CORA Cork Open Research Archive
Cartlann Taighde Oscailte Chorcaí

| | |
|---|---|
| Title | An exploration of challenges facing young adults with HF-ASD: the experiences of professionals |
| Authors | O'Connor, Daisy |
| Publication date | 2021-02-10 |
| Original Citation | O'Connor, D. (2021) An exploration of challenges facing young adults with HF-ASD: the experiences of professionals. Cork: Community-Academic Research Links, University College Cork. |
| Type of publication | Report |
| Link to publisher's version | https://www.ucc.ie/en/scishop/rr/ |
| Rights | ©2021, Daisy O'Connor. |
| Download date | 2026-11-16 07:30:38 |
| Item downloaded from | https://hdl.handle.net/10468/12095 |



UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

# An exploration of challenges facing young adults with HF-ASD: the experiences of professionals

Daisy O'Connor

**CARL Research Project**

in collaboration with

ASPECT

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

| | |
|---|---|
| **Name of medical student:** | Daisy O'Connor |
| **Name of civil society organisation/community group:** | ASPECT |
| **Name of community group liaison person:** | Yvonne Scriven |
| **Academic supervisor(s):** | Dr Louise Gibson |
| **Name and year of course:** | Medicine 5 |
| **Date completed:** | 10/02/21 |

## What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grass roots groups, single issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

## What is a CSO?

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

## Why is this report on the UCC website?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

**How do I reference this report?**

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: http://www.ucc.ie/en/scishop/completed/ [Accessed on: date].

**How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?**

The UCC CARL website has further information on the background and operation of Community-Academic Research Links at University College Cork, Ireland. http://carl.ucc.ie. You can follow CARL on Twitter at @UCC_CARL. All of our research reports are accessible free online here: http://www.ucc.ie/en/scishop/rr/.

CARL is part of an international network of Science Shops called the Living Knowledge Network. You can read more about this vibrant community and its activities on this website: http://www.scienceshops.org and on Twitter @ScienceShops. CARL is also a contributor to Campus Engage, which is the Irish Universities Association engagement initiative to promote community-based research, community-based learning and volunteering amongst Higher Education students and staff.

**Are you a member of a community project and have an idea for a research project?**

We would love to hear from you! Read the background information here http://www.ucc.ie/en/scishop/ap/c&vo/ and contact us by email at carl@ucc.ie.

**Disclaimer**

Notwithstanding the contributions by the University and its staff, the University gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Client Group, or users, to ensure that any outcome from the project meets safety and other requirements. The Client Group agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed to a very high standard and to the satisfaction of the Client Group.

# Abstract

Background:

There is a dearth of literature that addresses day to day challenges that face young adults with high functioning (HF) ASD. Previous studies in this area of research have reported high levels of anxiety with many finding everyday living overwhelming. It can be difficult to engage this cohort in research, therefore, health professionals who work closely with this group were chosen as a surrogate to address their difficulties. They are an undervalued resource in describing their experiences.

Objectives:

- To explore the challenges in everyday life for people with ASD
- To identify the role of ASPECT and the perspectives/ experiences of those who work there
- To identify ways in which the challenges can be overcome

Methods:

A qualitative study was undertaken with thirteen professionals working in ASPECT. The participants were from a varied background including education, social care and psychology. They were interviewed in three separate focus groups. The interviews were recorded and transcribed verbatim. Data analysis followed from this.

Results:

Challenges facing young adults with autism were divided into intrinsic and extrinsic challenges. This included communication, emotional regulation, vulnerability, boundaries, social imagination, bullying, isolation, lack of awareness in healthcare, funding and the family's understanding. A broad range of topics were also discussed regarding the role of ASPECT and their recommendations going forward.

Conclusion:

There is need for more awareness regarding autism and their struggles'. There is an onus on medical professionals to educate themselves on all members of their patient cohort. Hopefully with a more sensitive approach this will have a significant impact on their treatment.

# Introduction

## ASD and HF-ASD

Autism Spectrum Disorder, so-called because of its wide spectrum of symptoms, present with a range of difficulties in everyday interactions and relationships. ASD is defined according to the DSM V as "Persistent deficits in social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities" (1). Rates of autism have been increasing globally with 1% of the current Irish Population having a diagnosis of ASD (2). This may be due to an increasing prevalence of autism or due to an increased awareness of autism and its presentation (3). There is a higher incidence of autism in males with the male to female ratio at 4:1 (4). ASD can range to those with mild impairment with normal to above intelligence to those with severe autism who depend wholly on others for their care. High Functioning ASD (HF-ASD) is ASD without intellectual disability and makes up 25% of those with ASD. Of those with HF-ASD in Ireland, 75% are adults.

## Psychiatric co-morbidity

There are many obstacles to be overcome in the lives of people with autism. The greatest of which can be difficulties with mental health. Tove Lugnegård's study found that 70% of people with HF-ASD have had one major episode of depression with 50% having recurrent episodes of depression (4). When this is compared to the general Irish population without autism the prevalence of a major episode of depression is 12% (5). The prevalence for other psychiatric comorbidities such as anxiety disorder, ADHD and bipolar disorder are 50%, 30% and 9% respectively (4). When anxiety disorder is assessed in the general Irish population without ASD this falls to 10% (6).

## Interventions/ Supports available to people with ASD

Interventions and therapies are important in managing symptoms of ASD. Research regarding interventions in adults with ASD is especially lacking in comparison to that of children (7). Services are available, mainly a continuation from diagnostic services, for both ASD ID and ASD non-ID before the age of 18 years, but few supports remain after the transition into further education/employment. ASPECT is one of the few services of this kind in Ireland, offering one-on-one counselling to its service users. Few studies have been performed in the Irish population that explore the range of difficulties facing young adults with ASD non-ID, and the supports they need to engage in everyday activities. Hopefully,

with this knowledge, young adults with ASD will be better provided for and understood in the future.

ASPECT

ASPECT is a community organisation under the umbrella of Cork Association for Autism. They provide support to over three hundred adults with HF-ASD in Cork and Kerry. They aim to promote awareness, education and understanding of ASD non-ID.

# Objectives

The main aim is to explore the experiences of professionals working to support young adults with HF-ASD. Due to difficulties in engagement of people with autism, those working closely with them were chosen to partake. They highlighted the most pertinent issues for their clients.

Objectives include:

- To explore the challenges in everyday life for people with ASD
- To identify the role of ASPECT and the perspectives/ experiences of those who work there
- To identify ways in which the challenges can be overcome.

# Methods

**STUDY DESIGN AND DATA BASE:**

Why qualitative research?

- To identify variables of most concern to population including their perspectives, opinions and experiences of ASD and navigating healthcare and education systems (7)
- To allow those being interviewed to express their thoughts freely

- To encourage people to expand on their responses can open up new topic areas not initially considered (8)
- To provide in depth insight into what professionals working with HF-ASD understand to be the greatest challenges in the lives of their clients

Data base:

- Professionals working in ASPECT including those from education, psychology and education backgrounds were interviewed by myself in focus groups. All with experience of working one on one with people with HF-ASD. They are a definite undervalued resource in describing the challenges of people who might find it hard to do so.

## PARTICIPANTS AND PERIODS

Thirteen participants over a three-session period were included in this study. The focus groups took place at the ASPECT offices. Only the participants and I were present for the focus groups. There are currently twenty-five key workers in ASPECT, however, not all were able to attend on the dates planned. This was due to prior working engagements. The participants varied in age, with some only entering their second year working in ASEPCT and others having been there for sixteen years.

## PROCEDURES AND ANALYSIS

The interviews were semi-structured and recorded via an audio-recorder. Notes were taken during the focus groups and they lasted between an hour to two hours. The focus groups continued until data saturation. The recordings were then transcribed verbatim. Transcripts were not returned to the participants for comment. The data was analysed by thematic analysis. All the data collected for this project was stored securely on a password protected computer and data will be destroyed once work on this project is completed.

## TIMELINE AND ETHICAL APPROVAL

The Literature review was completed on the 25/03/19 with CREC then received on the 15/4/19. Information leaflets were then distributed with consent obtained for all participants by May 2019. Interviews were then conducted during July 2019. Data entry took place between October 2019 to January 2020 with analysis completed by April 2020. The project was then written up between November 2020 and February 2021.

# Results

Three broad themes were identified and further divided into subthemes. The first theme identified was “Intrinsic Challenges”. Intrinsic Challenges are those involving someone’s own difficulties relating to their underlying condition, knowledge and understanding of ASD or their own difficulties in dealing with it. Intrinsic challenges people face include communication, social naivety and insight or self-awareness. The second theme is “Extrinsic Challenges”. Extrinsic Challenges arise from society; the attitudes, knowledge and acceptance of those encountered by the person with ASD. Extrinsic Challenges included a lack of awareness, lack of peer acceptance and poor understanding of ASD. The third theme identified is ASPECT and Recommendations including the role of ASPECT, key workers frustrations and recommendations.

## Theme 1: Intrinsic Challenges

Communication issues proved to be a significant intrinsic challenge to the young people at ASPECT and includes expressive difficulties, rigid thinking, receptive difficulties and emotional intelligence.

### Expressive difficulties

*“it was a psychiatry appointment and it's just around trying to communicate exactly her experience in words in the moment was very difficult she's trying to be her own advocate you know with the absence of having someone with her. Yeah it's difficult”*

### Rigid thinking

*“a question like, what would be your weaknesses would be taken very literally whereas really at core you’re meant to be presenting strengths in terms of self-awareness”*

*“the person with Asperger's might be very direct and the person who's receiving can't receive that direct language”.*

### Receptive difficulties

*“after the meeting, I realized that she actually needed that support because the communication, she didn't understand what they were saying to her”*

*“I’m sure ye guys will have had this as well so you could say something to a client and they just completely miss what you’ve said, they won’t know what I’m even on about.”*

**Emotion recognition/intelligence**

*"an emotion can be basically a physical sensation in the body and whereas we give it a name. Whereas someone on the spectrum. They might have a totally different way of describing that emotion"*

*"the hunger, the sensation, yeah it's not recognized at all. And from, even trying to explore it they don't know what even they're exploring. Because it's not even there".*

Social Naivety was evident in many parts of their lives and often left them in a vulnerable position, at the hands of marketing ploys and often unaware of the social construct of boundaries.

**Vulnerability**

*"with females is that vulnerability regarding males when they're out. Keeping themselves safe in a social situation… even reflecting on that or even working on that or getting external supports for the Cork rape centre and stuff and still not having huge awareness of it like continuing to put themselves in these situations. Because they are vulnerable"*

**Marketing ploys**

*"he was like you know when I'm being healthy I might go to Subway and I was kind of like you know is it really that healthy and you know it's processed food and stuff like that. And he was like yeah because the slogan is "Always Fresh"*

**Awareness of boundaries**

*"I've had clients who've questioned lecturers, you know, put up their hand and told them that they're wrong and that's the wrong information. I've had another client who would also always answer every single question. So just those boundaries, knowing what's appropriate."*

*"to differentiate what's okay to talk to a peer about but not okay to your assistant manager and know that difference"*

The clients' understanding of ASD is an intrinsic challenge that is battled alone and included sensory processing and social imagination difficulties. Sensory Processing issues are atypical responses to sensory stimuli that interfere with their ability to fully participate at home, in education and in society (10). Social Imagination is the ability to imagine how another person may feel, think or experience or how a social situation may look (11). These facets of social interaction bring huge anxiety to the person with autism.

**Insight into their diagnosis**

*"they've been struggling all of their lives trying to understand why they're not functioning…whether it's social whether it's in employment whether it's just managing*

*anxiety or whatever like all the people that they know…they kind of grow up thinking there's something wrong with me"*

**Relief at diagnosis**

*"he always knew that there's something different about him and then being diagnosed, it was a relief for him. And then he was able to fit in so much better. Once he had that label on him and knew what the characteristics of being autistic were there was a big relief for him"*

**Social imagination**

*"Someone on the spectrum they're going to have a lot more difficulty imagining what it's going to look like, the social imagination, what am I going to say in that, how am I going to be…not being able to imagine or predict what questions might be asked."*

**Sensory processing**

*"one used to absolutely hate Christmas and used to feel very sick and get very nauseous and just never could understand why… we looked at the effect of flashing lights from a sensory perspective and the flashing lights on the Christmas tree…changing the Christmas tree lights in his home to an LED light that wasn't flashing took away so much."*

*"noise and people, you know, printers and all of that, which even just light alone can really affect people."*

*"he had said to me I walked down Patrick Street and I feel like I'm being boxed when it's busy…But if you're hypersensitive to something, a brush to somebody on the street or somebody knocks, you can actually feel like you're being physically hit."*

**<u>Theme 2: Extrinsic Challenges</u>**

Extrinsic challenges facing people with HF-ASD include bullying, isolation, challenges in the workplace and lack of external awareness of ASD by peer and family members.

**Bullying**

*"the majority of our clients, I do believe, have been bullied at some stage."*

*"the effect that bullying has on an individual and in the cases that I know of, it did have a huge impact on the individual and it would have led to very high suicidal ideation"*

**Isolation and Loneliness**

*"it would stem from bullying they would almost kind of celebrate the whole loner thing and almost make it part of their identity."*

*"I had a client who was six years in UCC, the only person he ever spoke to on campus was me…if you don't have a gang it's a very big college and you can be very lonely"*

**Absence of normal teen experiences**

*"mightn't have had that kind of peer experience of going out and doing typical teenager stuff."*

**Workplace**

*"there's a huge amount of our clients who are so capable and would be ideal for work and socializing and everything like that. Sometimes people outside that just don't understand them and kind of may not make the effort to understand them"*

*"There's not many reasonable adjustments being made for people, especially in interviews"*

*"noise and light...printers and stuff"*

**Lack of awareness amongst healthcare professionals**

*"...he had very, very difficult experiences because the nurse would come and just pull the arm or, you know, to take it, just not explain the process before it was going to happen."*

*"Mostly it's the different psychiatrist. It's the new face and the going, what's wrong with you? And there's a file like three files thick of, you know, mental health difficulties for maybe a 20 - year span".*

**Importance of Family's Understanding**

*"I think one of the factors that predict outcomes is definitely how supportive a family was around all of it around what autism is, around how to support the child."*

*"Oh, the variety of different stories would be, you know it's a cognitive delay my mother told me or it's something else."*

*"he was never told, it was never broken down and explored and that comes from his parents. There's a fear factor and a lack of understanding and a kind of oh my Johnny is just the same as everybody else"*

*"very often some of our clients don't even know they have a diagnosis of autism until they're 18, you know, or some of our clients were kind of told about it, but they don't understand it and how it affects them."*

## Theme 3: Role of ASPECT and recommendations

The third theme to evolve from the discussions was the Role of ASPECT and their use of experiential practice. Challenges for the ASPECT key worker were also discussed including communication with other services such as Psychiatry and Community services.

**Role of ASPECT**

"*as individual as each individual we work with"*

*"we're not qualified counsellors…not social workers…a key worker's role is very individual".*

*"there are so many positives in our clients! And I learn something from my clients every day because they're great they really are."*

*"I suppose it's our role to sign-post. And to advocate on their behalf for services"*

**Experiential Practice**

*"when we look for the evidence it's just not there to guide you sometimes just really practice based rather than evidence based."*

*"We exist yet there is no research done in this area ……it is the experiential practice…"*

**Funding challenges for the ASPECT key workers**

*"You can advocate until you are blue in the face but if there is no funding…"*

*"we can't openly take everybody who was diagnosed after 18 because we didn't get funding for them. And I know that sounds awful and it's wrong because it is."*

*"we are funded by disability services and they (Psychiatry services) are funded by the HSE mental health services"*

*"we're not trying to land stuff on them and walk away from the client".*

**Strained Relationships**

Between community organisations and psychiatry services sometimes described as *"a really good working relationship"* and at other times *"it's been like almost impossible to I suppose to get any kind of a good working relationship with them or you know any kind of collaboration"*

**Psychiatrists communication style**

*"The way a psychiatrist is trained to ask questions within, say, a clinical appointment is totally the opposite of what our clients need in communication style."*

*"Unfortunately, there are people diagnosing and using tools that shouldn't be diagnosing and using diagnostic tools"*

**Recommendations:**

**Liaison person**

*"there's definitely a need certainly for a stronger link, even like a liaison person, just some point of contact, because otherwise we're just key workers. Just another letter on a desk of, a very overloaded workload already"*

*"That's the trick of the psychiatrist allowing one of us to attend those appointments, not that we'd answer for the client but when the client has given their answer we might ask the next question that might give the more accurate answer"*

**Tailoring questions to suit patients**

*"more specific questions…have you been sleeping at night. You know how much sleep have you been getting…just very direct question sometimes you're going to get more. Or are you sleeping at day or night which is very common with our clients when they're depressed is the daytime sleeping"*

*"if they had that awareness that you can kind of tailor your question, I suppose, to give them the opportunity for success"*

**Focus on the positives**

*"there needs to be part of the report that says, but with intervention, will be able, rather than this idea at 15 well they can't do this and they'll never work full stop"*

*"I know it's considered a disability but there's an awful lot of ability within these people and I think for employers to focus on their abilities and using their perfectionism as a strength"*

*"really get to know the person…rather than getting to know what the disability is"*

**Visual aids**

*"There needs to be maybe a visual level where, you know, you're a one to five…What does fine mean for you?...probe more"*

**Part of every doctor's training**

*"you know this should be part of someone's training. This should be part of it"*

# Discussion

The key workers felt the main concerns were communication, emotional regulation, vulnerability, boundaries, social imagination, bullying, isolation, lack of awareness in healthcare, funding and the family's understanding.

Communication

Many of the key workers described their clients having expressive difficulties. Rigid thinking which frequently comes with autism also proved to be a communication hurdle. This is described as a black and white approach to situations. This in turn can be unfavourable during interviews when trying to show the best self. This black and white or rigid thinking can be of detriment to apt communication. The key workers also described receptive difficulties in meetings and medical appointments. This can be owed to a lack of emotional recognition or intelligence. This echoes many other studies which have focused on communication in autism (12)(13). However, few have gotten the perspectives of those working closest with them.

Vulnerability

Another intrinsic challenge established by the participants was social naivety. Some key workers described a lack of awareness among their clients to social dangers. It was apparent that their clients could be left in the hands of marketing ploys. There was an obvious lack of awareness of boundaries in everyday interactions in university. This could also occur in the workplace with some clients unaware of the hierarchy in employment.

Insight into diagnosis

Insight into their diagnosis can be a challenge for people with ASD (14). Their understanding of ASD and how it effects their lives is an intrinsic challenge needed to come to terms with. Often people can describe a relief at receiving a diagnosis and understanding how this condition has shaped their life. Some also described how sensory processing difficulties were very much part and parcel of understanding their diagnosis.

Sensory processing difficulties

Like many studies concerning anxiety and autism (15)(16), many of the afore mentioned intrinsic factors led to anxiety in their clients. Difficulties with social imagination led to great anxiety in some clients. Sensory processing difficulties can also lead to anxiety and avoidance, Anxiety was a common theme throughout the interviews which tied the anxiety in relation to social situations with their difficulties in imagination and excessive self-focus, specifically in social situations.

Bullying and Isolation

Extrinsic factors discussed in the focus groups included peers, University life and the workplace. Bullying is a major issue amongst people with autism with one key worker noting that effects can be felt for some time. The participants also described that some of their clients would isolate themselves after being bullied to make it their choice. Isolation and loneliness were a common theme. There is an obvious lack of peer acceptance and any deviation from the normal ridiculed.

Employment

The workplace can often be an extrinsic challenge. Many recent studies of Autism and Asperger's have focused on the transition from secondary into third level education in this cohort (17). The focus now needs to turn from those in third level entering the workforce. Up until now their lives have been quite structured, with bells and timetables. The time this stops on entering employment, can be a period of turmoil for those on the spectrum. The lack of clarity can be an issue. But greater than that is the importance of social cues in employment. People need to see the so-called black and white thinking as a positive rather than a negative and to be viewed as an advantage. The key workers also felt that there were no adjustments made for their clients. An adjustment could include phrasing a question for example in a way easier to understand for someone with autism without using metaphorical or abstract language. Sensory issues also came into play as a challenge for those on the spectrum in employment.

Healthcare awareness

Lack of awareness amongst health professionals is also an external challenge. This can include communication difficulties and a lack in continuity in care. Their experiences in hospital or health care settings are filled with angst. One participant described her clients experience in hospital where the reason for investigations was not explained. This uncertainty and lack of explanation was a huge cause of worry for the client which should be taken more into consideration while we are interns on our busy ward rounds. Different rotations and so forth results in new faces for each appointment which can be challenging. Busy schedules also mean there is a lack of time to fully explore issues or to overcome communication hurdles with the patient.

One element not addressed in this study was the physical health of the person with ASD. One can only postulate with the difficulties in accessing healthcare that this must translate into poorer physical health. There are increased rates of obesity, hypertension and diabetes in adults with autism (18). One study found those diagnosed with hyperlipidaemia and hypertension were less likely to be prescribed medication for such then those diagnosed with these conditions in the control group (19). In this aspect this study was less comprehensive than others.

The Family's Understanding

The key workers noted the importance of the family's understanding and support. Without the acceptance or understanding of the family unit it can be seen how that person can in turn struggle with understanding autism and how it has affected their life. Research has shown increased levels of stress in families with a child diagnosed with ASD in comparison to other developmental disorders like Cerebral Palsy and Down's Syndrome (20). Explaining somebody's diagnosis of autism as a child is important, however, from the interviews it was obvious that this did not always happen. One key worker had a possible reason for this failure of information, describing how sometimes parents can be afraid to admit their child has autism and decide not to address the issue at hand.

Role of ASPECT and Recommendations

The role of ASPECT is "*as individual as each individual we work with"* and I found that to be a heartening notion that their role morphs into whatever is necessary at any given time. The people working at ASPECT have a fantastic understanding of their clients and how to help them in different situations. The main role of ASPECT key workers is sign posting and advocating on their clients' behalf. They can advocate on a wide range of things from counselling to other mental health interventions. They view their role as levelling the playing field for their clients. This was such an important thread in an area that can often be filled with all the negatives of autism. The key workers also described a big chunk of their work as sign posting. The professionals of ASPECT described what they do as experiential or anecdotally based rather than evidence based with a clear lack of evidence in this area.

Challenges for the ASPECT keyworker

Funding issues and psychiatry services came up time and time again and illustrates the enormity of this problem. ASPECT receives funding when the client is a "school leaver". They are profiled from the HSE when leaving secondary school and then referred to ASPECT from that process. However, non-school leavers who would not have gone through that process will only receive limited funding. This can occur in someone who got a late diagnosis of autism. It does not seem fair that the age of an individual's diagnosis can determine whether they receive funding. There appeared to be strain in the relationship between the disability services and psychiatry services due to the different streams of funding.

Relationships between community organisations like ASPECT and Psychiatry services varied with some describing a good working relationship and at other times reporting difficulties ensuring collaboration. Key workers described a communication barrier in appointments with mental health professionals and had issues with the communication styles of psychiatrists. Instead of emphasising skills, training and support, a nihilistic view with no hope of improvement is proffered. Key workers can become quite frustrated as how they present to mental health professionals can be at times be completely different to ASPECT. People from different professions, with different training can find their approaches or their discipline's terminologies mutually incomprehensible. This is a common issue in the disability sector where you have multi-disciplinary teams with diverse training.

## Recommendations

The need for a more collaborative approach between psychiatry services and community organisations like ASPECT is crucial. A liaison person could be a useful idea for both parties. In addition, they proposed that key workers be allowed attend appointments with the client. They also recommend the use of more direct language in gauging how someone is feeling, stressing that disturbance in sleep patterns be explored as often indicative of depression in clients. This awareness also follows through with interviews in tailoring questions and so forth.

Increasing awareness of autism is an extensive recommendation of ASPECT. This is in all aspects of life from employment to medical services and to the public. ASPECT promote getting to know the person rather than the disability. Another essential facet stressed by the key workers was a focus on the positives of autism rather than the negatives. Strengths must be recognised in this cohort and seen as a positive in the workplace. ASPECT recommended the use of visual aids in appointments. This could assist in grounding the abstract notion of feeling. For that reason, ASPECT recommend that working with people with autism should be part of every doctor's training. The health care system does not realise the power they hold and the power in words. Reports filled with "won't" or "can't" are unlikely to really help the patient. The notion that nothing can be improved is always an unhelpful one.

## Strengths and Limitations

The sample size was a definite strength. This allowed data to be collected until saturation. My data was also audio-recorded which proved to be a great help when analysing as I could repeat listen. However, my main strength lay in the population itself. This is the first study of its kind in Ireland, which focussed on key workers with direct experience of working with HF-ASD clients. Their insights and opinions into the lives of their clients was invaluable for this project.

Weaknesses of my project included the large volumes of data to be transcribed. The undertaking of thematic analysis could also be considered a weakness with no prior experience. This project was entirely qualitative research which could be thought of as a weakness. However, you do not get insight with quantitative studies. Though it can be construed as subjective, qualitative remains valuable as it offers insight to the lived experience of the subjects and the experiential knowledge of professionals in the field.

## Implications of Findings

There is a need to increase awareness of ASD among employers, health care workers, schools, in university and in the public. ASD awareness should be part of medical training. More community-based support and collaboration with medical and psychiatry services. More qualitative research with the clients themselves (beyond the scope of FYP).

# Conclusion

Ramps and lifts have been constructed in healthcare for those with physical difficulties but there is a long way to go for those with social difficulties. As doctors we will have to treat a wide range of patients. There is an onus on medical professionals to become more informed about people with autism and try grasp an understanding of their difficulties. A more sensitive approach will have a significant impact on their lives and benefit their health outcomes to a great extent.

# References


1) American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). American Psychiatric Pub; 2013 May 22.
2) Sweeney MR, Staines A, Boison A. Autism Counts. A Report on Autism Spectrum Disorder prevalence estimation in the Republic of Ireland. Retrieved February. 2016;10:2018.
3) Kim YS, Leventhal BL, Koh YJ, Fombonne E, Laska E, Lim EC, Cheon KA, Kim SJ, Kim YK, Lee H, Song DH. Prevalence of autism spectrum disorders in a total population sample. American Journal of Psychiatry. 2011 Sep;168(9):904-12.
4) Lugnegård T, Hallerbäck MU, Gillberg C. Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. Research in developmental disabilities. 2011 Sep 1;32(5):1910-7.
5) Raftery MN, Sarma K, Murphy AW, De la Harpe D, Normand C, McGuire BE. Chronic pain in the Republic of Ireland—community prevalence, psychosocial profile and predictors of pain-related disability: results from the Prevalence, Impact and Cost of Chronic Pain (PRIME) study, part 1. Pain. 2011 May 1;152(5):1096-103
6) Walsh D, O'Hare A, Blake B, Halpenny JV, O'Brien PF. The treated prevalence of mental illness in the Republic of Ireland–the three county case register study. Psychological Medicine. 1980 Aug;10(3):465-70.
7) Wehman P, Schall C, Carr S, Targett P, West M, Cifu G. Transition from school to adulthood for youth with autism spectrum disorder: What we know and what we need to know. Journal of Disability Policy Studies. 2014 Jun;25(1):30-40.
8) Swinth Y, Tomlin G, Luthman M. Content analysis of qualitative research on children and youth with autism, 1993–2011: Considerations for occupational therapy services. American Journal of Occupational Therapy. 2015 Sep 1;69(5):6905185030p1-9.
9) Kisely S, Kendall E. Critically appraising qualitative research: A guide for clinicians more familiar with quantitative techniques. Australasian Psychiatry. 2011 Aug;19(4):364-7.
10) Ahn RR, Miller LJ, Milberger S, McIntosh DN. Prevalence of parents' perceptions of sensory processing disorders among kindergarten children. American Journal of Occupational Therapy. 2004 May 1;58(3):287-93.
11) Ten Eycke KD, Müller U. Brief report: new evidence for a social-specific imagination deficit in children with autism spectrum disorder. Journal of Autism and Developmental Disorders. 2015 Jan 1;45(1):213-20.
12) Biklen D, Schubert A. New words: The communication of students with autism. Remedial and Special Education. 1991 Nov;12(6):46-57.
13) Happé F, Ronald A, Plomin R. Time to give up on a single explanation for autism. Nature neuroscience. 2006 Oct;9(10):1218-20.

14) Schriber RA, Robins RW, Solomon M. Personality and self-insight in individuals with autism spectrum disorder. Journal of personality and social psychology. 2014 Jan;106(1):112.
15) Kerns CM, Kendall PC. The presentation and classification of anxiety in autism spectrum disorder. Clinical Psychology: Science and Practice. 2012 Dec;19(4):323-47.
16) Lang R, Regester A, Lauderdale S, Ashbaugh K, Haring A. Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: A systematic review. Developmental neurorehabilitation. 2010 Jan 1;13(1):53-63.
17) Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. Journal of autism and developmental disorders. 2011 May 1;41(5):566-74.
18) Cashin A, Buckley T, Trollor JN, Lennox N. A scoping review of what is known of the physical health of adults with autism spectrum disorder. Journal of Intellectual Disabilities. 2018 Mar;22(1):96-108.
19) Tyler CV, Schramm SC, Karafa M, Tang AS, Jain AK. Chronic disease risks in young adults with autism spectrum disorder: forewarned is forearmed. American journal on intellectual and developmental disabilities. 2011 Sep;116(5):371-80.
20) Estes A, Munson J, Dawson G, Koehler E, Zhou XH, Abbott R. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism. 2009 Jul;13(4):375-87.

## Student Declaration

LG and DOC designed the research study with LG providing expertise on the research topic. DOC contributed to the design of the work, acquisition and analysis of the data and drafting and writing of the report.

## Acknowledgments

Thanks to all the staff at ASPECT and Yvonne Scriven for taking part in my project. Also thank you to Dr Gibson for all your help and knowledge throughout the last few years.

Appendices

A checklist of items that should be included in reports of qualitative research.

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| **Domain 1: Research team and reflexivity** | | | |
| *Personal characteristics* | | | |
| Interviewer/facilitator | 1 | Which author/s conducted the interview or focus group? | 6 |
| Credentials | 2 | What were the researcher's credentials? E.g. PhD, MD | 1 |
| Occupation | 3 | What was their occupation at the time of the study? | 1 |
| Gender | 4 | Was the researcher male or female? | 1 |
| Experience and training | 5 | What experience or training did the researcher have? | 1 |
| *Relationship with participants* | | | |
| Relationship established | 6 | Was a relationship established prior to study commencement? | 7 |
| Participant knowledge of the interviewer | 7 | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | 7 |
| Interviewer characteristics | 8 | What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | 7 |
| **Domain 2: Study design** | | | |
| *Theoretical framework* | | | |
| Methodological orientation and Theory | 9 | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis | 7 |
| *Participant selection* | | | |
| Sampling | 10 | How were participants selected? e.g. purposive, convenience, consecutive, snowball | 6 |
| Method of approach | 11 | How were participants approached? e.g. face-to-face, telephone, mail, email | 7 |
| Sample size | 12 | How many participants were in the study? | 7 |
| Non-participation | 13 | How many people refused to participate or dropped out? Reasons? | 7 |
| *Setting* | | | |
| Setting of data collection | 14 | Where was the data collected? e.g. home, clinic, workplace | 7 |
| Presence of non-participants | 15 | Was anyone else present besides the participants and researchers? | 7 |
| Description of sample | 16 | What are the important characteristics of the sample? e.g. demographic data, date | 7 |
| *Data collection* | | | |
| Interview guide | 17 | Were questions, prompts, guides provided by the authors? Was it pilot tested? | 7 |

| | | | |
|---|---|---|---|
| Repeat interviews | 18 | Were repeat inter views carried out? If yes, how many? | 7 |
| Audio/visual recording | 19 | Did the research use audio or visual recording to collect the data? | 7 |
| Field notes | 20 | Were field notes made during and/or after the inter view or focus group? | 7 |
| Duration | 21 | What was the duration of the inter views or focus group? | 7 |
| Data saturation | 22 | Was data saturation discussed? | 7 |
| Transcripts returned | 23 | Were transcripts returned to participants for comment and/or | 7 |

| Topic | Item No. | Guide Questions/Description | Reported on Page No. |
|---|---|---|---|
| | | correction? | |
| **Domain 3: analysis and findings** | | | |
| *Data analysis* | | | |
| Number of data coders | 24 | How many data coders coded the data? | 7 |
| Description of the coding tree | 25 | Did authors provide a description of the coding tree? | N/A |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | 7 |
| Software | 27 | What software, if applicable, was used to manage the data? | N/A |
| Participant checking | 28 | Did participants provide feedback on the findings? | N/A |
| *Reporting* | | | |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number | 7 |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | 7 |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | 7 |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | 7 |