicate (Hanley et al., 2023a). Factors such as communication partners’ attitudes (Calculator, 1999; Johnson et al., 2006; Lund & Light, 2007; Moorcroft et al., 2019; Rombouts et al., 2016), expectations of both the individual (Calculator,

1999, Dennis, 2002; Hanley et al., 2023a, Moorcroft et al., 2019; Soto, 1997) and AAC (Hanley et al., 2023a; Hanley et al., 2023b; Rombouts et al., 2017b), knowledge (Hanley et al., 2022; Hanley et al., 2023a,; 2023b; Meuris et al., 2014) and uncertainty (Hanley et al., 2023a) may affect the effective and efficient use of AAC. Furthermore, resources such as time (Johnson et al., 2006; Rombouts et al., 2017a), availability of AAC (Bircanin et al., 2019; Hanley et al., 2023a; Mirenda, 2014) and support of other communication partners (Hanley et al., 2023b; Rombouts et al., 2017a) may also affect the use of AAC.

It is recognised that the factors influencing communication partners' use of AAC interconnect (Hanley et al., 2023a; Rombouts et al., 2016; Rombouts et al., 2017a). However, the nature and extent to which the factors influencing communication partners of individuals with severe/profound intellectual disability use of AAC interconnect remains unclear (Hanley et al., 2023b). Thus, there is an apparent need to obtain a nuanced understanding of the factors influencing communication partners' use of AAC and the relationships between these factors. Due to the ambiguity around the nature of the interconnectedness, the application of a framework would be useful in assisting to uncover such relationships (Heale & Noble, 2019).

Theoretical frameworks demonstrate the relationship among a set of concepts (Heale & Noble, 2019). Theory guided research connects and builds upon previous knowledge (Littzen-Brown, 2021). Theoretical and conceptual frameworks were identified in an integrative review examining the factors that influence communication partners' use of AAC (Hanley et al., 2023b). Although there were similarities between constructs used, no framework was used more than once (Hanley et al., 2023b). However, behavioural theories were present in two studies.

The RAA (Fishbein & Ajzen, 2010) and the TPB (Ajzen, 1991). The TPB was used to guide a study examining SLTs AAC decision-making (Rensfeldt Flink et al., 2022a). The RAA was used to discuss the findings of a qualitative study that outlined a discrepancy between communication partners' values and practice, where they valued consistent use, however they used AAC inconsistently (Rombouts et al., 2017a).

5.2 Theoretical Underpinnings and Hypothesis Development

Multiple behavioural theories exist, with some of the more prominent ones including the Theory of Reasoned Action (TRA, Fishbein & Ajzen, 1975), the TPB (Ajzen, 1991) and the RAA (Fishbein & Ajzen, 2010). In addition, multiple technology acceptance models stemming from behavioural theories have been developed including the TAM (Davis 1986; Davis et al., 1989), and the C-TAM-TPB (Taylor & Todd, 1995a). Adopting a technology model may align more closely with AAC (Rombouts et al., 2016). Therefore, behavioural theories and technology acceptance models were considered in the context of AAC. There is a need gain an in-depth understanding of the nature and extent to which the factors influencing the use of AAC relate (Hanley et al., 2023b). Therefore, a hybrid model, the C-TAM-TPB that includes the TPB, and the TAM constructs was explored. A brief overview of the TPB, the TAM and the C-TAM-TPB, their constructs and proposed relationships are outlined.

5.2.1 The Theory of Planned Behaviour

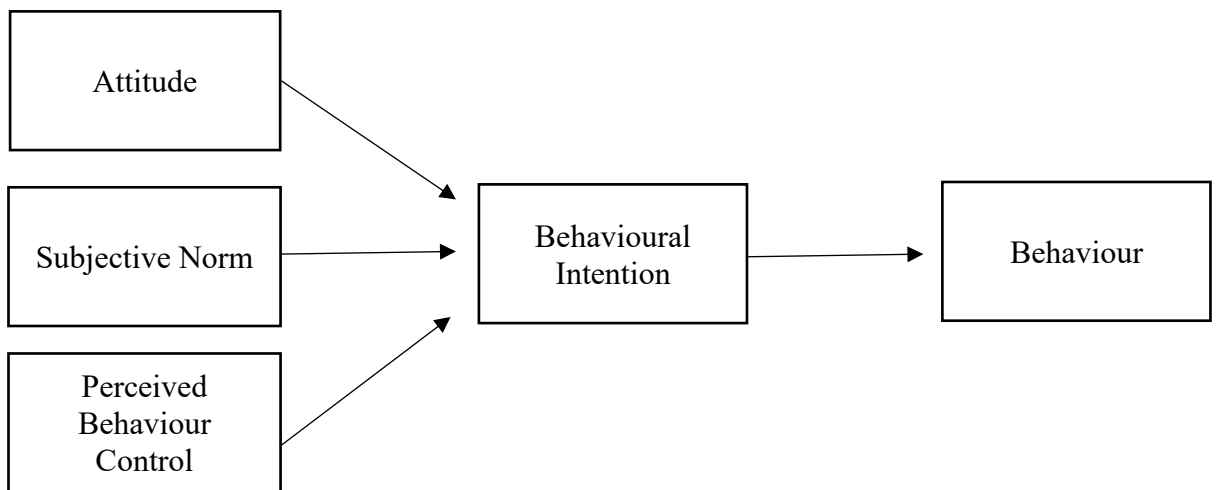
The TPB (Ajzen, 1991) stemmed from the TRA (Fishbein & Ajzen, 1975), adding one extra construct, perceived behavioural control, to explain the situations where one does not have complete control over their behaviour (Ajzen, 1991). The TPB postulates that attitude towards the behaviour, subjective norm, and perceived

behaviour control, impact people's behavioural intention toward the actual behaviour (Figure 5.1).

Behavioural intention is defined as “...*readiness to perform a behaviour*” (Fishbein & Ajzen, 2010, p. 21). Behavioural intention acts as a mediator amid attitude towards the behaviour, subjective norm, perceived behaviour control and actual behaviour (Cornally, 2014) and is the most important immediate antecedent of actual behaviour (Fishbein & Ajzen, 2010). When measured appropriately, using two or more items for reliability and applying the principle of compatibility, behavioural intention can account for an appreciable proportion of variance in actual behaviour (Fishbein & Ajzen, 2010). This is supported by the literature, where behavioural intention has been reported to account for 28% of variance in actual behaviour (Sheeran, 2002). Therefore, examining the antecedents of behavioural intention acts as a starting point to gain a more nuanced understanding of actual behaviour (Fishbein & Ajzen, 2010) i.e., AAC use.

Attitude is defined as “*An individual's positive or negative feelings (evaluative affect) about performing the target behaviour*” (Fishbein & Ajzen, 1975, p. 216). Subjective norm refers to “*The person's perception that most people who are important to him think he should or should not perform the behaviour in question*” (Fishbein & Ajzen, 1975, p. 302). Perceived behaviour control is defined as “*The perceived ease or difficulty of performing the behaviour*” (Ajzen, 1991, p. 188).

Figure 5.1 The TPB



(Ajzen, 1991)

5.2.2 The Technology Acceptance Model

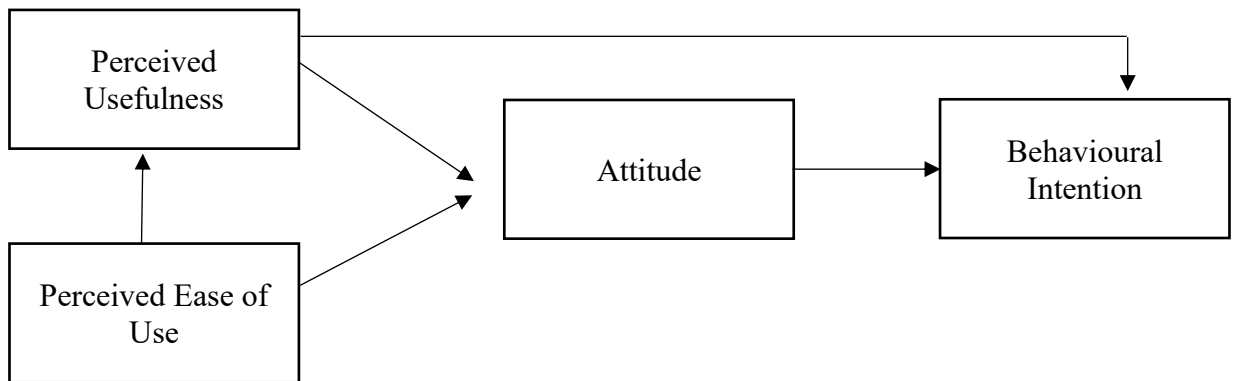
The TAM also derived from the TRA and proposes that behavioural intention is affected by attitude towards use, as well as the direct and indirect effects of perceived usefulness and perceived ease of use. Attitude is affected by perceived ease of use and perceived usefulness. Perceived ease of use has a direct impact on perceived usefulness (Davis et al., 1989; Teo, 2012; see Figure 5.2).

Perceived usefulness is defined as “*The degree to which a person believes that using a particular system would enhance his or her job performance*” (Davis, 1989, p. 320). In the context of this study, it is defined as the degree to which communication partners believe that using AAC would enhance their ability to support the individual with severe/profound intellectual disability to communicate.

Perceived ease of use is defined as “*The degree to which a person believes that using a particular system would be free of effort*” (Davis, 1989, p. 320). The TAM does not include the influence of social and control factors on behavioural intention (Taylor & Todd, 1995a) and the TPB does not include the influence of

perceived ease of use or usefulness factors on attitude and intention. Therefore, the C-TAM-TPB was explored.

Figure 5.2 The TAM



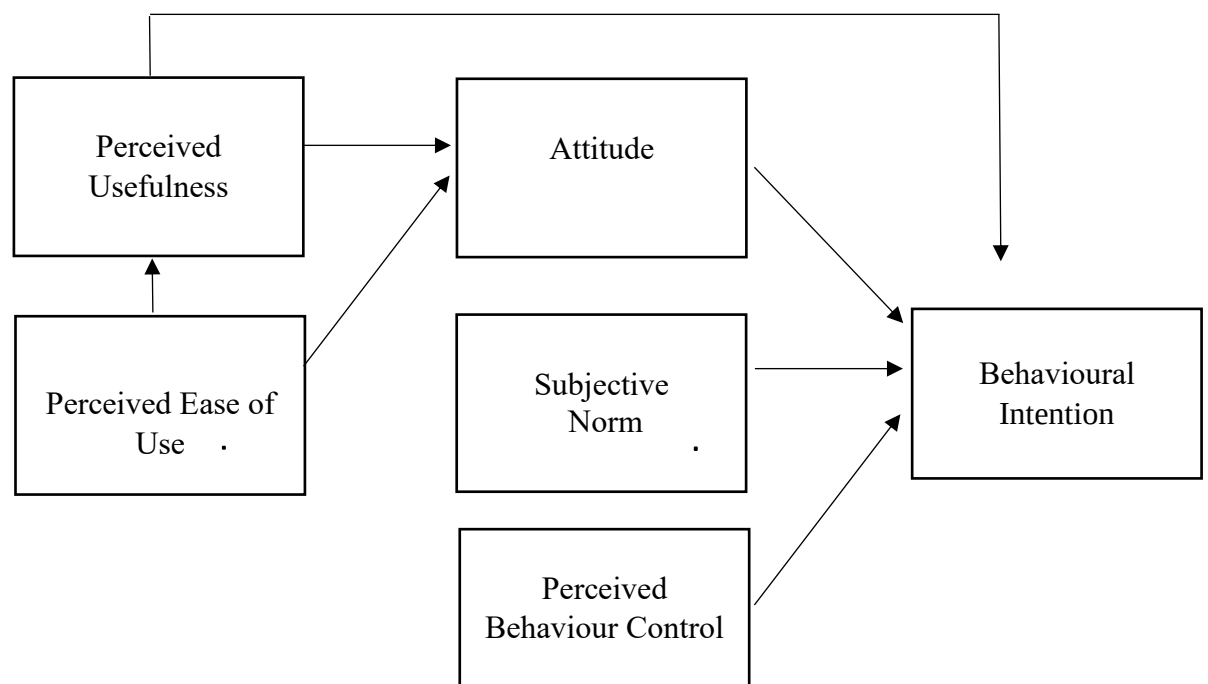
(Davis et al., 1989)

5.2.3 The Combined Technology Acceptance Model and Theory of Planned Behaviour

Taylor and Todd (1995a) developed an integrated model, the C-TAM-TPB (Figure 5.3) which combines the predictors of the TAM with the social and control factors of the TPB (Taylor & Todd, 1995a). The C-TAM-TPB offers the opportunity to examine the influence of communication partners' beliefs on their intention to use AAC as well as the influence of perceived usefulness and perceived ease of use on their attitudes towards using AAC. Given the importance of communication partners' view towards AAC on their use of it (Hanley et al., 2023b), understanding the impact of perceived usefulness on attitude may help practitioners to nurture positive attitudes towards using AAC. In addition, understanding the impact of perceived ease of use, perceived usefulness, attitude, subjective norm and perceived behaviour control on behavioural intention offers the potential to provide information to AAC developers. Therefore, this study was underpinned by the C-TAM-TPB to obtain a

comprehensive understanding of the factors influencing the intention of communication partners to use AAC and the nature and extent to which these factors relate. To the authors' knowledge, the C-TAM-TPB has not been used to investigate the intention of communication partners of persons with severe/profound intellectual disability to use AAC. The C-TAM-TPB constructs and their relationship to the findings on the use of AAC (Hanley et al., 2023a; Hanley et al., 2023b) are outlined in Appendix 22 and Appendix 23.

Figure 5.3 The C-TAM-TPB



(Taylor & Todd, 1995a)

5.3 Research Questions and Study Hypotheses

The following research questions underpinned by the C-TAM-TPB were posed.

1. To what extent does perceived ease of AAC use influence perceived usefulness of AAC?
2. To what extent does perceived usefulness and perceived ease of use influence communication partners' attitude towards using AAC?
3. To what extent does perceived usefulness, perceived ease of use, attitude, subjective norm and perceived behaviour control influence communication partners' behavioural intention to use AAC?

The following hypotheses based on the C-TAM-TPB were tested to answer the research questions:

H1. Perceived ease of use has a significant effect on the perceived usefulness of AAC.

H2. Perceived ease of use has a significant effect on attitude towards AAC.

H3. Perceived usefulness has a significant effect on attitude towards AAC.

H4. Perceived usefulness has a significant effect on the behavioural intention to use AAC.

H5. Attitude towards AAC has a significant effect on the behavioural intention to use AAC.

H6. Subjective norm has a significant effect on the behavioural intention to use AAC.

H7. Perceived behaviour control has a significant effect on the behavioural intention to use AAC.

5.4 Methods

5.4.1 Study Design

Ethical approval was sought and gained from the Social Research Ethics Committee, University College Cork (Log no.2023-098, Appendix 24). A cross-sectional, descriptive, correlational study using survey methods was undertaken.

5.4.2 Research Participants and Sampling

Non-probability, convenience and snowball sampling were used to recruit communication partners of persons with severe/profound intellectual disability using AAC in all settings (i.e., home settings, community settings, day services, residential services, schools, respite services). The eligibility criteria are outlined in Table 5.1. The study focused on the opinion of those who are communication partners of persons who use or will use AAC in the next 12 months as they are potential practitioners of AAC (Ning et al., 2021).

Table 5.1 Eligibility Criteria

Inclusion Criteria

- Those who are communication partners for at least three months of a person(s) with severe or profound intellectual and/or multiple disability (i.e., communicating at the earlier developmental communication stage) who uses or will use AAC in the next 12 months
- Living in the Republic of Ireland
- 18 years of age or older

Exclusion Criteria

- Communication partners of persons with mild or moderate intellectual disability who may use AAC
- Due to the nature of this study the following types of AAC will not be included: gestures, facial expressions and body movements

*Abbreviation: AAC, Augmentative and Alternative Communication

A power analysis was undertaken (Appendix 25). The following parameters were set; Power: 80%, statistical significance: 5%, and an estimated medium effect size of 0.15 (Cohen, 1988). The recommended sample was 157 participants where there would be no missing data. Missing data were then accounted for at 10%, the recommended sample was 175 participants.

5.4.3 Measurement and Piloting

A self-administered, previously validated questionnaire was used.

Participants were first asked to answer eight items to characterise the sample followed by a questionnaire containing 19 items (Taylor & Todd, 1995b) measuring the constructs of the C-TAM-TPB (Taylor & Todd, 1995a). The constructs and corresponding items are outlined in Table 5.2. Seven-point Likert-type scales, ranging from 1 (indicating “strongly disagree”) to 7 (indicating “strongly agree”), were used to rate the items. Seven-point Likert scales were used over smaller range rating scales as it is argued that they are more responsive to respondents’ honest feedback (Peterson, 1997; Yusoff & Mohd Janor, 2014).

The C-TAM-TPB items were adapted to the context of AAC on receipt of permissions from the author (Appendix 26) and journal (Appendix 27) where the scale was published (Taylor & Todd, 1995b). To assess construct validity of the original scale, Taylor and Todd (1995b) undertook a confirmatory factor analysis. The authors examined the factor loadings which indicated significant loadings for each item on its hypothesised construct ($p < 0.01$ in all cases). In addition, there was little variance in the X values within each construct, indicating that the items contributed equally to the formation of the construct (Taylor & Todd, 1995b). The squared multiple correlations between the items and the constructs were generally high indicating that the items generally shared substantial variance with their

hypothesised constructs (Taylor & Todd, 1995b). Internal consistency values for each construct were then calculated based on the X values from the confirmatory factor analysis, with ten of the 13 sub-scales above 0.7 (Taylor & Todd, 1995b). The two C-TAM-TPB sub-scales with lower internal consistency values were perceived behaviour control (0.68) and perceived ease of use (0.60) (Taylor & Todd, 1995b). The current study tested the internal consistency, or reliability, of the survey items using Cronbach alpha. Internal consistency of the constructs was deemed acceptable as the values of Cronbach's alpha for six of the seven constructs was higher than 0.7 (Cortina, 1993) (perceived usefulness α 0.734, perceived ease of use α 0.725, attitude α 0.774, subjective norm α 0.817, behavioural intention α 0.907, perceived behaviour control α 0.538).

As per Fishbein and Ajzen (2010), the measurement items were adapted to relate specifically to the target behaviour, that is, communication partners' use of AAC with persons with severe/profound intellectual and or multiple disability. The items' modification was conducted through expert review to reflect AAC context. Two researchers who are registered nurses in intellectual disability, independently reviewed the measurement instrument. No disagreements arose. Following the expert review, three lay persons including a primary school teacher, special needs assistant and healthcare assistant read the instrument to ensure the wording and questions were clear.

Table 5.2 C-TAM-TPB Constructs and Corresponding Measurement Items

Construct and Source	Item	Content
Perceived Usefulness (PU) (Taylor & Todd, 1995b)	PU1	Augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability will be of no benefit to me
	PU2	Using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability will improve my ability to support the individual's communication
	PU3	The advantages of augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability will outweigh the disadvantages
	PU4	Overall, using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability will be advantageous
Perceived Ease of Use (PEU) (Taylor & Todd, 1995b)	PEU1	Instructions for using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability will be hard to follow
	PUE2	It will be difficult to learn how to use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability
	PEU3	It will be easy to use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability when communicating
Attitude (ATT) (Taylor & Todd, 1995b)	ATT1	Using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability is a good idea
	ATT2	Using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability is a wise idea
	ATT3	Using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability is pleasant
	ATT4	I like the idea of using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability
Subjective Norm (SN) (Taylor & Todd, 1995b)	SN1	People who influence my behaviour would think that I should use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability
	SN2	People who are important to me would think that I should use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability
Perceived Behaviour Control (PBC) (Taylor & Todd, 1995b)	PBC1	I would be able to use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability
	PBC2	Using augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability is entirely within my control
	PBC3	I have the resources and the knowledge and the ability to make use of augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability

Behavioral Intention (BI) (Taylor & Todd, 1995b)	BI1	I intend to use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability in the next 12 months
	BI2	I intend to use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability to communicate in the next 12 months
	BI3	I intend to use augmentative and alternative communication with people with severe or profound intellectual and/or multiple disability frequently in the next 12 months

A pilot study was undertaken between the 20th and 31st of July 2023 with 10 participants to ensure that; (1) the questions were clear in the context of AAC and establish face validity, (2) for timing purposes and (3) to test the process of completing the online questionnaire via Qualtrics on different devices (Dillman et al., 2014). Given that individuals with severe/profound intellectual and/or multiple disabilities are a low incidence population (Hatton et al., 2016; Wilder et al., 2015), in an effort to keep the target group as large as possible (Kamstra et al., 2015) the pilot was undertaken with current communication partners of persons with mild and/or moderate intellectual disability and past communication partners of persons with mild, moderate, severe or profound intellectual disability. Participants included nurses (n=6), social care workers (n=2) and healthcare assistants (n=2). The survey took pilot participants an average of 15 minutes to complete. Questions were reported to be clear, easy to understand and answer and relevant, thus face validity was achieved (Mishra & Allen et al., 2023; Frantz & Holmgren, 2019). Therefore, no changes were made. No issues were reported relating to undertaking the questionnaire via Qualtrics.

5.4.4 Data Collection Procedures

An anonymous online survey via Qualtrics was utilised to collect data between the 31st of July 2023 and the 17th of September 2023. An invitation to participate (Appendix 28) was posted on social media platforms (Twitter, Facebook, Instagram and LinkedIn) explaining the purpose of the study. To enhance uptake of the survey, personalising with potential participants was attempted by including a picture of the researcher on the invitation flyer (Maes et al., 2020). People who were interested in participating were asked to click the link provided in the social media post, which brought them to a detailed information sheet that outlined the study purpose and details of how to proceed (Appendix 29). Those who were interested completed a screening process (Appendix 30) to ensure they met eligibility criteria followed by a consent form (Appendix 31). The screening items (n=3) and consent item had

response requirements, to ensure only those who met the eligibility criteria and provided informed consent could take part (Ball et al., 2019; Dillman et al., 2014). Custom designed error messages were applied to the eligibility and consent items to explain to potential participants why they could not proceed (Dillman et al., 2014). Once consent was provided via a tick box indicating yes, they were directed to the questionnaire.

The design of the survey can influence the response rate (Dillman et al., 2014). A simple and consistent layout was applied. The question area included clear instructions, the item stem, response options and navigation buttons to help respondents to focus on the question area (Dillman et al., 2014). The simple survey layout was formatted to meet the Web Content Accessibility Guidelines 2.1. Each section of the survey provided clear instructions to the respondents and noted that the questions may seem similar (Fishbein & Ajzen, 2010). To reduce nonresponse and measurement biases, responses to questions were not forced (Dillman et al., 2014). Respondents had the option to stop the survey at the point they were at and complete it later (Dillman et al., 2014). On completion, a custom thank you message (Appendix 32) was displayed to respondents and the researcher and thesis supervisors' names and contacts details were provided again (Dillman et al., 2014). To prevent respondents from taking the survey multiple times, the survey settings ensured that one response could be provided via the one system (i.e., phone, tablet, computer). Follow up reminders for online research may need to be condensed (Polit & Beck, 2021; Granello & Wheaton, 2004). Additional reminders may help to increase the response rate (VanMol, 2017). Therefore, the researcher reshared the social media post each week and contacted groups (such as advocacy groups, specific support groups) asking them to share the flyer.

5.4.5 Ethical Considerations and Research Integrity

Online surveys introduce new ethical considerations (Dillman et al., 2014). As recommended by the University College Cork guidance document for internet research,

ethical issues outlined by Eysenbach and Jill (2001) were considered. In addition, the ethical issues related to using social media for recruitment were also considered (Darko et al., 2022). This included informed consent and the right to withdraw, confidentiality and anonymity, potential harm, data management and consultation. To obtain informed consent, potential participants first saw the study flyer accompanying the social media post outlining the study purpose, estimated time required to complete the questionnaire, eligibility criteria and researchers' contact details. Those who clicked the link were directed to Qualtrics and presented with a detailed information sheet. The names and contact details of the researchers were provided, should they have had any questions. Participants provided consent via a tick box before they could undertake the questionnaire (Schmidt, 1997; Granello & Wheaton, 2004). Signatures were waived to ensure anonymity. Participants were informed that they could withdraw up until the point of submitting the final answer of the questionnaire. Voluntary participation, the right to ask questions by contacting the research team, the right to decline to answer questions and participate were communicated before beginning the data collection process. A data management plan was developed and adhered to.

5.4.6 Data Analysis

Data were downloaded from Qualtrics as a .csv file and transferred to SPSS27 for analysis. A codebook was prepared, and variables were defined via a variable view to accompany the dataset (Pallant, 2016). The dataset was screened by one researcher and checked by a second researcher. All missing data (less than 2%) were adjusted using a mean imputation method of the responses for that specific variable. Descriptive statistics were calculated to identify the characteristics of the respondents.

The survey items of a single construct were combined to give a mean score for each of the constructs $\sum (Q1+Q2+Q3+Q4)/4$ (depending on the number of items for each construct). The mean scores of the constructs were then checked for their mean, standard

deviation, skewness and kurtosis. Histograms were also used to explore data characteristics. The Shapiro Wilk test was undertaken to test for normality, with the p value in this test being less than 0.05 for perceived usefulness, attitude and behavioural intention. Therefore, the mean scores from these questions did not follow a normal distribution.

Transformations were undertaken, and included square root, natural logarithmic and box cox. The previous tests including the Shapiro Wilk test were repeated. The mean scores did not follow a normal distribution, data were closely examined using a histogram and normal curve and were observed to be positively skewed.

To determine the strength and direction of the relationship between constructs, correlations between the scores of the constructs were analysed using the Spearman's rank correlation as data were not normally distributed. Spearman rank correlation like other correlation coefficients is also an effect size measure. It represents the degree of correlation of the data after data have been converted to ranks. Thus, it captures the strength of relationships. To interpret the proportion of shared variance in the two ranked variables, this correlation coefficient was squared to measure the R^2 . It provides, for example, the percentage of the variance in ranked scores of x that can be explained by y.

The regression model was then fitted using an Inverse Gaussian Generalised Linear Model, as the data did not follow a normal distribution and were positively skewed. The regression coefficients, p values and corresponding Wald-Chi Square were checked to see which of the constructs influence behavioural intention and by how much. Higher Wald Chi-Square values indicate better predictive power for a set of variables.

5.5 Results

5.5.1 Participants

The majority of respondents were female (92.1%, n=140) and from the 25–34-year age group (34.9%, n=53). The highest level of education reported was a bachelor's degree

(55.3%, n=84). Most of the respondents were nurses (34.9%, n=53). Those who chose ‘other’ in response to the item related to category of communication partner (n=11) included managers (n=2), a person in charge (n=1), an occupational therapist (n=1), home tutor (n=1), behaviour therapist (n=2), behaviour support specialist (n=1), social care leader (n=1), special needs assistant/healthcare assistant (n=1) and assistant director of nursing/registered nurse practitioner (n=1). Regarding experience of using AAC, 32.2% (n=49) stated using AAC between 1-4years, 27.6% (n=42) stated using AAC between 5-9years and 33.6% (n=51) used AAC for 10 years or more. In response to weekly use, 41.4% (n=63) stated using AAC several times a day and 30.3% (n= 46) used it daily. In response to the item addressing who they used AAC with 78.3% (n=119/152) stated they would use AAC with persons with severe intellectual disability. Some respondents communicated with persons with severe, profound and profound intellectual and multiple disabilities, and therefore, selected more than one item in response to this question. Signing systems were the most used type of AAC (70.3%, n=107), followed by pictures of reference (68.4%, n=104). A minority reported (3.3%, n=5) other types of AAC they used, these included tobii dynavox, core boards, visual aids, choice boards, touch prompts, a BIG mac button, Canaan Barrie On-Body signing and Talking Mats. Respondents had the option of selecting all types of AAC they used and therefore, selected multiple items. Table 5.3 below outlines demographic characteristics of respondents and information about their use of AAC to characterise the sample.

Table 5.3 Demographic and AAC Usage Information of the Participants (n=152)

Demographic characteristics	Categories	Number	Percentage
Age-Group	18-24	10	6.6%
	25-34	53	34.9%
	35-44	40	26.3%
	44-54	38	25%
	55-64	10	6.6%
	65-74	1	0.7%
Gender	Female	140	92.1%
	Male	12	7.9%
Highest Level of Education	Junior cert.	3	2%
	Leaving cert.	7	4.6%
	Leaving cert. applied	1	0.7%
	Post leaving cert. qualification	24	15.8%
	Apprenticeship	1	0.7%
	Bachelor's degree	84	55.3%
	Masters	29	19.1%
	PhD	3	2%
Category of Communication Partner	Activity co-ordinator	1	0.7%
	Direct support worker	4	2.6%
	Family member	16	10.5%
	Healthcare assistant	17	11.2%
	Nurse	53	34.9%
	Teacher	15	9.9%
	Social care worker	7	4.6%
	Special needs assistant	13	8.6%
	Speech and language therapist	15	9.9%
	Other	11	7.2%
Experience of Using AAC	Less than a year	6	4.0%
	1-4 years	49	32.2%
	5-9 years	42	27.6%
	10 plus years	51	33.6%

	Not currently using augmentative and alternative communication	4	2.6%
Frequency of Using AAC	Several times a day	63	41.4%
	Daily	46	30.3%
	Several times a week	31	20.4%
	Once a week	7	4.6%
	Not currently using augmentative and alternative communication	5	3.3%
*Level of Intellectual Disability of AAC User	Severe Intellectual Disability	119	78.29%
	Profound Intellectual Disability	67	44.07%
	Profound Intellectual and Multiple Disability	69	45.39%
*Types of AAC Used	Signing system	107	70.3%
	Alphabet board	6	3.9%
	Objects of reference	96	63.1%
	Pictures of reference	104	68.4%
	Picture Exchange Communication System	78	51.3%
	Communication boards with symbols	97	63.8%
	Communication books with symbols	69	45.4%
	Eye-gaze device	20	13.1%
	Speech generating device	19	12.5%
	iPads or computer devices with AAC apps	72	47.4%
	Other	5	3.3%
	Not currently using AAC	4	2.6%

* Each respondent could tick multiple options, hence the totals may or may not add up to 152

5.5.2 Statistical Analyses

5.5.2.1 Relationships Between the Constructs

The hypotheses were tested using Spearman's rank correlation between the mean scores of each of these constructs (Table 5.4). The correlation coefficients which were

significant indicated a relationship between them. The R^2 is reported to show the proportion of shared variance in ranked variables.

Table 5.4 Correlation between Scores of Constructs

	Perceived Ease of Use Mean Score	Perceived Usefulness Mean Score	Attitude Mean Score	Subjective Norm Mean Score	Perceived Behavioural Control Mean Score
Perceived Ease of Use Mean Score	1				
Perceived Usefulness Mean Score	.170*		.	.	.
Attitude Mean Score	.357**	.524**		.	.
Subjective Norm Mean Score	.252**	.255**	.482**		.
Perceived Behaviour Control Mean Score	.307**	.247**	.458**	.421**	
Behavioural Intention Mean Score	.243**	.394**	.514**	.350**	.487**

* Correlation is significant at the 0.05 level (2-tailed) and ** Correlation is significant at the 0.01 level (2-tailed).

Based on the results in Table 5.4 the relationships between the constructs were assessed and reported.

1. *Relationship between perceived ease of use and perceived usefulness*: there was a positive weak correlation of 0.170 (significant at $p=0.05$) between perceived ease of use score and perceived usefulness score. 2.89% was the proportion of shared variance between these two ranked variables, thus, perceived ease of use had a significant positive effect on the perceived usefulness of AAC.
2. *Relationship between perceived ease of use and attitude*: there was a positive weak correlation of 0.357 (significant at $p=0.01$) between perceived ease of use score and attitude score. 12.74% was the proportion of shared variance between these two ranked variables, thus, perceived ease of use had a significant positive effect on the attitudes towards AAC.
3. *Relationship between perceived usefulness and attitude*: there was a positive moderate correlation of 0.524 (significant at $p=0.01$) between perceived usefulness score and attitude score. 27.5% was the proportion of shared variance between these two ranked variables, thus, perceived usefulness had a significant positive effect on attitude towards AAC.
4. *Relationship between perceived usefulness and behavioural intention*: there was a positive correlation of 0.394 (significant at $p=0.01$) between perceived usefulness score and behavioural intention score. 15.5% was the proportion of shared variance between these two ranked variables, thus, perceived usefulness had a significant positive effect on the behavioural intention to use AAC.
5. *Relation between attitude and behavioural intention*: there was a positive correlation of 0.514 (significant at $p=0.01$) between attitude score and behavioural intention score. 26.4% was the proportion of shared variance between these two ranked variables, thus, attitude towards AAC had a significant positive effect on the use intention of the AAC.

6. *Relationship between subjective norm and behavioural intention:* there was a positive correlation of 0.350 (significant at $p=0.01$) between subjective norm and behavioural intention score. 12.3% was the proportion of shared variance between these two ranked variables, thus, subjective norm had a significant positive effect on the intention to use AAC.
7. *Relationship between perceived behavioural control and behavioural intention:* there was a positive correlation of 0.487 (significant at $p=0.01$) between perceived behavioural control and behavioural intention score. 23.7% was the proportion of shared variance between these two ranked variables, thus, perceived behaviour control had a significant positive effect on the intention to use AAC.

5.5.2.2 The Extent to which Constructs Impacted Perceived Usefulness, Attitude and Behavioural Intention

The results of the regression model between perceived ease of use and perceived usefulness were not significant (p value=0.550, $\beta=0.061$, Wald's Chi-square $\chi^2=.357$). Therefore, we cannot say with certainty that perceived ease of use had a significant impact on perceived usefulness. The results of the regression model indicated that perceived usefulness (p value=0.000 and $\beta=0.253$, Wald's $\chi^2=27.5$) and perceived ease of use ($p=0.007$, $\beta=0.145$, Wald's $\chi^2=7.2$) both had a significant impact on communication partners' attitude towards using AAC. For a unit increase in the perceived usefulness score, the attitude towards using AAC increased by 0.253 when other factors were constant. For a unit increase in the perceived ease of use score, the attitude increased by 0.145 when other factors were constant.

The results of the regression model (Table 5.5) between perceived usefulness, perceived ease of use, attitude, subjective norm and perceived behaviour control and their influence on communication partners' intentions to use AAC showed that only attitude scores (p value=0.000 and $\beta=0.528$, Wald's $\chi^2=20.8$) and perceived

behavioural control scores (p value=0.000 and β =0.332, Wald's χ^2 =16.8) had a significant impact on behavioural intention.

Table 5.5 Results of the Regression Model

Parameter	B (regression coefficient)	95% Wald Confidence Interval		Wald Chi- Square	Significance
		lower	Upper		
(Intercept)	.933	-.007	1.873	3.784	.052
Perceived Usefulness score	.028	-.116	.172	.148	.700
Perceived Ease of Use score	-.087	-.208	.035	1.953	.162
Attitude score	.528	.301	.755	20.784	.000**
Subjective Norm score	.088	-.035	.211	1.969	.161
Perceived Behaviour Control score	.332	.173	.491	16.769	.000**
(Scale)	.003 ^a	.003	.004		

** Significant at $p=0.05$

For a unit increase in the attitude score, the behavioural intention increased by 0.528 when other factors were constant. Similarly, for a unit increase in the perceived behaviour control score, the behavioural intention increased by 0.332 when other factors were constant.

5.6 Discussion

This study aimed to understand the nature and extent to which the factors influencing communication partners' intention to use AAC interconnect by testing specific hypotheses underpinned by the C-TAM-TPB (Taylor & Todd, 1995a). Therefore, relationships between the constructs as outlined in the C-TAM-TPB using correlation coefficients and the value of R^2 were examined. A regression model was then fitted to assess the extent to which the five constructs impacted the behavioural

intention of communication partners to use AAC. The results of the correlation analysis indicated that there was a positive relationship between the constructs outlined in the C-TAM-TPB. Therefore, the C-TAM-TPB is useful in explaining the factors influencing the intention of communication partners to use AAC.

It has long been recognised in the literature that multiple factors impact communication partners' use of AAC (Calculator, 1999; Hanley et al., 2022; Hanley et al., 2023a; Hanley et al., 2023b; Johnson et al., 2006; Lund & Light, 2007; Moorcroft et al., 2019; Rombouts et al., 2017a). However, the nature and extent to which the factors interconnect remained unclear (Hanley et al., 2023b). Findings related to the factors influencing the use of AAC were predominantly from qualitative research (for example, Calculator, 1999; Lund & Light, 2007; Rombouts et al., 2017a; Rombouts et al., 2017b) with the exception of Rombouts et al. (2016), who undertook a quantitative, comparative, correlational study to examine the relations between KWS attitudes and use in 24 paid communication partners of persons with moderate and severe intellectual disability. Although there was an association between implicit attitude and the use of KWS, no association was evident between communication partners' explicit attitude scores (i.e., measured using a survey) and their use of KWS (Rombout et al., 2016). However, there are several methodological differences between the current and Rombouts et al. (2016) study. Rombouts et al. (2016) used the Unified Theory of Acceptance and Use of Technology (Venkatesh et al., 2003; Venkatesh et al., 2012) constructs to measure the explicit attitude of participants and to test their hypotheses underpinned by the RAA. Rombouts et al. (2016) adapted items from Liu et al. (2015) and Teo (2012) to the context of KWS (Rombouts et al., 2016). It was suggested that repeating the study with a larger sample and using a different analyses technique such as regression

analyses was warranted (Rombouts et al., 2016). Conversely, the current study used the C-TAM-TPB framework and corresponding constructs with a larger sample size, including communication partners of individuals at the earlier developmental communication stage, and correlation and regression analyses were utilised.

The findings of this study confirm that there is a positive relationship between communication partners' attitude and their intention to use AAC. This finding supports existing qualitative research that posits a close relationship between attitude and AAC use (Calculator, 1999; Hanley et al., 2023a; Lund & Light, 2007). Moreover, the extent to which attitude influences the intention to use AAC was identified, where a unit increase in the attitude score resulted in behavioural intention increasing by 0.528 when other factors were constant. The researchers infer that when communication partners have a more favourable attitude towards AAC they are more likely to use it.

Due to the significant influence that attitude towards AAC has on communication partners' intention to use it, it is important to identify what factors influence their attitude and thus, positively affirm their attitude towards using AAC. There is agreement that the relationship between attitude and use of AAC may be affected by multiple, interconnected factors (Hanley et al., 2023b; Johnson et al., 2006; Rombouts et al., 2016; Rombouts et al., 2017a). The current study has identified two factors that relate to and influence attitude towards using AAC. Firstly, there is a positive relationship between perceived usefulness and attitude. Communication partners' attitude was significantly influenced by their belief that AAC would improve their ability to support the individual to communicate. That is, for a unit increase in the perceived usefulness score, the attitude towards AAC increased by 0.253 when other factors were constant. To positively affirm

communication partners' attitudes, AAC developers and implementors should strive to introduce AAC that will improve partners' ability to support the individual to communicate. This raises the question of how to introduce AAC that will strengthen the perceived usefulness associated with it. Communication partners can have different experiences with AAC, some may find it useful, others may not (Rensfeldt Flink et al., 2020). Therefore, steps must be taken to identify what is deemed useful by communication partners and what goals they wish to achieve with the individual they support. AAC was reported to be successful in supporting individuals to communicate when it was tailored to their individuality (Hanley et al., 2023a). Their individual needs, abilities and preferences should be identified and the AAC tailored accordingly (Hanley et al., 2022; Hanley et al., 2023a; Light et al., 2021). However, communication partners may not always be aware of the benefits that AAC offers (Wilder et al., 2015) and may not perceive the need for it (Rombouts et al., 2017a). This finding further highlights the importance of increasing communication partners' awareness of the benefits that AAC can offer individuals with severe/profound intellectual disability and to the interaction (Hanley et al., 2023b).

Secondly, there was a positive relationship between perceived ease of use and communication partners' attitude. Moreover, perceived ease of use influenced communication partners' attitude. It is recognised that both learning to use AAC (Bircanin et al., 2019) and using AAC can be difficult (Marshall & Goldbart, 2008; Rensfeldt Flink et al., 2020; Hanley et al., 2023a). Continuously supporting communication partners to use AAC may help to positively influence the level of effort they associate with using it, which in turn may lead to a more favourable attitude towards AAC. Communication partners have reported that they want training to ensure they can support the individual needs of the people they support (Martin &

Alborz, 2014). They should be trained in AAC that is individually tailored to the person's needs, introducing training in AAC that does not match the person's individuality may result in that AAC being perceived as difficult to use and apply (Hanley et al., 2023a).

AAC designers have some degree of control over perceived usefulness and perceived ease of use. Therefore, the findings related to these constructs can offer direction as to where they should focus their efforts (Taylor & Todd, 1995b). Perceived usefulness and perceived ease of use do not remain static (Teo, 2012). Therefore, communication partners must be continuously supported, for example, as the individual progresses with an AAC system, pictures, core words etc. may be added. Communication partners must be trained in such changes and updates to ensure that they can continue to use the system to support the individual to communicate.

Perceived behaviour control relates to internal and external factors (Ajzen, 1991) and had an important influence on communication partners' intention to use AAC. This finding supports those from the literature, whereby communication partners' access to resources (Hanley et al., 2023a; Norburn et al., 2016) and their confidence in using AAC are recognised as influential factors (Norburn et al., 2016; Rombouts et al., 2017b). Resources such as time (Johnson et al., 2006, Rombouts et al., 2017a), training (Johnson et al., 2006; Koski et al., 2010; Rombouts et al., 2016), support (Rombouts et al., 2017a) and funding can influence the use of AAC (Hanley et al., 2023a). Communication partners high workloads can result in time constraints that negatively influence the use of AAC (Patel et al., 2018; Rombouts et al., 2017a; Wilder et al., 2015). Limited funding means that AAC is not readily available to individuals and their communication partners (Hanley et al., 2023a). As

communication is a basic human need and right (Brady et al., 2016), substantial efforts must be made to ensure this right is realised for individuals with severe/profound intellectual disability. Such efforts include prioritising resources affecting use including training, support and time. In addition, supporting communication partners to continuously develop their knowledge and skillset may improve their confidence using AAC. Perceived behavior control had a Cronbach alpha lower than 0.7 and therefore, the findings related to this construct must be tentatively considered in light of this.

Interestingly, subjective norm did not significantly influence the behavioural intention to use AAC. A potential explanation may be that the majority of participants had experience of using AAC. Subjective norm was found to be more important in predicting behavioural intention for those without prior experience (Taylor & Todd, 1995a).

5.6.1 Strengths and Limitations

Communication partners' behavioural intention to use AAC was examined rather than their actual use of it. While individuals may follow their behavioural intention to use AAC, it would be useful to examine the relationship between communication partners' behavioural intention to use AAC and their actual use of AAC. This study was, however, a starting point in testing hypotheses underpinned by a theoretical framework to gain a nuanced understanding of the factors influencing communication partners' readiness to use AAC, and thus, understand how to best prepare communication partners to effectively use AAC. Non-probability sampling strategies were employed, including convenience, and snowball sampling, limiting the generalisability of findings (Robinson, 2014).

Strengths of this study include the use of the C-TAM-TPB (Taylor & Todd, 1995a) to determine to nature and extent to which factors influencing the intention to use AAC relate. Data were collected using a previously validated instrument (Taylor & Todd, 1995b). This instrument was adapted to the context of AAC use through expert and lay person review followed by a pilot study. The use of social media platforms to recruit participants allowed the researcher to reach many different categories of communication partners, that can be hard to reach.

5.7 Conclusion and Implications

This study provides an in-depth understanding of the nature and extent to which factors influencing communication partners' intention to use AAC relate. This study offers practical implications to those who develop, design and implement AAC with communication partners of persons with severe/profound intellectual disability.

The findings indicated that attitude is a determinant of communication partners' intention to use AAC. Attitude towards AAC was influenced by perceived ease of use and perceived usefulness. Therefore, efforts should be made to strengthen the perceived usefulness and perceived ease of use associated with AAC. To strengthen the perceived usefulness associated with AAC, a number of approaches may be of merit. As communication partners may have different expectations towards AAC, professionals introducing AAC should meet with the individual and their communication partners to identify and understand what they deem to be useful, and therefore, collaboratively identify and plan their goals. The provision of training and information outlining the potential benefits of AAC is recommended to increase communication partners' awareness of the benefits that AAC can offer. As inexperienced users are more focused on the perceived usefulness compared to the constraining and facilitating factors that impact use (Taylor & Todd, 1995a), the

potential benefits as well as factors that impact use should be outlined to communication partners. Furthermore, to ensure the selected AAC supports the individual to communicate, a person-centred approach should be used when selecting AAC to ensure it is tailored to the individual. This approach was reported to result in successful AAC strategies (Hanley et al., 2023a) and therefore, may result in stronger perceived usefulness of AAC.

To ensure communication partners can use AAC with ease, they should be taught to use AAC and maintain their use of it. Training alongside effective support structures may help to continuously support and thus, maintain their use of AAC. The AAC training provided must incorporate individuals' unique communication needs and abilities, to ensure communication partners are trained to communicate and interact using person-centred AAC strategies. Moreover, supporting communication partners to continuously develop their knowledge may lead to an improved confidence and thus, perceived behaviour control in using AAC.

However, resources must also be made available to further strengthen their perceived behaviour control in using AAC, such as funding, support and time. The UNCRPD (UN, 2006) advocates for the acceptance and use of AAC. The findings indicated that access to sufficient resources influence the intention to use AAC. Therefore, it is recommended that policy documents emphasise the need to develop environments that respect and facilitate the consistent use of AAC alongside other tasks that need to be completed, ensure that individuals with severe/profound intellectual disability have access to communication partners who are sufficiently trained in using AAC and prioritise funding to ensure AAC is available and accessible.

The key findings from this thesis are discussed in Chapter 6 along with the strengths and limitations and recommendations for practice, policy, education and research. An overall conclusion is drawn.

Acknowledgements

We would like to thank Alice Kasemiire from the Centre for Support and Training in Analysis and Research, University College Dublin for consulting with the researcher to undertake a power analysis. We would also like to thank Dr Shelly Chakraborty for statistical consultation. Dr Shakraborty will be included in the authorship of this study for publication.

Funding

The authors received funding from the School of Nursing and Midwifery, University College Cork to assist with statistical consultation for the analysis.

Chapter 6. Discussion

In this final chapter, key findings from the thesis overall are discussed with reference to existing relevant literature. This thesis aimed to address a complex phenomenon, communication partners' experiences of using AAC with persons with severe/profound intellectual disability. The key findings relate to (i) communication partners' shared goal of maximising communication through AAC; and (ii) the multiple factors that enable the realisation of that goal.

The strengths and limitations of the thesis are discussed and recommendations for practice, policy, education and research are made before concluding with some closing thoughts.

6.1 Communication Partners' Shared Goal

While communication partners were unclear on the use and implementation of AAC (Hanley et al., 2022; Hanley et al., 2023a) they were clear on their commitment to communicating with individuals with severe/profound intellectual disability (Hanley et al., 2023a; Hanley et al., 2023b). This commitment was demonstrated in their attempts to realise their shared goal of maximising communication through AAC. They wished to maximise communication by supporting the individual to communicate to the best of their ability (Hanley et al., 2023a), share messages and to connect (Hanley et al., 2023b). Communication partners hoped that AAC would help them to realise their shared goal, albeit within a context of uncertainty (Hanley et al., 2023a).

A shared commitment to the communication partnership is fundamental for the effective and efficient use of AAC (Hanley et al., 2022). Communication partners' commitment was evidenced in their perseverance to use AAC to communicate with the individual (Hanley et al., 2023a). Support from willing

communication partners (Forster and Iacono, 2007; Wilder et al., 2015) who understand the considerable time and effort must be invested so the individual can reach their full potential is essential.

However, despite communication partners' commitment, AAC was not always used effectively and efficiently, and thus communication was not always maximised (Hanley et al., 2023a). Consequently, the shared goal was not realised. Multiple factors impacted the extent to which communication partners used AAC. Some factors consistently recurred such as adopting an individualised approach, knowledge, training, teamwork, communication partners' attitudes and beliefs, time, workloads, availability of AAC and funding. Further, the findings indicated that the factors were interconnected (Hanley et al., 2023a; Hanley et al., 2023b). There is agreement in the literature that the factors influencing communication partners' use of AAC are interconnected (for example, Calculator, 1999; Johnson et al., 2006; Rombouts et al., 2016; Rombouts et al., 2017a). However, the nature of, extent to, and relationship between the factors that influence communication partners of individuals with severe/profound intellectual disability use of AAC remained unclear (Hanley et al., 2023a; Hanley et al., 2023b).

The use of a theoretical framework facilitated interrogation of the factors that enable realisation of the shared goal (Hanley et al., 2023c). The findings from the quantitative study outlined the nature and extent to which factors interconnect to influence communication partners' intention to use AAC. Therefore, they must be considered collectively. The overall research findings provide nuanced information of how the shared goal can be achieved by using AAC and the factors that enable that goal.

6.2 Factors that Enable the Realisation of the Shared Goal

The following section discusses the key factors that enable the realisation of the shared goal and include, (i) implementing an individualised approach to AAC strategies and associated goals and (ii) strengthening communication partners' ability to adopt and use AAC.

6.2.1 Implementing an Individualised Approach to AAC Strategies and Associated Goals

AAC was reported to support the individual and interaction when an individualised approach to selecting the AAC and setting the associated goals was used. When an individualised approach was implemented, they had a greater chance of being able to use AAC, AAC was deemed useful and successful and therefore, used more consistently. These findings are consistent with the principles of a personalised approach to AAC intervention, where the AAC is selected and tailored based on the individual's needs, preferences and skills along with the preferences and values of communication partners (Light et al., 2021). However, this was not straightforward. Multiple factors were at play which are now discussed.

Perceiving AAC as useful for the individual and interaction had the greatest influence on attitude (Hanley et al., 2023b; Hanley et al., 2023c) which carried the greatest influence on communication partners' intention to use AAC (Hanley et al., 2023c). Similarly, communication partners' use of AAC was reported to be motivated by the perceived benefits for the user (Rombouts et al., 2017b). Therefore, communication partners must be convinced of the benefits that AAC can offer. However, the findings indicate that communication partners were not always aware that AAC could benefit individuals with severe/profound intellectual disability (Hanley et al., 2023a; Hanley et al., 2023b). This may be due to limited knowledge or low expectations towards both the individual and AAC (Hanley et al., 2023b).

Furthermore, their preconceived thoughts may impact the realisation of such benefits (Hanley et al., 2023b).

To realise the benefits, AAC needed to be used and experienced. When communication partners used AAC they had the opportunity to experience the benefits and thus, were encouraged to increase their use (Rombouts et al., 2017b). Consequently, AAC was deemed successful, usage increased and was more consistent.

A person-centred approach should be implemented when selecting AAC to ensure it is tailored to an individuals' unique needs, abilities, motivators and preferences (Hanley et al., 2022; Hanley et al., 2023a; Hanley et al., 2023c). It is understood that selecting AAC suitable for individuals with severe/profound intellectual disability can be challenging (Rensfeldt Flink et al., 2022a). Discussions between SLTs and communication partners strengthened the assessment process (Chadwick et al., 2018). Getting to know the individual by spending time with them and tuning into their individual communicative methods helped communication partners to recognise their individuality (Hanley et al., 2023a; Hanley et al., 2023b). Moreover, communication partners shared their expertise on AAC and experience with the individual which helped create a unique, individual profile that informed selection of suitable AAC (Hanley et al., 2023a). The information gathered should be used to select AAC and set associated goals.

AAC goals are challenging to set (Rensfeldt Flink et al., 2022a). The current findings indicate that communication partners wanted AAC to enable them to support individuals' communication (Hanley et al., 2023a; Hanley et al., 2023b). Implementing an individualised approach may ensure setting achievable and realistic goals informed by the persons abilities and needs. Similarly, O'Neill & Wilkinson

(2019) suggest that AAC should be centred around the individuals' current ability and future development. When the goal was supported by AAC, it encouraged communication partners to continue to engage with the AAC and the associated goals (Hanley et al., 2023a; Hanley et al., 2023b). As posited by the TPB, communication partners can form a favourable attitude and may not form a strong behavioural intention to use AAC if they believe they do not have control to use it (Ajzen, 1991; Fishbein & Ajzen, 2010). Similarly, Rombouts et al. (2017a) findings indicate that communication partners may believe in AAC but use it inconsistently (Rombouts et al., 2017a). The research findings suggested that this may be due to the influence of communication partners' knowledge, skillset and the resources supporting use (Hanley et al., 2022; Hanley et al., 2023a; Hanley et al., 2023b; Rombouts et al., 2017a; Rombouts et al., 2017b).

The findings indicate that internal factors (attitudes and beliefs) influence communication partners' use of AAC and can contribute to a supportive communicative environment. The following section discusses environmental factors influencing communication partners' use of AAC and the associated resources needed to promote and maintain their use of it.

6.3 Strengthening Communication Partners' Ability to Use AAC

Multiple environmental factors impacted communication partners' ability to use and maintain their use of AAC. Associated resources supporting use must be available to strengthen communication partners' ability to use AAC. The training (Hanley et al., 2023a) and support provided (Hanley et al., 2023c) may influence their perceived behaviour control, which influenced their behavioural intention as well as the ease of use associated with using AAC, which influenced communication partners' attitude (Hanley et al., 2023c). Therefore, the factors enabling the

realisation of the shared goal cannot be considered as separate entities. They must be addressed collectively to promote the optimal use of AAC.

The importance of knowledge development is clear (Hanley et al., 2022; Hanley et al., 2023a; Hanley et al., 2023b; Hanley et al., 2023c; Moorcroft et al., 2019; Meuris et al., 2014; Wilder et al., 2015). Training communication partners in AAC may develop their knowledge (Lund & Light, 2007). Importantly, identifying the appropriate training needed by communication partners is necessary so they can use AAC to communicate with the individual. In accordance with the current research findings, training should aim to develop knowledge and thus, increase communication partners' confidence and reduce the difficulty associated with using AAC (Hanley et al., 2022; Hanley et al., 2023a; Hanley et al., 2023b; Hanley et al., 2023c).

Communication partners valued practical aspects of training programmes (Rensfeldt Flink et al., 2020). This is not surprising, as they experienced difficulty learning to use AAC (DeBortoli et al., 2011; Rensfeldt Flink et al., 2020) and maintaining their use of it (Rombouts et al., 2017b). Training should not increase the effort associated with using AAC (Rombouts et al., 2016). Rather, actively supporting communication partners to learn to use AAC should reduce the effort associated with use and positively influence their attitude towards using AAC (Hanley et al., 2023c). Bunning (2018) suggested that the person's individual needs identified during the assessment should inform the content of the skills development programme. The importance of this was reflected in the findings of the qualitative study (Hanley et al., 2023a). Despite receiving training, a communication partner found AAC hard to use, indicating that the perceived effort associated with using AAC increased (Hanley et al., 2023a). Importantly, the training was not tailored to

the user's individuality. Communication partners' use of AAC was underpinned by their goal to maximise communication (Hanley et al., 2023a; Hanley et al., 2023b), thus, consulting with them to decide on AAC training that they believe will support the interaction may enable them to realise the shared goal. van der Meer et al. (2017) suggested that consulting with communication partners when implementing an AAC training program may have helped to ensure relevant skills were being taught.

While training is a fundamental resource, additional factors influenced the extent to which AAC was used and moreover, the use was maintained (Hanley et al., 2022; Hanley et al., 2023a; Hanley et al., 2023b).

Time constraints is an often-cited impediment to the provision of AAC training (Rensfeldt Flink et al., 2022b; Rombouts et al., 2017a). It is recognised that all categories of communication partners' experience competing demands between daily tasks and using AAC (for example, Hanley et al., 2023a; Patel et al., 2018; Rombouts et al., 2017a; Wilder et al., 2015). While it is recognised that communication partners must take time to use AAC with individuals in their everyday tasks, this must be facilitated by an environment that has sufficient people and resources available to limit the competing demands experienced.

Despite being identified as candidates for AAC, it may not be readily available to individuals (Hanley et al., 2023a). Sufficient funding must be available to provide and implement individualised AAC strategies. In the current research, insufficient funding impeded their ability to provide person-centred AAC strategies and interventions and therefore, interrupted the realisation of the shared goal. It is difficult to apply a person-centred approach for individuals when the funding is not available (Sheerin et al., 2024).

The above factors must be addressed by service providers and government bodies to ensure there is a systemic approach to promoting the optimisation of AAC (Hanley et al., 2023c). The factors identified in this research can be and must be addressed to ensure the right to AAC is realised and optimised for all.

6.4 Strengths and Limitations

This thesis has a number of strengths and limitations. The research findings should be considered in context of the strengths and limitations.

6.4.1 Strengths

Appropriate guidelines, standardised checklists and frameworks were used in each stage of this research, including the JBI guidance for MMSR; Whitemore and Knafl (2005) five stages of an integrative review; the PRISMA reporting guidelines (Moher et al., 2009); Sandelowski (2000; 2010) qualitative descriptive approach; the SRQR checklist (O'Brien, 2014); and the C-TAM-TPB (Taylor & Todd, 1995a).

Each stage of the research involved a different methodology and methods to answer the research questions needed to meet the overall research aim (Anguera et al., 2018).

The evidence base was established through a MMSR and integrative review (Hanley et al., 2022; Hanley et al., 2023b). This ensured that the research undertaken was informed by previous literature.

A number of steps were taken to enhance the trustworthiness of the qualitative study. Transferability was sought by including both professional and social partners; semi-structured interviews with open ended questions were used to collect data; the topic guide was informed by the findings of the MMSR and was piloted before data collection began; answers were verified with the participants

during each interview; audit trails were developed; finally, data were cross-checked with the supervisory team.

A key strength of the quantitative research is the use of the C-TAM-TPB (Taylor & Todd, 1995a). To the researcher's knowledge, the C-TAM-TPB was not previously used to examine the intention of communication partners' use of AAC with this population. The theoretical framework was purposefully selected following the integrative review as it clearly aligned with the studies in the integrative review and the second study in this thesis (Luft et al., 2022). A deeper understanding of the factors influencing communication partners' intention to use AAC as well as the nature and extent to which the factors relate has been achieved. Thus, the C-TAM-TPB provided a nuanced understanding of the multiple, complex factors that were identified in the MMSR, qualitative descriptive study and the integrative review by bringing them together in a coherent way.

Each stage of research is either published, accepted for publication or in preparation for submission. We believe this is an important strength of the research.

6.4.2 Limitations

This thesis and associated findings must also be considered in light of the following limitations.

Both review search strategies were restricted to English language, introducing language bias. Non-probability sampling strategies were employed in both primary studies and the majority of studies included in the reviews, posing the risk of limited generalisability of the quantitative findings and limited transferability of the qualitative findings. All participants were recruited from and living in the Republic of Ireland which further hinders generalisability and transferability of the findings.

The researcher was cognisant of her positionality, primarily related to her experience in her professional role as an intellectual disability nurse. Therefore, multiple strategies were employed to continuously identify and articulate her positionality (Holmes, 2020).

6.5 Recommendations

6.5.1 For Practice

Based on the research findings, it is recommended that the factors influencing the use of AAC are collectively addressed to promote effective and efficient use in practice.

Attitude carried the greatest influence on communication partners' intention to use AAC. To positively affirm communication partners' attitudes towards using AAC, it is recommended to identify and thus, introduce AAC that will benefit the individual and the interaction. For communication partners, AAC was deemed useful when it supported the individual to communicate and thus, enabled the realisation of the shared goal. To achieve this, it is recommended that AAC strategies are informed by the persons individuality. It is recommended that each communication partners' input is sought to gain an understanding of the person as an individual and enhance the AAC assessment. To maintain the use of AAC, communication partners must be aware of the process and timelines expected for the AAC goals as well as the potential facilitators, challenges and the benefits of AAC. It is recommended that the individual's progress is systematically monitored and documented to ensure it is recognised and the benefits of AAC are continuously realised.

6.5.2 For Policy

Communication is a fundamental human need and right recognised by the UNCRPD. Based on the current research findings, it is recommended that policy

advances the provision of person-centred AAC strategies that uphold individuals' right to communication by putting a number of supports in place. To increase accessibility of AAC that continuously supports the users' individual communication needs, it is recommended that sufficient funding is prioritised. To ensure a person-centred approach is implemented and maintained, the use of AAC must be planned for alongside other tasks that need to be completed. It is recommended that policy instigates the need for adequate support structures for all categories of communication partners to limit the competing demands experienced and facilitate the optimal use of AAC. In the context of service providers, adequate staffing levels are required. In the context of familial partners, policy must extend this to home settings, to ensure familial communication partners have adequate support to plan for the optimal use of AAC.

To ensure individuals with severe/profound intellectual disability have access to communication partners who are sufficiently educated and trained in communicating with them using AAC and in supporting them to communicate, policy needs to increase accessibility to training informed by the individual and their communication partners. Finally, it is recommended that AAC strategies are provided through the lens of the persons capabilities, building on their abilities and maximising their potential.

6.5.3 For Education

To promote the recognition and realisation of the individual's communication abilities and overall potential to use AAC, it is recommended that training programs increase communication partners' awareness of the person's subtle and individual communication attempts. Furthermore, it is recommended that training programs are informed by the persons individuality and incorporate clear instructions along with

hands on approaches for partners to learn to operate and use the AAC system with ease and confidence.

It is recommended that training programs outline the benefits of AAC, whilst informing communication partners of the facilitators and constraints associated with using AAC to ensure they know what to expect in terms of progress, timelines and outcomes. In addition, to ensure that a person-centred approach is applied to AAC strategies in an on-going and responsive way, it is recommended to support partners to understand that AAC needs can change or advance.

Finally, it is recommended that professionals who are involved in AAC assessments and provide AAC systems receive adequate education pertaining to the unique characteristics of individuals with severe/profound intellectual disability.

6.5.4 For Research

The findings indicate that the C-TAM-TPB is a viable theoretical framework to examine communication partners' intention to use AAC. To understand the relationship between behavioural intention and use, the researcher recommends using the C-TAM-TPB with the addition of the actual use construct. Furthermore, developing an intervention that addresses the constructs of the C-TAM-TPB and using the corresponding C-TAM-TPB instrument with the additional use construct pre and post-test warrants further exploration to test if the intervention changes beliefs and use of AAC.

The theoretical framework underpinned the current research in the context of individuals with severe/profound intellectual disability. Therefore, it is recommended to use the C-TAM-TPB in different AAC contexts. For example, with individuals recognised as AAC candidates, such as people with mild or moderate intellectual disability, people who have experienced stroke or individuals with Parkinsons.

Although it was beyond the scope of this research, future research is warranted to determine if the factors influencing the use of AAC differ for the different categories of communication partners, i.e., paid and familial.

6.6 Conclusion

To conclude, this research has explored communication partners' experiences of using AAC with individuals with severe/profound intellectual disability. AAC has the potential to address individuals' complex communication needs, and therefore, has increasingly received attention in recent years. However, multiple challenges are reported in successfully adopting and using AAC (Sigafoos et al., 2021). Due to the positive effects of AAC for this population (Danker et al., 2023; Hanley et al., 2023a; Roche et al., 2015) every effort must be made to overcome the challenges impeding the optimisation of AAC.

The research findings provide an in-depth understanding of communication partners' experiences of using AAC with persons with severe/profound intellectual disability. The findings explain the nature and extent of the relationship between multiple factors and communication partners' intention to use AAC. Moreover, the findings provide insight about the influence of factors on attitudes towards using AAC and intention to use AAC. Given communication partners' significant roles contributing to the success of AAC, understanding their experiences provides the opportunity to support their use of AAC in practice.

Rigorous methods were used to answer associated research questions to understand communication partners' experiences of using AAC. It can be challenging to establish and maintain interactions with individuals with severe/profound intellectual disability. Commitment to support the individual to communicate helped partners to persevere. However, commitment alone will not

support the successful use of AAC. Despite a strong commitment to communicating with the individual, communication partners' experienced difficulties realising the shared goal. The C-TAM-TPB brought the factors influencing communication partners' intention to use AAC together. Therefore, the factors must be considered collectively.

A key finding that emerged in each stage of the research was the importance of seeing the individual, their ability, needs, preferences and motivators and introducing AAC that maximised their potential. Individually tailored AAC was useable and thus, used. The need to prioritise AAC and the resources required to optimise its use is emphasised. When these factors are considered together, the factors influencing both attitude and intention to use AAC can be addressed to improve the extent to which communication partners' use AAC.

The findings contribute to existing knowledge and evidence. These findings and those of the existing literature were considered and implications and recommendations have been offered in relation to practice, policy, education and research. Each recommendation is made with a view to enhancing the ways that AAC can be used to improve interactions between individuals with severe/profound intellectual disability and their communication partners. Effective interactions and communication contribute to QoL. AAC can support individuals to communicate. However, they require their communication partners to make AAC available and use it. Targeting the factors influencing their communication partners' use of AAC may improve implementation and thus, provide individuals with severe/profound intellectual disability increased opportunities to communicate, participate and connect, and consequently, enhance their QoL. All supports must be leveraged, and every effort must be made to ensure individuals with severe/profound intellectual

disability potential is recognised, ability maximised and their right to communication is realised to ensure a good QoL.

References

- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision processes*, 50, 179-211.
- American Psychiatric Association. (2021, August). *What is intellectual disability?*
<https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>
- American Speech-Language-Hearing Association. (2002). Augmentative and Alternative Communication: Knowledge and skills for service delivery. *American Speech-Language-Hearing Association Supplement* 22, 97–106.
- American Speech-Language-Hearing Association. (2019). *Augmentative and alternative communication (AAC)*. <https://www.asha.org/Practice-Portal/Professional-Issues/Augmentative-and-Alternative-Communication/>
- Angelo, D. (2000). Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication*, 16(1), 37-47. <https://doi.org/10.1080/07434610012331278894>
- Angelo, D. H. (1997). AAC in the family and home. In S. Glennen & D. De Coste (Eds.), *Handbook augmentative communication* (pp. 523-545). Singular Publishing.
- Anguera, M. T., Blanco-Villaseñor, A., Losada, J. L., Sánchez-Algarra, P., & Onwuegbuzie, A. J. (2018). Revisiting the difference between mixed methods and multimethods: Is it all in the name? *Quality & Quantity*, 52(6), 2757-2770. <https://doi.org/10.1007/s11135-018-0700-2>

- Arvio, M., & Sillanpää, M. (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research*, 47(2), 108-112. <https://doi.org/10.1046/j.1365-2788.2003.00447.x>
- Assisted Decision-Making (Capacity) Act 2015, No. 64/2015. Stationery Office, Dublin.
- Bailey, C. R. (2018). *A guide to qualitative field research* (Third ed.). SAGE Publications, Incorporated. <https://doi.org/10.4135/9781071909614>
- Bailey, R. L., Parette, H.P. Jr., Stoner, J.B., Angell, M.E., & Carroll, K. (2006). Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools*, 37(1), 50–60. [https://doi.org/10.1044/0161-1461\(2006/006\)](https://doi.org/10.1044/0161-1461(2006/006))
- Balandin, S., & Iacono, T. (1998). AAC and Australian speech pathologists: Report on a national survey. *Augmentative and Alternative Communication*, 14(4), 239-249.
- Ball, H. L. (2019). Conducting online surveys. *Journal of Human Lactation*, 35(3), 413-417. <https://doi.org/10.1177/0890334419848734>
- Barnes, C., & Mercer, G. (2010). *Competing models and approaches. Exploring disability*.
- Batten, J., & Brackett, A. (2021). Ensuring rigor in systematic reviews: Part 5, quality appraisal, data extraction, synthesis. *Heart & Lung*, 50(5), 615-617. <https://doi.org/10.1016/j.hrtlng.2021.04.002>
- Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2016). Quality of life and quality of support for people with

- severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 409-421. <https://doi.org/10.1111/jar.12200>
- Bennett, M. K., Ward, E. C., & Scarinci, N. A. (2016). Exploratory investigation of communication management in residential-aged care: a comparison of staff knowledge, documentation and observed resident-staff communication. *International Journal of Language and Communication Disorders*, 51(3), 296-309. <https://doi.org/10.1111/1460-6984.12207>
- Beukelman, D. R., & Light, J.C. (2020). *Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs* (Fifth ed.). Paul H. Brookes Publishing Co.
- Beukelman, D. R., & Mirenda, P. (2005). *Augmentative & alternative communication: Supporting children & adults with complex communication needs* (Third ed.). Paul H. Brookes Publishing Co
- Beukelman, D. R., Ball, L.J., & Fager, S. (2008). An AAC personnel framework: Adults with acquired complex communication needs. *Augmentative and Alternative Communication*, 24(3), 255–267. <https://doi.org/10.1080/07434610802388477>
- Beukelman, D. R., Mirenda, P., Ball, L. J., Koch Fager, S., Garrett, K. L., Hanson, E. K., Lasker, J. P., Light, J. C., & McNaughton, D. B. (2012). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (Fourth ed.). Paul H. Brookes Publishing Co
- Biggs, E., Carter, E., & Gilson, C. (2019). A scoping review of the involvement of children's communication partners in aided augmentative and alternative communication modelling interventions. *American Journal of Speech-*

Language Pathology, 28(2), 743-758. https://doi.org/10.1044/2018_AJSLP-18-0024

Binger, C., Ball, L., Dietz, A., Kent-Walsh, J., Lasher, J., Lund, S., McKelvey, M., & Quach, W. (2012). Personnel roles in the AAC assessment process. *Augmentative and Alternative Communication*, 28(4), 278-288. <https://doi.org/10.3109/07434618.2012.716079>

Bircanin, F., Ploderer, B., Sitbon, L., Bayor, A. A., & Brereton, M. (2019). Challenges and opportunities in using augmentative and alternative communication (AAC) technologies: Design considerations for adults with severe disabilities. Paper presented at the 31st Australian conference on human-computer interactions, 184-196. <https://doi.org/10.1145/3369457.3369473>

Blackstone, S. W., Williams, M. B., & Wilkins, D. P. (2007). Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication*, 23(3), 191-203. <https://doi.org/10.1080/07434610701553684>

Blackstone, S.W. (1999). Communication partners. *Augmentative Communication News*. 12, 1-4.

Blain-Moraes, S., Chessier, S., Kingsnorth, S., McKeever, P., & Biddiss, E., (2013). Biomusic: A novel technology for revealing the personhood of people with profound multiple disabilities, *Augmentative and Alternative Communication*, 29(2), 159-173. <https://doi.org/10.3109/07434618.2012.760648>

Bradshaw, J. (2001). Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of*

Intellectual Disability Research, 45(3), 233-243.

<https://doi.org/10.1046/j.1365-2788.2001.00318.x>

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Moneo, B., Ogletree, B. T., Paul, D., Ronski M. A., Sevcik, R., Siegel, E., Schoonover, Snell, M., Sylvester, L., & Wilkinso, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, 121(2), 121-138. <https://doi.org/10.1352/1944-7558-121.2.121>

Bressan, V., Bagnasco, A., Aleo, G., Timmins, F., Barisone, M., Bianchi, M., Pellegrini, R., & Sasso, L. (2017). Mixed-methods research in nursing – a critical review. *Journal of Clinical Nursing*, 26(19-20), 2878-2890. <https://doi.org/10.1111/jocn.13631>

Brown, I. (2020). Life Planning for people with neurodevelopmental and intellectual disability: Effective support, quality of life, and community engagement. *Annali Dell'Istituto Superiore di Sanità*, 56(2), 168-170. https://doi.org/10.4415/ANN_20_02_06

Bruce, S. M., & Bashinski, S. M. (2017). The trifocus framework and interprofessional collaborative practice in severe disabilities. *American Journal Speech Language Pathology*, 26(2), 162–180. https://doi.org/10.1044/2016_AJSLP-15-0063

Brug, A. T., van der Putten, A. A., & Vlaskamp, C. (2013). Learn and apply: Using multi-sensory storytelling to gather knowledge about preferences and abilities of children with profound intellectual and multiple disabilities—three case studies. *Journal of Intellectual Disability Research*, 17(4), 339-360. <https://doi.org/10.1177/1744629513508384>

- Bruner, J. (1974). From communication to language- A psychological perspective. *Cognition*, 3,255-287.
- Bunning, K. (2018). Commentary on “promoting positive communication environments: a service evaluation”: the communication partnership as a focus for change. *Tizard Learning Disability Review*, 23(4), 201-206.
<https://doi.org/10.1108/TLDR-07-2018-0022>
- Burns, N., & Grove, S. K. (2005). *The practice of nursing research: Conduct, critique, and utilization* (Fifth ed.). Elsevier/Saunders.
- Calculator, S. (1999). AAC outcomes for children and youths with severe disabilities: seeing is believing. *Augmentative and Alternative Communication*, 15(1), 4-12.
<https://doi.org/10.1080/07434619912331278525>
- Calculator, S.N. (2009). Augmentative and alternative communication (AAC) and inclusive education for students with the most severe disabilities. *International Journal of Inclusive Education*, 13(1), 93–113.
<https://doi.org/10.1080/13603110701284656>
- Carey, E., Ryan, R., Sheikhi, A., & Dore, L. (2023). Exercising autonomy- The effectiveness and meaningfulness of autonomy support interventions engaged by adults with intellectual disability. A mixed-methods review. *British Journal of Learning Disabilities*, 51(3), 307-323.
<https://doi.org/10.1111/bld.12464>
- Carnaby, S. (2007). Developing good practice in the clinical assessment of people with profound intellectual disabilities and multiple impairment. *Journal of Policy and Practice in Intellectual Disabilities*, 4(2), 88-96.
<https://doi.org/10.1111/j.1741-1130.2007.00105.x>

- Cascella, P. W. (2004). Receptive communication abilities among adults with significant intellectual disability. *Journal of Intellectual & Developmental Disability*, 29(1), 70-78. <https://doi.org/10.1080/13668250410001662847>
- Central Statistics Office. (2016). *Census of Population 2016 – Profile 9 Health, Disability and Carer*. [Types of Disability - CSO - Central Statistics Office](#)
- Central Statistics Office. (2023, September). *Census 2022 Profile 4- Disability Health and Carers*. [Type of Disability - CSO - Central Statistics Office](#)
- Chadwick, D. D., Buell, S., & Goldbart, J. (2019). Approaches to communication assessment with children and adults with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 336-358. <https://doi.org/10.1111/jar.12530>
- Chadwick, D. D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A., & Harrington, G. (2013). Family voices: Life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 119-132. <https://doi.org/10.1111/jar.12003>
- Cheek, A. E., Harris, B. A., Koppenhaver, D. A., Garwood, J. D., & Laws, B. R. (2022). Technology-supported shared storybook reading in a rural classroom serving students with severe intellectual disabilities and complex communication needs. *Rural Special Education Quarterly*, 41(3), 140-152. <https://doi.org/10.1177/87568705221075758>
- Chung, Y., Carter, E. W., & Sisco, L. G. (2012). Social interactions of students with disabilities who use augmentative and alternative communication in inclusive classrooms. *American Journal on Intellectual and Developmental Disabilities*, 117(5), 349-367. <https://doi.org/10.1352/1944-7558-117.5.349>

- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (Second ed.). L. Erlbaum Associates.
- Connelly, L. M. (2016). Trustworthiness in qualitative research. *Medsurg Nursing*, 25(6), 435-436.
- Cooley, C. H. (1972). The looking glass self. In J. Manis, B. Meltzer (Eds.), *Symbolic interaction: A reader in social psychology* (pp. 231-233). Allyn and Bacon, Inc.
- Cope, D. G. (2014). Methods and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum*, 41(1), 89-91.
<https://doi.org/10.1188/14.ONF.89-91>
- Cornally, N. (2014). Theory of Planned Behaviour. In J. J. Fitzpatrick & G. McCarthy (Eds.), *Theories Guiding Nursing Research and Practice. Making Nursing Knowledge Development Explicit* (pp. 69–84). Springer Publishing Company.
- Cortina, J. M. (1993). What is coefficient alpha? an examination of theory and applications. *Journal of Applied Psychology*, 78(1), 98-104. <https://doi.org/10.1037/0021-9010.78.1.98>
- Coulter, D. (2005). Comprehensive health supports and health promotion. In K. C. Lakin & A. Turnbull (Eds.), *National goals and research for people with intellectual and developmental disabilities* (pp. 109-124), American Association on Mental Retardation.
- Coupe O’Kane, J., & Goldbart, J. (1998). *Communication before speech: Development and assessment*. David Fulton Publishers.

- Cronin, M. A., & George, E. (2020). The why and how of the integrative review. *Organisational Research Methods*, 26(1), 168-192.
<https://doi.org/10.1177/1094428120935507>
- Cummins, R. A. (2018). The golden triangle of happiness: Essential resources for a happy family. *International Journal of Child, Youth and Family Studies*, 9(4), 12-39. <https://doi.org/10.18357/ijcyfs94201818638>
- Cummins, R. A. (2020). Quality of life of adults with an intellectual disability. *Current Developmental Disorders Report*, 7(3), 182–187.
<https://doi.org/10.1007/s40474-020-00205-x>
- Dalton, C., & Sweeney, J. (2010). Communication supports in residential services: Research shows a mismatch between what staff perceive to be important when helping people express themselves and how they help them in reality, say Caroline Dalton and John Sweeney. *Learning Disability Practice*, 13(9), 14-19. <https://doi.org/10.7748/ldp2010.11.13.9.14.c8094>
- Dalton, C., & Sweeney, J. (2013). Communication supports in residential services for people with an intellectual disability. *British Journal of Learning Disabilities*, 41(1), 22-30. <https://doi.org/10.1111/j.1468-3156.2011.00717.x>
- Dammeyer, J., & Køppe, S. (2013). The relationship between body movements and qualities of social interaction between a boy with severe developmental disabilities and his caregiver. *Intellectual and Developmental Disabilities*, 51(3), 154-163. <http://dx.doi.org/10.1352/1934-9556-51.3.154>
- Danker, J., Dreyfus, S., Strnadová, I., & Pilkinton, M. (2023). Scoping review on communication systems used by adults with severe/profound intellectual disability for functional communication. *Journal of Applied Research in Intellectual Disabilities*, 36(5), 951–965. <https://doi.org/10.1111/jar.13133>

- Darko, E. M., Kleib, M., & Olson, J. (2022). Social media use for research participant recruitment: Integrative literature review. *Journal of Medical Internet Research*, 24(8), e38015-e38015. <https://doi.org/10.2196/38015>
- Davis, F. D. (1986). A technology acceptance model for empirically testing new end-user information systems: Theory and results [Dissertation, Massachusetts Institute of Technology].
- Davis, F. D. (1989). Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Quarterly*, 13(3), 319-340. <https://doi.org/10.2307/249008>
- Davis, F. D., Bagozzi, R. P., & Warshaw, P. R. (1989). User acceptance of computer technology: A comparison of two theoretical models. *Management Science*, 35(8), 982-1003. <https://doi.org/10.1287/mnsc.35.8.982>
- De Bortoli, T., Arthur-Kelly, M., Foreman, P., Balandin, S., & Mathisen, B. (2011). Complex contextual influences on the communicative interactions of students with multiple and severe disabilities. *International Journal of Speech Language Pathology*, 13(5), 422-435. <https://doi.org/10.3109/17549507.2011.550691>
- De Geeter, K. I., Poppes, P., & Vlaskamp, C. (2002). Parents as experts: The position of parents of children with profound multiple disabilities. *Child: Care, Health & Development*, 28(6), 443-453. <https://doi.org/10.1046/j.1365-2214.2002.00294.x>
- Dennis, R. (2002). Nonverbal narratives: Listening to people with severe intellectual disability. *Research and Practice for Persons with Severe Disabilities*, 27(4), 239-249. <https://doi.org/10.2511/rpsd.27.4.239>

- DePaepe, P. A., & Wood, L. A. (2001). Collaborative practices related to augmentative and alternative communication: Current personnel preparation programs. *Communication Disorders Quarterly*, 22(2), 77-86. <https://doi.org/10.1177/152574010102200203>
- Department of Health. (2014). *Value for Money (Transforming Lives) and Policy Review of Disability Services in Ireland- Steering Group Project Initiation Document*. Department of Health; Dublin.
- Department of Justice and Equality. (2017). *National Disability Inclusion Strategy 2017- 2021*. <http://www.justice.ie/en/JELR/dept-justice-ndi-inclusionstratgey-booklet.pdf/Files/dept-justice-ndi-inclusion-stratgey-booklet.pdf>
- Dey, I. (1993). *Qualitative Data Analysis. A User-Friendly Guide for Social Scientists*. Routledge.
- Dhollande, S., Taylor, A., Meyer, S., & Scott, M. (2021). Conducting integrative reviews: A guide for novice nursing researchers. *Journal of Research in Nursing*, 26(5), 427-438. <https://doi.org/10.1177/1744987121997907>
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2014). *Internet, phone, mail, and mixed-mode surveys: The tailored design method* (Fourth ed.). John Wiley & Sons, Inc.
- Disability Act 2005, No. 14/2005. Stationery Office, Dublin.
- Doody, O., & Bailey, M. E. (2017). Interventions in pain management for persons with an intellectual disability. *Journal of Intellectual Disabilities*, 23(1), 132–144. <https://doi.org/10.1177/1744629517708679>

- Doukas, T., Fergusson, A., Fullerton, M., & Grace, J. (2017). *Supporting people with profound and multiple learning disabilities. Core and essential service standards.*
- Edwards, R., & Holland, J. (2013). *What is qualitative interviewing?* Bloomsbury.
- Elmqvist, M., Crowe, B., Wattanawongwan, S., Reichle, J., Pierson, L., Simacek, J., Hong, E. R., Liao, C., & Ganz, J. B. (2023). Caregiver-implemented AAC interventions for children with intellectual or developmental disabilities: A systematic review. *Review Journal of Autism and Developmental Disorders*, <https://doi.org/10.1007/s40489-023-00394-2>
- Elo, S. & Kyngas, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107-115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x>
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K. & Kyngäs, H. (2014). Qualitative content analysis: a focus on trustworthiness. *SAGE Open*, 4(1), 1-10. <https://doi.org/10.1177%2F2158244014522633>
- Erickson, K., & Quick, N. (2017). The profiles of students with significant cognitive disabilities and known hearing loss. *Journal of Deaf Studies and Deaf Education*, 22(1), 35-48. <https://doi.org/10.1093/deafed/enw052>
- European Commission, Directorate-General for Employment, Social Affairs, and Inclusion, (2021). *Union of equality: strategy for the rights of persons with disabilities 2021-2030*, Publications Office. <https://data.europa.eu/doi/10.2767/31633>
- European Commission, Secretariat-General. (2017). *European pillar of social rights*, Publications Office. <https://data.europa.eu/doi/10.2792/95934>

- Eysenbach, G., & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *Bmj*, 323(7321), 1103-1105. <https://doi.org/10.1136/bmj.323.7321.1103>
- Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention and behavior: An introduction to theory and research*. Addison-Wesley.
- Fishbein, M., & Ajzen, I. (2010). *Predicting and changing behavior: The reasoned action approach*. Psychology Press.
- Fisher, K., Desroches, M., Marsden, D., Rees, S., Northway, R., Horan, P., Stych, J., Ailey, S., Trip, H., & Wilson, N. (2022). International nursing actions to reduce health inequities faced by people with intellectual and developmental disability. *Online Journal of Issues in Nursing*, 27(3).
<https://doi.org/10.3912/OJIN.Vol27No03Man07>
- Flynn, E. (2009). Ireland's compliance with the convention on the rights of persons with disabilities: Towards rights-based approach for legal reform. *Dublin University Law Journal*, 31, 357-385.
- Forster, S., & Iacono, T. (2007). Perceptions of communication before and after a speech pathology intervention for an adult with intellectual disability. *Journal of Intellectual and Developmental Disability*, 32(4), 302-314. <https://doi.org/10.1080/13668250701654425>
- Frantz, A., Holmgren, K., (2019). The work stress questionnaire (WSQ) - reliability and face validity among male workers. *BMC Public Health*, 19(1), 1580-1580. <https://doi.org/10.1186/s12889-019-7940-5>
- Friedman, C., & McNamara, E. (2018). Home- and community-based speech, language, and hearing services for people with intellectual and developmental

- disabilities. *Research and Practice for Persons with Severe Disabilities*, 43(2), 111-125. <https://doi.org/10.1177/1540796918775595>
- Friscic, J. (2021, March 5). *European Commission presents strategy for the rights of persons with disabilities 2021-2030*. Inclusion Europe. <http://www.inclusion-europe.eu/european-commission-presents-strategy-for-the-rights-of-persons-with-disabilities-2021-2030/>
- Gadd, T., & Cronin, S. (2019). New directions: A national framework for person-centred planning in services for persons with disability. HSE/NDA, Ireland.
- Garcia Iariarte, E., McConkey, R., & Gilligan, R. (2016). *Disability and human rights: Global perspectives*. Palgrave Macmillan.
- Goldbart, J. (2023). Communication as a human right for children with profound intellectual disabilities. *Developmental Medicine and Child Neurology*, 65(6), 725-726. <https://doi.org/10.1111/dmcn.15564>
- Goldbart, J., & Caton, S. (2010). Communication and people with the most complex needs: What works and why this is essential. Mencap, London.
- Goldbart, J., Chadwick, D., & Buell, S. (2014). Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability. *International Journal of Language & Communication Disorders*, 49(6), 687-701. <https://doi.org/10.1111/1460-6984.12098>
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105-112. <https://doi.org/10.1016/j.nedt.2003.10.001>

- Granello, D. H., & Wheaton, J. E. (2004). Online data collection: Strategies for research. *Journal of Counseling and Development*, 82(4), 387-393. <https://doi.org/10.1002/j.1556-6678.2004.tb00325.x>
- Griffiths, C., & Smith, M. (2016). Attuning: A communication process between people with severe and profound intellectual disability and their interaction partners. *Journal of Applied Research in Intellectual Disabilities*, 29(2), 124-138. <https://doi.org/10.1111/jar.12162>
- Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 12, 190–203. <https://doi.org/10.1111/j.1468-3148.1999.tb00076.x>
- Grove, S. K., Burns, N., & Gray, J. R. (2013). *The practice of nursing research: Appraisal, synthesis, and generation of evidence*. Elsevier Saunders.
- Gulati, S., & Sondhi, V. (2018). Cerebral palsy: An overview. *Indian Journal of Pediatrics*, 85(11), 1006-1016. <https://doi.org/10.1007/s12098-017-2475-1>
- Hanley, E. et al., (2023c). Examining the factors that influence the intention of communication partners of persons with severe/profound intellectual disability to use augmentative and alternative communication using the combined technology acceptance model and theory of planned behaviour. [Manuscript in preparation]. The School of Nursing & Midwifery, University College Cork.
- Hanley, E., Dalton, C., Lehane, E., & Martin, A. M. (2023a). Communication partners' perceptions of their roles and responsibilities in the design, planning and use of augmentative and alternative communication with persons with

- severe or profound intellectual disability: A qualitative descriptive study. [Manuscript in preparation]. The School of Nursing & Midwifery, University College Cork.
- Hanley, E., Lehane, E., Martin, A.M., & Dalton, C. (2023b). Factors influencing communication partners of persons with severe/profound intellectual disability use of augmentative and alternative communication: An integrative review. [Manuscript in preparation]. The School of Nursing & Midwifery, University College Cork.
- Hanley, E., Martin, A., Dalton, C., & Lehane, E. (2022). Communication partners experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review. *Journal of Intellectual Disabilities*, 27(4), 1107-1134. <https://doi.org/10.1177/17446295221115914>
- Hatton, C., Glover, G., Emerson, E., & Brown, I. (2016). People with learning disabilities in England 2015: Main report. Public Health England.
- Heale, R., & Noble, H. (2019). Integration of a theoretical framework into your research study. *Evidence-Based Nursing*, 22(2), 36-37. <https://doi.org/10.1136/ebnurs-2019-103077>
- Health Service Executive (2011). *Time to Move on from Congregated Settings A Strategy for Community Inclusion*. HSE, Dublin.
- Health Service Executive (2012). *New Directions: Report of the National Working Group for the review of HSE Funded Adult Day Services*. <https://www.hse.ie/eng/services/list/4/disability/newdirections/>
- Health Service Executive (2015). *Assisted Decision Making (Capacity) Act (2015)*. [Assisted Decision-Making \(Capacity\) Act \(2015\) - HSE.ie](https://www.hse.ie/eng/services/list/4/disability/newdirections/)

Health Service Executive (2016). *New Directions Benchmarking Report 2016*.

<https://www.hse.ie/eng/services/list/4/disability/newdirections/new-directions-benchmarking-report-2016.pdf>

Health Service Executive. (2019). *Time to Move on from Congregated Settings: A Strategy for Community Inclusion Annual Progress Report 2019*. HSE, Dublin.

Hermesen, M., Simons, R., van Veen, H., Prudon, A., Rooijackers, L., Otten, R., & Koordeman, R. (2022). Building high-quality interpersonal staff-client relationships with people with severe to profound intellectual disabilities and challenging behavior: Insights of professionals and relatives. *Journal of Intellectual Disabilities*, 0(0). <https://doi.org/10.1177/17446295221131443>

Hewitt, D., Calvey, J., McKim, J., & Mouriere, A. (2019). Communication, human rights and intensive interaction. *PMLD Link*, 31(1), 8-10.

Higgins, J. P. T., Green, S., & Cochrane Collaboration. (2008). *Cochrane handbook for systematic reviews of interventions*. Wiley-Blackwell.

Hodge, S. (2007). Why is the potential of augmentative and alternative communication not being realized? exploring the experiences of people who use communication aids. *Disability & Society*, 22(5), 457-471. <https://doi.org/10.1080/09687590701427552>

Holmes, A. G. D. (2020). "Researcher positionality – a consideration of its influence and place in qualitative research – a new researcher guide." *Shanlax International Journal of Education*, 8(4), 1-10.

Hong, Q. N., Fabregues, S., Barlett, G., Boardman, D., Cargo, M., Dagenais, P., Gagnon, M., Griffiths, F., Nicolau, V., O’Cathain, A., Rousseau, M., Vedel, I., & Pluye, P. (2018). The mixed methods appraisal tool (MMAT) version 2018

- for information professionals and researchers. *Education for Information*, 34(4), 285-291. <https://doi.org/10.3233/EFI-180221>
- Hong, Q. N., Pluye, P., Bujold, M., & Wassef, M. (2017). Convergent and sequential synthesis designs: Implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Systematic Reviews*, 6(1), 61-61. <https://doi.org/10.1186/s13643-017-0454-2>
- Hostyn, I., & Maes, B. (2009). Interaction between persons with profound intellectual and multiple disabilities and their partners: A literature review. *Journal of Intellectual & Developmental Disability*, 34(4), 296-312. <https://doi.org/10.3109/13668250903285648>
- Hourcade, J., Everhart Pilotte, T., West, E., & Parette, P. (2004). A history of augmentative and alternative communication for individuals with severe and profound disabilities. *Focus on Autism and Other Developmental Disabilities*, 19(4), 235-244. <https://doi.org/10.1177/10883576040190040501>
- Hourigan S., Fanagan S., & Kelly C. (2018). Annual Report of the National Intellectual Disability Database Committee 2017: Main Findings. Health Research Board, Dublin.
- Hsieh, H. F., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9): 1277– 1288. <https://doi.org/10.1177/1049732305276687>
- Hughes, R. P., Goodwin, M., & Travis, B. (2018). ‘What makes a good life?’ *PMLD Link*. 30(2), 32-35.
- Hughes, R. P., Redley, M., & Ring, H. (2011). Friendship and adults with profound intellectual and multiple disabilities and English disability policy: Friendship, profound disabilities, and policy. *Journal of Policy and Practice in*

Intellectual Disabilities, 8(3), 197-206. <https://doi.org/10.1111/j.1741-1130.2011.00310.x>

Hustad, K. C. (2007). Effects of speech stimuli and dysarthria severity on intelligibility scores and listener confidence ratings for speakers with cerebral palsy. *Folia Phoniatrica Et Logopaedica*, 59(6), 306-317. <https://doi.org/10.1159/000108337>

Hutchinson, N., & Bodicoat, A. (2015). The effectiveness of intensive interaction, A systematic literature review. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 437-454. <https://doi.org/10.1111/jar.12138>

International Communication Project. (2014). [International Communication Project 2014 - Communication Matters](#)

Jansen, S. L. G., van der Putten, A. A. J., & Vlaskamp, C. (2015). What makes a difference? Collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities: a literature review. [Manuscript in preparation]. Department of Special Needs Education and Youth Care, University of Groningen.

Johnson, H., Douglas, J., Bigby, C. & Iacono T. (2010). The pearl in the middle: A case study of social interactions in an individual with severe intellectual disability. *Journal of Intellectual and Developmental Disability* 35(3), 175-186. <https://doi.org/10.3109/13668250.2010.501026>

Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2009). Maximizing community inclusion through mainstream communication services for adults with severe disabilities. *International Journal of Speech-Language Pathology*, 11(3):180-190, <https://doi.org/10.1080/17549500902825265>

- Johnson, J. M., Inglebret, E., Jones, C., & Ray, J. (2006). Perspectives of Speech language pathologists regarding success versus abandonment of AAC. *Augmentative and Alternative Communication*, 22(2), 85-99.
<https://doi.org/10.1080/07434610500483588>
- Kamstra, A., van der Putten, A. A. J., & Vlaskamp, C. (2015). The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 28(3), 249-256. <https://doi.org/10.1111/jar.12134>
- Keen, D. (2014) Prelinguistic communication. In J. Arciuli & J. Brock (Eds.), *An introduction to communication in autism: Current findings and future directions*, (pp. 11-28). Benjamins.
- Kelly, B. D. (2017). The assisted decision-making (capacity) act 2015: What it is and why it matters. *Irish Journal of Medical Science*, 186(2), 351-356.
<https://doi.org/10.1007/s11845-016-1443-5>
- Kent-Walsh, J., & McNaughton, D. (2005). Communication partner instruction in AAC: Present practices and future directions. *Augmentative and Alternative Communication*, 21(3), 195-204.
<https://doi.org/10.1080/07434610400006646>
- Kent-Walsh, J., Binger, C., & Hasham, Z. (2010). Effects of parent instruction on the symbolic communication of children using augmentative and alternative communication during storybook reading. *American Journal of Speech-Language Pathology*, 19(2), 97-107. [https://doi.org/10.1044/1058-0360\(2010/09-0014\)](https://doi.org/10.1044/1058-0360(2010/09-0014))
- Kent-Walsh, J., Murza, K. A., Malani, M. D., & Binger, C. (2015). Effects of communication partner instruction on the communication of individuals

- using AAC: A meta-analysis. *Augmentative and Alternative Communication*, 31, 271-284. <https://doi.org/10.3109/07434618.2015.1052153>
- King, J. (1998). Preliminary survey of speech-language pathologists providing AAC services in health care settings in Nebraska. *Augmentative and Alternative Communication*, 14(4), 222-227. <https://doi.org/10.1080/07434619812331278396>
- Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Open University Press.
- Koski, K., Martikainen, K., Burakoff, K., & Launonen, K. (2010). Staff members' understanding about communication with individuals who have multiple learning disabilities: A case of Finnish OIVA communication training. *Journal of Intellectual and Developmental Disability*, 35(4): 279-289. <https://doi.org/10.3109/13668250.2010.517189>
- Kruithof, K., Willems, D., van Etten-Jamaludin, F., & Olsman, E. (2020). Parents' knowledge of their child with profound intellectual and multiple disabilities: An interpretative synthesis. *Journal of Applied Research in Intellectual Disabilities*, 33(6), 1141–1150. <https://doi.org/10.1111/jar.12740>
- Kulkarni, S. S., & Parmar, J. (2017). Culturally and linguistically diverse student and family perspectives of AAC. *Augmentative and Alternative Communication*, 33(3), 170-180. <https://doi.org/10.1080/07434618.2017.1346706>
- Light, J. (1989). Toward a definition of communication competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5(2), 137-144.

- Light, J. C., Arnold, K. B., & Clark, E.A. (2003). Finding a place in the “social circle of life”. In J.C. Light, D. R. Beukelman & D. R. Reichle (Eds.), *Communicative competence for individuals who use AAC: From research to effective practice*, (pp. 361-397). Paul H. Brookes.
- Light, J., & McNaughton, D. (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication? *Augmentative and Alternative Communication*, 30(1), 1-18. <https://doi.org/10.3109/07434618.2014.885080>
- Light, J., & McNaughton, D. (2015). Designing AAC research and intervention to improve outcomes for individuals with complex communication needs. *Augmentative and Alternative Communication*, 31(2), 85-96. <https://doi.org/10.3109/07434618.2015.1036458>
- Light, J., Barwise, A., Gardner, A. M., & Flynn, M. (2021). Personalized early AAC intervention to build language and literacy skills: A case study of a 3-year-old with complex communication needs. *Topics in language disorders*, 41, 209–231.
- Light, J., Collier, B., & Parnes, P. (1985). Communicative interaction between young nonspeaking physically disabled children and their primary caregivers: Part I – discourse patterns. *Augmentative and Alternative Communication*, 1(2), 74-83.
- Light, J., McNaughton, D., & Caron, J. (2019a). New and emerging AAC technology supports for children with complex communication needs and their communication partners: State of the science and future research directions. *Augmentative and Alternative Communication*, 35(1), 26-41. <https://doi.org/10.1080/07434618.2018.1557251>

- Light, J., McNaughton, D., Beukelman, D., Fager, S. K., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019b). Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication*, 35(1), 1-12. <https://doi.org/10.1080/07434618.2018.1556732>
- Lincoln, S. Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.
- Littzen-Brown, C. (2021, November 9). Theory guided research: what, why, and how? Nursology. [Theory-guided Research: What, Why, and How? | Nursology](#)
- Liu, L., Miguel Cruz, A., Rios Rincon, A., Buttar, V., Ranson, Q., & Goertzen, D. (2015). What factors determine therapists' acceptance of new technologies for rehabilitation—a study using the Unified Theory of Acceptance and Use of Technology (UTAUT). *Disability and Rehabilitation*, 37(5), 1–9. <http://dx.doi.org/10.3109/09638288.2014.923529>
- Lizarondo, L., Stern, C., Carrier, J., Godfrey, C., Rieger, K., Salmond, S., Apostolo, J., Kirkpatrick, P., & Loveday, H. (2020). Mixed methods systematic review. In E. Aromataris & Z. Munn (Eds.), *JBIM Manual for Evidence Synthesis*. JBI, 2020. <https://doi.org/10.46658/JBIMES-20-09>
- Luft, J. A., Jeong, S., Idsardi, R., & Gardner, G. (2022). Literature reviews, theoretical frameworks, and conceptual frameworks: an introduction for new biology education researchers. *CBE life sciences education*, 21(3), rm33. <https://doi.org/10.1187/cbe.21-05-0134>
- Lund, S. K., & Light, J. (2007). Long-term outcomes for individuals who use augmentative and alternative communication: Part III- contributing factors.

Augmentative and Alternative Communication, 23(4), 323-335.

<https://doi.org/10.1080/02656730701189123>

Lundy, L. (2007). 'voice' is not enough: Conceptualising article 12 of the United Nations convention on the rights of the child. *British Educational Research Journal*, 33(6), 927-942. <https://doi.org/10.1080/01411920701657033>

Lyle, D. (2019). *Understanding profound intellectual and multiple disabilities in adults* (First ed.). Routledge.

Lyons, G. (2005). The life satisfaction matrix: an instrument and procedure for assessing the subjective quality of life of individuals with profound multiple disabilities. *Journal of Intellectual Disability Research*, 49(10), 766–769. <https://doi.org/10.1111/j.1365-2788.2005.00748.x>

Maes, B., Lambrechts, G., Hostyn, I., & Petry, K. (2007). Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature. *Journal of Intellectual & Developmental Disability*, 32(3), 163–178. <https://doi.org/10.1080/13668250701549427>

Maes, B., Nijs, S., Vandesande, S., Van Keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J., Petitpierre, G., & Van der Putten, A. (2020). Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 34(1), 250–262. <https://doi.org/10.1111/jar.12803>

Mansell, J. (2010). Raising our sights: services for adults with profound intellectual and multiple disabilities. *Tizard Learning Disability Review*, 15(3), 5-12. <https://doi.org/10.5042/tldr.2010.0399>

- Mansell, J., & Beadle-Brown, J. (2012). *Active support: enabling and empowering people with intellectual disabilities*. Jessica Kingsley
- Marshall, J., & Goldbart, J. (2008). 'Communication is everything I think.' parenting a child who needs augmentative and alternative communication (AAC). *International Journal of Language & Communication Disorders*, 43(1), 77-98. <https://doi.org/10.1080/13682820701267444>
- Martin, A.M. (2020). Reconciling communication repertoires: a classic grounded theory of navigating interactions involving persons with severe/profound intellectual disability. [PhD Thesis, University College Cork].
- Martin, T., & Alborz, A. (2004). Supporting the education of pupils with profound intellectual and multiple disabilities: the views of teaching assistants regarding their own learning and development needs. *British Journal of Special Education*, 41(3), 309-327. <https://doi.org/10.1111/1467-8578.12070>
- McCain, G. C. (1988). Content analysis: a method for studying clinical nursing problems. *Applied Nursing Research*, 1(3), 146– 150.
- McCall, F., Marková, I., Murphy, J., Moodie, E., & Collins, S. (1997). Perspectives on AAC systems by the users and by their communication partners. *International Journal of Language & Communication Disorders*, 32(S3), 235-256. <https://doi.org/10.1080/13682829709177099>
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion, P. (2013). Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Research in Developmental Disabilities*, 34(1), 521-527. <https://doi.org/10.1016/j.ridd.2012.07.029>

- McCarthy, J., & Light, J. (2005). Attitudes toward individuals who use augmentative and alternative communication: Research review. *Augmentative and Alternative Communication*, 21(1), 41–55.
<https://doi.org/10.1080/07434610410001699753>
- McCord, M. S., & Soto, G. (2004). Perceptions of AAC: An ethnographic investigation of Mexican American families. *Augmentative and Alternative Communication*, 20(4), 209-227. <https://doi.org/10.1080/07434610400005648>
- McCormack, J., Baker, E., & Crowe, K. (2018). The human right to communicate and our need to listen: Learning from people with a history of childhood communication disorder. *International Journal of Speech Language Pathology*, 20(1), 142-151. <https://doi.org/10.1080/17549507.2018.1397747>
- Mead, G. H. (1970). Development of the self through play and games. In G. P. Stone & H. A. Farberman (Eds.), *Social psychology through symbolic interaction*, (pp. 537-545). Ginn Blaisdell.
- Meuris, K., Maes, B., & Zink, I. (2014). Key word signing usage in residential and day care programs for adults with intellectual disability. *Journal of Policy and Practice in Intellectual Disability*, 11(4):255-267.
<https://doi.org/10.1111/jppi.12093>
- Midtlin, H. S., Næss, K. B., Taxt, T., & Karlsen, A. V. (2015). What communication strategies do AAC users want their communication partners to use? A preliminary study. *Disability and Rehabilitation*, 37(14), 1260-1267. <https://doi.org/10.3109/09638288.2014.961659>
- Mirenda, P. (2014). Revisiting the mosaic of supports required for including people with severe intellectual or developmental disabilities in their communities.

Augmentative and alternative communication, 30(1), 19–27.

<https://doi.org/10.3109/07434618.2013.875590>

Mishra, M., & Allen, M. S. (2023). Face, construct and criterion validity, and test-retest reliability, of the adult rejection sensitivity questionnaire. *European Journal of Psychological Assessment: Official Organ of the European Association of Psychological Assessment*, <https://doi.org/10.1027/1015-5759/a000782>

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Group, T. P. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. E1000097. *PLoS Medicine*, 6(7).
<https://doi.org/10.1371/journal.pmed.1000097>

Moorcroft, A., Scarinci, N., & Meyer, C. (2019). A systematic review of the barriers and facilitators to the provision and use of low-tech and unaided AAC systems for people with complex communication needs and their families. *Disability and Rehabilitation: Assistive Technology*, 14(7), 710-731.
<https://doi.org/10.1080/17483107.2018.1499135>

Munde, V., & Vlaskamp, C. (2015). Initiation of activities and alertness in individuals with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 59(3), 284-292.
<https://doi.org/10.1111/jir.12138>

Murphy, K., & Bantry-White, E. (2021). Behind closed doors: Human rights in residential care for people with an intellectual disability in Ireland. *Disability & Society*, 36(5), 750-771. <https://doi.org/10.1080/09687599.2020.1768052>

- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 4(2), 83-87. <https://doi.org/10.1111/j.1741-1130.2007.00104.x>
- National Disability Authority. (2020, December). *Twenty Years of Disability Policy Development in Ireland*. <https://nda.ie/publications/20-years-of-disability-policy>
- National Disability Authority. (2023). *What we do*. [What We Do | Research, Policy & Monitoring | - National Disability Authority \(nda.ie\)](https://nda.ie/publications/20-years-of-disability-policy)
- National Disability Authority. (October 2022). *Overview of UNCRPD Article 21 in Ireland Right to Freedom of Expression and Opinion, and Access to Information*. [NDA-Review-Paper-on-UNCRPD-Article-21-Right-to-Freedom-of-Expression-and-Opinion-and-Access-to-Information.docx \(live.com\)](https://nda.ie/publications/20-years-of-disability-policy).
- National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (1992). Guidelines for meeting the communication needs of persons with severe disabilities. *Asha*, 34(7), 1-8.
- Neerinckx, H., & Maes, B. (2016). Joint attention behaviours in people with profound intellectual and multiple disabilities: the influence of the context. *Journal of Applied Research in Intellectual Disability*, 29(6), 574-584. <https://doi.org/10.1111/jar.12217>
- Netten, A., Beadle-Brown, J., Trukeschitz, B., Towers, A. M., Welch, E., Forder, J., Smith, J., & Alden, E. (2010). Measuring the outcomes of care homes: Final report (no. 2696/2). Personal Social Services Research Unit
- Newby, W., Loney, B., & Ashdown, R. (2019). Guest editorial: Communication. *PMLD Link*. 31(1), 1.

- Nieuwenhuijse, A. M., Willems, D. L., & Kruithof, K. (2023a). Special issue article; Understanding quality of life of persons with profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, <https://doi.org/10.1111/jppi.12473>
- Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., & Olsman, E. (2022). The perspectives of professional caregivers on quality of life of persons with profound intellectual and multiple disabilities: a qualitative study. *International Journal of Developmental Disabilities*, 68(2), 190-197. <https://doi.org/10.1080/20473869.2020.1737469>
- Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., & Olsman, E. (2023b). Parent perspectives on the assessment of quality of life of their children with profound intellectual and multiple disabilities in the Netherlands. *Research in Developmental Disabilities*, 139, 104536-104536. <https://doi.org/10.1016/j.ridd.2023.104536>
- Ning, Y., Yan, M., Xu, S. X., Li, Y., & Li, L. (2021). Shared parking acceptance under perceived network externality and risks: Theory and evidence. *Transportation Research. Part A, Policy and Practice*, 150, 1-15. <https://doi.org/10.1016/j.tra.2021.05.009>
- Norburn, K., Levin, A., Morgan, S., & Harding, C. (2016). A survey of augmentative and alternative communication used in an inner-city special school. *British Journal of Special Education*, 43(3), 289-306. <https://doi.org/10.1111/1467-8578.12142>
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine: journal of the Association of American Medical*

Colleges, 89(9), 1245-1251.

<https://doi.org/10.1097/ACM.0000000000000388>

Ogletree, B. T. (2021). *Augmentative and Alternative Communication: Challenges and Solutions*. Plural Publishing Inc.

Ogletree, B. T., Bartholomew, P., Kirksey, M. L., Guenigsman, A., Hambrecht, G., Price, J., & Wofford, M. C. (2016). Communication training supporting an AAC user with severe intellectual disability: Application of the communication partner instruction model. *Journal of Developmental and Physical Disabilities*, 28(1), 135-152. <https://doi.org/10.1007/s10882-015-9444-2>

Ogletree, B. T., Bartholomew, P., Wagaman, J. C., Genz, S., & Reisinger, K. (2012). Emergent potential communicative behaviors in adults with the most severe intellectual disabilities. *Communication Disorders Quarterly*, 34(1), 56-58. <https://doi.org/10.1177/1525740112456201>

O'Neill, T., & Wilkinson, K. M. (2019). Designing developmentally sensitive AAC technologies for young children with complex communication needs: Considerations of communication, working memory, attention, motor skills, and sensory-perception. *Seminars in Speech and Language*, 40;17;(4), 320-332. <https://doi.org/10.1055/s-0039-1692966>

Ouellette-Kuntz, H., Martin, L., & McKenzie, K. (2016). Population aging and intellectual and developmental disabilities: Projections for Canada. *Journal of Policy and Practice in Intellectual Disabilities*, 13(4), 254-260. <https://doi.org/10.1111/jppi.12172>

Pallant, J. (2016). *Spss survival manual: A step by step guide to data analysis using IBM SPSS* (Sixth ed.). McGraw-Hill Education.

- Parette, H. P., & Angelo, D. (1998). Impact of assistive technology devices on families. In S. L. Judge & H.P. Parette (Eds.), *Assistive technology for young children with disabilities: A guide providing family-centered services*, (pp. 148-183). Brookline.
- Parette, H.P., & Angelo, D. (1996). Augmentative and alternative communication impact on families: Trends and future directions. *Journal of Special Education*, 30(1), 77-98.
- Patel, K., Roche, L., Coward, N., Meek, J., & Harding, C. (2018). Promoting positive communication environments: A service evaluation. *Tizard Learning Disability Review*, 23(4), 192-200. <https://doi.org/10.1108/TLDR-04-2018-0009>
- Penninga, W., Nijs, S. L. P., van Bakel, H. J. A., & Embregts, P. J. C. M. (2022). Meaningful moments of interaction with people with profound intellectual disabilities: Reflections from direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 35(6), 1307–1316. <https://doi.org/10.1111/jar.13019>
- Persson, B. (2003). Exclusive and inclusive discourses in special education research and policy in Sweden: Special issue: Inclusive education policy and practice. *International Journal of Inclusive Education*, 7(3), 271–280.
- Peterson, R. A. (1997). A quantitative analysis of rating-scale response variability. *Marketing Letters*, 8(1), 9-21. <https://doi.org/10.1023/A:1007909424993>
- Petry, K., & Maes, B. (2006). Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual &*

Developmental Disability, 31(1),28-

38. <https://doi.org/10.1080/13668250500488678>

Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: the perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 35-46. <https://doi.org/10.1111/j.1468-3148.2004.00209.x>

Pino, A. (2014) Augmentative and Alternative Communication systems for the motor disabled. In *Disability Informatics and Web Accessibility for Motor Limitations* (pp. 105-152). IGI Global.

Polit, D. F., & Beck, C. T. (2004). *Nursing Research: Principles and Methods* (Seventh ed.). Lippincott Williams and Wilkins.

Polit, D. F., & Beck, C. T. (2021). *Nursing research: Generating and assessing evidence for nursing practice* (Eleventh ed.). Lippincott Williams & Wilkins.

Powell, T. W. (2008). The use of nonspeech oral motor treatments for developmental speech sound production disorders: Interventions and interactions. *Language, Speech & Hearing Services in Schools*, 39(3), 374-379. [https://doi.org/10.1044/0161-1461\(2008/035\)](https://doi.org/10.1044/0161-1461(2008/035))

Rackensperger, T., Krezman, C., McNaughton, D., Williams, M. B., & D'Silva, K. (2005). "When I first got it, I wanted to throw it off a cliff": The challenges and benefits of learning AAC technologies as described by adults who use AAC. *Augmentative and Alternative Communication*, 21(3), 165-186. <https://doi.org/10.1080/07434610500140360>

Reichle, J., York, J., & Sigafos, J. (1991). *Implementing augmentative and alternative communication: Strategies for learners with severe disabilities*. Brookes.

- Rensfeldt Flink A, Thunberg, G., Nyman, A., Broberg, M., & Åsberg Johnels, J. (2022a). Augmentative and alternative communication with children with severe/profound intellectual and multiple disabilities: Speech language pathologists' clinical practices and reasoning. *Disability and Rehabilitation: Assistive Technology*, ahead-of-print(ahead-of-print), 1-13. <https://doi.org/10.1080/17483107.2022.2137252>
- Rensfeldt Flink, A. (2022). Children with severe or profound intellectual and multiple disabilities – characteristics and communication interventions (ISBN 978-91-8009-926-4 (PDF)) [Dissertation, University of Gothenburg].
- Rensfeldt Flink, A., Åsberg Johnels, J., Broberg, M., & Thunberg, G. (2020). Examining perceptions of a communication course for parents of children with profound intellectual and multiple disabilities. *International Journal of Developmental Disabilities*, 68(2), 156-167. <https://doi.org/10.1080/20473869.2020.1721160>
- Rensfeldt Flink, A., Broberg, M., Strid, K., Thunberg, G., & Johnels, J. Å. (2022b). Following children with severe or profound intellectual and multiple disabilities and their mothers through a communication intervention: Single-case mixed-methods findings. *International Journal of Developmental Disabilities*, (ahead-of-print), 1-19. <https://doi.org/10.1080/20473869.2022.2031778>
- Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide, *Qualitative Research in Psychology*, 11(1), 25-41. <https://doi.org/10.1080/14780887.2013.801543>
- Roche, L., Sigafoos, J., Lancioni, G. E., O'Reilly, M. F., & Green, V. A. (2015). Microswitch technology for enabling self-determined responding in children

- with profound and multiple disabilities: A systematic review. *Augmentative and Alternative Communication*, 31(3), 246-
258. <https://doi.org/10.3109/07434618.2015.1024888>
- Rombouts, E., Maes, B., & Zink, I. (2016). Attitude and key word signing usage in support staff. *Research in Developmental Disabilities*, 55, 77-
87. <https://doi.org/10.1016/j.ridd.2016.03.016>
- Rombouts, E., Maes, B., & Zink, I. (2017a). The behavioural process underlying augmentative and alternative communication usage in direct support staff. *Journal of Intellectual & Developmental Disability*, 42(2), 101-
113. <https://doi.org/10.3109/13668250.2016.1219023>
- Rombouts, E., Maes, B., & Zink, I. (2017b). Beliefs and habits: staff experiences with key word signing in special schools and group residential homes. *Augmentative and alternative communication (Baltimore, Md.: 1985)*, 33(2), 87–96. <https://doi.org/10.1080/07434618.2017.1301550>
- Romski, M., & Sevcik, R. (2005). Augmentative communication and early intervention: Myths and realities. *Infants and Young Children*, 18, 174–185. <https://doi.org/10.1097/00001163-200507000-00002>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334-340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Sandelowski, M. (2010). What's in a name? qualitative description revisited. *Research in Nursing & Health*, 33(1), 77-
84. <https://doi.org/10.1002/nur.20362>
- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., Yeager, M. H. (2010). Intellectual disability: Definition,

classification, and systems of support (11th ed.). American Association on Intellectual and Developmental Disabilities.

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2019). The contemporary view of intellectual and developmental disabilities: Implications for psychologists. *Psicothema*, 31(3), 223-

228. <https://doi.org/10.7334/psicothema2019.119>

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021a). Twenty questions and answers regarding the 12th edition of the AAIDD manual: Intellectual disability: definition, diagnosis, classification, and systems of supports. American Association on Intellectual and Developmental Disabilities.

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021b). Ongoing transformation in the field of intellectual and developmental disabilities: Taking action for future progress. *Intellectual and Developmental Disabilities*, 59(5), 380-391. <https://doi.org/10.1352/1934-9556-59.5.380>

Schalock, R. L., Thompson, J. R., & Tasse, M. J. (2018). A systematic approach to personal support plans. American Association on Intellectual and Developmental Disabilities.

Schmidt, W. C. (1997). World-wide web survey research: Benefits, potential problems, and solutions. *Behavior Research Methods, Instruments, & Computers*, 29(2), 274-279. <https://doi.org/10.3758/BF03204826>

Sen, A. F. (2015). Communication and human rights. *Procedia, Social and Behavioral Sciences*, 174, 2813-2817. <https://doi.org/10.1016/j.sbspro.2015.01.972>

- Sheeran, P. (2002). Intention-behavior relations: A conceptual and empirical review. *European Review of Social Psychology*, 12(1), 1-36. <https://doi.org/10.1080/14792772143000003>
- Sheerin, F., Fleming, S., May, P., McCallion, P., McCarron, M., Naseer, A., Lalor, G., & D'Eath, M. (2024). Challenges in care and service provision for older adults with intellectual disabilities and complex age-related conditions in Ireland. *British Journal of Learning Disabilities*, 1–12. <https://doi.org/10.1111/bld.12572>
- Shogren, K. A., Schalock, R. L., & Luckasson, R. (2018). The use of a context-based change model to unfreeze the status quo and drive valued outcomes. *Journal of Policy and Practice in Intellectual Disabilities*, 15(2), 101-109. <https://doi.org/10.1111/jppi.12233>
- Sigafoos, J., & Couzens, D. (1995). Teaching functional use of an eye gaze communication board to a child with multiple disabilities. *British Journal of Developmental Disabilities*, 41, 114–125.
- Sigafoos, J., O'Reilly, M. F., Lancioni, G. E., & Sutherland, D. (2014). Augmentative and alternative communication for individuals with autism spectrum disorder and intellectual disability. *Current Developmental Disorders Reports*, 1(2), 51-57. <https://doi.org/10.1007/s40474-013-0007-x>
- Sigafoos, J., Roche, L., & Tait, K. (2021). Challenges in providing AAC intervention to people with profound intellectual and multiple disabilities. In B. T. Ogletree (Ed.), *Augmentative and alternative communication: challenges and solutions*, (pp. 243-267). Plural Publishing, Inc.
- Sigafoos, J., van der Meer, L., Schlosser, R. W., Lancioni, G. E., O'Reilly, M. F., & Green, V. A. (2016). Augmentative and alternative communication (AAC) in

- intellectual and developmental disabilities. In J. K. Luiselli, & A. J. Fischer (Eds.), *Computer-Assisted and Web-Based Innovations in Psychology, Special Education, and Health*, (pp. 255-285). Academic Press.
- Sigafoos, J., Woodyatt, G., Keen, D., Tait, K., Tucker, M., Roberts-Pennell, D., & Pittendreigh, N. (2000). Identifying potential communicative acts in children with developmental and physical disabilities. *Communication Disorders Quarterly*, 21(2), 77-86. <https://doi.org/10.1177/152574010002100202>
- Simpson, K., Beukelman, D., & Bird, A. (1998). Survey of school speech and language service provision to students with severe communication impairments in Nebraska. *Augmentative and Alternative Communication*, 14(4), 212-221. <https://doi.org/10.1080/07434619812331278386>
- Siu, E., Tam, E., Sin, D., Ng, C., Lam, E., Chui, M., Fong, A., Lam, L., & Lam, C. (2010). A survey of augmentative and alternative communication service provision in Hong Kong. *Augmentative and Alternative Communication*, 26(4), 289-298. <https://doi.org/10.3109/07434618.2010.521894>
- Skotko, B. G., Koppenhaver, D. A., & Erickson, K. A. (2004). Parent reading behaviors and communication outcomes in girls with rett syndrome. *Exceptional Children*, 70(2), 145-166. <https://doi.org/10.1177/001440290407000202>
- Smith, M., Manduchi, B., Burke, É., Carroll, R., McCallion, P., & McCarron, M. (2020). Communication difficulties in adults with intellectual disability: Results from a national cross-sectional study. *Research in Developmental Disabilities*, 97, 103557-103557. <https://doi.org/10.1016/j.ridd.2019.103557>

- Sonnenmeier, R. M., McSheehan, M., & Jorgensen, C. M. (2005). A case study of team supports for a student with autism's communication and engagement within the general education curriculum: Preliminary report of the beyond access model. *Augmentative and Alternative Communication*, 21(2), 101-115. <https://doi.org/10.1080/07434610500103608>
- Soto, G. (1997). Special education teacher attitudes toward AAC: Preliminary survey. *Augmentative and Alternative Communication*, 13(3), 186-197. <https://doi.org/10.1080/07434619712331278008>
- Soto, G., Müller, E., Hunt, P., & Goetz, L. (2001). Critical issues in the inclusion of students who use augmentative and alternative communication: An educational team perspective. *Augmentative and Alternative Communication*, 17(2), 62-72. <https://doi.org/10.1080/714043369>
- Stahl, N. A., & King, J. R. (2020). Expanding approaches for research: Understanding and using trustworthiness in qualitative research. *Journal of Developmental Education*, 44(1), 26–28. <http://www.jstor.org/stable/45381095>
- Stancliffe, R. J. (1995). Assessing opportunities for choice-making: a comparison of self- and staff reports. *American Journal of Mental Retardation: AJMR*, 99(4), 418-429.
- Stancliffe, R. J., Arnold, S. R. C., & Riches, V. C. (2016). The supports paradigm. In R. L. Schalock & K. D. Keith (Eds.), *Cross-cultural quality of life: Enhancing the lives of persons with intellectual disability*, (pp. 133-142). American Association on Intellectual and Developmental Disabilities.
- Stern, C., Lizarondo, L., Carrier, J., Godfrey, C., Rieger, K., Salmond, S., Apóstolo, J., Kirkpatrick, P., & Loveday, H. (2020). Methodological guidance for the

- conduct of mixed methods systematic reviews. *JBISIRIR-D-19-00169 synthesis*, 18(10), 2108–2118. <https://doi.org/10.11124/JBISIRIR-D-19-00169>
- Stillman, R., & Siegel-Causey, E. (1989). Introduction to nonsymbolic communication. In E. Siegel-Causey & D. Guess (Eds.), *Enhancing nonsymbolic communication interactions among learners with severe disabilities*, (pp. 1-12). Brookes.
- Stoner, J. B., Beck, A. R., Bock, S. J., Hickey, K., Kosuwan, K., & Thompson, J. R. (2006). The effectiveness of the picture exchange communication system with nonspeaking adults. *Remedial and Special Education*, 27(3), 154-165. <https://doi.org/10.1177/07419325060270030401>
- Sutherland, D. E., Gillon, G. G., & Yoder, D. E. (2005). AAC use and service provision: A survey of New Zealand speech-language therapists. *Augmentative and Alternative Communication*, 21(4), 295-307. <https://doi.org/10.1080/07434610500103483>
- Sutherland, D., van der Meer, L., Sigafoos, J., Mirfin-Veitch, B., Milner, P., O'Reilly, M. F., Lancioni, G. E., & Marschik, P. B. (2014). Survey of AAC needs for adults with intellectual disability in New Zealand. *Journal of Developmental and Physical Disabilities*, 26(1), 115-122. <https://doi.org/10.1007/s10882-013-9347-z>
- Tangen, R. (2008). Listening to children's voices in educational research: Some theoretical and methodological problems. *European Journal of Special Needs Education*, 23(2), 157-166. <https://doi.org/10.1080/08856250801945956>
- Taylor, S., & Todd, P. (1995a). Assessing IT usage: The role of prior experience. *MIS Quarterly*, 19(4), 561-570. <https://doi.org/10.2307/249633>

- Taylor, S., & Todd, P. A. (1995b). Understanding information technology usage: A test of competing models. *Information Systems Research*, 6(2), 144-176. <https://doi.org/10.1287/isre.6.2.144>
- Teo, T. (2012). Examining the intention to use technology among pre-service teachers: An integration of the technology acceptance model and theory of planned behavior. *Interactive Learning Environments*, 20(1), 3-18. <https://doi.org/10.1080/10494821003714632>
- The Joanna Briggs Institute (2014) Joanna Briggs Institute reviewers' manual: 2014 edition / supplement methodology for JBI mixed methods systematic reviews. Adelaide, Australia.
- The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. (1995). *Social science & medicine* (1982), 41(10), 1403–1409. [https://doi.org/10.1016/0277-9536\(95\)00112-k](https://doi.org/10.1016/0277-9536(95)00112-k)
- Thomas, A., Lubarsky, S., Varpio, L., Durning, S. J., & Young, M. E. (2020). Scoping reviews in health professions education: Challenges, considerations and lessons learned about epistemology and methodology. *Advances in Health Sciences Education: Theory and Practice*, 25(4), 989-1002. <https://doi.org/10.1007/s10459-019-09932-2>
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45-45. <https://doi.org/10.1186/1471-2288-8-45>
- Thompson, J. R., Schalock, R. L., Agosta, J., Teninty, L., & Fortune, J. (2014). How the supports paradigm is transforming the developmental disabilities service

- system. *Inclusion (Washington, D.C.)*, 2(2), 86-99. <https://doi.org/10.1352/2326-6988-2.2.86>
- Tomasello, M. (2001). Perceiving intentions and learning words in the second year of life. *Language acquisition and conceptual development*. Cambridge University Press.
- United Nations. (2019). *Disability Inclusion Strategy*. [UN Disability Inclusion Strategy](#)
- United Nations. (1948). *Universal declaration of human rights*.
<http://www.un.org/en/universal-declaration-human-rights/>
- United Nations. (2006). *Convention on the rights of persons with disabilities*.
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- United Nations. (2015). *Sustainable developmental goals, goal 10: reduce inequality within and among countries*. [Reduce inequality within and among countries - United Nations Sustainable Development](#)
- Uthoff, S. A. K., Zinkevich, A., Boenisch, J., Sachse, S. K., Bernasconi, T., & Ansmann, L. (2021). Collaboration between stakeholders involved in augmentative and alternative communication (AAC) care of people without natural speech. *Journal of Interprofessional Care*, 35(6), 821-831. <https://doi.org/10.1080/13561820.2020.1860918>
- van der Gaag, A. (1989). The view from Walter's window: social environment and the communicative competence of adults with a mental handicap. *Journal of Intellectual Disability Research*, 33(3): 221-227.
<https://doi.org/10.1111/j.1365-2788.1989.tb01469.x>

- van der Gaag, A. (1998). Communication skills and adults with learning disabilities: eliminating professional myopia. *British Journal of Learning Disabilities*, 26, 88-93. <https://doi.org/10.1111/j.1468-3156.1998.tb00057.x>
- van der Meer, L., Matthews, T., Ogilvie, E., Berry, A., Waddington, H., Balandin, S., O'Reilly, M., F., Lancioni, G., & Sigafoos, J. (2017). Training direct-care staff to provide communication intervention to adults with intellectual disability: A systematic review. *American Journal of Speech - Language Pathology (Online)*, 26(4), 1279-1295. https://doi.org/10.1044/2017_AJSLP-16-0125
- Van Mol, C. (2017). Improving web survey efficiency: The impact of an extra reminder and reminder content on web survey response. *International Journal of Social Research Methodology*, 20(4), 317-327. <https://doi.org/10.1080/13645579.2016.1185255>
- van Splunder, J., Stilma, J. S., Bernsen, R. M. D., & Evenhuis, H. M. (2006). Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: Cross-sectional study. *Eye (London)*, 20(9), 1004-1010. <https://doi.org/10.1038/sj.eye.6702059>
- Venkatesh, V., Morris, M. G., Davis, G. B., & Davis, F. D. (2003). User acceptance of information technology: Toward a unified view. *MIS Quarterly*, 27(3), 425-478. <https://doi.org/10.2307/30036540>
- Venkatesh, V., Thong, J. Y. L., & Xu, X. (2012). Consumer acceptance and use of information technology: Extending the unified theory of acceptance and use of technology. *MIS Quarterly*, 36(1), 157-178. <https://doi.org/10.2307/41410412>

- Verdugo, M. A., Navas, P., Gómez, L. E., & Schalock, R. L. (2012). The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, 56(11), 1036-1045. <https://doi.org/10.1111/j.1365-2788.2012.01585.x>
- Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research*, 49(10), 707-717. <https://doi.org/10.1111/j.1365-2788.2005.00739.x>
- Vos, P., De Cock, P., Petry, K., Van Den Noortgate, W., & Maes, B. (2013). Investigating the relationship between observed mood and emotions in people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research*, 57(5), 440-451. <https://doi.org/10.1111/jir.12021>
- Wager, E., & Wiffen, P. J. (2011). Ethical issues in preparing and publishing systematic reviews. *Journal of Evidence-Based Medicine*, 4(2), 130-134. <https://doi.org/10.1111/j.1756-5391.2011.01122.x>
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>
- Wilder, J., & Granlund, M. (2003). Behaviour style and interaction between seven children with multiple disabilities and their caregivers. *Child: Care, Health & Development*, 29(6), 559-567. <https://doi.org/10.1046/j.1365-2214.2003.00377.x>
- Wilder, J., Magnusson, L., & Hanson, E. (2015). Professionals' and parents' shared learning in blended learning networks related to communication and

- augmentative and alternative communication for people with severe disabilities. *European Journal of Special Needs Education*, 30(3), 367-383. <https://doi.org/10.1080/08856257.2015.1023002>
- Williams, B. (2000). More than an exception to the rule. In M. Fried-Oken & H. Bersani (Eds.), *Speaking up and spelling it out*, (pp.245-254). Paul H. Brookes.
- Williams, M. B., Krezman, C., & McNaughton, D. (2008). "Reach for the stars": Five principles for the next 25 years of AAC. *Augmentative and Alternative Communication*, 24(3), 194-206. <https://doi.org/10.1080/08990220802387851>
- Wood, S., & Standen, P. (2021). Is speech and language therapy effective at improving the communication of adults with intellectual disabilities?: A systematic review. *International Journal of Language & Communication Disorders*, 56(2), 435-450. <https://doi.org/10.1111/1460-6984.12601>
- World Health Organisation. (2023a). *Implementing the UN Disability Inclusion Strategy*. [Implementing the UN Disability Inclusion Strategy \(who.int\)](https://www.who.int/publications-detail/Implementing-the-UN-Disability-Inclusion-Strategy)
- World Health Organization. (2022). *ICD-11 for Mortality and Morbidity Statistics*. <https://icd.who.int/browse11/l-m/en#/http%253a%252f%252fid.who.int%252fid%252fentity%252f605267007>
- Wormnæs, S., & Abdel Malek, Y. (2004). Egyptian speech therapists want more knowledge about augmentative and alternative communication. *Augmentative and Alternative Communication*, 20(1), 30-41. <https://doi.org/10.1080/07434610310001629571>

Yusoff, R., & Mohd Janor, R. (2014). Generation of an interval metric scale to measure attitude. *SAGE Open*, 4(1), 215824401351676. <https://doi.org/10.1177/2158244013516768>

List of Appendices

Appendix 1 PhD Achievements

Achievement	Title	Date	Source
Oral Presentation at the School of Nursing and Midwifery's 20th Annual Research Conference: International Year of the Nurse and Midwife: Responding to Crisis, University College Cork	Communication partners' experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review	2020	841325b3d58b43ee89ee42c5b32326a2 (msecnd.net)
Oral Presentation at the International Association for the Scientific Study of Intellectual and Developmental Disabilities: Special Interest Research Group-Profound Intellectual and Multiple Disabilities 2022 Virtual International Conference Series	Communicating with persons with severe/profound intellectual disability through augmentative and alternative communication: Acknowledgement of family members roles and responsibilities	2022	Virtual Conference 2022 – March - IASSIDD
Published Paper, Journal of Intellectual Disabilities	Communication partners' experiences of	2022	Communication partners experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods

	communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review		systematic review - Edina Hanley, Anne-Marie Martin, Caroline Dalton, Elaine Lehane, 2023 (sagepub.com)
Oral Presentation at the International Association for the Scientific Study of Intellectual and Developmental Disabilities: Early Career Research Meeting of the Special Interest Research Group- Profound Intellectual and Multiple Disabilities 2023	Factors influencing communication partners' use of augmentative and alternative communication with persons with severe/profound intellectual disability: An integrative review	2023	Not yet available
Poster Presentation at the School of Nursing and Midwifery's Annual Research Conference: Nurses and Midwives: Impacting on a Healthy and Sustainable Future, University College Cork	Factors influencing communication partners' use of augmentative and alternative communication with persons with severe/profound intellectual disability: An integrative review	2023	https://x.com/edina_hanley/status/1641828944985960450?s=46
Poster Presentation at Shaping the Future of Intellectual Disability Nursing in	Communication partners' perceptions of their roles and	2023	https://x.com/am_martin_/status/1661367308265172994?s=46

Ireland Conference	responsibilities in the design, planning and use of augmentative and alternative communication with persons with severe/profound intellectual disability		
Awarded Outstanding Peer of the Year 2023 at the College of Medicine and Health, University College Cork, Bright Futures Event	Outstanding Peer of the Year	2023	Postgraduate Research Student Awards 2023 University College Cork (ucc.ie)

Appendix 2 Communication partners' experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review

Review Paper



Communication partners experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review

Journal of Intellectual Disabilities
2023, Vol. 27(4) 1107–1134
© The Author(s) 2022



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/17446295221115914
journals.sagepub.com/home/jid



Edina Hanley
University College Cork, Cork, Ireland

Caroline Dalton
University College Cork, Cork, Ireland

Anne-Marie Martin
University College Cork, Cork, Ireland

Elaine Lehane
University College Cork, Cork, Ireland

Abstract

People with severe/profound intellectual disability experience challenges in communicating and require their communication partners to adapt to their means of communication. Augmentative and Alternative Communication (AAC) is recognised as a potential means to meet their communication needs. Interventions need to be aimed at both the individual and their communication partners. We conducted a mixed methods systematic review of the literature to synthesise evidence on communication partners experience of communicating with adults with severe/profound intellectual disability through AAC. Eight publications met the inclusion criteria, they underwent thematic synthesis where four themes emerged. A shared commitment to communication partnership is fundamental for the effective and efficient use of AAC. However, there was a disconnect between communication partners perceptions of their roles and responsibilities. This review prompts further research to explore communication partners perceptions of their roles and responsibilities in the use of AAC with people with severe/profound intellectual disabilities.

Keywords

augmentative and alternative communication, communication, communication partners, severe/profound intellectual disability

Corresponding author:

Edina Hanley, School of Nursing and Midwifery, University College Cork National University of Ireland, College Road, Cork, Ireland. T12 AK54.
Email: edinahanley@gmail.com

Introduction

Communication is a basic human need and human right (Williams, 2000). Communicating effectively is a fundamental life skill (Fulya Sen, 2015) central to most life activities and impacts the quality of life (QoL) of individuals (Bennett et al., 2016). Powell (2008) describes communication as a complex process that involves the interaction of the cognitive-linguistic and motor systems. Similarly, Friedman and McNamara (2018) describe communication as “a series of complex and fluid interactions” (p.111) inclusive of, but not limited to the use and understanding of facial expressions, body language, gestures, reading, writing, speaking and listening.

The terminology and definition of intellectual disability has evolved over time (Brady et al., 2016). These changes represent the move from a medical oriented approach to disability, to a more person-centred perspective, focusing on the individual and their interaction with their environment (Brady et al., 2016). There is agreement that intellectual disability is characterised by substantial limitations in intellectual functioning and adaptive behaviour originating during the developmental stage (ICD-11, 2022; Schalock et al., 2021a). The 11th edition of the International Classification of Disease definition of intellectual disability was used and should be taken to include all individuals with severe/profound intellectual disability, including those with profound intellectual and multiple disability, which is a term used to describe persons with severe to profound intellectual disability as well as substantial physical impairment (Lyle, 2019; Nakken and Vlaskamp, 2007). Individuals with severe/profound intellectual disability experience significant communication difficulties (van Der Gaag, 1998) which can impact their wellbeing and QoL and tend to communicate at the earlier developmental stages. Therefore, strategies must be provided to ensure their communication needs are met. The focus of this review is on individuals who communicate at earlier developmental stages. Therefore, persons with severe/profound intellectual disability and persons with profound intellectual and multiple disability were included. Terms such as profound intellectual and multiple disabilities, severe/profound intellectual and multiple disabilities and complex disabilities are used in the literature. For accuracy and to remain true to the original work, the terminology of cited authors is being used in this review.

Individuals with severe/profound intellectual and/or multiple disability tend to function at pre-intentional communication stage and may experience sensory and physical disabilities and health issues (Coupe O’Kane and Goldbart, 1998; Erickson and Quick, 2017; Sigafos et al., 2021; van Splunder et al., 2006). Expressive communication tends to involve a range of subtle and idiosyncratic behaviours that may be individual to the person or context (Stillman and Siegel-Causey, 1989) such as eye gaze, body language and movements, changes in muscle tone, facial expressions, vocalisation (Brady et al., 2016; Coupe O’Kane and Goldbart, 1998; Parry Hughes et al., 2011; Petry and Maes, 2006). Their communication attempts can go unnoticed (Munde and Vlaskamp, 2015; Wilder and Granlund, 2003) or may be misunderstood (Grove et al., 1999). It is difficult to place meaning on an individual’s communicative behaviour, especially when these are idiosyncratic and therefore, communication breakdowns are common (Keen, 2014; Sigafos et al., 2021). Efforts must be taken to ensure an individual’s communication attempts are recognised and understood.

Communication partners need to be sensitive to individuals with severe/profound intellectual disability subtle behaviours to interpret these behaviours and respond, thus facilitating a two-way process of communicating (Coupe O’Kane and Goldbart, 1998). In the context of this review, communication partners include persons who have social relationships with AAC users (e.g., parents, siblings) and educational or care relationships with AAC users (e.g., teachers, health care professionals, residential staff members) (Kent-Walsh and McNaughton, 2005). Communication partners have a fundamental role in assessing adults with severe/profound intellectual disability.

They observe and interact with the person over an extended time and across different environments. Such experiences enable them to share their knowledge of the person's abilities (Cascella, 2004). Acknowledgement that all people can communicate creates a sense of responsibility for everyone who interacts with persons with severe/profound intellectual disability to recognise and enhance the individual's communication methods and opportunities (Brady et al., 2016).

The right of people with intellectual disability to have a means to communicate is recognised internationally (United Nations (UN), 2006). Augmentative and Alternative Communication (AAC) is recognised as one method of facilitating and supporting communication with persons with complex communication needs (Beukelman and Light, 2020). AAC is defined as *"an area of clinical practice that addresses the needs of individuals with significant and complex communication disorders characterized by impairments in speech-language production and/or comprehension, including spoken and written modes of communication"* (ASHA, 2019). Typically, forms of AAC are divided into unaided and aided forms of communication. Unaided communication includes gestures, facial expression, eye gaze, body postures and signs (Pino, 2014). Aided forms of communication include approaches which require some form of external support including physical objects or equipment such as symbol charts or books; it also refers to computer-based systems or Voice Output Communication Aids (VOCAs) (Pino, 2014). The goal of AAC intervention is to empower individuals to engage and participate in a variety of interactions and activities of their choice (Beukelman and Mirenda, 2005). However, learning to communicate through AAC is a complex process for both the AAC user (Bailey et al., 2006; Rackensperger et al., 2005) and their communication partners.

Given the complex communication needs of individuals with profound intellectual and multiple disability, it can be challenging to provide effective AAC interventions (Sigafoos et al., 2021). The four components of communicative competence for AAC users include linguistic, operational, social and strategic competence (Light, 1989; Light et al., 2003). Individuals who require AAC need support from their communication partners for successful communication as communication competence relies on both the AAC user and factors related to their communication partners and environment (Blackstone et al., 2007). Individuals are likely to interact with a range of communication partners, who have various roles in their lives (Kent-Walsh and McNaughton, 2005). Therefore, successful communication through AAC depends on both the individual and their communication partners using the AAC (Kent-Walsh et al., 2015). However, communication partners approach to communication may negatively impact upon AAC use. For example, communication partners have been found to control interactions, ask close ended questions, provide little opportunities for AAC users to start conversations or to respond and often interrupt the AAC users' utterances (Blackstone, 1999; Light et al., 1985). In addition, and more generally, Bradshaw (2001) discusses how communication partners may overestimate their use of nonverbal communication and underestimate their use of verbal communication. Therefore, they may not adapt their communication to the individual's understanding (Bradshaw, 2001). Attitudinal barriers where people presume individuals with complex communication needs cannot learn to use AAC also pose as challenges to successful AAC provision and use (Sigafoos et al., 2021). In addition, several studies have reported unmet needs of persons with intellectual disability and complex communication in relation to AAC provision (Siu et al., 2010; Sutherland et al., 2005; Sutherland et al., 2014). The absence of AAC for this population may be due to a possible lack of awareness or training (Sigafoos et al., 2021) and lack of access to professionals with expertise in AAC (Siu et al., 2010; Sutherland et al., 2005; Sutherland et al., 2014).

Professionals must be mindful of the impact of AAC on both the user and their communication partners. The introduction of AAC impacts both the AAC user and their family (Angelo, 1997;

Parette and Angelo, 1996; 1998). Therefore, professionals need to understand the affect AAC has on the family members (Angelo, 2000). More than half of families in a study by Angelo (2000) reported improvements in their child's QoL, communication and independence. Communication partners have expressed frustration towards AAC device malfunctions (McCord and Soto, 2004; Kulkarni and Parmar, 2017) and difficulty understanding the AAC system (McCall et al., 1997). Despite these findings, it has been found that AAC has the potential to support individuals' complex communication needs (Beukelman and Mirenda, 2005). With encouragement, support, instruction and practice AAC users can transition from AAC novices to competent AAC communicators (Beukelman and Mirenda, 2005). Similarly, individuals with profound intellectual and multiple disability may develop intentional or functional communication skills when an AAC mode is suitably developed with a systematic instructional program that is well designed (Reichle et al., 1991).

Internationally, The United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) provides a framework to promote, protect and ensure the rights of all people with a disability and encourages equal rights in all parts of life. The United Nations Convention on the Rights of Persons with Disabilities advocates accepting and facilitating the use of AAC. However, people with severe/profound intellectual disability continue to have unmet communication support needs (Brady et al., 2016). Changes in policy, legislation and regulation have transformed the approach to services for individuals with intellectual disability. People with severe/profound intellectual disability are more present and visible today than they were ever before (Brady et al., 2016) and the increase in the population of adults with an intellectual disability is expected to have an impact on the need for services and supports (Oulette-Kuntz et al., 2016). In addition, individuals with complex communication needs and their families have greater expectations to take part in a range of environments (Light et al., 2019). Increased expectations have led to a greater demand for access to AAC. To meet these individuals' variety of needs, service providers must consider new AAC supports, improved skill instruction and partner supports (Light and McNaughton, 2014; Light et al., 2019).

Given the potential of AAC to meet individuals with severe/profound intellectual disability complex communication needs, the challenges to successful AAC use and the significant role of communication partners in successful AAC provision and use, there is a need to explore communication partners experiences of using AAC with adults with severe/profound intellectual disability. The aim of this review was to explore communication partners' experience of communicating with adults with severe/profound intellectual disability through AAC with a view to identifying potential barriers and facilitators to successful AAC use. Such knowledge may be of value when planning AAC support for persons with severe/profound intellectual disability and implementing AAC with them and their communication partners.

Methods

Protocol and Registration

A review protocol was developed by the authors. However, it was not published.

Design

The Joanna Briggs Institute (JBI) guidelines for mixed methods systematic reviews (MMSR) were followed. MMSR combine the findings of effectiveness from quantitative research and participants'

Parette and Angelo, 1996; 1998). Therefore, professionals need to understand the affect AAC has on the family members (Angelo, 2000). More than half of families in a study by Angelo (2000) reported improvements in their child's QoL, communication and independence. Communication partners have expressed frustration towards AAC device malfunctions (McCord and Soto, 2004; Kulkarni and Parmar, 2017) and difficulty understanding the AAC system (McCall et al., 1997). Despite these findings, it has been found that AAC has the potential to support individuals' complex communication needs (Beukelman and Mirenda, 2005). With encouragement, support, instruction and practice AAC users can transition from AAC novices to competent AAC communicators (Beukelman and Mirenda, 2005). Similarly, individuals with profound intellectual and multiple disability may develop intentional or functional communication skills when an AAC mode is suitably developed with a systematic instructional program that is well designed (Reichle et al., 1991).

Internationally, The United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) provides a framework to promote, protect and ensure the rights of all people with a disability and encourages equal rights in all parts of life. The United Nations Convention on the Rights of Persons with Disabilities advocates accepting and facilitating the use of AAC. However, people with severe/profound intellectual disability continue to have unmet communication support needs (Brady et al., 2016). Changes in policy, legislation and regulation have transformed the approach to services for individuals with intellectual disability. People with severe/profound intellectual disability are more present and visible today than they were ever before (Brady et al., 2016) and the increase in the population of adults with an intellectual disability is expected to have an impact on the need for services and supports (Oulette-Kuntz et al., 2016). In addition, individuals with complex communication needs and their families have greater expectations to take part in a range of environments (Light et al., 2019). Increased expectations have led to a greater demand for access to AAC. To meet these individuals' variety of needs, service providers must consider new AAC supports, improved skill instruction and partner supports (Light and McNaughton, 2014; Light et al., 2019).

Given the potential of AAC to meet individuals with severe/profound intellectual disability complex communication needs, the challenges to successful AAC use and the significant role of communication partners in successful AAC provision and use, there is a need to explore communication partners experiences of using AAC with adults with severe/profound intellectual disability. The aim of this review was to explore communication partners' experience of communicating with adults with severe/profound intellectual disability through AAC with a view to identifying potential barriers and facilitators to successful AAC use. Such knowledge may be of value when planning AAC support for persons with severe/profound intellectual disability and implementing AAC with them and their communication partners.

Methods

Protocol and Registration

A review protocol was developed by the authors. However, it was not published.

Design

The Joanna Briggs Institute (JBI) guidelines for mixed methods systematic reviews (MMSR) were followed. MMSR combine the findings of effectiveness from quantitative research and participants'

experiences from qualitative research to increase the helpfulness of findings for decision makers (Bressan et al., 2016). Both perspectives are increasingly required to inform clinical, policy or organizational decisions (Lizorando et al., 2020). The universal steps of undertaking a systematic review apply to MMSR (Lizorando et al., 2020). However, there are differences in combining and integrating data. This MMSR followed a convergent integrated approach in keeping with the JBI methodology for MMSR. Specifically, this approach is a process of combining the data that was extracted from quantitative, qualitative and mixed methods studies. Data transformation was required to allow for the integration of qualitative and quantitative data.

Search strategy

A preliminary scoping search was undertaken with a specialist health sciences librarian. Databases were then selected based on the 'fit' with the topic area and return of relevant results.

In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) (Moher et al., 2009), a literature search of seven databases was conducted including CINAHL, Scopus, Academic Search Complete, PubMed, ERIC, Cochrane, and Linguistics Collection in January 2020 and reviewed again in January 2021. No new literature was identified. These databases are comprehensive for health, social care and education; areas of practice commonly supporting people with intellectual disability. English language was the only database filter applied. As per PRISMA (2009) guidelines one full electronic search strategy has been presented in this review (Supplementary Table 1).

The following key concepts were searched and combined: search terms referring to severe/profound intellectual disability (i.e. "Severe intellectual disability*" OR "Severe learning disability*" OR "severe mental retard*" OR "severe developmental disability*" OR "profound intellectual disability*" OR "profound mental retard*" OR "profound developmental disability*" OR "profound learning disability*" OR "pervasive intellectual disability*" OR "pervasive mental retard*" OR "pervasive developmental disability*" OR "pervasive learning disability*") were combined with search terms referring to AAC (i.e. "Augmentative and alternative communication" OR "AAC") which were combined with search terms referring to communication partners (i.e. Caregivers OR "communication partners" OR "family members" OR friends OR "support staff" OR teachers). The PICO (Population, Interest, Context) framework was used to refine the search concepts and parameters - "What are communication partners (Population) experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication (Interest) in community settings, day services, acute care settings, school, home settings in all countries (Context)?"

The inclusion of the key concept relating to caregivers resulted in a limited number of hits in CINAHL and Academic Search Complete. Therefore, a second search was completed in these databases without that search string to identify potential literature relevant to this topic.

Study Selection

Through database searching, 474 records were identified. A further 13 relevant records were identified through searching reference lists of included studies. All identified citations were transferred into EndNote and duplicates removed (n=12). Titles and abstracts of 475 records were screened by two independent reviewers for assessment against the inclusion and exclusion criteria (Table 2) with 376 records excluded.

Table 2. Inclusion and Exclusion Criteria**Inclusion Criteria****Population:**

Communication partners of adults who have severe/profound intellectual disability.

Communication partners must be 18 years or older.

Communication partners included either paid or unpaid partners.

Individuals with severe/profound intellectual disability may also have multiple disability. Therefore, adults with profound/multiple intellectual disability were also included.

No restrictions were placed on ethnicity or gender.

Phenomenon of Interest:

Studies that explored communication partners experiences of communicating with adults with severe/profound intellectual disability through Augmentative and Alternative Communication.

Context:

Studies that investigated communication partners of adults with severe/profound intellectual disability using AAC in community services, school, home settings, acute care settings, day services, during their day-to-day lives.

Types of studies:

Quantitative, qualitative and mixed methods studies.

Studies were only considered when the data relating to communication partners of adults with severe/profound intellectual disability could be clearly extracted.

Exclusion Criteria:

The person with whom the communication partner is communicating with does not have severe/profound intellectual disability.

The person with severe/profound intellectual disability or profound/multiple intellectual disability is not over the age of 18.

Communication is not supported by AAC.

The full text of the remaining 99 articles were assessed for eligibility. Eight of these 99 articles met the inclusion criteria. The rationale for excluding 91 full-text records is detailed in the PRISMA Flow diagram (Figure 1). Any disagreements that arose between the authors were settled through discussion.

The studies that met the inclusion criteria were assessed for methodological quality using the Mixed Methods Appraisal Tool version 2018 (MMAT; Hong et al., 2018). The MMAT includes a total of 25 criteria and 2 screening questions. The MMAT was developed to appraise qualitative research, randomized control trials, non-randomized control trials, quantitative descriptive studies and mixed methods studies. The scoring system was removed from the 2018 version of the MMAT as it is advised to provide a more detailed presentation of the ratings of each criterion (Hong et al., 2018). Exclusion of papers with low methodological quality is not encouraged. Therefore, before screening, the authors agreed that all studies regardless of the results of their methodological quality would undergo extraction and synthesis. The MMAT was applied by the authors (EH, AMM, CD, EL). Any disagreements were discussed as a group. To improve the transparency in reporting the appraisal process, a summary of the MMAT results is included (can be seen in Supplementary Table 3).

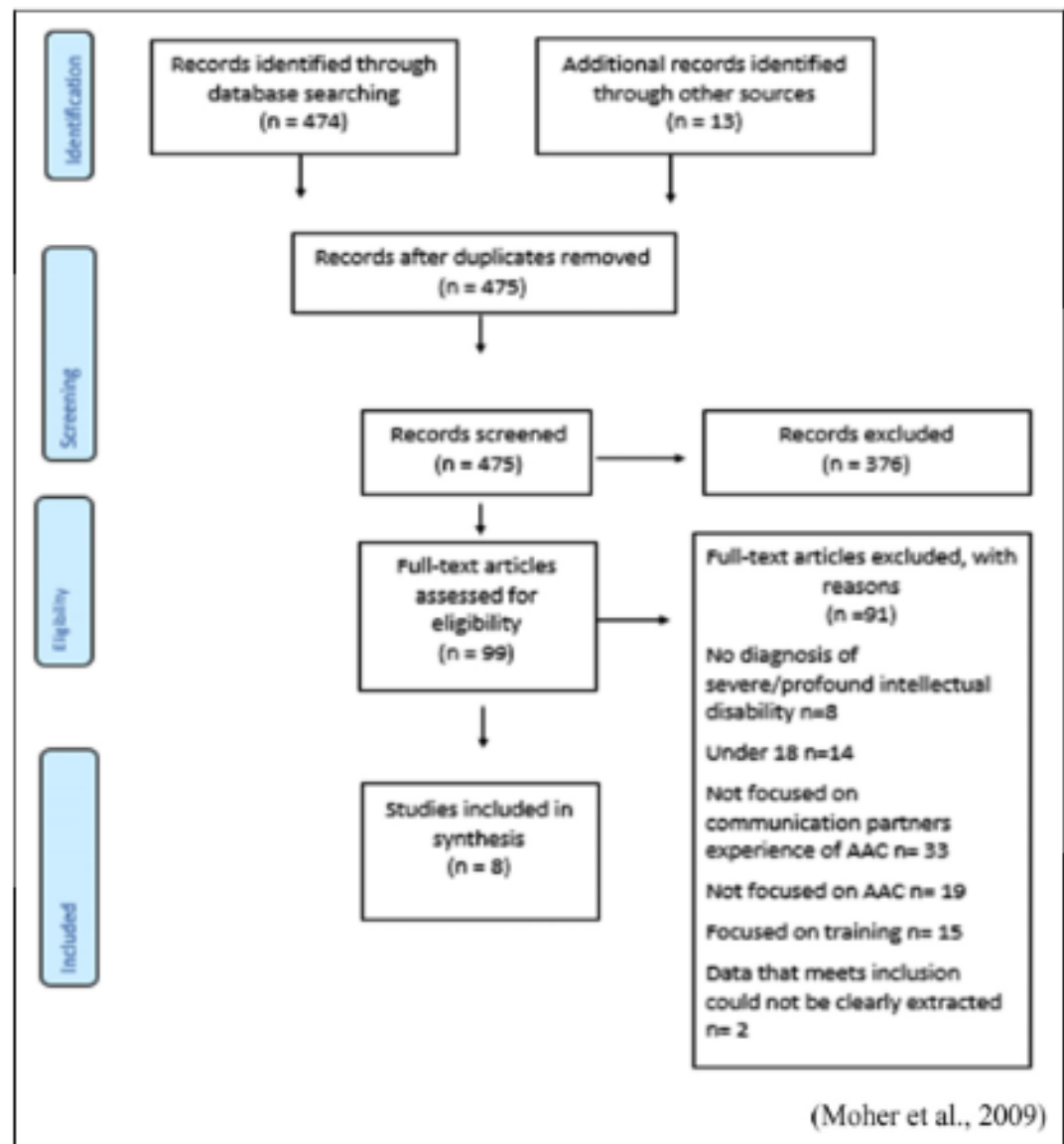


Figure 1. PRISMA Flow Diagram

Data Extraction

Data were extracted by the authors (EH, AMM, CD, EL). The data extraction was reviewed at a meeting with any disagreements discussed until they were resolved. The following information was extracted from all studies and documented in the data extraction form which included: (i) author, year, country (ii) research aim (iii) research approach and design (iv) sample approach, size, eligibility and setting (v) data collection methods (vi) data analyses (vii) key findings and conclusions (Table 4). Where studies collected data from communication partners of both adults and children, only data from the communication partners of adults were extracted.

Table 4. Summary of Data Extraction

Author, Year, Country	Research question or study aim	1. Research Approach 2. Design	1. Sample Approach 2. Sites 3. Eligibility 4. Setting	Data collection methods	Data Analysis	Key findings and conclusion
1. Rombouts E, Maas B and Zink J 2017 Belgium	Compare the views of direct support staff and SLTs who work with adults with intellectual disability of AAC	1. Qualitative 2. Comparative study	1. Non-probability Convenience 2. n=23 (9 SLTs, 1 OT, 15 direct support staff; 10 services in total) 3. All professionals were supporting at least one adult with a mild-severe intellectual disability who used AAC to communicate 4. Residential and day-care services	One-to-one Interviews with a flexible question sequence	Thematic analysis	1) SLTs believed that most clients would benefit from consistent use of KWS, direct support staff decided on AAC usage in the moment. 2) Both SLTs and direct support staff believed staff should encourage clients to use AAC, support staff's responsibility to maintain their clients' KWS skills. There was a contrast in these values and the AAC use. 3) Support staff used AAC less well. Restricted AAC use led to communication partners making assumptions about the message the client was communicating. 4) Time as a barrier. 5) SLTs and support staff have expertise in supporting individuals' communication.

(continued)

Table 4. (continued)

Author, Year, Country	Research question or study aim	1. Research Approach 2. Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key findings and conclusion
2. Rombouts E, Maas B and Zink I 2016 Belgium	To examine the relation between key word signing attitudes and usage in support staff	1. Quantitative 2. Comparative, Correlational Design	1. Nonprobability Convenience 2. n=24 3. 12 adults with an intellectual disability were recruited with two communication partners, A SLT or special educationalist who had completed the official KWS training program and a direct support staff with second hand KWS training 4. Group homes	Each service user was filmed during a dyadic interaction with their communication partners A survey to measure professionals' attitude towards KWS along with a single category Implicit Association Test (AT)	Conversational analysis To determine which items scores could be added to find a scaled score, the interitem relations were explored using PCA on 234 pilot surveys Welch t tests to compare the three scaled scores between IHT and 2HT Independent samples t test analysed the between-group difference in implicit attitude scores Difference in proportion of signed utterances in ANCOVA was conducted Correlational measures investigated the relation between attitude and sign production	(1) All communication partners from IHT and 2HT scored higher than four on all three scales (performance scale, effort scale, intention scale), suggesting that each communication partner had positive explicit attitudes. (2) Those with a more positive implicit attitude produced more signed utterances. There was no relation between explicit attitude and the number of signed utterances. (3) Training did not have a significant effect on signed utterances and KWS experience. Communication partners from IHT did produce more KWS because they knew more sign.

(continued)

Table 4. (continued)

Author, Year, Country	Research question or study aim	1. Research Approach 2. Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key findings and conclusion
3. Maerls K, Maes B and Zink J 2014 Belgium	How many Residential Programs and Day Care Programs for adults with Intellectual disability in Flanders use KWS with one or more clients? How many clients in these programs use KWS? How many signs do the clients using KWS comprehend and produce? What is the relationship between different characteristics of support staff, clients and service providers and the sign knowledge of the support staff and their clients?	1. Quantitative 2. Descriptive, comparative, correlation design	1. Non-probability Convenience 2. n=93 3. Provide services for adults with an intellectual disability 4. Residential and day care programs for adults with Intellectual disability in Flanders (Dutch speaking part of Belgium)	A telephone survey and written questionnaire	Descriptive statistics Mann-Whitney U tests used for categorical predictors Kruskal-Wallis H tests used to assess group differences with a continued outcome variable Chi-square tests used for categorical outcome variables FET was used if expected cell counts in a 2x2 table were fewer than 5 Spearman's correlation (r_s) for continuous predictors with a continuous or binary categorical outcome variable	1. Support staff were estimated to understand and produce fewer signs when their clients had a more severe Intellectual disability. The more severe their Intellectual disability the fewer signs the clients understood and produced. 2. Support staff produced more signs when an SLT taught them KWS as opposed to a support worker. 3. 0.0% of participants had a negative attitude towards KWS. 5. Staff attitude was more likely to be positive when KWS taught by a support worker over an SLT.

(continued)

Table 4. (continued)

Author, Year, Country	Research question or study aim	1. Research Approach 2. Design	1. Sample Approach 2. Size 3. Eligibility 4. Setting	Data collection methods	Data Analyses	Key findings and conclusion
4. Wilder J, Magnusson L and Hansson E 2015 Sweden	To discover professionals and parent's views and experiences who took part in online BLNs related to communication and AAC for persons with severe disability Explore the role of BLNs as a way of facilitating participation, exchanging knowledge and learning between parents and professionals of persons with severe disability	1. Qualitative 2. Educational intervention study and evaluation	1. Non-probability Purposeful 2. n=36 (15 parents; 13 mothers and 2 fathers of children/adolescents with profound and multiple intellectual disability) 2.1 professionals comprised of 20 females and 1 male 3. Working as a professional was a requirement Parents of a child or adolescent with profound multiple intellectual disability 4. Swedish Family Care Competence Centre	Four groups participated in four discussion sessions and an evaluation session	Thematic analysis	1. Parents and professionals involved with these individuals' viewed communication and interaction with persons with severe disability from an 'interactional approach'. 2. Important that person with intellectual disability is surrounded by supportive people and environment. 3. They recognise that individuals with severe disability are always communicating and interacting and communication is a human right. 4. There was a focus on new technology, mainly iPads and apps. An iPad is easy to use and portable, universal design discussed by all groups. 1. Staff had low confidence in using Makaton, both before the intervention started, and throughout the duration of the STARS project. Some staff had not used Makaton in previous roles or were unsure of specific Makaton signs. 2. Staff increased their use of objects of reference. 3. Training and ongoing support offered to staff during the STARS project did not result in a regular communication environment.
5. Patel K, Roche L, Coward, Meek N et al. 2018 United Kingdom	An evaluation of a training programme provided to staff to encourage supported communication environments for people with intellectual disability The STARS project was introduced with the aim to support staff in implementing communication interventions, including AAC	1. Quantitative 2. A service evaluation	1. Purposeful 2. n=4 (Provision A: 4 service users with severe and profound disability, aged between 55-79 and their support staff, 2 service users communicated non-verbally, 2 had very limited verbal skills) 3. Support staff of adults with intellectual disability 4. Residential homes	Observations of service users and staff were completed before, mid-way through and at the end of the programme. Staff were asked to informally comment on their confidence with using AAC	Descriptive analysis	

(continued)

Table 4. (continued)

Author, Year, Country	Research question or study aim	1. Sample Approach		Data collection methods	Data Analyses	Key findings and conclusion
		1. Research Approach	2. Design			
6. Goldbart J, Chadwick D and Buell S 2014 United Kingdom	What communication intervention approaches are most commonly used by SLTs working with children and adults with profound multiple intellectual disability? What rationales do SLTs give for selection and use of these intervention approaches? To what extent do the rationales given by SLTs for decision making around intervention selection equate to the EBP framework?	1. Quantitative 2. Explorative, Descriptive Investigation	1. Non-probability sampling Purposive and snowball design 2. n=55 3. SLTs working with children and/or adults with profound multiple intellectual disability in the UK 4. Represented all apart from two of the Higher education institutions in the UK with qualifying programs	Surveys via email or post Was piloted by 3 SLTs in Manchester Metropolitan University	Simple descriptive and comparative statistics used to analyse quantitative data Conceptual content analysis for qualitative data collected from open ended questions Rationales identified from the content analysis were reviewed and grouped using thematic analysis	1. 77.1% (27) of respondents used objects of references with adults. 2. 14.3% (5) of respondents used switches with adults. 3. 42.9% (15) used communication passports with adults. 4. 22.9% (8) used symbolic interventions with adults. 5. The SLTs' main rationale for using these interventions were the empowerment, development and behavioural preference of the clients.
7. Johnson H, Douglas J, Bigby C et al. 2010 Australia	What does social interaction look like for an adult with a severe intellectual disability? Who comprises her social network? How are social relationships experienced by her social network members?	1. Qualitative 2. Constructivist Grounded Theory Case Study	1. Probability Purposive 2. n=15 (1 central person with severe intellectual disability, 4 family members, 3 home support workers, 5-day support workers, 2 peers with an intellectual disability) 3. People Sandra could name when not in her presence, people with whom interactions were positive, people with whom an interaction lasted more than 15mins, people who were familiarised a special bond with Sandra. 4. A family home setting and a day centre in Australia.	Observations of Sandra over five months with field notes. Members of Sandra's social network were interviewed	Followed Charmaz's (2006) grounded theory guidelines Textual analysis Qualitative coding, line-by-line and examined for in vivo codes Questions applied to the data Focused coding as the data from each interview was compared and contrasted Metaphors developed	1. Communication varies across roles and domains, and this impacted on communication in different ways. 2. Social network was dense and knew each other to varying extents. 3. Relationship with social network was reported to be positive as members experience enjoying the individual's company. 4. Love, personal satisfaction, feeling fortunate.

(continued)

Table 4. (continued)

Author, Year, Country	Research question or study aim	1. Research Approach	2. Design	1. Sample Approach	2. Size	3. Eligibility	4. Setting	Data collection methods	Data Analysis	Key findings and conclusion
8. Womnase S and Abdel Malek Y 2004 Egypt	To explore speech therapists' knowledge and experiences of AAC. To identify training needs of speech therapists who work with persons with complex communication needs in Egypt	1. Quantitative 2. Descriptive, correlational Study		1. Non-probability Purpose 2. n=30 3. Licensed speech therapists in Cairo, university graduated and working with people with intellectual disability and complex communication needs 4. The two main Cairo hospital clinics that provided medical assessment and treatment services as well as speech-language therapy Mostly privately owned special schools/centres offering programs for persons with intellectual disability and complex communication				52 Item Likert type questionnaire with additional open-ended questions	Spearman ρ coefficients were used to determine any associations between respondents' evaluation of their own knowledge/ importance of learning about AAC and when they graduated and duration /experience as a S.T. A Mann-Whitney U test carried out to determine differences between work settings on the results of knowledge/importance of AAC	1. Only one respondent reported AAC worked very well for a person with a mild intellectual disability 2. Blissymbol's were introduced in two cases where AAC was not being used, to young adults with severe intellectual disability as well as physical, visual and hearing impairments with the aim to increase communication. Teachers and parents of these students/ clients reported that AAC didn't work well. 3. No respondents said that AAC was not important. 4. Nine respondents felt that SLTs should not be involved in providing therapy to persons with certain types of disability that were associated with complex communication needs. 5. SLTs who had received some information about AAC during undergraduate education believed their knowledge to be better than those who did not.

Data Transformation

Following the JBI convergent integrated approach for MMSR, the quantitative data was 'qualitized.' The quantitative data was 'qualitized' as codifying the quantitative data has a lower risk of errors compared to applying numerical values to the qualitative data (The Joanna Briggs Institute, 2014). 'Qualitizing' the quantitative data was achieved by extracting data from quantitative studies and translating quantities into textual descriptions (Lizorando et al., 2020). Once extracted, the quantities were translated into individual sentences to answer the research question. This was then pooled with the data that was directly extracted from qualitative studies (Stern et al., 2020). This allowed the quantitative and qualitative data to be combined (Hong et al., 2017).

Data Synthesis

Thematic synthesis was undertaken manually (Thomas and Harden, 2008). The synthesis of the results was carried out in three stages; (1) free line by line coding of the extracted data followed by (2) grouping of these codes into related areas to develop descriptive themes, then (3) developing analytical themes (Thomas and Harden, 2008). The assembled data were categorized and pooled together based on similar meanings to produce a set of integrated findings to answer the review question.

Research Integrity

Each researcher has the responsibility to make ethical decisions at each stage of the review process. Wager and Wiffen (2011) outline practical and ethical issues that need to be considered when planning and publishing a MMSR. These include avoiding plagiarism, providing transparency and ensuring accuracy.

In this review other people's words are indicated using double quotation marks and citation. It is acceptable to describe a person's work in your own words. To ensure transparency, those who worked on the review are acknowledged and statements regarding information about funding and competing interests are provided (Cochrane Collaboration, 2011). Each researcher has the responsibility to ensure accuracy in data extraction. The results are presented without bias and review limitations outlined. Data extraction was clearly planned, disagreements were resolved through discussion and all authors agreed on which data was to be included (Wager and Wiffen, 2011). This MMSR followed the JBI convergent integrated approach according to the JBI methodology for MMSRs.

Results

Background of included studies

Eight studies met the inclusion criteria. Three of these were qualitative (Johnson et al., 2010; Rombouts et al., 2017; Wilder et al., 2015) and five quantitative (Goldbart et al., 2014; Meuris et al., 2014; Patel et al., 2018; Rombouts et al., 2016; Wormnaes and Abdel Malek, 2004). Three studies were conducted in Belgium (Meuris et al., 2014; Rombouts et al., 2016; Rombouts et al., 2017), two in the United Kingdom (Goldbart et al., 2014; Patel et al., 2018) and the remainder were conducted in Australia, Sweden and Egypt (Johnson et al., 2010; Wilder et al., 2015; Wormnaes and Abdel Malek, 2004).

All studies considered the experiences of either support staff (i.e., support workers, teachers, personal assistants) or facilitators who supported communication partners and AAC users (i.e., Speech and Language Therapists (SLT) and Occupational Therapists) with a total of 256 professionals participating in seven of the eight studies selected. One study did not specify how many staff were included (Patel et al., 2018). Two (Johnson et al., 2010; Wilder et al., 2015) of the eight studies included both support staff and family members ($n = 19$) views and one study (Johnson et al., 2010) included two peers as communication partners.

Three studies used surveys and two studies used questionnaires as the data collection method. Meuris et al. (2014) used both written questionnaires and telephone surveys. Interviews were utilised by two studies. Observations were undertaken by two studies. Johnson et al. (2010) used both observations and interviews. Discussion sessions were held in one study (Wilder et al., 2015). Sample sizes ranged from 8 to 93 respondents.

Synthesis

Four major themes were identified relating to communication partners experiences of communicating with adults with severe/profound intellectual disability through AAC; (1) Knowledge of AAC, (2) Attitudes and AAC Use, (3) Shared Commitment to Communication Partnership, and (4) Suitability of AAC (Supplementary Figure 2).

Theme 1: Knowledge of AAC

Theme one captures the sources from which communication partners acquired information and knowledge about AAC, the impact of training on their knowledge and the value of having knowledge in AAC. Four articles reported on knowledge of communication and AAC (Meuris et al., 2014; Rombouts et al., 2016; Wilder et al., 2015; Wormnaes and Abdel Malek, 2004)

Acquiring Knowledge about AAC

Communication partners acquired their information and knowledge about AAC through several resources.

Training provided by SLTs to support workers increased knowledge and use. Support staff knew and produced more signs when trained by an SLT (Meuris et al., 2014; Rombouts et al., 2016) or at an official training program (Rombouts et al., 2016) rather than a support worker. However, there were mixed reports about SLTs preparedness to provide such training, where SLTs wanted more knowledge and training in AAC. Wormnaes and Abdel Malek (2004) reported that SLTs within their study wanted further training and education in AAC to support persons with complex communication needs. Thirty per cent (9/30) of their respondents suggested a need for training about signs or symbols (Blissymbol's, sign language, Makaton, pictures, tangible symbols) for SLTs who wanted to support people with little or no functional speech. SLTs within this study introduced Blissymbols to individuals with sensory impairments, which were reported to be unsuccessful. Introducing abstract symbols to such individuals highlights a lack of expertise (Wormnaes and Abdel Malek, 2004) as those who have significant cognitive and language limitations may find abstract symbols challenging to use. This suggests that SLTs within this study required further training and education in the selection of suitable AAC methods for persons with severe/profound intellectual disability.

Providing AAC information to SLTs during their education was beneficial to their knowledge level. SLTs received information about AAC through undergraduate education, postgraduate training, colleagues, books, journal articles, conferences, seminars, courses, workshops or television (Wormnaes and Abdel Malek, 2004). The value of providing information to professionals during their undergraduate education was highlighted where SLTs who had received this information evaluated their knowledge as greater than those who did not receive such information about AAC during their undergraduate education (Wormnaes and Abdel Malek, 2004). This suggests that more in-depth, extensive training may improve knowledge of AAC and result in professionals who feel knowledgeable in the field.

Knowledge and AAC Use

The relationship between knowledge and AAC use was captured by two studies. Communication partners knowledge about AAC could enhance or hinder AAC use (Rombouts et al., 2016; Wilder et al., 2015). A lower level of knowledge was considered a limiting factor to AAC use (Wilder et al., 2015). An enhanced knowledge of AAC led to increased use of AAC by communication partners (Rombouts et al., 2016).

To surmise, gaps in communication partners knowledge of AAC may result in unmet communication needs of persons with severe/profound intellectual disability. The importance of training and education around AAC use with persons with severe/profound intellectual disability to enhance the communication partners skillset is highlighted by the findings in this theme. SLTs have a fundamental role in facilitating AAC training. Therefore, they need to have sufficient training in and knowledge about AAC. Previous education about AAC may improve communication partners ability to communicate with persons with severe/profound intellectual disability who use AAC, potentially increasing the likelihood of meeting the individual's communication needs.

Theme 2: Attitudes and AAC Use

This theme captures the interplay between communication partners attitudes towards AAC, their personal characteristics and the relationship between attitude and AAC use. This theme includes findings from six studies (Johnson et al., 2010; Meuris et al., 2014; Rombouts et al., 2016; Rombouts et al., 2017; Wilder et al., 2015; Wormnaes and Abdel Malek, 2004).

Available evidence indicates that communication partners attitudes towards AAC was positive overall or at least they did not have a negative attitude towards AAC (Meuris et al., 2014; Rombouts et al., 2016; Wormnaes and Abdel Malek, 2004). Those who has a more positive implicit attitude produced more signed utterances. However, there was no relation between explicit attitude and the number of signed utterances (Rombouts et al., 2016). Wilder et al. (2015) highlighted communication partners' willingness to communicate as an important component in facilitating communication. Therefore, the available evidence would indicate that communication partners attitudes towards and willingness to use AAC may improve AAC usage.

Communication Partners Assumptions

While Johnson et al. (2010) found that knowing the individual with severe/profound intellectual disability was important to facilitate communication (Johnson et al., 2010), Rombouts et al. (2017) identified that it could be a potential barrier to communication when communication partners make assumptions about what the individual is communicating (Rombouts et al., 2017). When such

assumptions were incorrect, the AAC user may not clarify their intended message resulting in misunderstanding (Rombouts et al., 2017). In addition, when support staff knew the AAC user well, they felt there was less of a need for communication support. Consequently, the perceived need to use AAC was lowered and AAC use was less frequent. Direct support staff mainly used KWS when there was an acute need for communication support depending on each person's individual needs (Rombouts et al., 2017). This could result in limiting AAC use (Rombouts et al., 2017).

To surmise, communication partners' attitude may enhance or hinder AAC usage with adults with severe/profound intellectual disability. Communication partners' personal characteristics may promote AAC use with the individuals that they support. Knowing the individual well was cited as an important factor in AAC use. However, this may also hinder AAC use should communication partners make assumptions about the intended message on the premise that they know what they are communicating. Such assumptions could pose as a potential barrier to communication opportunities for individuals with severe/profound intellectual disability.

Theme 3: Shared Commitment to Communication Partnership

The shared commitment to communication partnership is fundamental for the effective and efficient use of AAC with adults with severe/profound intellectual disability. There are various factors that can enhance or hinder this commitment, including uncertain ownership of AAC roles and responsibility, time constraints and the inclusion of communication partners in intervention planning.

Perceptions about Roles and Responsibilities

Communication partners have various roles and responsibilities in supporting persons with severe/profound intellectual disability communication through AAC (Rombouts et al., 2017; Wormnaes and Abdel Malek, 2004). Skilled communication partners were acknowledged as having additional responsibility within the individuals' environment (Wilder et al., 2015).

Uncertain ownership of responsibilities was cited as a limiting factor to effective communication for AAC users (Wilder et al. 2015). Communication partners uncertain ownership could limit the individual's communication goals and overall progress of these goals (Wilder et al., 2015; Wormnaes and Abdel Malek, 2004). There was a disconnect between SLTs perceptions of their roles, where some SLTs saw their role as supporting persons with severe/profound intellectual disability and complex communication needs while others did not (Wormnaes and Abdel Malek, 2004). More than half (52% n=15.6) of the SLTs provided speech therapy to people with severe intellectual disability and complex communication needs. However, 30% (9/30) of SLTs did not see the provision of therapy to persons with disabilities associated with complex communication needs as part of the SLT role (Wormnaes and Abdel Malek, 2004). The SLTs believed psychiatrists should be responsible for working with people with severe or multiple disabilities and that AAC specialists should be responsible for working with those who do not gain from speech training (Wormnaes and Abdel Malek, 2004). Therefore, to ensure individuals with severe/profound intellectual disability communication needs are met, there needs to be a clear outline of each communication partner's roles and responsibilities in AAC use. From a professional perspective a decision needs to be made regarding roles and responsibilities for training and knowledge about AAC and its use.

Professional and Family Members Input

Communication partners have different areas of expertise that contribute to the AAC intervention (Rombouts et al., 2017). Support staff shared their expertise with SLTs and SLTs viewed this contribution as crucial for AAC implementation (Rombouts et al., 2017). However, a gap in the inclusion of other communication partners was noted in two studies. SLTs worked with professionals and family carers but did not mention the views of these partners as often as expected when choosing an intervention (Goldbart et al., 2014) or co-operate with them to gather information as regularly as expected when developing supportive communication environments (Wormnaes and Abdel Malek, 2004).

Time

The importance of communication partners spending time with individuals with severe intellectual disability to learn how to interact with them was cited (Johnson et al., 2010). Therefore, partners need to have sufficient time to support individuals to communicate. However, time constraints were recognised to be a potentially limiting factor for effective AAC use with persons with severe/profound intellectual disability (Rombouts et al., 2017; Wilder et al. 2015).

Time constraints were related to communication partners workload, such as completing a range of tasks implemented by multiple stakeholders (Rombouts et al., 2017). They led to difficulty in detecting subtle communication signs, resulting in missed opportunities for communication (Patel et al., 2018). Patel et al. (2018) stated that the difficulty in detecting subtle communication signs may be due to the higher demands of providing physical care. Skilled interpretation was needed to understand the individual's communication (Johnson et al., 2010) and it was a challenge to be persistent when communicating with individuals with delayed or subtle communication attempts (Wilder et al., 2015). Therefore, communication partners need sufficient time to recognise and interpret individuals' communication.

While SLTs understood that support staff had a high workload, they felt that their assessment of KWS and training as time demanding was unfair (Rombouts et al., 2017). Investing time into consistently using AAC would result in less deliberation in the future (Rombouts et al., 2017), resulting in time efficient supports for the future (Rombouts et al., 2017). In addition, the perceived time constraints were somewhat determined by the educational background of the staff. Support staff who had received care orientated education were not as involved in service users' communication needs, where a participant stated that carers viewed care as their primary responsibility. Therefore, pre-service education may provide support staff with guidance for their role as '*aided language stimulator*' (Rombouts et al., 2017, p. 109) which may help to further enhance their understanding of the continued and consistent use of AAC.

Communication partners hold different roles and responsibilities in meeting the communication needs of a person with a severe/profound intellectual disability through AAC. However, lack of ownership of such roles and responsibilities may result in limited communication for persons with severe/profound intellectual disability. The inclusion of all communication partners in deciding on an intervention may lead to increased understanding and ownership of roles and responsibilities in AAC use. To strengthen the shared commitment to communication partnership it is important that each person is aware of their individual roles and responsibilities in the design, planning and use of AAC.

Theme 4: Suitability of AAC

Certain methods of AAC were deemed more suitable in meeting the complex communication needs of adults with severe/profound intellectual disability than others.

Promoting Acceptance

Two studies found that certain methods of AAC use were reported to encourage inclusion and participation (Goldbart et al., 2014; Wilder et al., 2015). For most respondents, switch use was a route to intentional communication for persons with severe/profound intellectual disability or increased participation and interaction (Goldbart et al., 2014). Similarly, iPads were discussed as being able to overcome boundaries as they are well known and can improve acceptance and encourage inclusion (Wilder et al., 2015). Introducing a method of AAC that improves acceptance could increase the use of AAC with the person with a severe/profound intellectual disability in different environments.

One study highlighted the suitability of objects of references for supporting individuals with severe/profound intellectual disability (Goldbart et al., 2014). Objects of reference were the most used method of AAC with adults with profound and multiple intellectual disability within one study (Goldbart et al., 2014). They were deemed important to support service users understanding and encourage choice making (Goldbart et al., 2014). The importance of objects of reference for people with sensory impairment, specifically visual impairment was mentioned by 25% (9/36) of SLTs (Goldbart et al., 2014).

Individuals Communication Needs

The importance of recognizing individuals' communication needs emerged from five studies. The ability and needs of individuals with severe/profound intellectual disability needs to be considered when introducing AAC. This was evident where SLTs main rationale for the introduction of AAC was the 'empowerment, development and behavioural preferences' of the service user (Goldbart et al., 2014).

The more severe the level of intellectual disability the fewer KWS the person with the intellectual disability were estimated to understand and produce (Meuris et al., 2014). Despite this, signing systems were used with people with severe/profound intellectual disability in five studies (Goldbart et al., 2014; Meuris et al., 2014; Patel et al., 2018; Rombouts et al., 2017; Rombouts et al., 2016). In addition, support staff produced less signs when the service users had severe intellectual disability (Meuris et al., 2014). This impacts on the communication opportunities of persons with severe/profound intellectual disability who communicate through signs.

Symbolic approaches were reported as having the potential to be very motivating for persons with sufficient vision (Goldbart et al., 2014). However, Blissymbol's were introduced to adults with severe intellectual disability and sensory impairments including visual impairments, teachers and parents reported AAC did not work well in these cases (Wormnacs and Abdel Malek, 2004).

The AAC chosen and used must be tailored and suitable to each person with an intellectual disability individual need.

Discussion

This review aimed to explore communication partner's experiences of communicating with adults with severe/profound intellectual disability through AAC.

Findings suggest that increased use of AAC could be aligned with communication partners' increasing knowledge. Limited knowledge indicated lower usage. This finding is similar to Beukelman et al. (2008) where AAC success or failure was somewhat dependent on communication partners knowledge. In addition, in their Egyptian study, Wormnaes and Abdel Malek (2004) found that SLTs who received training during their undergraduate education felt more confident using AAC and those who believed they were more qualified in AAC supported more service users to use AAC (Wormnaes and Abdel Malek, 2004). In the hope of improving professional's knowledge of AAC, training other professionals, such as teachers and healthcare professionals in AAC during their undergraduate education may further improve the provision and use of AAC with this population. The requirement for pre-service and in-service education in AAC has been repeatedly advocated in the literature (Balandin and Iacono, 1998; King, 1998; Simpson et al., 1998; Sutherland et al., 2005; Wormnaes and Abdel Malek, 2004). In addition, Lund and Light (2007) stated that knowledge barriers could be reduced by ensuring service providers are trained in AAC. By reducing knowledge barriers of service providers, persons with complex communication needs will have better access to experienced professionals (Lund and Light, 2007).

Similarly, communication partners need to have knowledge of AAC systems, services and a skillset in interaction strategies to provide suitable support (Kent-Walsh et al., 2010). A need for training relating to suitable methods of AAC for adults with severe/profound intellectual disability and complex communication needs was identified. This is reflected in SLTs introduction of Blissymbols to individuals with sensory support needs (Wormnaes and Abdel Malek, 2004). This highlighted a potential knowledge gap as some individuals who have significant cognitive and language limitations have difficulty using abstract symbols (Wormnaes and Abdel Malek, 2004). They benefit from expressing themselves using fewer abstract representations such as objects (Light et al., 2019). Objects of reference were reported to be successful when used (Goldbart et al., 2014). In addition, signing systems were used in five studies (Goldbart et al., 2014; Meuris et al., 2014; Patel et al., 2018; Rombouts et al., 2017; Rombouts et al., 2016). However, as severity of intellectual disability increased, communication partners estimated that fewer KWS were understood and produced by the individual (Meuris et al., 2014). This finding highlights the importance of having knowledge of AAC techniques that are individualized to each person and their needs. This concurs with the wider literature about feature matching, where team members work to match the individuals who require communication supports with the AAC (Ogletree, 2021). Having an awareness of individual's complex communication needs may optimize the selection of suitable interventions that will offer each person the equal opportunity to communicate.

Individuals with severe/profound intellectual disability have complex and specific communication needs, therefore interventions should be specific to these needs. A person centred and individualised approach to supporting communication is recommended. One way of achieving this is to develop personal support plans to maximise individuals human functioning dimensions (Schalock et al., 2021b). In addition, the supports model concentrates on the match between individuals and their environments, whereby disability is "*the expression of limitations in individual functioning within a social context*" (Schalock et al., 2021b: p.6). In line with the supports model, strategies and resources need to promote individuals' development and interests as well as enhance their well-being. Such support systems need to be person centred, outcome oriented, co-ordinated, comprehensive, include choice, inclusive environments and both generic and specialised supports

(Coulter, 2005; Schalock et al., 2019; Shogren et al., 2018; Stancliffe et al., 2016; Thompson et al., 2014). In addition, support plans should match an individual's needs (Schalock et al., 2018). It is recognised that it is challenging (Munde and Vlaskamp 2015) to develop interventions that match the individuals' abilities and needs. Therefore, the form of AAC used should be reflective of communication and functional needs of the individual AAC user.

The role of the SLT in training communication partners in AAC and improving their skillset was highlighted. Both support staff and service users knew more signs when they were taught by a SLT compared to a support staff. This is important as the success of interactions of persons using AAC is dependent on their own skills and that of their communication partners (Kent-Walsh and McNaughton, 2005).

There is agreement in the literature that AAC is a team approach that includes multiple stakeholders (De Paepe and Wood, 2001; Beukelman et al., 2008; Beukelman and Mirenda, 2005; Ogletree, 2021). Everyone who uses AAC with the individual should be involved in the team (ASHA, 2002). In addition, collaboration between team members can result in positive outcomes for AAC users and their family members (Lund and Light, 2007) and facilitate AAC success and implementation (Uthoff et al., 2021). The uncertain ownership of AAC roles and responsibility is a key finding of this review (Wilder et al., 2015; Wormnaes and Abdel Malck, 2004). This can lead to limited provision and use of AAC with adults with severe/profound intellectual disability. Firstly, SLTs uncertainty around providing support to persons with complex communication needs indicates that potentially, services may not be provided. This finding arose from an Egyptian study and therefore, should be considered within this cultural context. Furthermore, a participant in Lund and Light's (2007) qualitative study discussed encountering a number of SLTs who did not think AAC was part of their profession. This suggests that a lack of clarity around professional responsibility may lead to inconsistency in access to certain services, which could result in unmet communication needs for persons with severe/profound intellectual disability. Therefore, all team members need to be aware of their own and other team members roles and responsibilities when supporting individuals with severe/profound intellectual disability to communicate through AAC.

The findings of this review indicate that collaboration between stakeholders is sub-optimal to what is recommended. Family views and wishes did not inform the rationale for certain AAC methods used by SLTs (Goldbart et al., 2014) and SLTs did not gather information from parents within natural settings (Wormnaes and Abdel Malck, 2004). This concurs with the literature that family carers felt that they were not included by professionals in decision making about their family members lives (Chadwick et al., 2013; Goldbart and Canton, 2010). In line with the recommended use of a holistic approach teams are required to ensure multiple perspectives are heard and included (Schalock et al., 2021b). In addition, the supports model actions outline the importance of working with the individual and their family to develop personal goals, support needs and strategies (Schalock et al. 2021b). Similarly, there is an increased recognition of the need to facilitate family centred care in the field of intellectual disability. The importance of collaborative, family centred AAC decision making is repeatedly documented within the literature (Angelo, 2000; Bailey et al., 2006; Sonnenmeier et al., 2005; Soto et al., 2001).

A greater number individuals are seeking and receiving AAC services than ever before due to more individuals presenting with complex communication needs and families and professionals recognizing the positive impact of AAC (Light et al., 2019). Therefore, it is important that family members and all other appropriate communication partners are involved in the design, planning and use of AAC with and for the person with severe/profound intellectual disability with the intention of increasing their awareness of its importance and their roles and responsibilities. Similarly, De Geeter

et al. (2002) suggest that parents take on more responsibilities when they are actively involved in making decisions.

Including all appropriate communication partners in the decision-making process may further increase their understanding of their responsibilities, therefore leading to an increase in their ownership of such responsibilities and potentially facilitating a collaborative AAC approach. It is recognised that responsibilities of stakeholders can vary and be shared when a collaborative relationship is developed (Beukelman et al., 2008).

The findings of this MMSR indicate that clarity is required about the roles and responsibilities of all communication partners of individuals with severe/profound intellectual disability involved with AAC use. Given communication partners fundamental role in supporting individuals with severe/profound intellectual disability AAC use, uncertain ownership of roles and responsibilities creates an impediment to meeting their communication needs. Further research is required to explore communication partners perceptions of their roles and responsibilities and those of other communication partners when implementing AAC and supporting persons with a severe/profound intellectual disability to communicate and interact. From a practical standpoint, understanding communication partners' perceptions of their roles and responsibilities and those of other partners involved could be valuable for facilitating collaboration between all stakeholders involved. Having knowledge of such perceptions could help to inform organisational policy and direct the future of AAC implementation with persons with severe/profound intellectual disability and their communication partners.

This review focused on communication partners perspectives. Certain methods of AAC were identified that were deemed more suitable in supporting individuals with severe/profound intellectual disability needs. While it was beyond the scope of this review to explore the appropriateness of AAC for persons with severe/profound intellectual disability, this topic merits further investigation. Therefore, it is important to consider the appropriateness of AAC or structured programs in supporting these persons individual communication needs.

Strengths and Limitations of the Review

The findings of this MMSR should be considered in the context of its limitations. The risk of bias was increased by not publishing the review protocol. Language biases may have been introduced as the studies were only published in English, which may have led to relevant studies being missed. Psychology databases were not included. It is recognised that they can cover papers of interest on this topic. However, in consultation with the subject librarian seven databases were selected based on the 'fit' with the review topic and the return of relevant results.

The presence of strengths within this MMSR are also acknowledged. Two authors screened the title and abstract of the articles and assessed the full text articles for eligibility. Selection bias was not a feature of this MMSR as all studies were included regardless of their quality rating using the MMAT. The thematic synthesis process was robust. The translation process, through the development of descriptive and analytical themes, was done in a rigorous way that ensured transparency in reporting the results (Thomas and Harden, 2008).

Conclusion

This review provides insight into the experiences of communication partners who communicate with adults with severe/profound intellectual disability through AAC. There is a disconnect between communication partners' perceptions of their roles and responsibilities in the use of AAC with adults with severe/profound intellectual disability. Clarity is required about the roles and responsibilities of each communication partner using AAC with adults with severe/profound intellectual disability to increase the likelihood of the individual's communication needs being met. Therefore, further research is required to explore communication partners' perceptions of their roles and responsibilities in AAC use with this population to advance understanding, improve communication partnerships and practice.

Acknowledgements

This review is part of the first authors PhD project. We would like to thank Donna O'Doibhlin, the subject librarian for helping to develop the search strategy. We would also like to thank Professor John Browne for the information provided during the module PG7016 Systematic reviews for the health sciences.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iDs

Edina Hanley  <https://orcid.org/0000-0001-7453-3668>

Caroline Dalton  <https://orcid.org/0000-0003-4396-2800>

Supplemental Material

Supplemental material for this article is available online.

References

- American Speech-Language-Hearing Association (2019) Augmentative and Alternative Communication (AAC). Available at: <https://www.asha.org/public/speech/disorders/AAC/> (Accessed 21 August 2019)
- American Speech-Language-Hearing Association (2002) Augmentative and Alternative Communication: Knowledge and skills for service delivery. *American Speech-Language-Hearing Association Supplement* 22: 97–106.
- Angelo DH (1997) AAC in the family and home. In: Glennen S and DeCoste D (eds) *The handbook of augmentative communication*. San Diego: Singular Publishing, pp.523–545.
- Angelo DH (2000) Impact of augmentative and alternative communication devices on families. *Augmentative and Alternative Communication* 16(1): 37–47.
- Bailey RL, Parette HP Jr, Stoner JB et al. (2006) Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools* 37(1): 50–60.
- Balandin S and Iacono T (1998) AAC and Australian speech pathologists: Report on a national survey. *Augmentative and Alternative Communication* 14(4): 239–249.

- Bennett MK, Ward EC and Scarinci NA (2016) Exploratory investigation of communication management in residential-aged care: a comparison of staff knowledge, documentation and observed resident-staff communication. *International Journal of Language and Communication Disorders* 51(3): 296-309.
- Beukelman DR and Light JC (2020) *Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs* (5th ed.). Baltimore: Paul H. Brookes Publishing Co.
- Beukelman DR and Mirenda P (2005) *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (3rd ed.). Baltimore: Paul H. Brookes Publishing Co.
- Beukelman DR, Ball LJ and Fager S (2008) An AAC personnel framework: Adults with acquired complex communication needs. *Augmentative and Alternative Communication* 24(3): 255-267.
- Blackstone SW (1999) Communication partners. *Augmentative Communication News* 12: 1-4.
- Blackstone SW, Williams MB and Wilkins DP (2007) Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication* 23(3): 191-203.
- Bradshaw J (2001) Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of intellectual disability research* 45 (3): 233-43.
- Brady NC, Bruce S, Goldman A et al. (2016) Communication Services and Supports for Individuals With Severe Disabilities: Guidance for Assessment and Intervention. *American Journal on Intellectual and Developmental Disabilities* 121(2): 121-138.
- Bressan V, Bagnasco A, Aleo G et al. (2016) Mixed-methods research in nursing - a critical review. *Journal of Clinical Nursing* 26(19-20): 2878-2890.
- Cascella PW (2004) Receptive communication abilities among adults with significant intellectual disability. *Journal of Intellectual and Developmental Disability* 29(1): 70-78.
- Chadwick DD, Mannan H, Iriarte Garcia E et al. (2013) Family voices: the lives of families of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities* 26(2): 119-132
- Cochrane Collaboration. The Cochrane Handbook for Systematic Reviews of Interventions. Available at: <http://www.cochrane.org/training/cochrane-handbook> (accessed 27 January 2020)
- Coulter D (2005) Comprehensive health supports and health promotion. In: Lakin KC and Turnbull A (eds) *National goals and research for people with intellectual and developmental disabilities* Washington, DC: American Association on Mental Retardation, pp.109-124.
- Coupe O'Kane J and Goldbart J (1998) *Communication Before Speech: Development and Assessment* (2nd ed.) London: David Fulton Publishers.
- De Geeter KI, Poppes P and Vlaskamp C (2002) Parents as experts: The position of parents of children with profound multiple disabilities. *Child: Care, Health and Development* 28(6): 443-453.
- De Paepe PA and Wood LA (2001) Collaborative practices related to augmentative and alternative communication- Current personnel preparation programs. *Communication disorders quarterly* 22(2): 77-86
- Erickson K and Quick N (2017) The profiles of students with significant cognitive disabilities and known hearing loss. *Journal of Deaf Studies and Deaf Education* 22(1): 35-48.
- Friedman C and McNamara E (2018) Home- and Community-Based Speech, Language, and Hearing Services for People with Intellectual and Developmental Disabilities. *Research and Practice for Persons with Severe Disabilities* 43(2): 111-125.
- Fulya Sen A (2015) Communication and Human Rights Communication and Human Rights. *Procedia - Social and Behavioral Sciences* 174: 2813-2817.
- Goldbart J and Caton S (2010) *Communication and People with the Most Complex Needs: What works and why this is essential*. Mencap, London.
- Goldbart J, Chadwick D and Buell S (2014) Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability. *International Journal of Language Communication Disorders* 49(6): 687-701.

- Grove N, Bunning K, Porter J et al. (1999) See what I mean: interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 12(3): 190-203.
- Hong QN, Pluye P, Bujold M et al. (2017) Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Systematic Review* 6: 61.
- Hong QN, Pluye P, Fàbregues S et al. (2018) The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information* 34: 1-7
- Johnson H, Douglas J, Bigby C et al. (2010). The pearl in the middle: A case study of social interactions in an individual with a severe intellectual disability. *Journal of Intellectual and Developmental Disability* 35(3): 175-186.
- Keen D (2014) Prelinguistic communication. In Arciuli J and Brock J (eds) *An introduction to communication in autism: Current findings and future directions*. Benjamins, pp. 11-28.
- Kent-Walsh J and McNaughton D (2005) Communication Partner Instruction in AAC: Present Practices and Future Directions. *Augmentative and Alternative Communication* 21(3): 195-204.
- Kent-Walsh J, Binger C and Hasham Z (2010) Effects of parent instruction on the symbolic communication of children using augmentative and alternative communication during storybook reading. *American Journal of Speech-Language Pathology* 19 (2): 97-107.
- Kent-Walsh J, Murza K, Malani M et al. (2015) Effects of communication partner instruction on the communication of individuals using AAC: A meta-analysis. *Augmentative and Alternative Communication* 31(4): 271-284.
- King J (1998) Preliminary survey of speech-language pathologists providing AAC services in health care settings in Nebraska. *Augmentative and Alternative Communication* 14(4): 222-227.
- Kulkarni SS and Parmar J (2017) Culturally and linguistically diverse student and family perspectives of AAC. *Augmentative and Alternative Communication* 33(3): 170-180.
- Light (1989) Toward a definition of communication competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication* 5(2): 137-144.
- Light J and McNaughton D (2014) Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication. *Augmentative and Alternative Communication* 30(1): 1-18.
- Light J, Collier B and Parnes P (1985) Communicative interaction between young nonspeaking physically disabled children and their primary caregivers: Part I – Discourse patterns. *Augmentative and Alternative Communication* 1(2): 74-83.
- Light J, McNaughton D, Beukelman DR et al. (2019) Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. *Augmentative and Alternative Communication* 35(1): 1-12.
- Light JC, Arnold KB and Clark EA (2003) Finding a place in the “social circle of life”. In: Light JC, Beukelman DR and Reichle J (eds). *Communicative competence for individuals who use AAC: From research to effective practice*. Baltimore: Paul H. Brookes, pp.361-397.
- Lizarondo L, Stern C, Carrier J et al. Chapter 8: Mixed methods systematic reviews. In: Aromataris E and Munn Z (eds). *JBI Manual for Evidence Synthesis*. JBI, 2020. Available from <https://synthesismanual.jbi.global>. <https://doi.org/10.46658/JBIMES-20-09>
- Lund SK and Light J (2007) Long-term outcomes for individuals who use augmentative and alternative communication: Part III – contributing factors. *Augmentative and Alternative Communication* 23(4): 323-335,

- Lyle D (2019) *Understanding profound intellectual and multiple disabilities in adults* (1st ed). London: Routledge.
- McCall F, Markova I, Murphy J et al. (1997) Perspectives on AAC systems by the users and by their communication partners. *European Journal of Disorders of Communication* 32(3): 235-256.
- McCord MS and Soto G (2004) Perceptions of AAC: An Ethnographic Investigation of Mexican-American Families. *Augmentative and Alternative Communication* 20(4): 209-227.
- Meuris K, Maes B and Zink I (2014) Key Word Signing Usage in Residential and Day Care Programs for Adults With Intellectual Disability. *Journal of policy and practice in Intellectual Disabilities* 11(4): 255-267.
- Moher D, Liberati A, Tetzlaff J, et al. (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ*.
- Munde Vand Vlaskamp C (2015) Initiation of activities and alertness in individuals with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research* 59(3): 284-292.
- Nakken H and Vlaskamp C (2007) A Need for Taxonomy for Profound Intellectual and Multiple Disabilities. *Journal of Policy and Practice in Intellectual Disability* 4(2): 83-87.
- Oglethorpe BT (2021) *Augmentative and Alternative Communication: Challenges and Solutions* (1st ed.) San Diego, CA: Plural Publishing Inc.
- Ouellette-Kuntz H, Martin L and McKenzie K (2016) Population Aging and Intellectual and Developmental Disabilities: Projections for Canada. *Journal of Practice and Policies in Intellectual Disabilities* 13(4): 254-260.
- Parette HP and Angelo D (1996) Augmentative and Alternative Communication impact on families: Trends and future directions. *Journal of Special Education* 30(1): 77-98.
- Parette HP and Angelo D (1998) Impact of assistive technology devices on families. In: Judge SL and Parette HP (eds) *Assistive technology for young children with disabilities: A guide providing family-centered services*. Cambridge, MA: Brookline, pp.148-183.
- Parry Hughes R, Redley M and Ring H (2011) Friendship and Adults with Profound Intellectual and Multiple Disabilities and English Disability Policy. *Journal of Policy and Practice in Intellectual Disabilities* 8(3): 197-206.
- Patel K, Roche L, Coward N et al. (2018) Promoting positive communication environments: a service evaluation. *Tizard learning disability review* 23(4): 192-200.
- Petry K and Maes B (2006) Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual and Developmental Disability* 31(1): 28-38.
- Pino A (2014) Augmentative and Alternative Communication systems for the motor disabled. In: *Disability Informatics and Web Accessibility for Motor Limitations*, IGI Global: Hershey, PA, USA, pp. 105-152.
- Powell TW (2008) The use of nonspeech oral motor treatments for developmental speech sound production disorders: interventions and interactions. *Language, Speech, and Hearing Services in Schools* 39(3): 374-9.
- Rackensperger T, Krezman C, McNaughton D et al. (2005) "When I first got it, I wanted to throw it off a cliff": The challenges and benefits of learning AAC technologies as described by adults who use AAC. *Augmentative and Alternative Communication* 21(3): 165-186.
- Reichle J, York J and Sigafoos J (1991) *Implementing augmentative and alternative communication: Strategies for learners with severe disabilities*. Brookes.
- Rombouts E, Maes B and Zink I (2016) Attitude and key word signing usage in support staff. *Research in Developmental Disabilities* 55: 77-87.
- Rombouts E, Maes B and Zink I (2017) The behavioural process underlying augmentative and alternative communication usage in direct support staff. *Journal of Intellectual and Developmental Disability* 42(2): 101-113.

- Schalock RL, Luckasson R and Tassé MJ (2021a) Twenty questions and answers regarding the 12th edition of the AAIDD manual: Intellectual disability: definition, diagnosis, classification, and systems of supports. American Association on Intellectual and Developmental Disabilities
- Schalock RL, Luckasson R and Tasse MJ (2021b) Ongoing Transformation in the Field of Intellectual and Developmental Disabilities: Taking Action for Future Progress. *Intellectual and Developmental Disabilities* 59(5): 380-391.
- Schalock RL, Luckasson R and Tassé MJ (2019) The contemporary view of intellectual and developmental disabilities: Implications for psychologists. *Psicothema* 31(3): 223-228.
- Schalock RL, Thompson JR and Tasse MJ (2018) *A systematic approach to personal support plans*. Washington DC: American Association on Intellectual and Developmental Disabilities.
- Shogren KA, Schalock RL and Luckasson R (2018) The use of a context-based change model to unfreeze the status quo and drive change to enhance personal outcomes of people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(2): 101-109.
- Sigafoos J, Roche L and Tait K (2021) Challenges in providing AAC intervention to people with profound intellectual and multiple disabilities. In: Ogletree BT (eds) *Augmentative and Alternative Communication: Challenges and Solutions* San Diego CA: Plural Publishing, Inc, pp. 243-267.
- Simpson KO, Beukelman DR and Bird A (1998) Survey of school speech and language service provision to students with severe communication impairments in Nebraska. *Augmentative and Alternative Communication* 14(4): 212-221.
- Siu E, Tam E et al. (2010) A survey of augmentative and alternative communication service provision in Hong Kong. *Augmentative and Alternative Communication* 26(4): 289-298.
- Stanciliff RJ, Arnold SRC and Riches VC (2016) The supports paradigm. In: Schalock RL and Keith KD (eds) *Cross-cultural quality of life: Enhancing the lives of persons with intellectual disability*. Washington, DC: American Association on Intellectual and Developmental Disabilities, pp. 133-142.
- Stern C, Lizarondo L, Carrier J et al. (2020) Methodological guidance for the conduct of mixed methods systematic reviews. *JBIR Database of Systematic Reviews and Implementation Reports*. 18, [10.11124/JBIRSRIR-D-19-00169](https://doi.org/10.11124/JBIRSRIR-D-19-00169).
- Stillman R and Siegel-Causey E (1989) Introduction to nonsymbolic communication. In: Siegel-Causey E and Guess D (eds) *Enhancing nonsymbolic communication interactions among learners with severe disabilities*. Baltimore: Brookes, pp.1-12. International Statistical Classification of Diseases and Related Health Problems (11th ed; Version 02/2022; ICD-11; World Health Organization, 2022).
- Sonnenmeier R, McSheehan M and Jorgensen CM (2005) A Case Study of Team Supports for a Student with Autism's Communication and Engagement within the General Education Curriculum: Preliminary Report of the Beyond Access Model. Augmentative and Alternative Communication. *Augmentative and Alternative Communication* 21(2):101-115.
- Soto G, Muller E, Hunt P et al. (2001) Critical issues in the inclusion of students who use augmentative and alternative communication: An educational team perspective. *Augmentative and Alternative Communication* 17: 62-72.
- Sutherland D, van der Meer L et al. (2014) Survey of AAC needs for adults with intellectual disability in New Zealand. *Journal of Developmental and Physical Disabilities* 32: 587-598.
- Sutherland DE, Gillon GG and Yoder DE (2005) AAC use and service provision: A survey of New Zealand speech-language therapists. *Augmentative and Alternative Communication* 21: 295-307.
- The Joanna Briggs Institute (2014) Joanna Briggs Institute Reviewers' Manual: 2014 edition / Supplement Methodology for JBI Mixed Methods Systematic Reviews. Adelaide, Australia.
- Thomas J and Harden A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology* 8:45.

- Thompson JR, Schalock RL, Agosta J et al. (2014) How the supports paradigm is transforming service systems for persons with intellectual and related developmental disabilities. *Inclusion*, 2(2): 86-99.
- United Nations (2006) Convention on the Rights of Persons with Disabilities. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (Accessed on 25 October 2019)
- Uthoff SAK, Zinkevich A, Boenisch J et al. (2021) Collaboration between stakeholders involved in augmentative and alternative communication (AAC) care of people without natural speech. *Journal of Interprofessional Care* 35(6): 821-831.
- van Der Gaag A (1998) Communication skills and adults with learning disabilities: eliminating professional myopia. *British Journal of Learning Disabilities* 26: 88-93.
- van Splunder J, Stilma JS, Bernsen RMD et al. (2006) Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: Cross sectional study. *Eye*, 20(9): 1004-1010.
- Wager E and Wiffen PJ (2011) Ethical issues in preparing and publishing systematic reviews. *Journal of Evidence Based Medicine* 4(2): 130-134.
- Wilder J and Granlund M (2003) "Behaviour Style and Interaction between Seven Children with Multiple Disabilities and Their Caregivers." *Child: Care, Health and Development* 29(6): 559-567.
- Wilder J, Magnusson L and Hanson E (2015) Professionals' and parents' shared learning in blended learning networks related to communication and augmentative and alternative communication for people with severe disabilities. *European Journal of Special Needs Education* 30(3): 367-383.
- Williams B (2000) More than an exception to the rule. In : Fried-Oken M and Bersani H (eds) *Speaking up and spelling it out*. Baltimore, MD: Paul H. Brookes, pp. 245-254.
- Wormnaes S and Abdel Malek Y (2004) Egyptian Speech Therapists Want More Knowledge About Augmentative and Alternative Communication. *Augmentative and Alternative Communication* 20(1): 30-41.

Appendix 3 Communication partners' experience of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review protocol

Review question

The research question guiding the mixed method systematic review is: (1)

What are communication partners' experience of communicating with adults with severe/profound intellectual disability through AAC?

Searches

Key terms will be searched in multiple online databases (i.e., CINAHL, PubMed, ERIC, Cochrane, Academic search complete, Linguistics Collection, Scopus) in January 2020. These databases are comprehensive for health, social care and education, areas of practice commonly supporting people with intellectual disability. Abstracts and full-text articles will be independently screened by two authors. The reference lists of the included studies will be searched. All authors will agree on the included studies. The search strategy will be restricted to English language. The PRISMA (2009) guidelines will be used to report the results of this review (Moher et al., 20009).

Types of study to be included

Quantitative, qualitative and mixed methods studies. Studies will only be considered when the data relating to communication partners of adults with severe/profound intellectual disability can be clearly extracted. The search will be limited to studies published in or translated to English. No limits other than language will be applied during the literature search.

Condition or domain being studied

This review will consider studies that empirically explore or examine communication partners' experience of communicating with adults with severe/profound intellectual disability through AAC. Studies that focus on aided and/or unaided AAC use will be included.

Participants/population

The population of interest are communication partners of adults who have severe/profound intellectual disability. Communication partners must be 18 years or older. Communication partners included either paid or unpaid partners. Individuals with severe/profound intellectual disability may also have multiple disability. Therefore, adults with profound/multiple intellectual disability were also included. No restrictions were placed on ethnicity or gender. Studies that include communication partners of individuals with a mild, moderate or no intellectual disability, the person with severe/profound intellectual disability or profound/multiple intellectual disability is not over the age of 18 and communication is not supported by AAC will be excluded.

Intervention(s), exposure(s)

For the purpose of this review AAC is defined as “*an area of clinical practice that supplements or compensates for impairments in speech-language production and/or comprehension, including spoken and written modes of communication*” (ASHA, 201). Both aided and unaided AAC will be included.

Comparator(s)/control

Not relevant

Context

The context of the review focuses on studies that investigated communication partners of adults with severe/profound intellectual disability using AAC in community services, school, home settings, acute care settings, day services, during their day-to-day lives.

Main outcome(s)

- (1) To gain a better understanding of communication partners’ experiences of communicating with adults with severe/profound intellectual disability through AAC.
- (2) To identify potential barriers and facilitators to effective AAC use.

Additional outcome(s)

None

Data extraction (selection and coding)

Identified studies will be exported into EndNote and duplicates removed. To minimise bias, two authors will independently assess the inclusion of the studies by screening the title and abstracts and exclude those that do not meet the inclusion criteria. A third and fourth author will be consulted in the case of a disagreement. The full texts will be assessed by two authors based on the eligibility criteria. This process will be presented in a PRISMA flow chart.

Data will be extracted by the authors (EH, AMM, CD, EL). The data extraction will be reviewed at a meeting with any disagreements discussed until they are resolved. The following information will be extracted from all studies and documented in the data extraction form: (i) author, year, country (ii) research aim (iii) research approach and design (iv) sample approach, size, eligibility and setting (v) data collection methods (vi) data analyses (vii) key findings and conclusion.

Risk of bias (quality) assessment

The studies that meet the inclusion criteria will be assessed for methodological quality using the Mixed Methods Appraisal Tool version 2018 (MMAT; Hong et al., 2018).

Strategy for data synthesis

Thematic synthesis will be undertaken manually (Thomas & Harden, 2008). The synthesis of the results will be carried out in three stages; (1) free line by line coding of the extracted data followed by (2) grouping of these codes into related areas to develop descriptive themes, then (3) developing analytical themes (Thomas & Harden, 2008).

Analysis of subgroups or subsets

Not applicable

Contact details for further information

Edina Hanley

Organisational affiliation of the review

School of Nursing and Midwifery, University College Cork

Review team members and their organisational affiliations

Ms Edina Hanley. University College Cork

Dr Anne-Marie Martin. School of Nursing and Midwifery, University College Cork

Dr Caroline Dalton. School of Nursing and Midwifery, University College Cork

Dr Elaine Lehane. School of Nursing and Midwifery, University College Cork

Type and method of review

Systematic review

Anticipated or actual start date

January 2020

Anticipated completion date

January 2021

Funding sources/sponsors

None

Conflicts of interest

None

Language

English

Country

Ireland

Appendix 4 PRISMA Reporting Guidelines for the MMSR

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	33
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	33
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	35-40
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	40
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	41
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	42, 44
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	41, 42
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	297
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	43
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	46

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	46
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	45
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	59, 60
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			

Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	69-74
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	74
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	75
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data), role of funders for the systematic review.	28 (published paper)

Page 1 of 2

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

Page 2 of 2

Appendix 5 Search Strategy for the MMSR

PubMed	Number of hits
S1((severe intellectual disabilit* [Title] OR severe mental retard* [Title] OR severe learning disabilit*[Title])) OR (severe intellectual disabilit* [Title/Abstract] OR severe mental retard* [Title/Abstract] OR severe learning disabilit*[Title/Abstract])	2,883
S2 (profound intellectual disabilit* [Title/Abstract] OR profound mental retard* [Title/Abstract] OR profound learning disabilit*[Title/Abstract])	772
S3(pervasive intellectual disabilit*[Title/Abstract] OR pervasive learning disabilit*[Title/Abstract] OR pervasive mental retard*[Title/Abstract])	832
S4 (augmentative [Title/Abstract] AND alternative communication [Title/Abstract] OR AAC[Title/Abstract])	4,948
S5(caregivers [Title/Abstract] OR communication partners [Title/Abstract] OR teachers [Title/Abstract] OR support staff [Title/Abstract] OR family members [Title/Abstract] OR friends [Title/Abstract])	168,482
S1 OR S2 OR S3	4,371
S4 and S5	145
S1 OR S2 OR S3 AND S4 AND S5	1

Appendix 6 Quality Appraisal using the MMAT

Wormnaes, S., & Abdel Malek, Y. (2004). Egyptian Speech Therapists Want More Knowledge About Augmentative and Alternative Communication. <i>Augmentative and Alternative Communication</i> , 20(1), 30-41.					
Category of studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?				Pg. 31
	Do the collected data allow to address the research questions?	Yes			Pg. 33, Table 1; pg. 34 table 2; pg. 35 table 3
4.Quantitative Descriptive	4.1. Is the sampling strategy relevant to address the research question?	Yes			Pg. 31/32, Sample group
	4.2. Is the sample representative of the target population?	Yes			Pg. 32
	4.3. Are the measurements appropriate?	No			Pg. 33, development of survey instrument
	4.4. Is the risk of nonresponse bias low?	Yes			Pg. 31
	4.5. Is the statistical analysis appropriate to answer the research question?	Yes			Pg. 32
Goldbart, J., Chadwick, D., & Buell, S. (2014). Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability. <i>International Journal of Language Communication Disorders</i> , 49(6), 687-701.					
Category of studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?	Yes			Pg. 691
	Do the collected data allow to	Yes			Pg. 692-696

	address the research questions?				
4.Quantitative Descriptive	4.1. Is the sampling strategy relevant to address the research question?	Yes			Pg. 691
	4.2. Is the sample representative of the target population?	Yes			Pg. 691 participants
	4.3. Are the measurements appropriate?	Yes			Pg. 691 survey development and piloting
	4.4. Is the risk of nonresponse bias low?	Yes			Pg. 691 sampling and recruitment
	4.5. Is the statistical analysis appropriate to answer the research question?	Yes			Pg.691
Wilder, J., Magnusson, L., & Hanson, E. (2015). Professionals' and parents' shared learning in blended learning networks related to communication and augmentative and alternative communication for people with severe disabilities. <i>European Journal of Special Needs Education</i> , 30(3), 367-383					
Category of studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?	Yes			Pg. 367, Introduction
	Do the collected data allow to address the research questions?	Yes			Pg. 373-378
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	Yes			Pg. 371

	1.2 Are the qualitative data collection methods adequate to address the research question?	Yes			Pg. 371, 372, 378, 379
	1.3 Are the findings adequately derived from the data?	Yes			Pg. 372, 373
	1.4 Is the interpretation of results sufficiently substantiated by data?	Yes			Pg. 373-377
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes			Pg. 378 Discussion
Rombouts, E., Maes, B., & Zink, I. (2016). Attitude and key word signing usage in support staff. <i>Research in Developmental Disabilities</i> , 55, 77-87.					
Category of Studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?	Yes			Pg. 79 Aim
	Do the collected data allow to address the research questions?	Yes			
4.Quantitative Descriptive	4.1. Is the sampling strategy relevant to address the research question?	Yes			Pg. 79 2.1, convenience sampling
	4.2. Is the sample representative of the target population?	Yes			Pg. 79, participants
	4.3. Are the measurements appropriate?	Yes			Pg. 80

	4.4. Is the risk of nonresponse bias low?			Can't tell	Pg. 79 Convenience sample of 12 adults with intellectual disability with two communication partners each. There are no further details about response.
	4.5. Is the statistical analysis appropriate to answer the research question?	Yes			Pg. 691
Rombouts, E., Maes, B., & Zink, I. (2017). The behavioural process underlying augmentative and alternative communication usage in direct support staff. <i>Journal of Intellectual and Developmental Disability</i> , 42(2), 101-113.					
Category of studies	Methodological Criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?	Yes			Pg. 102
	Do the collected data allow to address the research questions?	Yes			Pg. 104-107
1.Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	Yes			Pg. 102
	1.2 Are the qualitative data collection methods adequate to address the research question?	Yes			Pg. 103
	1.3 Are the findings adequately derived from the data?	Yes			Pg. 103 Analysis
	1.4 Is the interpretation of results sufficiently substantiated by data?	Yes			Pg. 104-107
	1.5 Is there coherence between qualitative data	Yes			

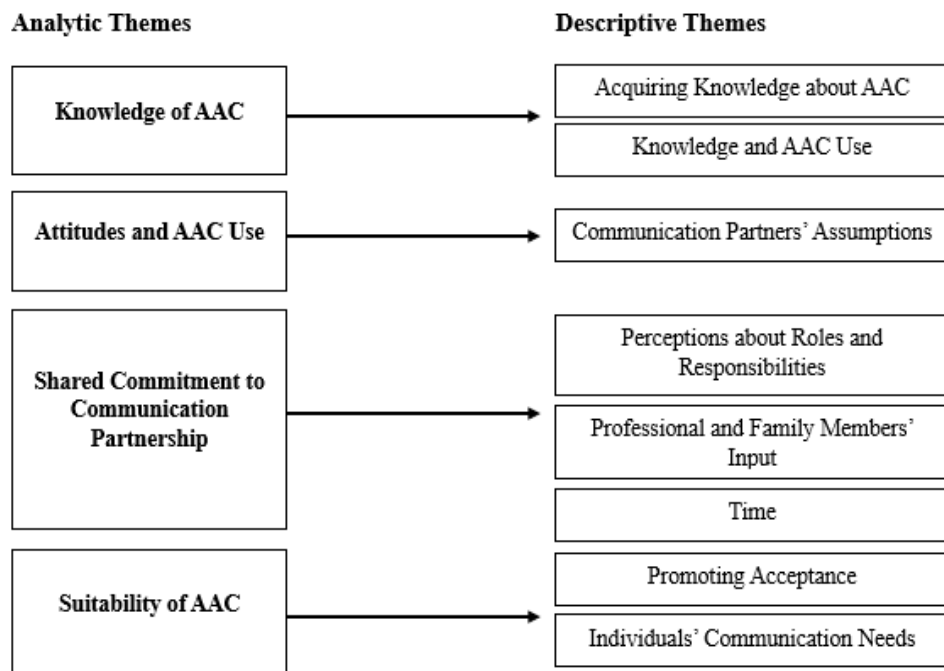
	sources, collection, analysis and interpretation?				
Meuris, K., Maes, B., & Zink, I. (2014). Key Word Signing Usage in Residential and Day Care Programs for Adults with Intellectual Disability. <i>Journal of policy and practice in Intellectual Disabilities</i> , 11(4), 255-267.					
Category of studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?	Yes			Pg. 256
	Do the collected data allow to address the research questions?	Yes			Pg. 259-262
4.Quantitative Descriptive	4.1. Is the sampling strategy relevant to address the research question?	Yes			Pg. 256, 259, Participants
	4.2. Is the sample representative of the target population?	Yes			Pg. 260, Phase two results
	4.3. Are the measurements appropriate?	Yes			Pg. 260
	4.4. Is the risk of nonresponse bias low?	Yes			Pg. 260, 261
	4.5. Is the statistical analysis appropriate to answer the research question?	Yes			Pg. 259
Patel, K., Roche, L., Coward, N., Meek, J., & Harding, C. (2018). Promoting positive communication environments: a service evaluation. <i>Tizard learning disability review</i> , 23(4), 192-200.					
Category of Studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?	Yes			Pg. 193 An inner-city service evaluation

	Do the collected data allow to address the research questions?	Yes			Pg. 195, 196
3.Quantitative non-randomized	3.1. Are the participants representative of the target population?	Yes			Pg. 194 participants
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?			Can't tell	The number of communication attempts were counted but there is not rigorous information provided about how this was done.
	3.3. Are there complete outcome data?			Can't tell	As above
	3.4. Are the confounders accounted for in the design and analysis?				The authors have not identified this in the design and merely mentioned that confounders such as a new team working together for the first time, trying to get used to new service users, might have contributed to the increased use of AAC, as opposed to the impact of receiving education on AAC. Pg.196-197.
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	Yes			Pg. 194
Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2010). The pearl in the middle: A case study of social interactions in an individual with a severe intellectual disability. <i>Journal of Intellectual and Developmental Disability</i> , 35(3), 175-186.					

Category of studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	Are there clear research questions?	Yes			Pg. 177
	Do the collected data address the research questions?	Yes			
1.Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	Yes			Pg. 177
	1.2 Are the qualitative data collection methods adequate to address the research question?	Yes			Pg. 177
	1.3 Are the findings adequately derived from the data?	Yes			Pg. 179
	1.4 Is the interpretation of results sufficiently substantiated by data?	Yes			Pg. 180-183
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes			Pg. 179

(Hong et al., 2018)

Appendix 7 Analytical and Descriptive Themes in the MMSR



Appendix 8 Ethical Approval from the Social Research Ethics Committee 1



Ethics Committee, Social Research <srec@ucc.ie>
to me ▾

Wed, Aug 12, 2020, 8:30 AM



Dear Edina

The Social Research and Ethics Committee has now approved your application Log 2020-131 entitled "Communication Partners Perceptions of their Roles and Responsibilities in the use of Augmentative and Alternative Communication with Persons with Severe/Profound Intellectual Disability."

The committee wishes you every success with your research.

All the best

Liz



Coordinator, Social Research Ethics Committee, University College Cork | srec@ucc.ie | Phone +353 (0)21 4903234

Independent Thinking, Shared Ambition: [UCC Strategic Plan 2017-2022](#)

Watch [University College Cork: River of Life](#)

Save our Spark. Help secure essential state funding.

Take action now www.saveourspark.ie

Appendix 9 Ethical Approval from the Service Provider



[Redacted Name]

to me ▾

Tue, Sep 22, 2020, 6:47 PM



Hi Edwina,

I'm just letting me know that the Executive Team gave approval for your research project to proceed at today's meeting. Wishing you the best with your research!

Kind regards,

[Redacted Signature]

Appendix 10 Standards for Reporting Qualitative Research Checklist

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	76
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	76-77

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	78-79
Purpose or research question - Purpose of the study and specific objectives or questions	79

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	79-80
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	82
Context - Setting/site and salient contextual factors; rationale**	80
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	80
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	79-80
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	80-81
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection, if/how the instrument(s) changed over the course of the study	80

Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	83
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	81
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	81
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	82

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	84-99
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quotes: 87, 89, 91, 92-95, 97, 98, 101

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	99-102
---	--------

Limitations - Trustworthiness and limitations of findings	102
--	-----

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	None
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Reported in paper

(O'Brien et al., 2014)

Appendix 11 Information Sheet 1

Purpose of the Study

The study is concerned with communication partner's perceptions of their roles and responsibilities in the design, planning and use of Augmentative and Alternative Communication with persons with a severe/profound intellectual disability. It is being completed as part of the requirements for an MSc in Medicine and Health at UCC.

What will the study involve?

Should you choose to participate, you will be asked to take part in a one-to-one interview online at a time and date that is convenient to you. The interview will be audio or video recorded depending on your preferred mode and is expected to take approximately 30 minutes to complete. Due to the current climate with Covid-19, the interviews will take place on Microsoft Teams. The researcher will send you an invitation for a meeting should you choose to participate.

Why have you been asked to take part?

You have been asked to participate as you communicate with people with a severe/profound intellectual disability using Augmentative and Alternative Communication.

Do you have to take part?

There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the interview. Once the interview has been concluded, you can choose to withdraw your details at any time in the subsequent two weeks.

Will your participation in the study be kept confidential?

You will remain anonymous throughout the thesis. No information that will disclose your identity will be included in the final thesis. Pseudonyms will be used in relation to any extracts or quotes you provide. All of the information you provide will be kept confidential and anonymous and will be available only to the researcher (Ms. Edina Hanley) and the researcher's supervisors (Dr Caroline Dalton, Ms. Anne-Marie Martin, Dr Elaine Lehane). The only exception is where information is disclosed which indicates that there is a serious risk to you or to others.

What will happen to the information which you give?

The data will be kept confidential for the duration of the study. Once the interview is completed, the recording will immediately be transferred to an encrypted laptop and wiped from the recording device. The interview will then be transcribed by the researcher, and all identifying information will be removed. Once this is done, the recording will also be deleted and only the anonymised transcript will remain. This will be stored on Microsoft Teams SharePoint. The data will be stored for ten years. The information you provide may contribute to research publications and/or conference presentations. The data will contribute to a thesis.

What will happen to the results?

The results will be presented in the thesis. They will be seen by my supervisory team and examiners appointed by the university. The study findings will be published in a peer reviewed journal.

What are the possible benefits of taking part?

Participating in the research study offers you the opportunity to share your experiences of communicating with a person with a severe/profound intellectual disability using Augmentative and Alternative Communication. It is hoped that such

information will help communication partners to decide how augmentative and alternative communication can be of optimum use for persons with a severe/profound intellectual disability.

What are the possible disadvantages of taking part?

I do not envisage any negative consequences for you in taking part. It is possible that talking about your experience may cause some distress. We can speak about how you are feeling and if you subsequently feel distressed, supports will be arranged for you as appropriate.

Who has reviewed this study?

Approval has been granted by the Social Research Ethics Committee in UCC and the Service Providers Research Committee.

Any further queries?

If you need any further information, you can contact me:

Edina Hanley

e.hanley@umail.ucc.ie

Note: phone number was provided but removed for thesis.

My research supervisors can be contacted at:

Caroline Dalton:

c.doconnor@ucc.ie

Anne-Marie Martin:

A.martin@ucc.ie

Elaine Lehane:

E.Lehane@ucc.ie

If you agree to take part in the study, please sign the consent form overleaf.

Thank you.

Appendix 12 Consent Form 1

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Edina Hanley to be audio/video recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed: Date:

PRINT NAME:

Appendix 13 Interview Schedule

1. Tell me about your experience of using AAC?
2. Were you involved in the selecting or designing of AAC chosen and used with the person with a severe/profound intellectual disability?
 - a. If you were involved, can you tell me about your role?
 - b. If not, would you have liked to be involved?
3. What type of AAC was chosen?
 - a. Why were that type chosen?
4. Who else was involved in deciding on the type of AAC?
 - a. What was their role?
5. Do you communicate with anyone else in the person's network?
 - a. Do you communicate with others in his/her network about AAC?
 - b. Do you discuss your experience of AAC with the other communication partners?
6. Can you tell me about your everyday role in using AAC?
7. Do you have someone that you can go to report issues?
 - a. How is the system reviewed?
 - b. Who do you think is most suitable to take this role and why?
 - c. Where do you think your role lies?

Appendix 14 Debrief Form

Thank you for participating in the research study ‘Communication partners’ perceptions of their roles and responsibilities in the use of augmentative and alternative communication (AAC) with persons with severe/profound intellectual disability’.

The aim of the study is to answer the following questions:

1. What are communication partners’ perceptions about their roles and responsibilities in the use of AAC when communicating with persons with severe/profound intellectual disability?
2. Who do they believe should be involved in the communication partnership with persons with severe/profound intellectual disability using AAC?

If you have any questions or queries you can contact me:

Edina Hanley e.hanley@umail.ucc.ie

Note: phone number removed for thesis.

My research supervisors can be contacted at:

Caroline Dalton c.doconnor@ucc.ie

Anne-Marie Martin A.martin@ucc.ie

Elaine Lehane E.Lehane@ucc.ie

Appendix 15 Sample Coding Sheet

Meaning Units	Condensation	Codes
I suppose we look at the person and see how they're communicating...	We see how the individual is communicating	Look at the person's communication
Add to that instead of trying to change what they have or whatever.	Add to how they communicate	Build on the individual's communication
I always try to look at what they have and then build on that.	Look at what they have and build on that	Build on the individual's communication

Appendix 16 Sample Critical Reflection

Interview 3

I feel that this interview went well. At first, we had some technological difficulties setting up the teams meeting, but this was soon resolved. I feel that the time spent trying to sort the teams meeting helped us to build a casual relationship, which in turn made the interview very casual and the conversation flowed.

All the research questions were answered in detail by the participant. I feel that I provided sufficient feedback to the participant in this interview. I ensured we spoke of persons with severe/profound intellectual and/or multiple disabilities as the participant was a communication partner of individuals with mild and moderate intellectual disability also. When the interviewee spoke about mild and moderate intellectual disability, I brought the focus back to the context and aim of this research.

Compared to the first two interviews, I did not say 'yeah' as much throughout the interview. I waited for the participant to finish what she was saying before asking another question. At one point of the interview, I felt emotional when it was mentioned about AAC being introduced and not working as it was not used. This emotion stemmed from my role as a nurse. I had to ensure that I listened with the ears of a researcher. I took some subtle deep breaths and kept my focus on the interviewee's words and experience as a communication partner while parking my own experience as a nurse. I feel that I had pre-empted that this may have been a potential situation and that my preparatory reflection helped at that point. I benefit from being comfortable in communicating with other professionals and families each day in my job as a nurse, however I am also aware that this could lead to me preempting questions during the interview. Therefore, through this awareness and

continued reflection I will ensure that I am hearing what the participants are saying and staying close to that.

Appendix 17 Sample Memo

Memo 02/04/2021

Research questions: (1) What are your roles and responsibilities?
(2) Who should be involved?

Professional and familial partners are included, roles and responsibilities differ, however an underlying principle of respect for all roles is evident.

(1) Professionals The SLPs and CNVs role is to build the foundation, in order to do this they assess the environment and the people in it. Is the environment set up to provide opportunities to communicate? They provide training to build awareness and understanding.

Codes relate to the AAC users ability, their strengths, needs, preferences. What is their ability, and how can it be leveraged? This knowledge is gained via assessment, and also familiar partners' knowledge and experience. Professionals are reliant on those partners who are on the ground, to share their knowledge of the AAC user, to implement it, give feedback, refer, and provide those opportunities to communicate. Such a process, where everyone is recognized and involved, helps to build a trusting relationship.

02/04/2021 (cont.)
2) Those partners 'on the ground'; refers to those who are familiar partners, those who support them day-to-day. This includes both familial and professional partners (an MIA, teacher, the CNB was familiar to some - had groups with individuals but Covid-19 interrupted). They discussed their roles and responsibilities in selecting pictures/objects etc to be used, sharing information about the individual, reporting issues to SRT/CNB, using the AAC, providing the AAC user with time and opportunities. They also relied on SRTs and CNBs for assessments, training, their expertise in selection, remaining issues and strategies to progress.
- The combined action of a group.

They worked as a team. However, Covid-19 interrupted regular communication, which was reported to negatively impact the overall goal, as not everyone was up-to-date on targets and plans.

Memo

05/04/2021

An Overarching Theme: Optimize the individual Ability to Communicate

Thoughts on this;

Participants wanted to support the person (AAC user) to communicate to the best of their ability. AAC was a means to help to achieve this, to support the individual to communicate. They appeared motivated, this was apparent in their attempts to achieve this goal; teamwork, training, multimodal AAC etc. This goal was not always achieved; this raises the question: what inputs on reaching a shared goal? i.e. optimizing the individual's ability to communicate. They shared a goal but did they share understanding of it?

- Organizational approach to communication, AAC, the partnership and it's importance in facilitating AAC use
- Individual approach: consistently or inconsistently using AAC, why? Does it support the users abilities/needs/preferences? Some felt they knew what the individual was communicating they realized that others may not and AAC could help to promote continuity of communication.

Reaching this goal was not a linear process. A

(cont)

Number of barriers and facilitators were reported and appear in the codes (for eg. access, availability, time, the 'fit' of AAC between the user (individuality taken into account during selection), knowledge, training, attitudes etc. Referring to these as barriers and facilitators may not be the best approach, what's the core message? These are the factors that influence this shared goal.

Appendix 18 PRISMA Reporting Guidelines for the Integrative Review

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	106
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	106
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	109-112
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	112
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	112
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	113, 115
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	113
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	338
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	114-115

Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	117
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	117
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	116
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	137-139
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	

Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	153-157
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	157
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	158
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Included in paper for publication

Page 1 of 2

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

Page 2 of 2

Appendix 19 Integrative Review Protocol

What are the factors influencing communication partners of persons with severe/profound intellectual disability use of augmentative and alternative communication? An Integrative Review

Edina Hanley, Elaine Lehane, Anne-Marie Martin, Caroline Dalton

Citation

Edina Hanley, Elaine Lehane, Anne-Marie Martin, Caroline Dalton. What are the factors influencing communication partners of persons with severe/profound intellectual disability use of augmentative and alternative communication? An Integrative Review. PROSPERO 2022 CRD42022361886 Available from: https://www.crd.york.ac.uk/prospERO/display_record.php?ID=CRD42022361886

Review question

The research questions guiding this integrative review are: (1) What are the factors influencing communication partners' use of Augmentative and Alternative Communication (AAC)? (2) Is there an intersection between these factors and communication partners' use of AAC? (3) What theories or conceptual frameworks have been used to explore the factors influencing communication partners' use of AAC?

Searches

Key terms were searched in multiple online databases (i.e., CINAHL, PubMed, ERIC, Cochrane, Academic search complete, Linguistics Collection, Scopus, PsycArticles and PsycINFO) between the 2nd and 3rd August 2022. These databases are comprehensive for health, social care, psychology and education, areas of practice commonly supporting people with intellectual disability. Abstracts and

full-text articles were independently screened by two authors. The reference lists of the included studies were searched. All authors agreed on the included studies.

The search strategy was restricted to English language. The PRISMA (2009) guidelines will be used to report the results of this review (Moher et al., 20009).

Types of study to be included

This integrative review will include qualitative, quantitative and mixed methods studies that assess and/or explore factors influencing or impacting on communication partners' use of AAC. Systematic reviews, integrative reviews, meta-analyses, meta-syntheses, books, book reviews, editorials and purely theoretical papers that addressed the above will be excluded. The search will be limited to studies published in or translated to English. No limits other than language will be applied during the literature search.

Condition or domain being studied

This review seeks to synthesise the evidence related to the factors influencing communication partners of persons with severe/profound intellectual disability use of AAC. It will consider studies that empirically explore or examine communication partners' use of AAC with persons with severe/profound intellectual disability and the factors influencing communication partners' use of AAC. The review will also consider studies that examine the intersection between communication partners' use of AAC and influential factors. Studies that evaluate the types of AAC most suitable for persons with severe/profound intellectual disability and that focus on assistive technology will be excluded. Studies that focus on aided and/or unaided AAC use will be included.

Participants/population

The population of interest are communication partners of persons with severe/profound intellectual disability or profound intellectual and multiple disabilities using AAC to communicate. Studies that include communication partners of individuals with a mild, moderate or no intellectual disability will be excluded. Studies that did not focus on AAC or factors influencing communication partners' use of AAC will be excluded.

Communication partners include two main categories of communication partners, those who have a social role and those who have a professional role (Kent-Walsh & McNaughton, 2005). For the purpose of this review, those with a professional and social role will be included.

Intervention(s), exposure(s)

For the purpose of this review AAC is defined as “*an area of clinical practice that supplements or compensates for impairments in speech-language production and/or comprehension, including spoken and written modes of communication*” (ASHA, 2019). Both aided and unaided AAC will be included.

Comparator(s)/control

Not relevant

Context

The context of the review focuses on persons who communicate at the earlier developmental stages which includes persons with severe/profound intellectual disability and persons with profound intellectual and multiple disability. This review aims to explore the context in which they communicate by examining factors that influence communication partners' use of AAC.

All studies related to factors influencing communication partners' use of AAC with persons with severe/profound intellectual disability, regardless of age, in any geographic area in all contexts (i.e., community settings, day services, residential services, schools, home settings) will be included in the review. This review will consider studies that investigate communication partners of persons with severe/profound intellectual disability using AAC in community services, school, home settings, acute care settings, day services, during their day-to-day lives. The communication partners will either be professional or social in their roles.

Main outcome(s)

- (1) To identify the factors influencing communication partners' use of AAC
- (2) To determine any intersection between influencing factors and AAC use
- (3) To identify existing theoretical or conceptual frameworks used to address the factors influencing communication partners' use of AAC and the intersection between these factors and AAC use

Additional outcome(s)

None

Data extraction (selection and coding)

Identified studies will be exported into EndNote/Covidence and duplicates removed. To minimise bias, two authors will independently assess the inclusion of the studies by screening the title and abstracts and exclude those that do not meet the inclusion criteria. A third and fourth author will be consulted in the case of a disagreement. The full texts will be assessed by two authors based on the eligibility criteria. This process will be presented in a PRISMA flow chart.

Data will be extracted independently by two authors. To begin, data will be extracted from a few studies, and this will be reviewed by the team to decide if the extracted data are suitable, if any additional data need to be extracted or if any clarification is required (Batten & Brackett, 2021). In cases of disagreement the third and/or fourth author will be consulted until consensus has been reached. The following data will be extracted for each study; authors, country, aim, methodology, participants and sample characteristics, instruments/measures, variables of interest, guiding theories/conceptual frameworks (when they have been used) and key findings. The findings will be extracted with particular emphasis on the factors that influence communication partners' use of AAC and intersection between these factors and their AAC use.

Risk of bias (quality) assessment

Evaluating quality scores in a review that includes different research designs is complex (Whittemore & Knafl, 2005). However, quality should be addressed in a meaningful way (Whittemore & Knafl, 2005). Studies will not be excluded based on quality (Hutchinson & Bodicoat, 2015). Hutchinson and Bodicoat (2015) state that when there is limited literature available it is more beneficial to critique the identified papers and “*use the deficits in quality to inform future research*” (Hutchison & Bodicoat, 2015, p.3). A score will not be applied (Lang et al., 2022) as using such a rigid approach may not be suitable when a review includes various types of empirical studies (Whittemore & Knafl, 2005). Therefore, to allow for the appraisal of diverse studies with different research designs, we will implement several measures to ensure the quality of the studies included in the review (Lang et al., 2022). For example, scientific databases will be searched for peer-reviewed studies published in journals (Lang et al., 2022). The clarity of the study aim (Opoku

et al., 2021), the methodological approach (Lang et al., 2022) and data presented in each study will be considered (Lang et al., 2022).

Strategy for data synthesis

The analysis will focus on generating themes from the following areas to answer the research questions: 1) The factors influencing communication partners' use of AAC, both challenges and facilitators, where the similarities, differences and patterns will be grouped accordingly 2) The intersection between the identified factors and communication partners' use of AAC and 3) The theories used in the studies will be compared to identify how they guided research on this topic. Therefore, the extracted data will be compared to allow for the grouping of similar data into categories and themes using thematic analysis. Thus, the data will be reduced, displayed, compared which will allow for the drawing of conclusions that will be verified (Whittemore & Knafl, 2005).

The study findings will be presented in the form of descriptions and narrations and a figure to capture the themes and sub-themes. The first author will undertake the analysis, which will be reviewed and refined with the assistance of the second, third and fourth authors.

Analysis of subgroups or subsets

Not applicable

Contact details for further information

Edina Hanley

Organisational affiliation of the review

School of Nursing and Midwifery, University College Cork

Review team members and their organisational affiliations

Ms Edina Hanley. University College Cork

Dr Elaine Lehane. School of Nursing and Midwifery, University College Cork

Dr Anne-Marie Martin. School of Nursing and Midwifery, University College Cork

Dr Caroline Dalton. School of Nursing and Midwifery, University College Cork

Type and method of review

Systematic review, Other

Anticipated or actual start date

02 August 2022

Anticipated completion date

24 October 2022

Funding sources/sponsors

None

Conflicts of interest

None

Language

English

Country

Ireland

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Communication; Communication Aids for Disabled; Communication Disorders;

Humans; Intellectual Disability

Date of registration in PROSPERO

02 October 2022

Date of first submission

21 September 2022

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Appendix 20 PICo Framework

Population	Communication partners of persons with severe/profound intellectual disability
Interest	Factors influencing communication partners' use of AAC
Context	With persons with severe/profound intellectual disability in community settings, day services, school, home settings in all countries

Appendix 21 Database Search: Academic Search Complete undertaken in August 2022 and May2023

Search Term No.	Search String	No. of Hits	No. Of Hits
		03/08/2022	31/05/2023
1	TI (AAC OR “Augmentative and Alternative Communication”) OR AB (AAC OR “Augmentative and Alternative Communication” OR DE "MEANS of communication for people with disabilities" OR (DE "Augmentative Communication"))	2,782	2,893
2	TI (“Severe intellectual disabilit*” OR “Severe learning disabilit*” OR “severe mental retard*” OR “severe developmental disabilit*”) OR AB (“Severe intellectual disabilit*” OR “Severe learning disabilit*” OR “severe mental retard*” OR “severe developmental disabilit*”)	2,013	2,042
3	TI (“profound intellectual disabilit*” OR "profound mental retard*" OR "profound developmental disabilit*" OR "profound learning disabilit*") OR AB (“profound intellectual disabilit*” OR "profound mental retard*" OR "profound developmental disabilit*" OR "profound learning disabilit*")	1,032	1,046
4	TI (“pervasive intellectual disabilit*” OR "pervasive mental retard*" OR "pervasive developmental disabilit*" OR "pervasive learning disabilit*") OR AB (“pervasive intellectual disabilit*” OR "pervasive mental retard*" OR "pervasive developmental disabilit*" OR "pervasive learning disabilit*")	34	40
5	TI (“Multiple and Complex Disabilities” OR (DE "Multiple Disabilities")) OR AB (“Multiple and Complex Disabilities” OR (DE "Multiple Disabilities"))	1,704	1,755
6	2 OR 3 OR 4 OR 5	4,621	
7	TI (Caregivers OR carer OR “communication partners” OR family OR parents OR mother OR father OR siblings OR friends OR “support staff” OR “support worker” OR teachers OR educator OR “speech and language therapists” OR “speech therapist” OR “speech pathologists” OR “speech language pathologist” OR assistant) OR AB (Caregivers OR carer OR “communication partners” OR family OR parents OR mother OR father OR siblings OR friends OR “support staff” OR “support worker” OR teachers OR educator OR “speech and language therapists” OR “speech therapist” OR “speech pathologists” OR “speech language pathologist” OR assistant OR (DE "Caregivers")) OR (DE "Parents") OR	899,322	930,580

	("DE "Family") OR (DE "Mothers") OR (DE "Fathers")) OR (DE "Siblings") OR (DE "Speech Therapists") OR (DE "Teachers") OR (DE "Special Education Teachers")		
8	1 AND 7	806	853
9	6 AND 8	27	27

Appendix 22 Theoretical Development

Previous Findings Considered in Light of the Theoretical Frameworks Identified

Communication partners have an essential role supporting people with severe/profound intellectual disability to communicate using AAC. Given the importance of their input, a MMSR was undertaken to explore communication partners' experiences of communicating with adults with severe/profound intellectual disability using AAC (Hanley et al., 2022). The findings indicated a disconnect between communication partners' perceptions of their roles and responsibilities in the use of AAC with this population, which was found to negatively influence AAC use (Hanley et al., 2022). Therefore, a qualitative descriptive study was undertaken to explore communication partners' perceptions of their roles and responsibilities in the design, planning and use of AAC with persons with severe/profound intellectual disability. The findings captured participants' shared commitment to individuals with severe/profound intellectual disability, in supporting the individual to communicate and to be heard (Hanley et al., 2023a).

Despite participants' commitment and sense of hope, AAC was reported to be used inconsistently at times (Hanley et al., 2023a). The findings of the qualitative descriptive study demonstrated a multitude of diverse factors influencing the execution of a complex process, i.e., meaningful communication using AAC (Hanley et al., 2023a). These factors included time, knowledge, training, availability, teamwork, access to AAC, uncertainty, the compatibility of AAC with the individual's ability, communication partners' attitudes towards AAC and their expectations of individuals with severe/profound intellectual disability and AAC. It was not the purpose of the qualitative study to examine the relationship between the factors that influence AAC use on optimising the individual's communication.

Therefore, an integrative review was undertaken to gather the empirical research to better understand the factors affecting communication partners' use of AAC and the intersection between these factors (Hanley et al., 2023b).

Two themes emerged in the integrative review; (1) Achieving Meaningful Communication and (2) Communication Partners' Preparedness to Use AAC. Achieving meaningful communication involved identifying the individual's communication methods and encouraging them to communicate. The latter was dependent on the former. Communication partners' preparedness influenced their use of AAC and thus, their ability to achieve meaningful communication. This preparedness was impacted by their preconceived thoughts about and knowledge of AAC, nurturing their belief in AAC, and the interpersonal dynamic between network members, i.e., the people involved in supporting the individual's communication (Hanley et al., 2023b). The findings indicate that communication partners' beliefs may influence their use of AAC. The findings indicated the need to better understand the relationship between communication partners' beliefs and their use of AAC; providing a clear line of evidence on what beliefs need to be developed to support and optimise their use of AAC.

The findings indicate that the factors influencing communication partners' use of AAC are complex and may be interconnected at times (Hanley et al., 2023a; Hanley et al., 2023b). Therefore, to better understand the relationships between these factors and test specific hypotheses, the use of a theoretical framework is recommended. Several behavioural theories and models were explored, and the above findings were considered in light of these, with communication partners' use of AAC being the target behaviour.

Behaviour Theories

The TRA (Fishbein & Ajzen, 1975), TPB (Ajzen, 1991), the TAM, (Davis, 1986; Davis et al., 1989), C-TAM-TPB (Taylor & Todd, 1995a) and the Unified Theory of Acceptance and Use of Technology (UTAUT, Venkatesh et al., 2003) were explored. The TRA explores the relationship between attitudes and actions, outlining the progress from beliefs to actions (Rombouts et al., 2017a). The TPB stemmed from the TRA, adding one extra construct, perceived behavioural control, to explain the situations where one does not have complete control over their behaviour (Ajzen, 1991). TPB postulates that three main factors, attitude towards the behaviour, subjective norm, and perceived behavior control impact persons' intention toward the actual behaviour. Behavioural intention acts as a mediator amid attitudes, subjective norms, perceived behaviour control and actual behaviour (Cornally, 2014).

The TRA and TPB were developed to explain human behaviour in general (Rahman et al., 2017). The UTAUT and TAM were developed to explain technology acceptance (Rahman et al., 2017). TAM derived from the TRA and UTAUT derived from eight models, including the TPB, TAM and C-TAM-TPB. TAM postulates that attitude is influenced by perceived usefulness and perceived ease of use, which further influences intention. TAM aims to provide a means to trace the impact of external factors on internal beliefs, attitudes and intentions (Davis, 1989). The UTAUT proposes four components of behavioural intention and actual behaviour; performance expectancy, effort expectancy and social influence are proposed to impact intention, and intention and facilitating conditions influence actual behaviour (Venkatesh et al., 2003). Age, gender, experience and voluntariness are moderating factors.

Taylor and Todd (1995a) developed an integrated model, the C-TAM-TPB which combines the predictors of the TAM with the social and control factors of the TPB to produce a hybrid model (Taylor & Todd, 1995a). This hybrid model offers the opportunity to examine the interconnectedness between factors influencing persons' behaviour.

The previous findings were considered in light of the above models. The TAM may be a suitable lens to examine the factors influencing communication partners' use of AAC. The TAM offers a mechanism to explain the formation of attitude by proposing that perceived usefulness and perceived ease of use influence attitude. In contrast, UTAUT includes independent constructs and attitude is not one of them. The findings indicate that both perceived ease of use and perceived usefulness can affect communication partners' use of AAC. Communication partners' view towards AAC may be influenced by the benefits that AAC offers to the interaction and the individual. Communication partners who felt that AAC would be beneficial and support the individual's communication and overall interaction were more likely to have a positive view towards using it (Hanley et al., 2023b). They were also more likely to consistently use AAC (Hanley et al., 2023a; Hanley et al., 2023b). Partners who felt that AAC would not support the individual's communication were more likely to use alternative approaches.

Communication partners' may intend to use AAC however, where they have limited knowledge, time, access, support, available AAC, funding and experience uncertainty, their use of AAC may be negatively impacted. This is reflected in the TPB, where intentions can be present, but perceived behaviour control can prevent people from acting on intentions (Fishbein & Ajzen, 2010). All these factors are captured collectively in the C-TAM-TPB (Taylor & Todd, 1995a).

Recommendations

The C-TAM-TPB (Taylor & Todd, 1995a) offers the opportunity to examine the influence of communication partners' beliefs on their use of AAC as well as the influence of the perceived usefulness and ease of use on their attitudes towards using AAC. Gaining a nuanced understanding the impact of perceived usefulness on attitude may help AAC practitioners to promote positive attitudes towards using AAC. In addition, understanding the impact of perceived usefulness, attitude, subjective norm and perceived behaviour control on intention to use AAC offers the potential to provide information to AAC developers.

Appendix 23 Unpacking the Constructs of the C-TAM-TPB

Items influenced by	Construct	Perceived Usefulness: “ <i>The degree to which a person believes that using a particular system would enhance his or her job performance</i> ” (Davis, 1989, p. 320)
	Concept	Person believes in existence of positive use-performance relationship, question 1, 2, 3, 4
	Dimension	-----
	Qualitative Descriptive Findings	1.Hopeful that AAC would help them maximise the individual's ability to communicate and reported that it did at times. 2.Those who believed AAC would optimise the individual’s communication were more inclined to consistently use it. 3.When AAC was not believed to optimise communication, some used alternative approaches.
	Integrative Review Findings	1.Those who felt AAC would add value i.e., benefit both the individual and interaction had a more favourable view towards AAC.
	Sub-Scales Identified	1.Perceived Usefulness Sub-Scales: Davis, 1989; Davis et al., 1989; Taylor & Todd, 1995b; Teo, 2012; Venkatesh & Davis, 2000 2.Performance Sub-Scale: Rombouts et al., 2016

Items influenced by	Construct	Perceived Ease of Use: “ <i>The degree to which a person believes that using a particular system would be free of effort</i> ” (Davis, 1989, p. 320)
	Concept	Mental and physical effort associated with use, question 5, 6, 7
	Dimension	Easy to learn; Clear and Understandable; Easy to use
	Qualitative Descriptive Findings	1.AAC was reported to be hard to use. 2.Partners needed to learn how to use it, which takes time. 3.Increased difficulty associated with using AAC when an access barrier was present.
	Integrative Review Findings	1.Difficulty learning to use AAC posed as a barrier to use.
	Sub-Scales Identified	1.Perceived Ease of Use Sub-Scales: Davis, 1989; Davis et al., 1989; Taylor & Todd, 1995b; Teo, 2012; Venkatesh & Davis, 2000 2.Effort Sub-Scale: Rombouts et al., 2016

Items influenced by	Construct	Attitude: “ <i>An individual’s positive or negative feelings (evaluative affect) about performing the target behaviour</i> ” (Fishbein & Ajzen, 1975, p. 216)
	Concept	Evaluation of the given behaviour, question 8, 9, 10, 11
	Dimension	An individual’s <i>belief</i> that performing the behaviour is favourable or unfavourable; bad/good; wise/foolish; pleasant/unpleasant; liked/disliked.
	Qualitative Descriptive Findings	1.Partners who reported that AAC supported the user's communication appeared to have a more favourable attitude towards AAC and its use. 2.Alternatively, where AAC did not support or optimise the AAC users’ communication, participants were uncertain about AAC.
	Integrative Review Findings	1.AAC deemed helpful/valuable/beneficial when it supported the individual’s communication and helped partners to achieve meaningful communication.
	Sub-Scales Identified	1. Attitude Sub-Scale: Davis et al., 1989; Ajzen, 1991; Taylor & Todd, 1995b; Teo, 2012; Rombouts et al., 2016

Items influenced by	Construct	Subjective Norm: “ <i>The person’s perception that most people who are important to him think he should or should not perform the behaviour in question</i> ” (Fishbein & Ajzen, 1975, p. 302)
	Concept	Injunctive Norm, question 12, 13
	Dimension	Whether one <i>believes</i> their social network wants them to perform the behaviour.
	Qualitative Descriptive Findings	1.Reported using AAC because the SLT introduced it.
	Integrative Review Findings	1.The support for AAC funnelled through the team members and affected acceptance and the extent to which it was used.
	Sub-Scales Identified	1.Subjective Norm Sub-Scale: Ajzen, 1991; Taylor & Todd, 1995b; Venkatesh & Davis, 2000; Teo, 2012 2.Social Influence Sub-Scale: Rombouts et al., 2016

Items influenced by	Construct	Perceived Behaviour Control “ <i>The perceived ease or difficulty of performing the behaviour</i> ” (Ajzen, 1991, p. 188)
	Concept	-Autonomy to perform the behaviour, question 15 -Capacity to perform the behaviour, question 14, 16
	Dimension	-Capacity to perform the behaviour: the <i>belief</i> that one can, is able to or is capable of performing a given behaviour. A person’s confidence that they can perform a behaviour if they wanted to. -Autonomy to perform the behaviour: the perceived level of control of performing the behaviour and the belief that the behaviour is ‘up to me’.
	Qualitative Descriptive Findings	1.Capacity: Lower confidence in using AAC when knowledge was limited, experienced a level of uncertainty in their own use of AAC. 2.Autonomy: Time constraints, high workloads, lack of funding, availability and AAC that did not match the individual’s ability impacted the extent to which it was used.
	Integrative Review Findings	1.Capacity: Knowledge and support 2.Autonomy: Availability, funding, training, time constraints, high workloads
	Sub-Scales Identified	1.Perceived Behaviour Control Sub-Scales: Ajzen, 1991; Taylor & Todd, 1995b 2.Facilitating Conditions Sub-Scale: Teo, 2012; Rombouts et al., 2016

Items influenced by	Construct	Behavioural Intention: “ <i>...readiness to perform a behaviour</i> ” (Fishbein and Ajzen, 2010, p. 21).
	Concept	Behaviour Intention, questions 17, 18, 19
	Dimension	Person’s estimate of the likelihood or perceived probability of performing a given behaviour
	Qualitative Descriptive Findings	1.Intention was greater when they believed AAC would lead to optimal communication for the AAC user; team working led to a sense of motivation; when the required resources were available intention was stronger.
	Integrative Review Findings	1.Intended to continue using AAC when they believed in its benefits and were prepared.
	Sub-Scales Identified	1.Behavioural Intention Sub-Scales: Davis et al., 1989; Teo, 2012; Taylor & Todd, 1995b; Rombouts et al., 2016; Venkatesh et al., 2003

Appendix 24 Ethical Approval from the Social Research Ethics Committee 2

RE: Log number 2023-098 - Approved Inbox x



Ethics Committee, Social Research <srec@ucc.ie>
to me ▾

Thu, Jul 20, 11:42 AM



Dear Edina

The Social Research and Ethics Committee has now approved your application Log 2023-098 entitled "Examining the Factors Influencing Communication Partners of Persons with Severe/Profound Intellectual Disability Intention to use Augmentative and Alternative Communication using the Combined Technology Acceptance and Theory of Planned Behaviour Model".

The committee wishes you every success with your research.

All the best,

Claire

Appendix 25 Sample Size Calculation

Report: Sample size calculation

Date: 04/07/2023

Table 1: Minimum sample size



Effect size	80% power	Adjusted for 10% drop out
Your choice = 0.30	87	97
Large = 0.35	77	86
Medium = 0.15	157	175
Small = 0.02	1064	1183

The calculation was made for different effect sizes. The significance level used is 5%. From your experience, if you don't expect dropouts, you can ignore the last column in the table.

Appendix 26 Approval to Use the C-TAM-TPB Instrument from the Author

Seeking permission to use the C-TAM-TPB scale External Inbox x ↕ 🖨 🔗

 **Edina Mary Hanley** 

Dear Professor Todd,

Mon, Mar 13, 1:31 PM ★ ↶ ⋮

My name is Edina Hanley. I am emailing to ask permission to use the instrument measuring the constructs of the C-TAM-TPB Model in my research study.

My PhD research is focused on communication partners' use of augmentative and alternative communication with persons with severe/profound intellectual disability. Having conducted systematic and integrative reviews, your C-TAM-TPB Model is the most appropriate to guide this research study, which aims to gain a comprehensive understanding of the factors influencing communication partners' use of augmentative and alternative communication with persons with severe/profound intellectual disability.

I would be grateful for your permission to use your instrument outlined in your 1995 paper, 'Understanding Information Technology Usage: A Test of Competing Models' to test the C-TAM-TPB models' hypotheses of this current study. Specifically, I was hoping to use the items for the C-TAM-TPB constructs: attitude, subjective norm, perceived behavioural control, behavioural intention, perceived usefulness and ease of use as outlined in your 1995 paper 'Assessing IT Usage: The Role of Prior Experience'. I am also seeking permission to access the scoring of the instrument's items as they relate to the C-TAM-TPB model. I plan to pilot the items to ensure they apply to the context of augmentative and alternative communication.

You will of course be accurately cited and acknowledged in my dissertation and any subsequent publications. I can send you a copy of my research study once it is complete, should you wish.
Thank you in advance for your time in considering this request.

Kind regards,
Edina Hanley, PhD student, BSc, RNID

 
to me, Elaine ▼ Tue, Mar 14, 8:29 AM ☆ ↶ ⋮

Edina. You are most welcome to use these instruments as you see fit.

Good luck with your research. Regards. Peter.

Peter Todd

On Mar 13, 2023, at 14:23, Edina Mary Hanley 
...

Appendix 27 Approval to Use the C-TAM-TPB Instrument from the Journal

Seeking permission to use sub-scales of the instrument measuring the Decomposed TAM

External Inbox x

E

Edina Mary Hanley

Mon, Mar 13, 1:53 PM

★ ↶ ⋮

My name is Edina Hanley. I am emailing to ask permission to use sub-scales in the instrument published in Taylor and Todd (1995) paper 'Understanding Information Technology Usage: A Test of Competing Models' in my research study.

My PhD research is focused on communication partners' use of augmentative and alternative communication with persons with severe/profound intellectual disability. Having conducted systematic and integrative reviews, the C-TAM-TPB Model is the most appropriate to guide this research study, which aims to gain a comprehensive understanding of the factors influencing communication partners' use of augmentative and alternative communication with persons with severe/profound intellectual disability.

I contacted the copyright clearance centre to seek permission, who advised me to contact the publisher of the paper. I am aware that the instrument was published in the 1995 paper, 'Understanding Information Technology Usage: A Test of Competing Models' in Information Systems Research. I would be grateful for your permission to use this instrument to test the C-TAM-TPB models' hypotheses of this current study. Specifically, I was hoping to use the sub-scales and their items for the C-TAM-TPB constructs: attitude, subjective norm, perceived behavioural control, behavioural intention, perceived usefulness and ease of use. I am also seeking permission to access the scoring of the instrument's items. I plan to pilot the items to ensure they apply to the context of augmentative and alternative communication.

The authors and journal will of course be accurately cited and acknowledged in my dissertation and any subsequent publications. I can send you a copy of my research study once it is complete, should you wish.

Thank you in advance for your time in considering this request.

Kind regards,
Edina Hanley
PhD student, BSc, RNID

Mon, Mar 13, 2:31 PM

★ ↶ ⋮

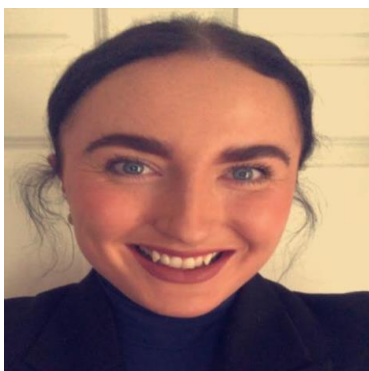
Hi Edina,

I have additionally checked with the Director of Publications and it is fine to use the sub-scales in the instrument (published in Taylor and Todd (1995) paper 'Understanding Information Technology Usage: A Test of Competing Models') in your research study as long as you cite that ISR article as the source of the instrument. Please let me know if you have additional questions.

All the best,

 Managing Editor

Appendix 28 Invitation Flyer Posted to Social Media



School of Nursing and Midwifery, University College Cork

An Invitation to Participate in Research

‘Examining the Factors that Influence the Intention of Communication Partners of Persons with Severe/Profound Intellectual Disability to use Augmentative and Alternative Communication using the Combined Technology Acceptance Model and Theory of Planned Behaviour’

What is the aim of this research?

The aim of this study is to **gain a deeper understanding of the factors influencing communication partners’ intention to use augmentative and alternative communication/AAC** with persons with severe or profound intellectual and/or multiple disability. It is hoped that this research will **assist in supporting the use** of augmentative and alternative communication with persons with severe or profound intellectual and/or multiple disability.

Am I eligible to take part?

To take part in the study, you will need to meet the criteria detailed below:

- You are a communication partner (for at least three months) of a person(s) with severe or profound intellectual and/or multiple disability who uses or will use AAC in the next 12 months
- Living in the Republic of Ireland-please note this is purely jurisdictional
- You are 18 years of age or older

Augmentative and Alternative Communication can take many forms, **examples** include but are not limited to; Lámh, pictures, objects of reference, PECS, eye-gaze devices, communication boards with symbols (e.g., objects, pictures, photographs, line drawings, visual-graphic symbols, printed words) or computers, handheld devices, or tablet devices with symbols that generate speech through synthetically produced or recorded natural (digitised) means. **Due to the nature of this study the following types of AAC will not be included: gestures, facial expressions and body movements.**

What will be involved?

You will be asked to complete an online questionnaire examining the factors influencing your intention to use Augmentative and Alternative Communication in

the next 12 months. This will take 10-15 minutes. Questions include: 'I like using Augmentative and Alternative Communication' .

Who is undertaking the research?

The research is being undertaken by Ms Edina Hanley (a Registered Nurse in Intellectual Disability and Full-Time PhD student), Dr Elaine Lehane, Dr Anne-Marie Martin and Dr Caroline Dalton at the School of Nursing and Midwifery, University College Cork, Ireland.

Interested in taking part?

If you would like to take part, please **follow the link attached to this post. Further information is provided there. If you have any questions please contact me,** Edina Hanley at e.hanley@umail.ucc.ie

Appendix 29 Information Sheet 2

Thank you for considering participating in this research project. The purpose of this document is to explain what the work is about and what your participation would involve to enable you to make an informed choice.

What is this study about?

The purpose of this study is to examine the factors that influence communication partners' intention to use augmentative and alternative communication with persons with severe/profound intellectual disability.

This study will also examine the relationship between some of these factors and their impact on communication partners' intention to use augmentative and alternative communication.

Augmentative and alternative communication can take many forms. It includes, but is not limited to:

Signing systems such as Lámh,

Pictures,

Line-drawings,

Objects of reference,

Picture Exchange Communication System (PECS),

Eye-gaze devices,

Speech Generating Devices,

Communication boards with symbols (e.g., objects, pictures, photographs, printed words),

Computers, handheld devices, or tablet devices (e.g., iPads) with symbols that generate speech through synthetically produced or digitized means, e.g. The go talks app.

Due to the nature of this study the following types of augmentative and alternative communication will not be included: gestures, facial expressions, and body movements.

What is involved?

If you choose to participate, you will be asked a number of screening questions to ensure you meet the inclusion criteria of the study. If you meet these criteria, you will be asked to answer some demographic questions such as age to provide some context for the study findings. You will be asked to complete a questionnaire, which includes statements such as ‘I like the idea of using augmentative and alternative communication’. This should take 15 minutes in total to complete.

Do I have to take part?

No. Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions. You maintain the right to change your mind and withdraw from the study at any stage up to the point of pressing ‘submit’. If you wish to withdraw, click the X icon on the top right-hand corner of the browser. Once you press ‘submit’, your data will be collated with that of other participants and can no longer be retracted.

Will I remain anonymous?

Yes. All information you provide will be anonymous as personally identifying information will not be gathered. This means your answers cannot be traced back to you.

What will happen to the information I provide?

The anonymous data will be stored on the University College Cork supported cloud storage platform, Microsoft Teams SharePoint. Data will be backed up on the

University College Cork supported cloud storage platform, Microsoft OneDrive. The data will be stored for a minimum of ten years.

The information you provide will contribute to a thesis, research publications and may contribute to conference presentations.

Are there any risks involved?

We do not anticipate any negative outcomes from participating in this study. Should you experience any distress, you can choose not to answer questions or to withdraw from the study. Should you have any concerns arising from participating in the research, or should it raise any issues for you, the contact details for the research team members below may be of assistance. Please do not hesitate to contact us.

If you need any further information, you can contact me:

Edina Hanley at e.hanley@umail.ucc.ie

My research supervisors can be contacted at:

Caroline Dalton:

c.doconnor@ucc.ie

Anne-Marie Martin:

A.martin@ucc.ie

Elaine Lehane:

E.Lehane@ucc.ie

This study has obtained ethical approval from the University College Cork Social Research Ethics Committee (Log no.2023-098)

If you are interested in partaking in this study, please click next to answer screening questions, should you meet the criteria and if you agree to take part in this study, please complete the consent form on the next page.

Appendix 30 Screening Items

Instructions: Please select the answers that apply to you.

- Please confirm that you are over 18 years of age

Yes ☐

No ☐

-Please confirm that you are living in the Republic of Ireland

Yes ☐

No ☐

-Please confirm that you are a communication partner for at least three months of a person or persons with severe or profound intellectual and/or multiple disability who uses **or** will use augmentative and alternative communication in the next 12 months

Yes ☐

No ☐

Appendix 31 Consent Form 2

-Do you consent to participate in this study?

Yes ☐

No ☐

Appendix 32 Thank You Message Displayed to Participants on Completion of the Survey

We would like to thank you for participating in this study. We appreciate and value your contribution and the time you took to complete the questionnaire.

Should you have any questions please do not hesitate to contact me, Edina Hanley and my supervisory team at:

Edina Hanley:

e.hanley@umail.ucc.ie

Caroline Dalton:

c.doconnor@ucc.ie

Anne-Marie Martin:

A.martin@ucc.ie

Elaine Lehane:

E.Lehane@ucc.ie

We do not anticipate any negative outcomes from partaking in this study. Should you experience any distress arising from this process please do not hesitate to contact us using the above email addresses and we will direct you to support services if required.

Again, thank you sincerely for your participation and contribution to this study. I will post updates re: findings/publications on social media channels where invitation was circulated.