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# *Another Side to Their Story:*

# *Including People with Down syndrome in an Initial Exploration of the Social Fabric of Their Emotional Well-Being*

Sarah Dunphy

**CARL Research Project**

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| **Name of student(s):** | Sarah Dunphy |
| **Name of civil society organization/community group:** | Down Syndrome Cork |
| **Supervisor(s):** | Lydia Sapouna |
| **Name and year of course:** | Social Work 4th Year |
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## What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a service provided by research institutes for the Civil Society Organisations (CSOs) in their region which can be grass roots groups, single issue temporary groups, but also well structured organisations. Research for the CSOs is carried out free of financial cost as much as possible.

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).

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## How do I reference this report?

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

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Group.

# EXECUTIVE SUMMARY

## BACKGROUND TO THE STUDY

The project ran as part of the Community Academic Research Links CARL programme in University College Cork. Down Syndrome Cork were the community organisation. They provide support and services to adults and children with Down syndrome and their families in Cork city and county. The intended participants of the inclusive qualitative research study were members of Down Syndrome Cork. The organisation raised the topic of mental health for adults with Down syndrome in light of anecdotal evidence of poor mental health for some of their members. The project was then developed through a consultative process and approved by the board of Down Syndrome Cork.

## RESEARCH AIMS

Receive input from Down Syndrome Cork members regarding engaging in research and of their preferred ways that the topic of emotional well-being is explored. Investigate the emotional well-being of Down Syndrome Cork members by capturing a contextual snapshot of the emotional lives of the participants. Appraise the dominant constructions of Down syndrome and their relevance in conducting this study. Undertake a comprehensive critical review of influential perspectives in inclusive research discourse. Provide discussion on the implementation and accomplishment of inclusive research practices throughout this study. Conduct a thematic analysis of the data collected in the interviews regarding emotional well-being. Provide findings and recommendations to inform future research and service delivery for Down Syndrome Cork.

## METHOD

Drawing from inclusive research guidelines, an inclusive accessible approach to recruiting a sample was employed. Four participants with Down syndrome participated. Pre and post consultation group sessions were held in conjunction to one on one semi structured interviews. The exact method and process of the research interviews was informed by pre consultation and safeguards for the well-being of the participants were agreed in that session. The data was subject to inductive thematic analysis. The identified themes were further verified by participants in the post consultation session.

## KEY FINDINGS

**The Pursuit of Romance:** Romantic relationships featured as significant factors in shaping the participant's emotional lives. The concept, pursuit and engagement in romantic relationships featured as a clear theme. In the pursuit of romance what appeared to differ in the experience for the participants of this study from their more 'typical' peers are the barriers to engaging in healthy romantic relationships. Such as a limited peer group and facilities available in which to romantically meet someone. Many people with Down syndrome remain in the same network of peers and services for their entire lives which then heightens the impacts of conflict or relationships coming to an end. They may not have enough of an appropriate degree of separation from romantic partners.

**Responsibility, Mastery and Achievement:** The extent that the participants are able to take part in valued activities or perform tasks that are viewed by themselves and others as valuable, important and worthwhile was identified as highly influential in their emotional lives. The successful fulfilment of tasks, activities and responsibilities creating a sense of achievement which was predominantly identified as a source of enhanced emotional well-being. This was one area where participants acknowledged feeling bad. Unsuccessful attempts to complete tasks, fulfil responsibilities and experiencing barriers to achieving engagement due to cognitive limitations were identified as a source of diminished emotional well-being.

**We Never Feel Bad:** was consistent theme present in the data. A disproportionate amount of difficulty in recognising, describing and recalling feeling bad appeared to be present. Participants who spoke in relative detail about feeling good and positive experiences then became quite limited in their language and memory when asked about feeling bad.

## RECOMMENDATIONS

- Services and supports that safeguard the level of vulnerability the participants may have in relationships could be of benefit.

- Facilitating participation in valued activities or perform tasks could promote emotional well-being. Facilitation would likely be enhanced by promoting self-efficacy and providing support to mitigate the diminishment of emotional well-being that may be caused by the challenges of undertaking those tasks and activities. Support does not have to be formal, family was identified as a current source of highly valued support.

- It may be beneficial to holding workshops to increase emotional literacy. To enhance participant's identification and recognition of a broader spectrum of emotions. Follow on research on the difficulty that was present in discussing feeling bad would be beneficial.

## *Acknowledgements*

First and foremost, I wish to acknowledge the participants of the project. Thank you for your valuable time, assistance and contribution in conducting this research. I hope I have accurately captured your side of the story and adequately highlighted what you consider to be important. I am also grateful to all those family and staff members of Down Syndrome Cork who facilitated our work together. Particularly my liaison person Julie Gill and Karen O Sullivan Coordinator of Services.

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My family in Dublin who have spurred me on, taken pride in my academic accomplishments and supported me however they could. Those friends and loved ones in Cork who I could always rely on. I acknowledge my own commitment and respect for the ethos, values and ethics of social work, may that commitment remain proud and strong throughout my future career.

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# *Chapter 1 Introducing the Research*

## 1.1 Introduction

In introducing the research this chapter provides background to the development of the study and the rationale for the research. The aims and objectives of the study are put forth and the research questions outlined. Pertinent ethical considerations and their significance to the study are discussed. The methodological standpoint guiding the research is provided. Finishing with a chapter summary and an overview of the chapters to follow.

## 1.2 Background to Development of the Project

I have endeavoured to conduct an inclusive qualitative research study with people with Down syndrome. The project ran as part of the Community Academic Research Links CARL programme in University College Cork. My dissertation is linked with Down Syndrome Cork, a community organisation providing support and services to adults and children with Down syndrome and their families in Cork city and county. The intended participants were members of Down Syndrome Cork. The organisation raised the topic of mental health for adults with Down syndrome in light of anecdotal evidence of poor mental health for some of their members. The project was developed through a consultative process and approved by the board of Down Syndrome Cork.

### 1.3 Research Rationale

The academic publication of qualitative research that includes people with intellectual disabilities as the direct participants has increased but they are in the minority of papers published in the field (Beail & Williams, 2014). It has long been made evident throughout the literature that without a concerted effort to do more direct research with people with intellectual disabilities, this field of research will be left with a significant gap in its knowledge base (*ibid*, 2014,Ware 2004). This study hopes to make a contribution to addressing the current gap in the knowledge base.

#### 1.3.1 Inclusive Research Approach

It is acknowledged here that the literature on disability research makes distinction between participatory, empowering and emancipatory research paradigms (Barton, 2005, Chappell, 2000 Kiernan, 1999).To avoid this report being taken over by the complex politics and debate dominant in the discourse this study describes its approach as 'participation in inclusive research'. Wherein the project is situated as: having the ability to achieve an increased level of participation, with a high possibility to be empowering in how the participants experience taking part and in giving voice to their lived experiences. Emancipation through the research is perceived to be an ambition beyond realisation at this time. It is contended that the foundations of empowerment requisite in achieving emancipation have not been strengthened enough to fully support such an ambition (Hanley, 2005). The distributions and disparities of power pertaining to this are further discussed in review of the literature.

### 1.3.2 Reframing the Topic

Upon review of the relevant literature a rationale for reframing the research topic from a clinical concept of mental health to a more holistic concept of emotional well-being developed. Due to the extent to which people with Down syndrome have been subject to pathological constructs, there is an absence of recognition that the emotions of people with Down syndrome occur in response to environmental and social conditions (Castro, et al, 2014, Smith, 2011, Hughes, 1998). In light of this disparity this research was reframed from the initially proposed clinical concept of mental health to a more holistic concept of emotional well-being. The project design proceeded to be developed around inclusive research principles (National Disability Authority, 2002, 2009).

### 1.3.3 Examining the Achievement of an Inclusive Approach

The related literature has long drawn attention to the lack of detail in many inclusive research studies on the process of including people with intellectual disabilities (Walmsley, 2004). This absence remains evident and in many ways inclusive research is still in its infancy. In addressing this as well as investigating the topic of the emotional well-being of people with Down syndrome, this research takes an in-depth look at the achievement of an inclusive approach to conducting the study. It was considered important to acknowledge what did or did not work as this may help researchers to engage more effectively with people with Down syndrome in future studies. A review of relevant literature also details the impacts that the social fabric that research occurs may have. The complexities evidenced in that review support and promote the need for inclusive studies to provide analysis of inclusive research practices in action.

### 1.3.4 Addressing the Gap in the Current Knowledge Base

Research has shown while existing studies serve in '*addressing a wide range of issues…we are not at a stage where we can review a body of qualitative research on a particular aspect of people with intellectual disability*' (Beail & Williams, 2014, p. 93). In light of this an inductive approach to the research was employed whereby themes stemmed from the data rather than the researcher developing the themes through the prior review of relevant studies (Braun & Clarke, 2006).

## 1.4 The Relevance of Social Work Practice to Inclusive Research

A recent study which 'involved people with dementia in a systemic review' (Fisher & Wade, 2016), helps to demonstrate the relevance and value of social work practice in inclusive research. The study was conducted by a multi-disciplinary team, the majority of which were of the social work discipline. The impact of social work values and skills is evident throughout the study. Cognitive impairment was not seen as an insurmountable barrier to the involvement of these service users in the research but as a complication to adapt to and work around to gather valuable data. The researchers drew attention to matters such as the importance of ensuring that consideration for ethical approval is not constructed in a manner which is so overprotective it becomes disempowering and negates the service user's freedom to not only choose but to also have that decision hold weight. The study had a specific aim 'of providing an environment that enhanced personhood and supported engagement'. Placing high emphasis '*that observing and monitoring in an appropriate manner must take place to safeguard and fulfil responsibility to not cause harm'* (*ibid*, 2016, p.115).

This provides an excellent example of an innovative, ethical and inclusive approach to research from a social work perspective that is appropriate for participants whose cognition differs from what is typical. An earlier paper regarding participatory research on learning disabilities discusses the valuable role that social work practitioners can play in conducting inclusive research. Identifying shared features such as the use of thoughtful sensitive approaches to interviewing and the transmission of warmth, empathy and unconditional positive regard. Furthermore the reflectivity inherent in social work practice is fitting in its application to reflective research which seeks to examine both the research process and the findings that are produced (Atkinson, 2005b). Drawing from a social work perspective this study shall endeavour to apply a reflexive, person centred approach to producing this research.

## 1.5 Research Aims & Objectives

This study aims to gain an insight into the understanding and experience of emotional well-being for people with Down syndrome. The research seeks to achieve this by capturing a contextualised snapshot of the emotional lives of the participants. In the conduction of this research the researcher aims to be mindful of the responsibility they perceive ethical research to have for the constructs it promotes and produces. In the accomplishment of these aims the research objectives are as follows

- Receive input from Down Syndrome Cork members regarding engaging in research and of their preferred ways that the topic of emotional well-being is explored.
- Investigate the emotional well-being of Down Syndrome Cork members by capturing a contextual snapshot of the emotional lives of the participants. The exact method and process would be informed by consultation.
- Appraise the dominant constructions of Down syndrome and their relevance in conducting this study.
- Undertake a comprehensive critical review of influential perspectives in inclusive research discourse.
- Provide discussion on the implementation and accomplishment of inclusive research practices throughout this study.
- Conduct a thematic analysis of the data collected in the interviews regarding emotional well-being and provide findings informing further research and service delivery for Down Syndrome Cork and its members.

## 1.6 The Significance of Ethical Considerations

There are many ethical guidelines relating to the inclusion of people with disabilities in research. In Ireland alone the National Disability Authority have produced the following publications *'Guidelines for Including People with Disabilities in Research'* (2002), '*Ask Me Guidelines for Effective Consultation with People with Disabilities'* (2002), and '*Ethical Guidance for Research with People with Disabilities'* (2009). Putting the recommendations of the publications guiding inclusive research into practice remains challenging, particularly in the context of intellectual disability.

> *'The power imbalances between people with learning disabilities and the researchers continue to be camouflaged by a rhetoric of participation. One of the keys to progress is to clarify what roles supporters of inclusive research, can play, and how we can develop our skills'*
>
> (Walmsley, 2004, p. 66).

In a concerted attempt to progress beyond such rhetoric, this study has provided a detailed discussion of the implementation and achievement of inclusive research principles. In approaching this study, social research is not seen as a detached observance and investigation of a fixed world or static phenomena, but as an endeavour which produces the concepts, constructs and paradigms which shape a world of active phenomena (Holloway, 1997).

## 1.7 Research Questions

In establishing a basis for the way the members of Down Syndrome Cork would want me to discover more and to tailor the research to their preferences the following questions guided consultation with them:

- How is the opportunity to partake in research received?
- What research processes can be agreed and established?
- How is the topic of emotional well-being received?

Via consultation the further research questions relating to the topic of emotional well-being developed as:

- What are the factors that impact the participant's emotional well-being?
- What aspects of those factors make the participants feel good or feel bad?
- What does help or would help the participants manage feeling bad?

Through the secondary research an additional question was identified as:

- To what extent is inclusive research achieved in this study?

## 1.8 Methodological Standpoint

This research is approached from an interpretivist ontological position as a preliminary investigation into an individualistic social phenomena: emotion. Essentially producing objective knowledge through social research is deemed as improbable because '*social reality is a shifting and contradictory thing that only lends itself to short lived, small-scale and partial accounts by researchers'* (Denscombe, 2010, p. 123). In keeping with an inductive approach to the study, an inductive analysis of data will be employed, whereby the themes shall stem from the data, rather than the researcher developing the themes through the prior review of related studies (Braun & Clarke, 2006).This approach is also fitting in light of the absence of an adequate body of research to develop themes from (Beail & Williams, 2014).

## 1.9 Chapter Summary

This chapter has provided the title and background to the development of this study. As outlined in conjunction to investigating the topic of emotional well-being through a qualitative inclusive research study, the inclusive research process itself is subject to study. The rationale for the research and its aims and objectives were put forth including the relevance of social work practice. The research questions were outlined. Pertinent ethical considerations and their significance to the study were discussed. The methodological standpoint guiding the research was provided.

**Subsequent Chapter Overview**

**Chapter 2 Appraising Social Constructions of Down syndrome**

This chapter examines a number of influential constructs of disability, then sharpens the focus to people with Down syndrome. Providing analysis of the salience of the constructs in relation to this study.

**Chapter 3 Dominant Perspectives in Inclusive Research**

This chapter examines the development of inclusive approaches to researching intellectual disability in greater detail. Finishing with discussion on managing the oppressive features of social research and the relevance of social work practice in conducting inclusive research.

**Chapter 4 Research Design and Methodology**

This chapter presents the epistemological position and methodological approach of this study. Documenting the recruitment of the sample, research design, ethical considerations, data analysis and the bias and limitations of the study.

**Chapter 5 Examination of the Extent that Inclusive Research was Achieved**

In attending to the research aim to provide a clear account of the extent that inclusive research practices were achieved in this study, this chapter outlines each stage of the research process, documents the inclusive elements and discusses the achievement of and restriction to their implementation.

## Chapter 6 Inclusive Research Practice Findings & Recommendations

This chapter will examine the key factors found to diminish and enhance engagement in inclusive research during this study, providing findings and recommendations in relation to facilitating participation in inclusive research.

## Chapter 7 Emotional Well Being Findings & Recommendations

This chapter discusses the research findings from the interviews which were conducted with four participants with Down syndrome. Through a process of thematic analysis three main themes were identified as having the most significant impact on the participant's emotional well-being. The pursuit of romantic relationships, responsibility, mastery and achievement, the final theme relates to a consistent assertion by the participants that they '*never feel bad*.' Recommendations relating to each theme are made.

# *Chapter 2 Appraising Social Constructions of Down syndrome*

## 2.1 Introduction

This chapter will examine a number of influential constructs of disability, then sharpen the focus to people with intellectual disabilities and Down syndrome, providing an analysis of the salience of these constructs in relation to this study throughout.

## 2.2 Constructing Disability and Down syndrome

There is abundant discourse on the 'problems' or problem of people with Down syndrome. The nature and origins of those 'problems' are generally viewed as individual or personal (Smith, 2011) What is less examined or included in the dominant discourse is the nature of the social, political and environmental constructs originating from the world which people with Down syndrome inhabit (Hughes, 1998, Goffman, 2006). The reduction of the diverse spectrum of human physicality and cognition to a sharp distinction between what is normal or pathological is now examined.

## 2.3 Forging a Normal or Pathological Dichotomy

Canguilhem contributed some prominent arguments on the impact of the medical profession constructing and disseminating categories of 'normal' and 'pathological'. He viewed the devotion of medicine to the establishment of a 'norm' as a denial of the natural diversity of human biology. He argued that 'to normalise, is to impose a requirement on an existence' which then means those 'whose, variety, disparity, with regard to the requirement, present themselves as a hostile' (Canguilhem, 1991).

### 2.3.1 Foucault

Foucault's seminal sociological analysis of medicine or 'the science of bodies' described what he termed 'panoptic practices' of classifying and dividing the population into categories relating to digress or deviance from typical norms. These 'panoptic practices' greatly contributed to a medical or individual model of disability, whereby the impairment itself became of central concern. Historically these practices were oppressive in their creation of a series of institutions which allowed for the removal of people with physical and mental impairments from everyday life. Contributing to cultural prejudice and creating societal structures which privilege those of 'normative' mental and physical function. Foucault contended that the standardisation of what is the 'norm' created hierarchies of deviance, based on progressively subjective judgements, compromising the legitimacy of medicine's claim to objectivity. He viewed the examination, propagation and dissemination of these categories of pathology in the modern era as a form of oppression and exploitation of those it deemed deviant (Foucault, 1976).

### 2.3.2 A Natural Occurrence on the Diverse Spectrum of Human Physicality

Over the past number of decade's people with Down syndrome and their advocates have sought to change the view of Down syndrome as an illness and contend that their extra chromosome is a naturally occurring aspect of human biology (Down syndrome Ireland, 2012, Smith, 2011). Through this lens, Down syndrome is viewed as a natural occurrence on the diverse spectrum of human physicality and cognition rather than as a defect. The construction of norms of physical and cognitive function results in a society geared to maintain its determined norms. An analysis of the commission of these constructs through research will now be provided.

## 2.4 The Medical Model

Historically, in constructing disability, the medical model has been dominant, this model contends that physical or mental impairments are the main cause of problems experienced by people with disabilities (Oliver, 1990, 2009). The bio medical model can be said to be characterised by '*the reduction of a complex set of interrelation factors, social, economic, political, environmental and personal to one constituent aspect, the biology'* (McCluskey, 1997, p 55). The medical model is particularly significant to the social construction of Down syndrome. People with Down syndrome differ from what is typical both physically and cognitively due to an additional chromosome, engage with medical services more frequently and are generally treated for a range of physical health complications throughout their lives. This model can be viewed as oppressive in its reductionism because it diminishes the personhood and heterogeneity of individuals with Down syndrome.

## 2.5 The Commission of Constructs through Research

It is predominantly the disciplines of medicine and psychology that have focused on researching intellectual disability, mainly in the commission of constructs which emphasis deviance, pathology, and clinical perspectives of people with intellectual disability (Stone & Priestley 1996, Dowse, 2009, Beail & Williams, 2014). People with Down syndrome have long been the subjects of such study and are predominantly known or viewed from these perspectives (Smith, 2011).

## 2.6 Critical Engagement with Clinical Research Studies

It is generally uncontested that as a group, people with intellectual disabilities have a history of subjection to stigmatisation, which remains prevalent today. People with Down syndrome have readily identifiable features, an intellectual disability that is socially and cognitively heterogeneous, with unique physical characteristics, none of which are subscribed high societal value (Goffman, 2006). A study of self-awareness in young adults with Down syndrome provides some points of relevance in the conduction of this study. The unique physical characteristics of Down syndrome may be particularly salient for people with Down syndrome in their self-recognition of difference. Coping strategies in response to perceived difference and stigma include *'minimisation of disability, overcompensation such as working harder and being more compliant'* (Cunningham & Glenn, 2007, p 359). This researcher was cognisant of the possibility of heightened compliance in carrying out this study. Studies such as Paterson et al. 2012 offer further discussion on the potentially negative impact stigma may have in relation to the emotional well-being of people with Down syndrome. This study provided evidence that, of those who took part, participants who presented as most cognisant of their subjection to stigma, were also those who then presented as having the lowest levels of self-esteem. The causal relationship between the experiences of stigma in lowering of self-esteem is not definitive, it could also be the case that low self-esteem is a mitigating factor pertaining to the increased perception of being stigmatised (Paterson et al, 2012). Commissioning social constructs which further stigmatise in research could perpetuate a cycle where the social constructs which stigmatise are being maintained by those researching the adverse emotional impacts of the stigma.

### 2.5.1 Drawing down these Paradigms

In drawing down these paradigms and their possible impacts for the people who participated in this study. When a medical model is the most frequent lens through which a person is understood their personhood may be diminished. It becomes less and less important to hear from them regarding their experiences, this can creating a partial account of their live. For people with Down syndrome accounts from a medical perspective are of dependence, pathology, intervention and treatment. The articulation of alternative accounts may serve to create a more balanced and full picture of the lives of people with Down syndrome (Atkinson, 2005, Goodley, 1996, Gray & Ridden, 1999). Due to the high prevalence of clinical studies of the condition, people with Down syndrome are vulnerable to heightened subscriptions of pathology. Furthermore people with Down syndrome have expressed a desire to break away from those pathological labels. '*A person does not "suffer" from Down syndrome, nor are they "afflicted". It is not a disease…it is a chromosomal condition which results in an extra copy of the 21st chromosome'* (Down syndrome Ireland, 2012). As attendance to the mental health of people with Down syndrome has also become an area of concern, this too has predominantly been from a medical perspective. In addressing these imbalances for the purposes of this research diagnostic labels derived from a bio medical model of mental health shall not be used. It is acknowledged that a body of such research indicates that the experience of mental health difficulties such as depression is thought to be commonly evident amongst people with intellectual disabilities (Prasher, 1999). However, research such as this may also limit the recognition of the emotions of people with Down syndrome as occurring in response to environmental and social conditions.

## 2.7 A Social Model of Disability

As a disabled rights movement led by people with disabilities emerged, its activists produced a comprehensive critique of the experts, professionals and researchers who studied, categorised and described the experience of disability (Barnes & Mercer, 1994, Stone & Priestley, 1996, Oliver, 1992). An alternative model of disability was constructed which ascribed significant aspects of disablement for people with disabilities as social in origin. An important stage in the development of a social model of disability can be traced to the Union of Physically Impaired against Segregation (UPIAS) publishing its manifesto Fundamental Principles of Disability in the 1970's. This manifesto was ground breaking in that it was written by people with disabilities and in it distinguishing between impairment and disability. Impairment was viewed as 'having a defective limb, organ or mechanism of the body' (UPIAS, 1976, p.3), whilst disability was asserted as:

> *'The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in mainstream society'*
>
> (*ibid*, 1976, p.3).

Effectively the social model delimits disability as a product of oppressive social structures and excluding practices (Abberley, 1987) Significant in that '*If disability is understood as socially created construction, its meaning may be altered by social and political action'* (Hughes, 1998, p.26). Proponents of the social model placed emphasis on dismantling social barriers and cultivating positive disability identities as a means to access equal opportunities and achieve full integration as equal citizens (UPIAS, 1976, Finkelstein, 1980, Oliver, 1990).

### 2.7.1 Limits to the Thesis of Social Oppression

A social constructionist view of intellectual disability would certainly lends support to the thesis of 'social oppression' put forth by the disabled rights movements' activists. Some members of the movement identified restrictions to the social model construction (Shakespeare & Watson, 2002). Particularly in relation to its minimisation of the impacts of the actual physical and intellectual restrictions experienced. Denial or minimisation that there are physical and cognitive restraints lying beyond alleviation via the re construction of social attitudes or removal of environmental barriers suppresses significant aspects of the experience of disability for many people (Morris, 1996). Furthermore, it can be argued that the social model of disability is hinged on the premise that there is a state of society functioning in such an equitable manner, it may be countered that such a state of society does not exist (Hughes, 1998).

## 2.8 All Constructions of Social Problems are Open to Contention

All constructions of social problems are open to contention. In this case the contestation concerns understanding disability as a simple natural state whereby the occurrence of physical or cognitive impairments are what disables. In contrast to, disability as a state which is subject to public attitudes, political, medical and legal processes, whereby the social constructions that result are disabling (Abberly, 1987). As discussed this contestation has predominantly taken the form of the medical versus the social model of disability. A critical deconstruction of disability reveals '*the extent to which disability can be best understood not as a natural/unnatural and unitary condition but rather as a phenomenon subject to competing constructions*' (Hughes, 1998, p. 86).

## 2.9 A More Holistic View

This research is of the view that a balance between the medical and social paradigms provides a more holistic view *'the problem with bio medicine is not that it is ineffective in what it does, but that it is too effective in certain domains to the detriment of other aspects of life and society* ' (Tucker, 1997, p 28). To claim a medical perspective has no application would lead to a partial attendance to the experience of disability. When the interrelation of factors is recognised it becomes a lot more possible to have *'person: environment exchanges that release peoples potential for further growth and promote diverse, supportive environments that release human potential'* (Germain & Glitterman, 1996, p.6).

## 2.10 Chapter Summary

This chapter examined a number of influential constructs of disability, sharpened the focus to people with Down syndrome and intellectual disability and provided analysis of the salience of these constructs in relation to this study. The chapter to follow will critically discuss dominant perspective in inclusive research.

# *Chapter 3 Dominant Perspectives in Inclusive Research*

## 3.1 Introduction

This chapter will now examine the development of inclusive approaches to researching intellectual disability in applied social science in greater detail. Provide background to the development of inclusive research practices, critically engage with the dominant perspectives and apply a theoretical perspective of participation. Finishing with discussion on managing the oppressive features of social research and the relevance of social work practice in conducting inclusive research.

## 3.2 Disability and Applied Social Research

A focus on the short comings of medical and psychological research in relation to people with Down syndrome has been provided. Proponents of the disabled rights movement have levelled significant criticism toward social research both in its perpetration of social constructions which they deem oppressive and in its failure to include people with disabilities in the research process in inclusive, participatory, empowering or emancipatory ways. Empowering or emancipatory knowledge was to be generated in a manner which recognised the heterogeneous people behind these constructions of disability as experts relatively silenced to date whose voices ought to be heard (Barnes & Mercer 1994, Goodley & Moore, 2000).

### 3.3 An Historical Overview of the Developments in Researching Intellectual Disability

Historically people with intellectual disabilities have had research done to them as the subjects of study and analysis but not as participants. The development of inclusive participatory research challenged such approaches and concepts of emancipatory research emerged (Oliver, 1992, Zarb, 1992, Kiernan, 1999, Walmsley, 2001, Burton, et al., 2004, Hanley, 2005). Discourse in the field began to examine the complexities of incorporating these concepts into approaches to research with people with intellectual disabilities. Approaches to such research predominantly employed methodologies such as personal narrative (Goodley, 1996, Atkinson & Walmsley, 1999, Gray & Ridden, 1999, Atkinson, 2005), followed by the incorporation of group research methods (Chapman & McNulty, 2004, Townson et al., 2004, Gates & Waights, 2007). A further call for researchers to make their research accessible to people with intellectual disabilities and to involve them in the planning of research followed (Chappell, 2000, Gilbert, 2004, Walmsley, 2004, Townsend, 2011).Such studies have included people with intellectual disabilities in identifying relevant research questions and the production of an accessible research article thereafter (Garbutt, et al, 2009). Progressing to studies in which people with intellectual disabilities were involved in collecting and analysing research data and in the dissemination of research findings (Goodley & Moore, 2000, Kramer, et al, 2011, Wyre Forest Self-Advocacy & Tarleton, 2005, NIID, 2009).

### 3.4 Research and Intellectual Disability Today

More recently in social science, recognition that the people being studied are participants as opposed to subjects, is more widely espoused. Social science is not absolved of a role in commissioning constructions of intellectual disability which distort and pathologies. Oliver's contention that social scientists '*merely offer descriptive and theoretical accounts which leave medical and psychological approaches unchallenged'* (Oliver, 1990) remains applicable. Justification in relation to the benefits for those who are the subject of studies and responsibility for the constructs to which the findings contribute has become increasingly called for (Dowe, 2009). Over the course of the last number of decades stakeholders have called for a move towards a research paradigm which is essentially transformative, informative, contributes to the collective experience and understanding of disabled people and challenges the ways in which disability is socially produced (Bury, 1996, Wamsley, 2003. Carlton, 2010). Qualitative research to date has helped to access knowledge that people with intellectual disabilities possess regarding their own lives and experiences (Atkinson, 1997, Beail & Williams, 2014). The existing studies serve in '*addressing a wide range of issues, and we are not at a stage where we can review a body of qualitative research on a particular aspect of people with intellectual disability*' (Beail & Williams, 2014, p. 93). It remains today that far more time has been spent thinking and talking about the way research could be or should be, than has been spent on actually going out and implementing changes to research practice (Zarb, 1992). The broader social constructs which may be influential to the dominant agendas present in inclusive research are now examined

### 3.5 Normalisation and Social Role Valorisation.

Walmsley (2001) offered critical discussion on the dominant agendas in intellectual disability research. Relevant here is commentary on the normalisation or social role valorisation approach to research in intellectual disability. Normalisation and Social Role Valorisation are influential approaches to establishing and enhancing social value for those in society who have been subject to devaluation. One of the key factors in the distribution of value is perception of difference. In conditions that construct certain groups or individuals who differ from what is 'typical' in aspects such as their appearance, communication, behaviour or ability and then that difference is perceived negatively, those groups and individuals become devalued. Normalisation is an approach to enhancing inclusion of these groups and individuals via the *'Utilisation of means which are as culturally normative as possible, in order to establish and or maintain personal behaviours and characteristics which are as culturally normative as possible'*. (Wolfensberger, 1972, p.28) Social Role Valorisation builds upon Normalisation principles. '*The primary goal of Social Role Valorisation is to retain or regain the good things in life for devalued and vulnerable people and groups'* (Race, 1999). Drawing from these perspectives a way to undo the processes of devaluation that people with intellectual disabilities have been subjected to is to revalue them by facilitating their adaption of attributes and features which are as culturally normative as possible. This approach falls short of challenging the values themselves, which are produced from a non-disabled perspective, approaches such as these do not challenge the measures of value imposed or the roles they prescribe but accept and promote them.

### 3.5.1 Critique

These approaches can be critiqued in that they promote adaptation and conformity to societal constructs built upon categorisations of difference which perpetrate the devaluation of certain groups. Arguably if the societal structures of power are adapted to privilege ‘typical groups’ and the valued societal roles are constructed around the abilities of 'typical groups', when those roles are uncritically accepted, an aspect of disadvantage for those with differing needs and abilities remains unchallenged. In research drawing from these perspectives the value of people with intellectual disabilities and the quality of their lives is often determined by comparisons to how closely the lives of people with intellectual disabilities model the lives of nondisabled people (Walmsley, 2001). Further to this it can be contended that critique of these approaches is applicable in challenging the manner in which being a participant in research is constructed as a valuable social role which enhances inclusion.

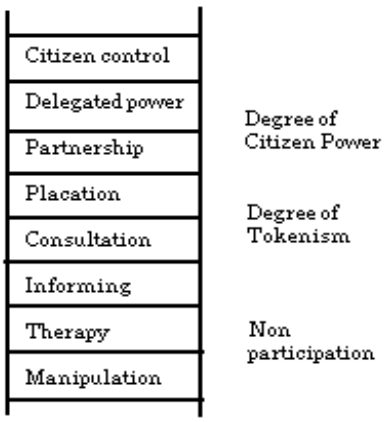
## 3.6 Sectional Agenda

Political and policy studies of disability such as Puttman (2005) have argued that the proportion of people with disabilities whom are politically active in the disabled movement is limited. Because of this there may be goals and rights sought by the broader population missing from the disabled movements established agenda. Furthermore the goals and rights currently championed by the movement may in fact not represent the views of all those concerned. The disabled rights movement and the political agenda it produced can be described as having emerged from a sector of the disabled community. Particularly salient in relation to people with intellectual disabilities whose voice are in the minority within the movement.

It may be reasonably concluded that the level of importance assigned to participation in inclusive research may not accurately reflect the views of the broader population. The literature points toward a need to confront on a more fundamental level whether the questions asked by research or if indeed participation in inclusive research is viewed by the desired participants as worthwhile or necessary.

### 3.7 The Ladder of Citizenship Participation

The facilitation of participation and inclusion as a means of redressing the power structures of research is an intricate process. As previously acknowledged it is contended that '*The power imbalances between people with learning disabilities and the researchers continue to be camouflaged by a rhetoric of participation*' (Walmsley, 2004, p. 66). In an attempt to move beyond such rhetoric Arnstein's 'Ladder of Citizen Participation' provides a theoretical framework through which a critically examination of participation can be conducted (Arnstein, 1969).




The ladder depicts eight levels of participation each rung corresponds to the extent of power afforded to participants. Whilst still a simplification of the varying degrees of power via participation it provides some direction on the level of complexity involved.

The ladder begins with rungs 1 and 2 of ’non-participation’ described as processes of ‘Manipulation’ and ‘Therapy’ seen as seeking to enable those in power to ‘educate’ or ‘cure’ the participants but not necessarily enable participants to evaluate or contribute to the planning, implementation and conduct of said programmes of cure and education. The ladder then depicts progress in the third and fourth rungs of ‘tokenism’ described as processes of ‘Informing’ and ‘Consultation’. These processes are seen as those in power proffering the extent of participation as, participants be heard but without assurance that those views will be regarded or heeded by those in power. If restricted to such levels the process of being heard has no significant impact because it has no clout. The fifth rung ‘Placation’ is described as furthering the process of token participation, wherein participants have an increased ability to advise but those in power retain the right to ultimately decide. Certainly in the case of this study the right to decide will likely relatively remain with the researchers. The uppermost rungs are not readily directly applicable here but serve to demonstrate the levels of participation viewed as most legitimate. Rung 6 ‘Partnership’ is described as processes whereby participants are enabled to engage in a more meaningful way by taking part in negotiations and conducting transactions with those traditionally in power. The top rungs of ‘participation’ describe processes of ‘Delegated Power’ and ‘Citizen Control’. In these processes participants have obtained a majority of the means of decision making such as votes or seats or have gained the authority to fully manage power as they see fit (Arnstein, 1969). This depiction of the processes of power involved in achieving genuine participation remains simplified but helps to demonstrate the significant challenges to facilitating participation in inclusive research.

### 3.7.1 Applying the Theoretical Framework to this Study

By seeking to gain input from the participants of this study on the proposed research topic an attempt to facilitate their contribution to the planning and implementation of the research will be made. However, heightened compliance is a feature of intellectual disabilities and service users. Recognition that a number of factors limiting the extent to which participation can be facilitated remains. These relate to time constraints, long standing power differentials and the influence of social constructs which diminish the confidence and esteem of participants asserting themselves fully. In this case there is no guarantee or assurance that the views of the participants will be observed beyond this study or the research base of Down Syndrome Cork or lead to change, assuming the participants identify a need for change. In the information provided on partaking in the research, care was taken not to overstate the likely impact the study would have. Emphasis was placed on ensuring the research process itself would be a positive rewarding experience which attempted to enhance esteem. When the benefits of participation are uncertain, the process must strive to be empowering, as it cannot excuse or minimise the relevance of the participants experience of research by allowing the subvert perspective that the discomfits of the experience are for the greater good. The uppermost rungs of the ladder were less possible to directly apply to this study which demonstrates the limits to achieving full participation and the importance of acknowledging such limits is recognised.

### 3.8 The Oppressive Features of Social Research

In approaching this research, it is acknowledged that '*Applied social research by its nature concerns itself…with social problems, focusing its attention on the deviant, the problematic or marginal'* (Lee, 1993, p 19). Research is an activity which has been strongly critiqued in relation to its ethical treatment of participants. It is an activity with the potential to perpetuate structures of oppression, maintain stereotypes and further pathologies of its participants. It is noted in the literature that the 'concerns and complaints of minority communities concerning research are remarkably consistent across a range of groups and research situations' (*ibid*, 1993, p156-157). Members of these communities have contended that the generation of academic knowledge is an activity culpable in oppression. Expert discourses can serve to generate knowledge which is garnered by appropriation and emerges from constructions which further marginalise those it relates to. Marginalisation describes a process by which particular groups are often homogenised and subjected to social exclusion from the dominant culture. Their expression of their own culture and heterogeneity tends to be significantly curtailed. Further difficulty in bringing forth the voices absent in the research of minority communities stems from the manner in which the assigned expectation of homogeny can then lead to the fulfilment of a homogenous role and adaption of that identity by those it relates to. This can be described as 'internalised oppression' (Freire, 1972).

### 3.8.1 Responsibility for the Broader Social Constructs Research Produces

Concern for the likelihood of research contributing to the people experiencing the social problems under investigation being further problematised and marginalised in the process, requires attention toward moderating constructions of social problems which may be deemed oppressive by those who experience them. This research study asserts a responsibility for the impact the generation of such research has on the people who partake in it. It is contended those impacts occur not just in the course of conducting research studies but also in the broader social constructs those studies may produce. This discussion on the past, present and future of inclusive research with people with intellectual disabilities indicates restrictive boundaries as characterising the social relations of research. The majority of research methodologies to date are appropriate for researching participants with typical cognition. What is innovative in the Irish context is The Inclusive Research Network, a network of people with intellectual disabilities, researchers and stakeholders such as advocates, community organisations and service providers. Coming together to create forums for people with intellectual disabilities and the supporters to conduct research and submit on issues that they consider important. So that the resulting research is useful and aims to make a positive difference in the lives of people with intellectual disabilities (National Federation of Voluntary Bodies, Inclusive Research Network (IRN), 2016).

### 3.9 Chapter Summary

This chapter examined the development of inclusive approaches to researching intellectual disability in applied social science in greater detail. Background to the development of inclusive research practices was provided. Critically engaging with the dominant perspectives and applying theoretical perspectives of participation. The chapter to follow will provide the research design and methodology.

# *Chapter 4 Research Design and Methodology*

## 4.1 Introduction

This chapter will present the epistemological position and methodological approach to this study. The recruitment of the sample, research design, ethical considerations, data analysis and the bias and limitations of the study shall be discussed.

## 4.2 Philosophical Underpinnings

This research is being approached from an interpretivist ontological position this approach would contend that the social world is subjective in that it is constructed and interpreted by people rather than being an objective phenomenon which can be measured empirically. Thus, social research is not seen as a detached observance and investigation of a fixed world and static phenomena but as an endeavour which produces the concepts, constructs and paradigms which shape a world of active phenomena. In keeping with this epistemological position this research seeks to capture a contextualised snapshot of the participant's emotional lives.

### 4.3 Research Positionality

In approaching the research from an interpretivist ontological position the likely differing interpretations of emotion are not viewed as problematic because the data is not intended as pervasive of a broad frame of understanding or toward the establishment of a 'truth'. Due to differing cognition amongst the participants there will be a level of variance to the interpretation of the interview prompts. It could not be guaranteed that each participant would conceive of feeling good or bad in the same way each participant's interpretation is seen as valid. This acceptance of each participant's heterogeneity regarding their interpretation of the prompts and conception of emotion is in keeping with the epistemological underpinnings of the study. The research contends that what it has sought to capture is a fair representation of the individual phenomena of emotions as each participant saw them (Alston & Bowles, 2003, Barton, 2005, Denscombe, 2010).

#### 4.3.1 Reconstructing the Position of Expert

This research sought to recognise and draw from the knowledge and expertise that members of Down Syndrome Cork have regarding both: what are the suitable and preferred ways to engage them in research and their experience of emotion. The reconstructing of the position of expert may enhance the participation, collaboration and inclusion of the participants with Down syndrome in this research (Knox, et al, 2000).

### 4.4 Sampling Recruitment Process

Down Syndrome Cork was the research base and the only requirement to participate was that the participants were members who had Down syndrome and were over 18. The sampling strategy began by holding a brief introductory talk, to which all the relevant members were invited to. This was considered to be the most accessible format for the majority of the prospective sample. This approach was selected so that the process was inclusive and began as open to all.

### 4.5 Pre Consultation

Following the introductory session, a consultation group was intended to get input from the interested members on how they would like the research to be approached, aiming to make it a collaborative process throughout by establishing a basis for the way the members would want this researcher to discover more. Dependent on that consultation the further data collection method likely to be chosen was semi structured interviews with pre and post consultation regarding the research process. The data provided in the consultation group would be used so that the research was tailored to the groups' preferences. Through the use of consultation and planning groups there can be some assurance that the views and concerns of participants with intellectual disabilities are included in the research. In keeping with an interpretivist approach this research sought to create an open dialogue with the participants. Verbal communication was considered the most accessible format to conduct the research through. As abstract concepts may have been beyond the scope of this research the dialogue was mindful of this. During the group consultation session, it became apparent that highly structured interviews would be unsuitable.

### 4.6 Interviews

Semi-structured interviews were chosen as it would likely be difficult to compose them with certainty that each participant interpreted the questions the same way. In-depth interviews were considered to be beyond the time-frame that this study would allow for. Significant time would foreseeably be needed 'to establish a relationship with the respondents in which they feel free to openly express their inner thoughts and feelings' (Alston & Bowles, 2003, p. 118).

#### 4.6.1 Combining Narrative & Semi-Structured

Semi-structured interviews were chosen drawing from a narrative approach. Narrative interviewing does not have to equate to an unstructured format. It is acceptable to 'carefully plan ahead for subsequent questions asked because of limited available time' (Carey, 2009, p.139). It is advised in the literature that novice interviewers are likely to be more competent starting with semi structured interviews as they may lack the experience requisite to competently conduct unstructured interviews. Maintaining a structure to the interviews ensured not to overestimate the researcher's current level of experience. The interview was adapted as a narrative approach which retained a light semi structure. This was done by composing a list of prompts to be delivered in a manner where interviewer interventions remained restricted. Allowing the spontaneous pattern of a speaker's narration in response to each prompt to be completed fully before voicing the next prompt. Keeping the essential nature of narrative interviewing whereby 'interventions are reduced to a minimum and drained of any particular content, for as long as possible you give up control' (Wengraf, 2001, p113), in the hope the participant takes control in voicing what they deem to be worthwhile and valid in their response.

## 4.7 Data Analysis

In keeping with the overall inductive approach to this research an inductive analysis of data was employed wherein the themes stemmed from the data rather than the researcher seeking to identify and link specific themes developed through the prior review of previous studies (Braun & Clarke, 2006). This was also in light of the previously acknowledged absence of an adequate body of research from which to develop themes (Beail & Williams, 2014). The interview data was subject to a process of thematic analysis outlined in the work of (Braun & Clarke, 2006). Data from each interview was transcribed verbatim, details such as pauses or possible verbal indications of discomfort were included in the transcripts. Each transcript was rechecked against the interview recording to ensure accuracy. Each data item was attended to equally in the process of coding. Data items heterogeneous to individual interviews were excluded and themes were generated from data items homogenous to two or more data sets collating all the relevant data extracts to each theme identified. The analysis sought to implement a constant comparative method that consisted of the repetitive study of each of the data sets to identify and summarise their shared findings which then informed the construction of themes. As coherent and distinctive themes were developed, the themes were then rechecked against each other and against the original data set.

### 4.8 Identification of Themes

The emergence of identified themes was then documented on a thematic map to assist in the further analysis and reflection on the interpretation of the data. Core themes were identified and the researcher would contend that each '*theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set'* (*ibid*, 2006, p.82).

In keeping with the methodological position of this study it is also acknowledged that themes did not exclusively emerge from the data, the researcher used their judgment when identifying core themes and it is accepted that other researchers may have drawn out different core themes from the data. As highlighted by Whittaker (2012) researchers are unable to entirely remove their own bias, experience and views from the research process but must remain aware of such influences whilst engaging in research processes.

## 4.9 Ethical Considerations

Whilst it is acknowledged that '*Standard ethical guidelines for social research cover many of the ethical issues adequately for most research with people with disabilities'* (National Disability Authority, 2009, p. 20), in '*Ethical Guidance for Research with People with Disabilities'* (*ibid*, 2009) six key principles for ethical research practice are outlined

- Promoting the inclusion and participation of people with disabilities in research and research dissemination
- Ensuring that research is accessible to people with disabilities
- Avoiding harm to research participants
- Ensuring voluntary and informed consent before participation in research
- Understanding and fulfilling relevant legal responsibilities
- Maintaining the highest professional research standards and competencies.'

These principles can be viewed as procedural ethical considerations. The objectives, intents, aspirations and expectations of researchers, the particular field of study, university or government bodies and academia itself, create a complex web of influence on the manner in which research is conducted, data analysis or interpretation and the constructs which are produced.

Ethics in practice should be an ongoing consideration in areas such as: ensuring ongoing assent or consent, handling relationships that develop during the research process, managing unanticipated distress or unexpected revelations sensitively and in ensuring that any insurmountable barriers to inclusion in aspects of a project are not experienced as rejection or exclusion. Relevant from the previously mentioned study by Atkinson is discussion on the ethics

of building equal relationships in research with people with intellectual disabilities. Atkinson identifies that such an approach 'means that not only is rapport built up to facilitate the research, but real feelings are engendered between the researcher and the participant(s)' (Atkinson, 2005b, p. 427). Notwithstanding the limitations of this study in relation to the lack of requisite time to build such a rapport, this limitation also meant that the participants would be more protected from forming relationships they may perceive as lasting friendships which once the study drew to a close could then leave them open to feelings of rejection. The central ethical considerations for this project are facilitating inclusion and participation whilst ensuring voluntary informed consent is maintained throughout. This will require attention and management for the duration of the research and will be clearly documented throughout.

### 4.10 Bias and Limitations

A key area of bias and limitation in this study is in regard to the re-negotiation of the power relations. The achievement of full participation in this research for the participants with Down syndrome is an ambitious undertaken beyond the scope and scale of this research study. A further limitation is that the demographic attributes of this study are narrow. It is recognised that the analysis involved a modest amount of data but contended that the coding process remained methodical, consistent and comprehensive throughout. Further discussion of the bias and limitations relating to the achievement of participation in inclusive research shall be provided in the chapter to follow.

### 4.11 Chapter Summary

This chapter has discussed the philosophical underpinnings and research positionality of this project and described the approach to recruiting a sample, gave an overview of the overall

research design and provided documentation of the thematic analysis of the data. Followed by discussion on some of the ethical considerations and bias or limitations to the study. The chapter to follow will provide an in-depth examination of the extent that participation in inclusive research was achieved.

# *Chapter 5 Participation in Inclusive Research*

## 5.1 Introduction

In attending to the research aim to provide a clear account of the extent to which participation in inclusive research was achieved in this study, this chapter will outline each stage of the research process, document the inclusive elements and discuss the achievement of and restriction to their implementation.

## 5.2 Sampling

The sampling strategy began by inviting all the potential participants to a brief introductory talk. This approach was selected to enhance inclusion and begin the process as open to all. Every member of Down Syndrome Cork over the age of 18 was sent an invitation. Whomever chose to attend and then choose to volunteer from the talk could be a further research participant. The researcher chose to deliver the information verbally because it was considered to be the most accessible format for the majority of the prospective sample. Whilst cognisant of literacy being a possible barrier to participation, an accessible simple invitation was sent out to potential participants who were the intended audience for the talk. The invitation welcomed them to come meet the researcher, hear about the proposed study and ask any questions that they may have. A more detailed information sheet was sent out for family members who would be facilitating the potential participant's attendance at the talk. The sampling method was guided by concern that the spirit of collaboration the study sought to establish may have been lost if the information was conveyed to the desired participants second-hand. It was requested that the family members direct their own questions to the researcher by either by phone or email and were welcome to

approach the researcher before or after the talk. This was to ensure the introductory session remained a participant led forum.

In examining the achievement of participation and inclusion during the research sampling process, it is acknowledged that there were unavoidable limitations to the levels of participation and inclusion that could be accomplished with certainty. Once the invitations and information sheets were sent out, the recipients were at liberty to do as they wished with the material which they may not have been passed along to every potential participant. The intended understanding of the material provided may not have been successfully established. Any predispositions toward nonparticipation that were present may have remained due to issues unbeknown and unaddressed in the material.

### 5.3 Consent

Whilst it would remain the family members who provided official consent for the participants taking part, this approach was intended to ensure the participants were involved in making an informed decision about consenting to take part on the basis of accessible information provided directly to them. Throughout this research there was attempt to manage the features which could be oppressive, such as the possibility of consent being unintentionally coerced, by making it an ongoing process. For example, on-going consent was sought during interviews by checking with each participant every couple of prompts if they wished to answer more.

### 5.4 Consultation Group

The consultation then sought to discover the level of interest they had in taking part in research, how the topic of emotions and emotional well-being was received by them, to garner input

regarding the kind of communication methods that were preferred by the group. Consultative research generally tends to help identify projects which are of the greatest relevance and concern to the target population. At the introductory talk four willing participants attended, they led the way for the consultation group to take place there and then. The intended adaptive approach to this study was implemented in following their lead consent was provided.

### 5.4.1 Conducting the Group

The format of this consultation group was that the researcher brought their ideas for the research to the group, seeking to establish the relevance of the proposed topic and to receive further ideas on the specific direction and focus for the research directly from the potential participants. In the consultation it emerged that the participants had little interest in the planning of the research and immediately wished to tell me about themselves and their feelings. This researcher found points made in Gates and Waights (2007) reflection on conducting research via focus groups with people with intellectual disabilities relevant. That discussion outlines the importance of 'avoiding persevering with a topic when they either don't understand or have no personal experience of it'. A pertinent point made is that 'If a topic has no relevance to participants or their life, they will not be interested in discussing it, any more than anyone else would' (Gates & Waights, 2007). The purpose of the research appeared to illicit little interest and or be of no relevance to this group. No concerns regarding the research process where expressed. The proposed topic of emotions was unanimously accepted with little discussion or query. By insisting that the participants persevered further in discussing the topics it would have likely created pressure and discomfort, compromising the ethics and values of this research.

### 5.4.2 Use of Power

In relation to how the research would be conducted the participants expressed a preference to do the research as a group. However, in this case a group format was judged not entirely suitable because all four participants in the group were in romantic relationships with one another creating a discernible impact on the group dynamic. This researcher deemed one to one consultation as a more appropriate way to effectively consult and garner the views of all the participants. One on one semi structured interviews were agreed as the next stage. At this point the researcher assumed an authoritative role by directing the group. A level of compromise was maintained in reaching agreement with the participants to have a post consultation group after the one on one interview stage.

## 5.5 Safeguards

Opportunity and space for the group participants to raise any concerns or objections was facilitated. The participants expressed that they would find it hard to voice discomfort in the interviews. Safeguards were agreed in preparation for the likelihood of unexpressed discomfort with the topic becoming apparent during the interviews. This was done through open discussion agreeing to use the method of a piece of coloured card on the table they could simply touch if they wished to stop and to check in every few prompts throughout each interview that the participant wished to answer more.

Heightened compliance may have come into play in relation to the group participant's acceptance of the research topic the researcher is cognisant that the topic of emotional well-being may have remained imposed. The use of consistent warm approval to all answers throughout the interview rather than neutrality was planned. Cool neutrality could likely have been

misconstrued as disapproval and created unintended discomfort. This style of interview could create an environment where the participants felt tested diminishing their freedom of expression. Consistent warm approval was intended to increase the participants comfort in answering as they saw fit and so that possible tendencies toward compliance could be mitigated. The time necessary to form the type of relationship with the participants whereby the participants felt comfortable and able to open up and voice their sensitive, inner most thoughts and emotions during the interviews was considered to have been beyond the scope of this study.

### 5.6 Interviews

Further to the concern the researcher had that a formal structure may make the participants feel under pressure to give 'correct' answers producing a possible compliant response as opposed to them speaking freely of their own volition, as well as using a lightly structured narrative approach, some aspects of a Rogerian person centred approach were applied in conducting the interviews (Rogers, 1961). Consistent warmth and approval of all answers was conveyed throughout each interview. Reassurance there were no right or wrong answers was provided to each participant consistently and at regular intervals. If the researcher was unsure they had an accurate understanding of what an interviewee had said, an attempt to understand by repeating back to them or asking them to say more was made. If the interviewee displayed discomfort or distress explaining their meaning the researcher did not pursue it further.

### 5.7 Post Consultation Group

A key inclusive element to the post consultation group was the brief accessible presentation of the themes identified in the interviews. At this stage confirmation that the participants agreed with the themes identified was sought. This was also an opportunity to change or add to the

themes. The communication between the researcher and participants of this study was notably more fluid in the post consultation group and did illicit richer data. Feedback was that each participant had enjoyed the experience and was happy with the findings so far. They remained of the view that group participation was their preferred research method because they felt more comfortable in a group setting. The findings from the post consultation shall be discussed in greater depth in the findings and recommendations chapter to follow.

### 5.8 Chapter summary

This chapter documented the inclusive elements of this research and discussing the achievement of and restriction to their implementation. The chapters to follow will provide the findings and recommendations relating to inclusive research practice.

# *Chapter 6 Inclusive Research Practice Findings & Recommendations*

## 6.1 Introduction

In contribution to developing the adequacy of approaches to participation in inclusive research, this study provided a detailed outline of its inclusive research design and methodology in Chapter 4 Research Design and Methodology. In addition, a reflective account of attempting to produce inclusive research was provided in Chapter 5 Implementing Inclusive Research Practices. This chapter will now examine the key factors found to diminish and enhance engagement in inclusive research during this study, providing findings and recommendations in relation to facilitating participation in inclusive research.

## 6.2 Factors Found to Diminish Inclusive Participation in this Research

The consultation processes utilised in this study were somewhat successful in attempting to renegotiate power relations. Through consultation the participants did have the opportunity to freely engage with the researcher, the chance for them to direct the study was facilitated, and some feedback was garnered in the consultative processes. There is a risk of minimising the power imbalance by assuming that, the conditions for the assertion of the views of the target sample and the participants who were successfully recruited, were more conducive than they may have actually been.

## 6.3 Overestimated Importance Assigned to Participation in Inclusive Research

The purpose of the study was not of great concern to its participants and attendance at the research introduction talk was low. As previously documented the purpose of the research appeared to illicit little interest and or be of no relevance to this group. No concerns regarding

the research process where expressed. The proposed topic of emotions was unanimously accepted with little discussion or query. In the broader scheme outlined in the literature review, the disinterest evident may be indicative that the importance assigned to research production is indeed a product of a sectional rather than universal representation of the views of people with disabilities. Findings from conducting this study appear to give some indication that the significance and importance assigned to participation in inclusive research may be overestimated in the literature.

### 6.4 Heightened Compliance

Opportunity and space for the group participants to raise any concerns or objections to the research topic was facilitated. The proposed topic of emotions was unanimously accepted with little discussion or query. The researcher is cognisant that the topic of emotional well-being may have remained imposed. Heightened compliance may have been a factor in their acceptance of the research topic. This possibility is supported by the participant's expression that they would find it hard to voice discomfort in the interviews previously documented in this study. This researcher is also cognisant that during the pre-consultation stage the abstraction of an enquiry regarding research, which the participants had yet to experience, may have been a factor in their lack of interest, enquiry after the fact could possibly elicit richer data.

### 6.5 Factors Found to Enhance Engagement in This Research

To ensure adequate engagement with the participants it depicts, research is obliged to adapt to their requirements not merely impose its own. '*Communication requires both a sender and recipient and therefore in addition to supporting adults with Down syndrome with their communication, it is essential that changes are also made within society'* (*ibid*, 2014, p. 284).

This research attempted to adapt to the requirements of the participants and found the following of particular note in doing so.

### 6.6 Preference for a Group Setting

The participants expressed a clear preference to participate in the research as a group because they felt more comfortable in that setting in both pre and post consultation. During the pre-consultation the researcher assumed an authoritative role by directing the group and asserting one on one semi structured interviews as the next stage and took account of their preference by including the post consultation session. The significance of the preference for a group setting was evident in that the participant's confidence appeared notably increased in the preferred group setting. However, this may also be due to increased familiarity with the task of participation.

### 6.7 Enhanced Confidence and Engagement During Post Consultation

The post consultation group provided an opportunity for the participants to give input on the process of the research should they wish to do so. Each participant's confidence in contributing and asking questions seemed greatly enhanced during the post consultation stage. A study investigating the links between '*Communication and self-esteem in adults with Down syndrome*' (Cavenagh, et al., 2014) is of some relevance here, the participants of that study identified unfamiliar persons, situations, and novel tasks as factors which increase their communication difficulties. The study indicated that familiarity enhanced confidence improving communication. Notably participants of this study's confidence in contributing and asking questions seemed greatly enhanced in the post consultation and elicited richer data which may be further indicative that familiarity with the task can enhance communication (*ibid*, 2014). This has broader

significance in indicating a possible limitation to participatory studies which involve a one off instance of engagement between researchers and participants.

### 6.8 Conclusion & Recommendations

The unequal distribution of power between researchers and the researched has been outlined as a significant factor in inclusive research throughout the literature review and in the subsequent chapters regarding research design and practice. In renegotiating these power differentials '*Effective change will entail personal, contextual and institutional factors. It is very important to beware of romantic and decontextualised views or rhetoric with regard to research practice'* (Barton, 2005, p. 322). The negotiation of more equal power relations between those in the position of researcher and those being researched is a complex, time consuming, challenging and ever evolving process. Fulfilling the privileged position of researcher and exercising the power of the position in an ethical and respectful manner was a key concern throughout the study but a substantial power differential remained present and should be acknowledged.

> '*The subjects of research and researchers themselves are never outside the power of institutions and social processes…reflective accounts of research are important because they remind readers that scholars are always products of their culture and history'*
>
> (Dowse, 2009, p. 141)

When conducting research with participants who have experienced social constructions which assign stigma, minimise their abilities, direct their activities, assume authority over, impose views and values upon and assert power over their lives in myriad of different ways. Long standing power differentials and the influence of social constructs will diminish the

confidence and esteem of that participants asserting themselves fully. To claim to redress the power imbalances in a number of consultations is at worst disingenuous and at best idealistic. The establishment of inclusive approaches to research in intellectual disability are still in their infancy. In the field of intellectual disability persistent, in-depth, critical consideration and attention to the locus, functions, conduct and production of researchers appears fundamental to the process of developing adequate approaches to inclusive research.

# *Chapter 7 Emotional Well Being Findings & Recommendations*

## 7.1 Introduction

This chapter will provide the findings from the interviews conducted with four participants with Down syndrome. Through a process of thematic analysis previously outlined three main themes were identified from the interview data then verified by the participants in the post consultation group. The themes identified as having the most significant impact on the participant's emotional well-being were: 'the Pursuit of Romantic Relationships' and 'Responsibility, Mastery and Achievement'. The final theme diverges in that it relates to a consistent assertion by the participants that they 'Never Feel Bad.' It is acknowledged that this was an initial exploration of emotional well-being. In light of this the weight of the findings shall not be overstated. The themes are linked to the broader field of research to support recommendations, whilst being mindful not to overstate their application.

## 7.2 The Pursuit of Romance

Romantic relationships featured as significant factors in shaping the participant's emotional lives. The concept, pursuit and engagement in romantic relationships featured as a clear theme. In the pursuit of romance what appeared to differ in the experience for the participants of this study from their more 'typical' peers are the barriers to engaging in healthy romantic relationships that people with Down syndrome tend to experience. People with Down syndrome have a limited peer group and limited facilities available in which to romantically meet someone. This means that they are often restricted to engaging in romantic relationships in educational or care settings, such settings are not always entirely suitable in doing so and may place additional

stresses on these relationships. These stresses would seem to likely stem from them not having an appropriate degree of separation from romantic partners. Many people with Down syndrome remain in the same network of peers and services for their entire lives which then heightens the impacts of conflict or relationships coming to an end

### 7.2.1 Previous Studies of Romance

The first inclusive research study in Ireland on relationships and supports was developed by the Inclusive Research Network (Inclusive Research Network, 2010) on the basis that people with intellectual disabilities identified the importance of the topic to them. The concept, pursuit and engagement in romantic relationships also featured as a clear theme in another study the IRN produced (Garcia Iriarte, et al. 2014b). Further evidencing the importance that the pursuit of romance has in the lives of people with intellectual disabilities.

Empirical research regarding the experience of romantic love by people with Down syndrome can help to create a greater awareness of the emotional needs of persons with Down's syndrome. Findings from a study seeking to establish a '*Conceptualization of Romantic Love Among Adults with Down's Syndrome'* (Castro, et al., 2015) provides data which suggests that the participants of the studies conceptualisation and emotional experience of romantic love did not differ greatly from the experience and conceptualisation of people with 'typical cognition'. These findings are further supported by an earlier study by (Arias, et al, 2009).

### 7.2.2 Public Perceptions

Another relevant international study which was both qualitative and inclusive in its design, drew from the personal narratives of people with intellectual disabilities. The results also indicated the

importance of relationships and sexuality (Haya, et al, 2014). This study supports the need for a '*breaking away from outdated misconceptions about sexuality and the emotions of people with disability'* the researchers identified that some of the difficulties encountered and expressed by the participants *'appear to be related to the normative view that makes a person with disability doubt themselves and their ability to feel, share, desire or love*' (*ibid*, 2014, p. 61). What is original to Ireland is that since 2001 the Irish National Disability Authority have commissioned national surveys approximately every five years to establish public attitudes toward people with disabilities. For over a decade on a number of occasions, survey participants have been asked their views on the right of people with various disabilities to engage in sexual relationships. These participants consisted of a nationwide representative sample of 1000+ Irish adults, the surveys were conducted with a cross-section each time as opposed to the same sample being recruited longitudinally. The data indicated that survey participants 'chief concerns were around a person's capacity to decide and the potential for abuse' (National Disability Authority, 2002, 2007, 2011). In further study and discussion of this survey data researchers have put forth that people with intellectual disabilities are at risk of being '*unnecessarily stereotyped if the public is uneducated about the steps that can be taken to support people in developing their capacity to decide'* and *'in the prevention of abusive relationships'* (Leavey & McConkey, 2013).

### 7.2.3 Recommendations Relating to the Pursuit of Romance

Public recognition and acceptance of the rights and desires of people with intellectual disabilities to have such relationships can influence public policy. Public promotion of such recognition and awareness may be of benefit. Research data such as (Leavey & McConkey, 2013, National Disability Authority, 2011) may demonstrate that determining factors in shaping normative views of relationships and sexuality for people with intellectual disabilities may relate more to

concerns for their vulnerability, not an outdated view of people with intellectual disabilities as not being sexual or emotional beings. Recommendations of previous studies are that support to engage in relationships needs to be enhanced to facilitate the rights of people with intellectual disabilities to have relationships like everyone else (Inclusive Research Network, 2010). Additional backing for that recommendation is evident in this study. This is an important progressive shift as the level of vulnerability the participants may have in relationships can be safeguarded via services and supports. The data from this study evidences that services and supports that safeguard the level of vulnerability the participants may have in relationships could be of benefit.

### 7.3 Responsibility, Mastery and Achievement

The extent that the participants are able to take part in valued activities or perform tasks that are viewed by themselves and others as valuable, important and worthwhile was identified as highly influential in their emotional lives. The successful fulfilment of tasks, activities and responsibilities creating a sense of achievement which was predominantly identified as a source of enhanced emotional well-being. This was one area where participants acknowledged feeling bad, unsuccessful attempts to complete tasks, fulfil responsibilities and experiencing barriers to achieving engagement due to cognitive limitations were identified as a source of diminished emotional well-being. In relation to managing those feelings the immediate family was the most frequently and strongly identified support, followed closely by their peers which includes platonic friends and romantic relationships. In the previously mentioned inclusive study on relationships the importance of support from friends was also specifically highlighted. The findings of that study indicate the importance of family support in the participants' identification that 'family help you through everything' (NIID, 2010, p.28). In this study family support was

valued in practical and emotional terms, participant's indicated being with family as a source of comfort when distressed, and that the care and time spent with them by their families made them feel good.

### 7.3.1 Correlations with Previous Studies

The theme is supported by data from a large scale nationwide study with people with intellectual disability as co-researchers regarding living with an intellectual disability in Ireland in the 21st century and the ways that they felt that life could be improved for them. In this research productivity and contribution to a workforce were assigned significant value, both as a current source of pride and satisfaction and as a future ambition. (*ibid*, 2010, Garcia Iriarte, et al. 2014b). A study conducted by Payne & Jahoda (2004) although drawing from a bio medical model offers further evidence of note. They found that a higher level of difference between the level of ability people with intellectual disabilities believed themselves to have and that which they were perceived to have by others could be associated with increased depressive symptomology. This may stem from the adverse impact of believing in their abilities then being exposed to a process of indoctrination in which their belief in themselves is subject to suppression and limits to their power to employ self-efficacy are imposed. The finding that the successful fulfilment of valued tasks activities and responsibilities creating a sense of achievement enhancing emotional well-being correlates to those of a previous study on the relationship between social comparison, self-esteem and depression in people with intellectual disabilities. That study found a significant association between processes of social comparison, their impacts on self-esteem and the presence of depressive symptomology in people with intellectual disability. These processes appear to impact in a similar way as to what has been found in research on the presence of depressive symptomology in people with typical cognition.

Further to this the study concludes that if a person possesses attributes and fulfils roles which they perceive positively and elicit feelings of self-worth, they can provide an effective buffer, which counters the negative impacts of poor social comparisons (Dagan and Sandhu, 1999).

### 7.3.2 Recommendations Related to Responsibility Mastery and Achievement

Findings from this study and others may indicate the way the participants feel about themselves, the sense they have of their self-worth, is related to the extent to which they are able to take part in valued activities or perform tasks that are viewed by themselves and others as valuable, important and worthwhile. Facilitating participation in valued activities or perform tasks could promote emotional well-being. That facilitation would likely be enhanced by promoting self-efficacy and providing support to mitigate the diminishment of emotional well-being that may be caused by the challenges of participating in those tasks and activities. The value the participants placed in the support their immediate families provide can be viewed as empowering for families in recognising the contribution they make to the emotional well-being of these participants and that support does not always need to be formal.

## 7.4 We Never Feel Bad

Finally, a consistent theme present throughout the data was *'I never feel bad'*. When this assertion was probed in interview and queried in the post consultation group, the theme evolved as '*I don't want to talk about that'* to '*it's very hard to talk about feeling bad*'. This was significant in that a disproportionate amount of difficulty in recognising, describing and recalling feeling bad appeared to be present. Participants who spoke in relative detail about feeling good and positive experiences then became quite limited in their language and memory when asked about feeling bad. This would seem to indicate that it was not an overall cognitive limitation but

was particular to the subject of feeling bad. It would be conjecture for this study to attempt to identify the exact reason for the discrepancy. However, there was sufficient data to demonstrate discomfort in discussing feeling bad and indicators of denial in response that that discomfort.

### 7.4.1 Recommendations in Relation to Never Feeling Bad

The barrier to speaking about feeling bad may have stemmed from discomfort with discussing a sensitive topic with an unfamiliar person. What could be of benefit is holding workshops aimed at increasing emotional literacy. Not necessarily at a therapeutic level of intervention more so to enhance the participant's identification and recognition of a broader spectrum of emotions. If the suppression of negative emotional states is diminishing the participants' emotional well-being facilitating emotional expression may enhance it. This finding would benefit from further research a longitudinal study with the same participants may prove successful in determining the cause of this discrepancy.

## *Final Reflection*

The social relations that occur in the process of research production are constructed within a disparity of power. Very often this disparity cannot be entirely redressed. The hierarchy of power in existence between me as a researcher and them as participants could not be negated. However, this research is deemed successful in the manner it accentuates the voices of its participants within that disparity of power. The findings from this study hope to strengthen the necessary empowering foundations for future emancipation. '*In a culture of domination, power relations are a means of silencing particular voices, thus within such an historical and cultural context*

*finding a voice is an essential part of the struggle for freedom'* (Barton, 2005, p. 319).Research has a strong influence on societal attitudes and perceptions towards those it concerns. To be in a position to conduct a research study is linked to societal advantages such as possessing typical cognitive abilities. When the benefits and desirability of participation in research are uncertain, then the research process itself must surely strive to be empowering, because it cannot excuse or minimise the relevance of the participant's experience of research, by allowing the subvert perspective that any discomfort experiences is for the greater good. Significant responsibilities and ethical obligations are linked the privilege of being in a position to conduct research. I hope my endeavour to fulfil those responsibilities and ethical obligations has been adequate.

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## *Appendices 1-5*

Appendix 1: Participant Invitation to Introductory Session

Appendix 2: Introductory Session Information Sheet

Appendix 3: Interview Information Sheet

Appendix 4: Interview Consent Form

Appendix 5: Thematic Presentation

## Appendix 1 Participant Invitation to Introductory Session

| |
|---|
| A picture of the researcher was included here. |

Hi all,

My name is I am a UCC student.

I would like to do a project with Members of Down Syndrome Cork as part of my studies. I want to know if you like my idea and if you want to work together.

I am coming to Down Syndrome Cork on **Monday 22nd of Feb at 7.30pm** to meet you.

I hope you can come and listen to my ideas and tell me what you think.

Please bring all your questions and suggestions.

I am looking forward to meeting you.

# Appendix 2 Introductory Session Information Sheet

**Information for Parents and Guardians**

Hi All,

My name is I am in my final year of my degree in Social Work at UCC. I am doing research which explores emotional wellbeing and I hope to do it in partnership with members of Down Syndrome Cork.

**My background**

I have a certificate in Disabilities Studies. I have worked as a personal assistant with people with physical and intellectual disabilities for almost five years. I have volunteered as a mentor on the Certificate in Contemporary Living in UCC. I am committed to finding empowering ways to work with people with disabilities.

**The project**

This project intends to learn about the emotional experiences and well-being of members with Down syndrome. With emphasis on what they think about taking part in the research and their preferred ways of taking part. The research intends to explore emotional wellbeing, however it is up to the participants to decide if this is a topic they want to talk about.

The process will begin by finding out if the members want to take part. Then go on to establish how they would like to take part and what the participants think are the best questions to facilitate discussing emotional well-being. This type of project develops as the people that take part give their views. It's important to know I will always give you a copy of the questions that will be asked before they are put to participants. You will then have the time to decide if you wish to consent to taking part.

I aim to ensure this is a positive and rewarding experience, which also serves to advocate for the issues the participants say are important to them. Simply asking people what they think, feel, and want can enhance their sense of worth. This research values the views of all those involved and will be carried out with respect and sensitivity.

I have provided project details below for parents and guardians who may want more information prior to bringing your family member to meet me.

I hope that anyone at all interested will come along to meet me then you can all make up your own minds about taking part.

**Getting involved**

At my introductory talk I will

- Introduce myself and explain the project in person
- Find out what level of interest there is in taking part

I won't be asking any questions yet. I will be introducing myself and explaining what the project is. I will then provide consent forms for those who wish to take part with details of the next stage in the research.

**The next stage**

For those that decide to consent to taking part the questions at the next meeting will be

- How they want to work with me e.g. in a group or one on one
- Any worries they have about taking part
- What they think that I should ask about
- What they think about talking to me about emotions

It's important to note taking part in this research is voluntary at each stage of the process. Taking part in any stage does not mean they have to take part in another stage. There will be no more than three sessions. The first to plan, the second to ask, and the last to go over what they have said and make sure they are happy for me to use it in my project.

**For your information**

The first introduction meeting is aimed at providing the information that's given to you here to those taking part.

I would like to explain this project in person to your family member. I thought that giving a talk in person with the space for them for to ask questions would be a good way to provide the information to them. It will be a relaxed informal meeting before starting the project.

Parents who want to come to support their family member are very welcome.

**I would please ask all parents and guardians to contact me with their own questions separately to the introductory meeting.**

**If you have a query or require any further information please don't hesitate to contact me via email at or by phone at**

I hope that anyone at all interested will come along to meet me then you can all make up your own minds about taking part.

Thank You

# Appendix 3 Interview Information Sheet

**Research on the Emotional Well-Being of Down Syndrome Cork Members**

The research is attempting to capture a snapshot of the emotional well-being of the participants. This includes enquiring as to what does or could help the participants to manage difficult or sad feelings and promote their emotional wellness.

Whilst carrying out this work the researcher is also seeking to make it a participatory process and an empowering experience, discussion on achieving this will also be included.

This project hopes to contribution to knowledge which is based on the first-hand accounts of people with intellectual disabilities in recognition of their expertise regarding their own lives. This research may provide insights into how the participants wish to be supported so as to promote their emotional well-being.

***What will the one on one interview stage of this research involve?***

Interviews will be carried out by and will last approx. 60minutes because they are vulnerable adults a parent should be present throughout the interview. The interviews will be recorded with your consent and then transcribed.

**Is confidentiality guaranteed?**

Confidentiality and anonymity are protected throughout. Confidentiality and anonymity are guaranteed to a certain degree. Limits to confidentiality are in relation to a participant disclosing the experience of harm or abuse. There are limits to anonymity in that participants will be identified as Down Syndrome Cork members and there may be awareness within the organisation of who took part. The interview recordings will be saved on a password secured laptop and backed up onto a USB key stored in a secure place they will be deleted on completion of the final report.

**The interview**

Following on from the pre interview group consultation each interview will begin by checking in with the participant to see if they are still happy to go ahead and are clear about what's involved in the interview. I will go over the following before starting the interview

- Request their permission to record by demonstrating recording my own voice and playing it back.
- That research means to find out more. Not just so I can know more but so that other people can read about it too.
- That what they tell me will add to what people think about Down syndrome.
- I will not use their name when I write it up but I will say they are members of Down Syndrome Cork.

The interview itself will be semi structured and use prompts to allow the participant to talk freely. I will begin by telling them that I wish to ask about what makes them feel good, what makes them feel bad and what they think does or could help manage difficult or sad feelings. Participants will be assured that there are no right or wrong answer. I will be using coloured cards placed on the table during the interview that they can simply touch if they want to stop at any point. I hope using the cards will be most comfortable for them.

The interview will be a series of prompts. Each participant will respond to different prompts the aim is to generate a narrative on the subject allowing participants to speak freely.

*Good feelings are? Bad feelings are? What is a good mood like for you? What is a bad mood like for you? What makes you feel good? I feel good if… What makes you feel bad? I feel bad if… When do you feel you're best? When do you feel you're worst? What do you do when you feel good? What do you do when you feel bad? What makes you feel better if you are feeling upset? If you were upset what would help?*

I will check back in at regular intervals the participant is happy to continue by asking, 'Do you want to answer more?'

I will then finish each interview by requesting their feedback on the experience of taking part in research. What they found good or not so good and if there are any changes they would recommend.

**Consent**

I have provided a separate consent form for you to sign. Please note upon signing you can still withdraw from the research at any stage.

Thank You

Please do not hesitate to contact me should you have any further questions.

# Appendix 4 Interview Consent Form

## Consent Form for Research on the Emotional Well-Being of Down syndrome Cork Members

The research is attempting to capture a snapshot of the emotional well-being of the participants. This includes enquiring as to what does or could help the participants to manage difficult or sad feelings and promote their emotional wellness. You have been provided with an information sheet and may contact the researcher: with any further questions.

In signing this consent form you are indicating that you consent to your family member participating in the interview on a voluntary basis and agree with the plans for the use and storage of any data collected. You may still withdraw from this research at any stage.

**Provision of Consent**

As per the information provided and with their agreement I _____

Provide consent for my family member _____ to take part in this research.

Thank you for your time and participation

Kind Regards

## Appendix 5 Thematic Presentation

# FAMILY

# FRIENDSHIPS

# GIRLFRIENDS & BOYFRIENDS

# FEELS GOOD TO HELP + DO A GOOD JOB

**NOT UNDERSTANDING**
**NOT BEING ABLE TO DO**
**= FEELS BAD**

**IT HELPS TO TALK AND BE WITH MY**
**FRIENDS AND FAMILY**