THE UNIVERSITY OF HULL

# The Prenatal Narratives and Lived Experience of Individuals with Down's Syndrome

being a Thesis submitted in partial fulfilment
of the requirements for the degree of

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by Charlotte Bryony Bell, BSc (Hons) Psychology, University of Hull

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## OVERVIEW

This portfolio has three parts: a systematic literature review, an empirical paper and appendices. This thesis aims to explore the opinions and experiences of prenatal testing from the perspective of parents of children with Down's Syndrome and the lived experiences of personal growth in individuals with Down's Syndrome.

### Part one: Systematic Literature Review

This review aims to draw together the experiences and opinions of parents of individual living with Down's Syndrome on prenatal testing. Twelve studies were identified for inclusion in this review. Five superordinate themes were identified through thematic synthesis; decision-making and reason for not testing, professionals, post-test emotions, societal opinions, opinions on the logistics of testing. Conclusions and implications are discussed.

### Part two: Empirical Paper

Part two contains a qualitative empirical study, exploring the opportunities and experiences of personal growth of individuals with Down's Syndrome.

Six individuals with Down's Syndrome were interviewed using semi-structured interviews. These were analysed using interpretive phenomenological analysis. Four superordinate themes were identified. This research highlighted the opportunities and ability for individuals living with Down's Syndrome to experience personal growth, a marker of quality of life. The need to further acceptance and provision of opportunities is also discussed.

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# Part One: Systematic Literature Review

This paper is written in the format specified in the journal

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Please see Appendix K for submission guidelines

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# ***Parents of individuals with Down's Syndrome: opinions and experience of prenatal testing.***

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## Abstract

There is an option to have prenatal screening in order to know whether a foetus has a chance of being born with a condition or birth defect. One of the main screening tests offered is screening for Down's Syndrome. The availability of this screening is somewhat controversial and often cause for discussion within society. Further to this, the way in which this screening test and subsequent results are delivered can prompt difficult emotions in parents. This review aims to draw together the experiences and opinions of parents of individuals living with Down's Syndrome, in order to explore the implications and potential impact of prenatal testing. Twelve studies were identified for inclusion in this review, and analysed using Thematic Synthesis (Thomas & Harden, 2008). Five superordinate themes were identified; decision making and reason for not testing, professionals, post-test emotions, societal opinions, opinions on the logistics of testing. The results suggest that there are still varied opinions and experiences of prenatal testing and that these can often depend on interactions with society and professionals.

**Keywords:** downs syndrome; prenatal testing; opinions; experiences; parents

## Introduction

Prenatal screening and testing is used to try and determine whether a foetus has a likelihood of being born with a genetic condition or birth defect. This can aid in determining the different options available for prospective parents including management of the pregnancy and delivery planning to help protect the baby (Terry, 2010).

In the United Kingdom prenatal screening is offered to all women through the National Health Service (NHS). These tests screen for Down's Syndrome, Edwards Syndrome, Patau's Syndrome, sickle cell disease and thalassemia (Antenatal Results and Choices, 2021). Guidance provided by government in the United Kingdom suggests that women can choose to have a prenatal diagnosis (using chorionic villus sampling or amniocentesis) following a high chance result from prenatal screening test. Diagnostic tests are also offered if there are unexpected structural findings at a 20-week scan. These diagnostic tests carry a one in 200 chance of miscarriage (Department for Public Health, 2022).

Following a positive test result for a genetic condition or birth defect an individual can decide whether to continue with the pregnancy. This is a personal choice and information to help the individual make an informed decision is provided through support groups, healthcare professionals and on the government website (Department of Public Health, 2021). However this information options and support may not be provided in all countries outside of the UK.

Prenatal testing is most well known in relation to testing for Down's Syndrome. Down's Syndrome is a genetic disorder, which causes distinct physical features and different degrees of intellectual disability (World Health Organisation, 2020). In the UK it is estimated that one in every 1,000 babies born will have the condition (Down's Syndrome Association, 2020).

Due to its availability, both prospective mothers and professionals may view screening for Down's Syndrome as routine. This potentially diminishes the importance of information being provided to make an informed decision (Skirton & Barr, 2007). Despite prenatal testing and diagnosis being a medical procedure one must also take into consideration the psychological wellbeing of parents and their children (Buckley & Buckley, 2008). It is important to understand the experiences of those who have undergone prenatal testing, in order to improve the delivery of this procedure and after care. Further to this the opinions of parents who did not undergo prenatal testing must also be included, in order to provide insight into their retrospective opinions on the need for testing and how the lack of prenatal diagnosis may impact their care.

Personal experiences can be used by other individuals for support and information relating to decision making and option consideration (Entwistle et al., 2011). It is important to not only focus on patient satisfaction on one specific procedure but overall patient experience in order to improve service delivery (Needham, 2012).

This literature review attempts to compile and understand the experience of prenatal testing procedures and opinions of all parents whose children were born with Down's Syndrome, whether they agreed to prenatal testing or not.

This knowledge could be used to guide mental health professionals in counselling those experiencing emotional distress following prenatal testing.

The following questions were addressed: What do parents of individuals living with Down's Syndrome think of prenatal testing? What was the experience of the tests and/or diagnosis? What was the interaction like with professionals during the time of testing and/or diagnosis? What are their ideas about the impact of testing on themselves and others?

## Method

### *Search Strategy*

The articles included in this review were found through using the EBSCO search engine. Four research databases were used in the search: Academic Search Premier was used as a multidiscipline database, capturing literature which may not have been accessible through the discipline specific databases; MEDLINE and CINAHL Complete were used to search for academic journals covering medicine, nursing, pharmacy and other allied health professional related research; APA PsycInfo was used to search for mental health and psychology based journals. Reference lists of all included articles were searched to identify any further literature not obtained through the initial search. This search was carried out in March 2022 and included papers up to and including this date.

### *Search Terms*

The search terms were developed following identification of terms and key words in articles deemed relevant to the research aims. The search terms developed and chosen were:

**(parent* or caregiver* or mother* or father*)**

**AND TI**

**(“down* syndrome" or "trisomy 21" or down* or trisomy)**

**AND**

**(“prenatal test*" or "prenatal screen*" or "pre-natal test*" or "pre-natal screen*" or "prenatal diagnosis" or "pre-natal diagnosis”)**

The asterisk Boolean operator was used to ensure articles that included alternative forms of the words were captured in the search. Further to this the search was limited to peer reviewed articles to control for the quality of articles and English language.

### *Screening and Selection Strategy*

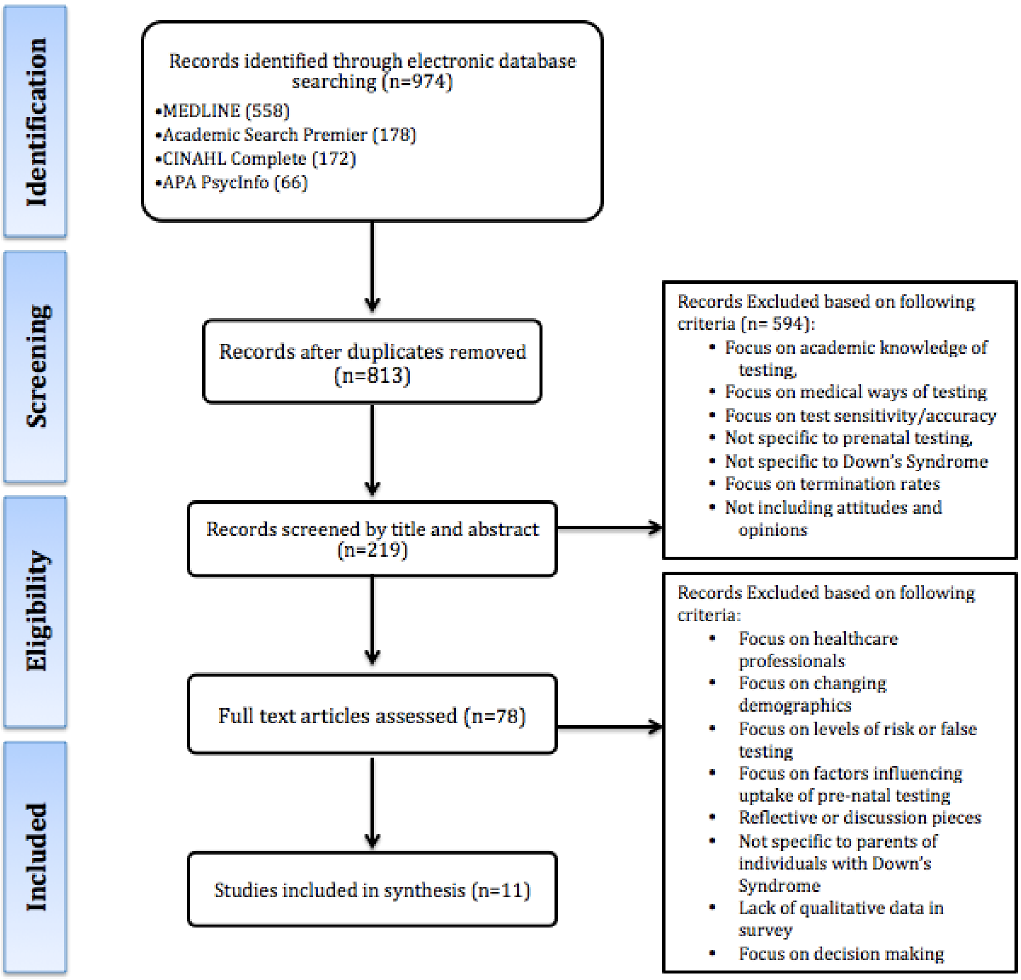
Following the removal of duplicates at total of 813 records were retrieved from the search. The articles were screened by their titles for relevance and a total of 219 records were then screened by their title and abstract. The 78 remaining records were then reviewed in full and screened against the inclusion and exclusion criteria (See Table 1). Twelve studies were deemed appropriate to be included in the synthesis (See Figure 1).

*Table 1. Inclusion and Exclusion Criteria*

| Criteria | Reason |
|---|---|
| ***INCLUSION*** | The aim of the review it to focus on the parent and caregiver perspective rather than that of professionals. |
| Only include studies, which focus on the opinions and experience of parents, not professionals. | |
| Only include parents of individuals living with Down's Syndrome. | The aim of the review is to focus on opinions of parents of children with Down's Syndrome, as this is one of the main diagnoses given prenatally. |
| Include both qualitative and quantitative survey studies that include direct quotes and space for participant's own descriptions. | The aim of the review is to gather opinions and experiences. Qualitative data is suitable. Qualitative data can also be extracted from quantitative survey studies. |
| Include both parents who have had prenatal testing and also received diagnosis at birth due to not testing. | The aim of the review is to understand the opinions of parents with children living with Down's Syndrome and their opinions on testing. Including just those who have experienced prenatal testing would not give an important perspective of the reasons why some parents chose to not test. |
| ***EXCLUSION*** | Studies included may elude to ethics, but the focus of this review is on the experiences of care and opinions of Prenatal Testing not policies and ethics |
| Do not include studies specific to ethics and professional development. | |

| | |
|---|---|
| Do not include articles focusing on prior knowledge of testing. | Studies included focus on opinions of testing, although knowledge of tests may be included in a wider context, this should not be the sole focus on studies included. |
| Do not include articles focusing on purely quantitative data and statistics. | This review aims to capture qualitative data and opinions and experiences rather than statistics such as uptake of tests. |
| Do not include articles with a focus on factors influencing screening for Down's Syndrome. | The review aims are not focused on influencing factors, but instead the opinions overall on Prenatal Testing. |

*Figure 1. – Flow diagram detailing Screening and Selection process* (adapted from PRISMA 2020 Flow diagram, Page et al., 2021)



### *Quality Assessment*

The papers included were both qualitative and quantitative and as such the Mixed Methods Appraisal Tool ([MMAT], Hong et al., 2018) was used to conduct a quality assessment. This critical appraisal tool was selected as it encompasses qualitative research, randomised controlled trials, non-randomised studies, quantitative descriptive studies and mixed method studies. This tool is based on rating the inclusion of methodological criteria (See Appendix C) with a score of '+' indicating inclusion or presence and '–' indicating lack of or uncertainty of inclusion of this methodological criteria. This was the rating for each of the MMAT questions and the overall result was out of 7 indicated by '+++++++'.

An inter-rater reliability check was conducted. Two research papers were selected at random and rated by another researcher. Any discrepancies in the ratings were discussed until an agreement was formed.

Out of the included papers all of them collected data that addressed the research questions. Further to this all were found to either have a suitable approach (qualitative) or sampling strategy relevant to the research question. For the quantitative survey data three out of five were scored to not have a low non-response bias. A summary table of the result of the quality assessment can be found in *Appendix D*. The quality assessment tool was not used to exclude any studies from the analysis, as a limited number of studies were identified for inclusion in this review. Instead the quality assessment provided information to be considered during the synthesis.

### *Data Extraction*

Key findings were extracted from each paper, following article selection, using a bespoke data extraction table (See Table 2). This form was developed in consideration of what information would be useful for the review and included research aims, design and findings.

### *Data Synthesis*

Thematic synthesis, outlined by Thomas and Harden (2008), was selected for the analysis and synthesis of the included papers. This method was chosen, despite a number of the quantitative studies being included, as the data presented was derived from surveys and qualitative data was extracted for inclusion.  No data of numerical value from the quantitative survey studies results were included. The data included from such studies was limited to qualitative statements provided within 'free text' answers or descriptive statements.

The researcher completed line-by-line coding, using the application NVivo (QSR International Pty Ltd., 2020), to identify applicable codes for the experience and opinions of parents with regard to prenatal-testing. During this process the researcher created multiple codes and considered how each related to one another. These codes were then organised into descriptive subordinate themes. The identified subordinate themes further interpreted and grouped into higher order superordinate themes, each encompassing a number of the identified subordinate themes (See Table 2).

## Results

### *Overview of Included studies*

The 12 papers included in this review were published between 2004-2020. The research included took place in a range of countries. Two studies were conducted in the Netherlands (Tymstra et al., 2004; van Schendel et al., 2017) and three in the United States of America (Hurford et al., 2013; Nelson Goff et al., 2013; Kellogg et al., 2014). One study from Denmark (Lou et al., 2020), Israel (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019), Australia (How et al., 2019) and Canada (Inglis, Hippman & Austin, 2011) respectively were included. Participants of all included studies were parents of one or more individuals living with Down's Syndrome. One study from Australia focused specifically on father's experiences. Of the studies included six used interviews as a way to collect the data, one of these also used focus groups. Six used surveys to collect both qualitative and quantitative data.

*Table 2. Data Extraction Table*

| Author and Country | Research Aims | Method and design | Participants | Key Findings | Quality Rating |
|---|---|---|---|---|---|
| Canbulat, N., Demirgöz Bal, M. and Coplu, M., 2014.<br>Turkey | The aim of this study was to explore a deeper insight into experiences of Turkish mothers living with/diagnosed with Down syndrome (DS) baby. | Qualitative, semi-structured interviews. Analysed using thematic analysis | 11 women who had a prenatal diagnosis of Down's Syndrome | Mothers' emotional reaction after diagnosed DS – fear anxiety & guilt<br>Mother and healthcare professional interactions<br>Mother's coping with diagnosed DS – religion and fatalism | +++++++ |
| How, B., Smidt, A., Wilson, N.J., Barton, R. and Valentin, C., 2019.<br>Australia | Research question: What are the views of Australian fathers towards the availability of NIPT in relation to their lived experience of parenting their child with Down syndrome? | Qualitative, semi-structured interviews.<br>Symbolic interactionist framework, in-depth interviews | 5 fathers for children with Down's Syndrome between the ages of 13month – 7years old. All with university education. | Fathers valued NIPT as an information-giving tool that allowed autonomous parental choices t<br>Need for balanced information about the reality of raising a child with Down syndrome. | +++++++ |
| Hurford, E., Hawkins, A., Hudgins, L. and Taylor, J., 2013. | To assess the timing of women's decisions to continue a pregnancy after prenatal diagnosis. To determine whether women | Quantitative and Qualitative, survey with narrative space.<br>Analysed using | 56 mothers who received a prenatal test and diagnosis of Down's Syndrome | Anxiety during pregnancy after diagnosis<br>Future decision for PNT | ++++++ |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| USA | retrospectively felt that having received a diagnosis prenatally was valuable and in what ways, and to assess factors that affected their decision to continue the pregnancy. | conceptual content analysis |  | Factors effecting decision making; religion and connection to baby |  |
| Inglis, A., Hippman, C. and Austin, J.C., 2012.<br>Canada | Examine the views and opinions of parents of individuals with Down syndrome (DS) related to prenatal testing for DS and the use of age-based criteria to determine eligibility for this testing. | Qualitative and Quantitative, survey with narrative space.<br>Descriptive statistics and verbatim quotes, no specific analysis | 101 parents (88 female, 13 male) of children with Down's Syndrome | Parents of individuals with DS had different opinions with regards to prenatal testing for DS<br>Some parents felt PNT enabled termination and perceived this as being able to positively plan | +++++ |
| Kellogg, G., Slattery, L., Hudgins, L. and Ormond, K., 2014.<br>USA | This study assesses how mothers of children with Down syndrome perceive NIPT, especially the impact they think it will have on their families and other families with children who have Down syndrome | Quantitative, survey. Qualitative free text comments analysed into themes | 73 mothers of children with Down's Syndrome | Mothers of children with Down syndrome would consider using or recommending NIPT in a pregnancy<br>Worry of increased termination<br>Professionals should aim to give a balance view | +++++ |
| Lou, S., Lanther, M.R., Hagenstjerne, N., Petersen, O.B. and Vogel, I., 2020. | To explore how parents of prenatally diagnosed children with DS experienced the diagnostic process and their decision | Qualitative, semi structured interview analysed using thematic analysis | 9 Couples of children who had been prenatal diagnosed | The couples stressed that DS was not the worst that could happen<br>Need for experiential | +++++++ |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| Denmark | to continue the pregnancy. |  |  | knowledge<br>Delivery of the DS result<br>Interaction with health-care professionals. |  |
| Nelson Goff, B.S., Springer, N., Foote, L.C., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G.E. and Cross, K.A., 2013.<br>USA | This study attempted to establish a clearer description of: the initial emotions and experiences; the adjustment process in light of the diagnosis; and the impact of the responses of support on their coping and adjustment | Qualitative, survey data, content analysis | 161 parents (146 female, 15 male) of children with Down's Syndrome | Negative experiences with medical professionals during the diagnosis process<br>Emphasize providing effective education, resources, and practical information from reliable sources. | +++++++ |
| Nov-Klaiman, T., Raz, A.E. and Hashiloni-Dolev, Y., 2019.<br>Israel | To investigate the views of parents on pros and cons of NIPS; the social context of decision-making about NIPS; and views on life with DS and termination of pregnancies | Qualitative, semi-structured interviews, grounded theory, thematic analysis | 20 (19 female, 1 male) parents of children with Down's Syndrome | Criticized the imbalanced information provided by professionals regarding DS<br>Discriminating message from professionals<br>Public ignorance surrounding DS. | ++++++ |
| Skotko, B.G., 2005.<br>USA | This study was undertaken to ask mothers who had children with Down syndrome after receiving a prenatal diagnosis: How was the process and what, if | Qualitative and Quantitative data, survey.<br>Qualitative data analysed using Constant | 141 mothers who had a prenatal diagnosis of Down's Syndrome | Frustration with the process<br>Mothers positive and negative experiences of how diagnosis is conveyed, | +++++++ |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  | anything, could be improved? | Comparative Method |  | what information is provided and lack of referrals for support. |  |
| Tymstra, T., Bosboom, J. and Bouman, K., 2004.<br>Netherlands | To gain insight into the motives and experiences of women who had decided to continue with the pregnancy after Down's Syndrome had been diagnosed in the foetus. | Qualitative using interviews. Analysis unspecified. | 10 mothers who underwent prenatal testing and received a positive diagnosis | Decision making following diagnosis<br>Lack of understanding of choice by some social and medical workers;<br>Support from members of the family, friends and acquaintances<br>Negative reactions | ++++++ |
| van Schendel, R.V., Kater-Kuipers, A., van Vliet-Lachotzki, E.H., Dondorp, W.J., Cornel, M.C. and Henneman, L., 2017.<br>Netherlands | Exploring the attitudes of parents of children with Down syndrome towards non-invasive prenatal testing (NIPT) and widening the scope of prenatal screening. | Qualitative, focus groups, semi-structured interviews analysed using thematic content analysis | 27 parents (23 female, 4 male) of children with Downs Syndrome (2 relatives) recruited through Dutch Down Syndrome Foundation. | Worries about eugenics, loss of diversity in society<br>Enabling preparation for baby with a safety option | +++++++ |

*Key Findings*

It was found in this review that despite the differing countries many parents shared similar views. These were not all in favour of prenatal testing. Upon analysis five superordinate themes were identified: decision making and reason for testing, professionals, post-test emotions, societal opinions and opinions on the logistics of testing. Within these superordinate themes 15 subthemes were also identified (See Table 3).

*Table 3. Superordinate and Subordinate Themes*

| Superordinate Theme | **Decision making and reason for testing or not testing** | **Impact of Professionals on experiences and opinions** | **Post-Test Emotions** | **Societal Opinions** | **Opinions on the Logistics of Testing** |
|---|---|---|---|---|---|
| Subordinate Theme | Decision making-autonomy<br>Future PNT decision<br>Extent of preparation and information seeking | Experience of interactions with Professionals during pregnancy and care<br>Information provided about Down's Syndrome by professionals<br>Delivery of results | Feeling about decision to continues<br>Feeling about results | Negative social language<br>Implications of testing<br>Lack of social support<br>Support from others | Availability of testing<br>Safety of different tests<br>Lack of information about tests |

## Decision-making and reasons for testing or not testing

### *Decision making- Autonomy*

One of the main reasons that individuals believed that prenatal testing or diagnosis is beneficial is to give parents autonomy over the pregnancy.

Although termination is not an option in all countries, studies found that parents who had prenatal testing, valued knowing about their child's diagnosis prior to birth and being able to make decisions accordingly (Kellogg et al., 2014; Inglis, Hippman & Austin, 2011; van Schendel et al., 2017; How et al., 2019; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019). They considered how other parents might feel different about their ability to raise a child with Down's Syndrome and how termination is a better outcome than 'forcing' someone to have a child they could not provide for or take care of effectively.

> *"First, fathers acknowledged that NIPT allowed couples to know the diagnosis beforehand, thus allowing for autonomy of choice to continue or terminate their pregnancy. I think ... alot of people don't want to raise a child with Down syndrome and with the screening, it gives them the option to do it. And I believe that's a better outcome than .. . forcing people to raise children they didn't want to have"*
>
> (How et al., 2019, p.300)

There was also a sense of responsibility on the parent to understand whether the child they were carrying had Down's Syndrome prior to birth. The tests also provide information about signs of other abnormalities other than chromosomal issues, such as heart defects (Tymstra et al., 2004)

### *Future Prenatal Testing Decision*

There were mixed opinions from parents as to whether they would undergo prenatal testing in the future. There was no pattern in their preferences based on their previous decision to test or not.

Some parents who underwent prenatal testing with their current child would opt for testing in the future, and may make a decision to terminate the future pregnancy, due to their worries about not being about to support two children with additional need and health issues. They were also satisfied with learning of their current child's diagnosis during pregnancy and would see no reason to not undergo testing in the future (Hurford et al., 2013; Van Schendel et al., 2017; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019).

Some parents who received prenatal testing did not find it helpful to receive the diagnosis prior to birth as it affected them emotionally during pregnancy and allowed other people to have input into their decision making with regards to termination (Hurford et al., 2013).

> *I was pretty stressed during my pregnancy because of the diagnosis. I had a hard time seeing her as anything other than her diagnosis."*
>
> (Hurford et al, 2013, p. 590)

Not all participants in the included studies used prenatal testing themselves. Most of these individuals explained that they think that knowing their child would be born with Down's Syndrome would have caused them to experience emotional distress during their pregnancy, or prompt them to have to make a decision about termination, which they did not want. (Inglis, Hippman & Austin, 2011; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019). Other reasons reported for not participating in prenatal testing included the risks involved with diagnostic tests, availability of testing, lack of knowledge and religious beliefs (Nelson Goff et al., 2013).

> *"We think that a mother who knows during pregnancy that there is a high risk for DS – many times it can bring to a state of great emotional stress during the entire pregnancy, because the imagination works, and the emotional stress works extra time. It harms both the mother and the fetus. And we know of mothers who remained in this emotional crisis after giving birth because of this thing. [Shmuel, ultraorthodox, head of a DS organization, father of 7. The second with DS] "*
>
> (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019, p1122-1123)

However some parents who previously did not choose prenatal testing suggested they would do so in the future to have access to resources and support during pregnancy, to avoid the surprise at birth, to avoid having additional children with special needs and to be better prepared (Nelson Goff et al, 2013).

### *Extent of Preparation and Information Seeking*

Some parents used prenatal testing as a way to gain information in order to prepare for the birth of their child. Others saw the prenatal tests as routine and an opportunity to have scans or interactions in order to see their baby.

Both parents who did and did not have prenatal testing noted one of the benefits of prenatal testing was having time to prepare for the birth of a child with Down's Syndrome and other potential health difficulties. This allowed those who underwent testing time to gain knowledge and early interventions if needed (Nelson Goff et al., 2013; Hurford et al., 2013; Kellogg et al., 2014; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019; How et al., 2019; Lou et al., 2020).

Some parents explained that having a diagnosis prior to birth helped them to avoid feelings of surprise or shock at time of birth. Allowing them to enjoy the birth rather than it being overshadowed by a diagnosis (Nelson Goff et al., 2013; Lou et al., 2020).

> *One participant stated, "Looking back, I am glad that we did prenatal testing just so that we could be prepared and knowledgeable before our son was born. It made delivery day a happy day – and not one that was tainted with a diagnosis"*
>
> (Nelson Goff et al., 2013, p 451)

In one of the included studies, early prenatal testing was seen as important as it not only gave the parents time to prepare for their child's birth but their family and friends too (How et al., 2019). One mother included in the study conducted by van Schendel et al. (2017) did not have prenatal testing available at the time of her pregnancy. It was noted that the testing would have been helpful, with regards to risks at birth, as there could have been preparation by medical professionals. Some parents simply wanted to have prenatal testing purely for their own information, to confirm the pregnancy and see the baby (Tymstra, Bosboom & Bouman, 2004; Kellogg et al., 2014; Lou et al., 2020).

Some parents who had prenatal testing did not acknowledge what the tests being done were for. They describe the tests as being routinely offered. They also describe going to the scans as a way of seeing the baby and it just being part of the pregnancy process (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019; Lou et al., 2020).

*"We just went with the flow, I guess. We did not really think about the potential consequences. Because it is just such an integral part to being pregnant … going to those scans. Oh, and it is really nice to get to see your baby without having to pay a thousand bucks for it [laughs]. (Mother 3, first child)"*

(Lou et al., 2020, p. 3)

Further to this, some parents did not contemplate what a positive result on one of the tests would mean. They did not think about their child actually being born with any sort of disability or what social and ethical difficulties may arise for them as parents (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019; Lou et al., 2020).

*""Disability? No, we didn't think about that at all. From our perspective, during pregnancy you do tests and if everything is normal – the pregnancy is normal. We didn't think that something might happen. No, we didn't think about it. Absolutely not." [Noa, age 43, secular, mother of 3. Eldest with DS]"*

(Nov-Klaiman, Raz & Hashiloni-Dolev, 2019, p. 1124)

## Impact of Professionals on Experiences and Opinions

### *Experience of Interactions with Professionals During Pregnancy and Care*

Parents had both positive and negative experiences with professionals during their pregnancy. With regards to how information is delivered about Down's Syndrome, it was found that parents appreciated being given all the information about different options with compassion about their situation. This information included termination but did not solely focus on this (Nelson Goff et al., 2013.; How et al., 2019; Lou et al., 2020). However, some mothers had termination discussed with them by their healthcare professionals in detail following prenatal testing, despite not wanting to terminate. This was upsetting to them, as they would have liked their professionals to ask if they wanted the detailed information (Skotko, 2005):

> *"However, two fathers acknowledged that there were some health professionals that delivered matter of fact information about Down syndrome in a compassionate way and gave them a variety of options about the pregnancy. our ... obstetrician .. . she was really good she told us the news gave us our options .. . That we could terminate, that we could continue the pregnancy, if we continue the pregnancy we could have Anne adopted out. (Chad) "*

(How et al., 2019, p. 298)

A number of parents, who did not have prenatal testing, reported that they often felt pressure to make decisions about tests quickly. Further to this those parents who were religious found that newer doctors who were not familiar with their religious choices would try to convince them to take the tests, by stressing their importance (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019; How et al., 2019).

During the pregnancy parents, who had prenatal testing, appreciated when their child was referred to positively, putting emphasis on the normalcy of the pregnancy rather than focusing on the diagnosis. This was also mirrored by those parents who did not find out their child had Down's Syndrome prior to birth (Nelson Goff et al., 2013; How et al., 2019; Lou et al., 2020):

*"A good friend who is an [obstetrician] delivered my baby. She told me she was beautiful, and she was perfect, and she was quite sure she had Down syndrome" (Participant #39)."*

(Nelson Goff et al., 2013)

Parents often mentioned professional opinions on Down's Syndrome and termination of pregnancy. Within the studies included in this review these were often more negative that positive. Often there was an assumption that termination was the next step after a positive prenatal test (Nelson Goff et al., 2013; van Schendel et al., 2017; How et al., 2019; Lou et al., 2020).

*"how we interpreted ... the urgency that the doctor that phoned us up saying that there was a spot for the test the following day ... as you can come in, get tested and terminate like everybody else does."*

(How et al., 2019, p. 297)

Further to this, parents also suggested that, from their perspective, it seemed that healthcare professionals opinions were formed from out-dated information. Within the included studies this out-dated information was about prospects for the child in the future, perpetuation of negative stereotypes, or general unfamiliarity about Down's Syndrome. The concern of this is that negative opinions or lack of understanding from healthcare professionals could lead to them inadvertently influencing decision making throughout the pregnancy (Nelson Goff et al., 2013; Kellogg et al., 2014; van Schendel et al., 2017; Lou et al., 2020). One of the studies by Tymstra et al. (2004) mentioned that interactions with professionals were positive but also the decision to continue the pregnancy was occasionally met with shock, but understanding.

> *"Some felt that the HPs had painted an unnecessarily grim picture of DS based on what couples perceived as out-dated information: She [the obstetrician] said that people with Down syndrome never get past the mental age of 8 … that they could not get smarter than that. Or have a functional level higher than that. And those were "the good ones." (Mother 5, first child)"*

(Lou et al., 2020, p 4)

### *Information Provided about Down's Syndrome by Professionals*

Information given by professionals to parents who underwent prenatal testing was often not deemed sufficient to answer all of the questions that a diagnosis of Down's Syndrome can raise. The information given tended to focus on listing medical symptoms and problems such as heart and organ issues and intellectual difficulties. This was often presented as statistics and percentages that parents struggled to comprehend (Kellogg et al., 2014; van Schendel et al., 2017; How et al., 2019; Lou et al., 2020).

It was suggested that there was a need for the focus of the information provided to include future aspects of living with Down's Syndrome from medical professionals, rather than this information needing to be sought out through different support groups and the internet (Canbulat, Demirgöz Bal & Coplu, 2014; van Schendel et al., 2017; Lou et al., 2020).

> *"Father: Well, the paediatrician was really good … but it took a while before we talked to him. But there is this clinical approach to Down syndrome at the hospital and for us … it was not about quantifiable stuff … it was quality of life: how do people manage? Not about percentages or risks. And the hospital … well, they were not very experienced in dealing with this emotional side. (Couple 4, first child)"*
>
> (Lou et al., 2020, p. 4)

### *Approach to the Delivery of Results by Professionals*

There were both positive and negative experiences of delivery of results following prenatal testing. Those parents who had a positive experience explained that the results had been given by professionals in person with the use of professional and empathetic language. Parents explained being taken seriously and the result being presented in a neutral way, was a better experience (Tymstra et al.,2004; Skotko, 2005; Lou et al., 2020). Some parents explained that the delivery of results was a negative experience for them. The results were often delivered over the telephone without the professional checking if they had any other family member present (Tymstra et al.,2004; Skotko, 2005).

The language used when delivering the diagnosis was also not satisfactory for some of the parents. For example, when delivering the results professionals often used insensitive terms such as 'I'm sorry' or 'Unfortunately…' or 'There's something wrong…' this resulted in resentment towards the professional delivering the news and unnecessary anxiety. Some of these parents also had requested to be told by their own General Practitioner but were denied this (Tymstra et al., 2004; Skotko, 2005):

## Post Test Emotions following Diagnosis of Down's Syndrome

### *Feeling about Results*

Parents reported a mixture of emotions about receiving their child's diagnosis of Down's Syndrome. There was an initial shock of the diagnosis, alongside a range of other negative emotions such as fear or worry, whether the diagnosis was received prenatally or not, but receiving the diagnosis early allowed parents time to process this emotion. The thoughts that accompanied these emotions were what their child's future would be, a fear of the unknown, and how it might impact them as a family (Hurford et al., 2013; Nelson Goff et al., 2013; Canbulat, Demirgöz Bal & Coplu, 2014; Lou et al., 2020). A small number of parents in one study reported having an immediate acceptance of the diagnosis, seeing their child as a gift or blessing (Nelson Goff et al., 2013).

*"Although shock, fear, and grief were reported by most parents as their preliminary reactions, whether they learned of the diagnosis before or after the birth, a few parents reported more positive initial reactions, like feeling that their child was a gift and blessing (Prenatal #1 and #9), or feeling a sense of relief or peace and immediate acceptance at the diagnosis (Postnatal #7 and #50)."*

(Nelson Goff et al., 2013, p 452)

In one of the studies parents commented on the emotions they experience whilst waiting for the results of the prenatal tests. They mainly reported the stress and worry during this period of time. One participant described this stressful waiting, as being akin to receiving the prenatal diagnosis (Canbulat, Demirgöz Bal & Coplu, 2014).

*"Another participant (33 years old, 16 weeks of gestation) said that: "It is very hard to wait for amniocentesis results. I felt like dying. I counted the days. It was very, very stressful. I wish I had never got it done.""*

(Canbulat, Demirgöz Bal & Coplu, 2014, p. 149)

Some parents who had prenatal testing reported that they were able to celebrate the birth of their child, more than if they had not received a prior diagnosis (Nelson Goff et al., 2013). Many parents adapted to life with their child quickly, focusing on their positive impact on the family and the community, and what they could achieve in their futures (How et al., 2019; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019). Parents also described comparing the diagnosis to other health conditions and this giving them a new, more positive, perspective on Down's Syndrome, allowing them to adapt more easily (Nelson Goff et al., 2013).

### *Feeling about Decision to Continue*

Following their emotions about the test results parents described more positive emotions and thoughts about their decision to continue with the pregnancy. Many parents described that their child's diagnosis was linked to their destiny as parents, needing to safeguard and protect their child. Trusting spiritually that this child was meant for them (Hurford et al., 2013; Canbulat, Demirgöz Bal & Coplu, 2014; Lou et al., 2020). Further to this there were parents who did not agree with the idea of termination of pregnancy despite the challenges they may face delivering a child with Down's Syndrome (Hurford et al., 2013; Canbulat, Demirgöz Bal & Coplu, 2014; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019). One parent in the study by Nov-Klaiman, Raz & Hashiloni-Dolev (2019) explained how their acceptance of the diagnosis was quick and they wanted their community to not 'pity' them.

Many parents in the study by Tymstra et al. (2004) described their decision to continue with the pregnancy to be based on 'little things'. One parent specifically describes meeting a family with a child with Down's Syndrome and this observation 'decided' it for them. Another describes developing greater understanding through reading and developing a confidence against the negative portrayal of Down's Syndrome. Although overall the thoughts and emotions were positive, there were some parents that queried their own decision. This seemed to be due to the general opinions of others in society and their view that other parents were more likely to opt for termination (Lou et al., 2020).

> *"I feel that I made the absolute best decision to continue my pregnancy because my daughter is a complete joy and I can't imagine my life without her. Even with her Down syndrome…Yes, termination would have been easier FOR ME. But I don't like the person I would've been had I made that choice. … No one can say who those combined, configured genes will produce. I'm finding that my bundle of combined, configured genetic material has a smile that brightens up a room like sunshine streaming through a window … Yes, all the appointments get really tiring, but it's so worth it to find out who this person is."*
>
> (Hurford et al., 2013, p. 591)

## Societal Opinions

### *Negative social language*

Both parents who did and did not undergo testing explained their experience of the negative social language and assumptions about Down's Syndrome. Many parents referenced the preconception that having Down's Syndrome is a severe disability that would 'lumber' parents. (Hurford et al., 2013; Tymstra et al., 2004; Nelson Goff et al., 2013; How et al., 2019; Lou et al., 2020). More specifically in the study by Skotko (2005) several mothers reported their healthcare professionals using out-dated and unacceptable language to describe Down's Syndrome, with the term 'mongoloid' being used as recently as 1997.

Some parents held the opinion that prenatal testing for Down's Syndrome perpetuated the negative discourses in society. Mothers in the Netherlands explained how the prenatal tests are described in the media as 'Down's tests' and there is a perception, by mothers, that the government labels Down's Syndrome as something that should not exist, by providing these tests (van Schendel et al., 2017). Similarly women in Israel explained their experiences of the social-medical discourses in the country. Reporting that they feel their society is less accepting of disabilities, and children with Down's Syndrome are seen as a 'problem' that needs to be 'fixed'. This is also how it is portrayed in some media. These mothers thought that the prenatal tests for Down's Syndrome add to this negative portrayal (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019).

Other parents did not directly mention negative social language, but made statements against negative societal opinions and generalisations (Lou et al., 2020).

> *"I have seen kids a lot worse than Down syndrome […] Autism, severe physical disability, that is worse … (Mother 3, first child) Some syndromes are really horrible, you know, like constant fractures or peeling off skin … that stuff you see on TV. It doesn't hurt to have Down syndrome. I mean, it is not a life of suffering. (Mother 8, third child)"* (Lou et al., 2020, p. 4)

### *Lack of social support following Prenatal Results*

Parents experienced a lack of social support both at the point of prenatal testing and upon the birth of their child. They describe people in their social circle and family's having a negative opinion of Down's Syndrome and pushing for termination if prenatally diagnosed (Tymstra et al., 2004; How et al., 2019).

They also describe having to ‘fight’ for resources and care for their child (van Schendel et al., 2017; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019).

Some parents also reported that following prenatal testing and birth of their child they lost family and friends, as they found it ‘too difficult to cope’. Two parent’s also said that having a child diagnosed with Down’s Syndrome caused difficulties at work to the point of dismissal, although these difficulties were not clarified (Tymstra et al., 2004):

> *“In some cases, it had led to the breakdown of relationships between family or friends (“I don’t see some of my family anymore, they found it too difficult and we lost touch soon after the birth”; “We asked some friends if they would be the godparents, but they couldn’t cope with caring for a handicapped child”). Two of the respondents said that the situation had led to problems at work (“The situation at work became so bad that it led to dismissal”).”*
>
> (Tymstra et al., 2004, p. 94)

### *Implications of testing*

Some parents expressed worries that offering prenatal testing may impact societal opinions about individuals right to be alive, as termination is often offered. Others saw prenatal testing as a potential lead to eugenics.

There was a concern shared amongst parents, who both did and did not undergo testing, that prenatal testing would lead to an increase in termination, as this seemed to be the predetermined pathway many professionals expected

(Kellogg et al., 2014; How et al., 2019; Lou et al., 2020). Some parents disagree with the tests being a way to provide an option for termination, but think they could be helpful just to provide information to the parents prior to birth. Allowing parents to prepare both mentally and practically with thing such as perinatal care (Inglis, Hippman & Austin, 2011).

Others did not hold this same opinion, and agreed that families and parents should be given a choice if they feel they are unable to take care of the child (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019). Similarly some parents supported screening to avoid the child suffering if there are other physical medical issues. They also supported testing for more disorders as a way to reduce the focus on Down's Syndrome (van Schendel et al., 2017).

Parents also worried that early prenatal testing for Down's Syndrome and other disabilities could be a form of eugenics with the aim to eradicate difference and disability in societies (Kellogg et al., 2014; van Schendel et al., 2017; How et al., 2019). Further to this a number of parents held the opinion that normalising testing for Down's Syndrome would lead to increased negativity towards the diagnosis, resulting in individuals being less accepted (van Schendel et al., 2017).

In opposition to this, two parents shared their views that disabilities should be tested and controlled for, but those individuals who are born despite testing should be supported and provided for (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019).

*"I don't think that nowadays, when technology is so advanced, and you can detect so many things during pregnancy – I don't think children with disabilities,*

> *including Down syndrome, should be born. If they are already born, if it was not found during pregnancy – of course they should be given everything possible. But why… Why let these kids be born if… Why? Why do people do these tests in the first place? [Noa, age 43, secular, mother of 3. Eldest with DS]"*
>
> (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019, p. 1126)

### ***Support from others***

Parents of individuals with Down's Syndrome found that, although many of their experiences with society were negative, support groups were a place of understanding and knowledge. These groups are often offered after prenatal testing, as well as after birth.  Parents explained that these groups helped them feel supported by other people who had gone through the same or similar experience, and felt more positive in their decision to continue with the pregnancy (Skotko, 2005; Nelson Goff et al., 2013; How et al., 2019). However, one parent in the study by van Schendel et al. (2017) suggested that some groups portray Down's Syndrome in an overly positive way in order to work against the social narrative. They suggested that neither these groups nor the negative stories show the reality.

There was an idea from a few parents that the best source of knowledge and information was from parents and people living with Down's Syndrome. Sharing their own experiences to help people understand (Nelson Goff et al., 2013; van Schendel et al., 2017). Other parents mirrored this opinion searching for information from other peoples experiences of Down's Syndrome, asking questions and receiving 'real life answers' to help with their adjustment process (Tymstra et al., 2004; How et al., 2019; Lou et al., 2020). This was found to be an experience by both prenatal and postnatal diagnosis parents (Nelson Goff et al., 2013).

> *"One woman had visited a couple who themselves had a DS child ("My sister's friend has got a child with DS and we went to see her. We saw that she was a really bright and cheerful little girl"). In this way, they try to get a picture of what (life with a child with) DS involves."*
>
> (Tymstra et al., 2004, p. 93)

## Opinions on the Logistics of Testing

### *Availability of testing*

Parents also commented on the availability of prenatal testing, although different countries have different levels of availability. A number of parents in the study by Inglis, Hippman & Austin (2011) supported the idea that there should be age-based eligibility criteria for testing. There was a suggestion by one parent that they themselves would not have undergone the testing at a younger age due to the risks, and therefore they supported an older age cut off. Further to this, a few parents held a similar view that a younger parent may not handle the results emotionally or be able to take care of a newborn with Down's Syndrome at an older age and therefore supported the tests being available to women older than 35 (Inglis, Hippman & Austin, 2011).

However, more than half of the parents in this same study supported diagnostic testing being available to women of all ages. They suggested that denying access seems ‘paternalistic’ by medical professionals. Further reasoning for supporting full availability was allowing informed decision making for all and also an awareness of potential financial difficulties of caring for a child with Down’s Syndrome.

> *“One participant who felt diagnostic testing for DS should be available for all women commented: ‘‘Because of our age, we are in a financial position to offer our son a lot, and we can afford the help we need… One said: ‘‘I believe all tests etc. should be available to all women and the info results provided to them to make an informed decision. To deny one group of women access to a test on the basis of age seems to me a very paternalistic or patronizing action by the medical decision makers.’’”*
>
> (Inglis, Hippman & Austin, 2011, p. 747)

Some parents also mentioned the financial aspect of prenatal tests, as in some countries these tests are not a standard provision. It was suggested that the financial cost would impact test uptake for those who wish to have it (Nov-Klaiman, Raz & Hashiloni-Dolev, 2019). When asked if they thought the test cost should be reimbursed, parents though that this would prompt people to take the test without understanding the consequences of the results. However, they also acknowledged that not reimbursing the cost, could lead to Down’s Syndrome children only being born to people in lower socioeconomic classes, potentially perpetuating the aforementioned stigma of Down’s Syndrome (van Schendel et al., 2017).

### *Safety of different tests*

When giving opinions on prenatal testing some parents referred to the safety of different tests and commented on the safety of non-invasive prenatal screening. Non-invasive prenatal screening was seen as the most accurate and safe procedure to be undertaken (van Schendel et al., 2017; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019).

Parents also noted that other tests offered carry a risk of miscarriage, whereas non-invasive tests are conducted from blood work and therefore do not hold this same risk (van Schendel et al., 2017; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019). Further to this in the study by Nov-Klaiman, Raz & Hashiloni-Dolev (2019) Parents commented on how finding out earlier through the non-invasive tests, although not a diagnosis, allows termination to be a potential option, even in more religious areas.

### *Lack of information about tests*

Parents also spoke about how there is a lack of information about tests, or that information given if confusing. Many parents noted their own confusion between screening tests and diagnostic tests. At the time they had the prenatal screening done, and their tests came back with a low-risk, they understood that to mean their baby would not have Down's Syndrome. Consequently a few parents commented on the false reassurance screening tests can provide them (Skotko, 2005; van Schendel et al., 2017; Nov-Klaiman, Raz & Hashiloni-Dolev, 2019; Lou et al., 2020). One mother reported not understanding what conditions were tested for. She instead requested a test for spina bifida, as this was a condition in her family, and through this was told about the abnormalities in her foetus' chromosomes (Tymstra et al., 2004).

> *"One (young) woman with spina bifida in the family wanted to have her foetus tested for this and did not realise that the tests could also show up abnormalities in the chromosomes."* (Tymstra et al., 2004, p. 93)

## Discussion

This review aimed to explore and understand the experience and opinions of parents who have children living with Down's Syndrome on prenatal testing. The parents included in the studies of this review had experience of either prenatal testing or diagnosis at birth.

The results showed that there was a mixed opinion on prenatal testing overall. The view that prenatal testing is helpful for prospective parents was not exclusive to those individuals who had previously had testing. Some parents, who did not have prenatal testing, held the opinion that prenatal testing should not be offered, as it could result in termination of pregnancy and othering of those already living with the diagnosis.

Some parents, who had prenatal testing, explained having negative emotions about the results of the tests. Similarly those who received a diagnosis at birth also experienced difficult emotions. However due to the early diagnosis those who were tested felt able to reconcile these emotions prior to the birth of their child.

During the process of diagnosis, interactions with healthcare professionals, societal opinions, and information provided about the tests impacted the parents' emotions and experience. Several parents explained that they received out-dated information and perceived negative opinions from professionals. Many parents included in this review experienced negative emotions, either about the diagnosis or their medical professional. This supports the idea that the psychological wellbeing of parents must be considered throughout the process of prenatal diagnosis of Down's Syndrome (Buckley & Buckley, 2008).

Within this review it was found that parents thought prenatal testing could have an impact on both themselves and their social circle. It was also found that parents experienced differences in social support. Some parents reported loosing friends or family due to the diagnosis and how this negatively impacted their emotional experience (Tymstra et al., 2004). Other parents reported feeling part of a community (Skotko, 2005; Nelson Goff et al., 2013; How et al., 2019). These differences in experience indicate how social support can mediate the higher levels of stress having a child with a disability may put on parents. Similar to findings by Asberg, Vogel, & Bowers (2008) that stress levels can be lessened through a parents perceived social support.

The findings of this review also highlighted the differences in experience that parents had with professionals. Many reported that they felt as if termination of the pregnancy was the expected outcome, this was either consciously or subconsciously portrayed by professionals. This supports importance of the more recent movement in genetic counselling away from just the provision of information to acknowledging the psychological impact and distress this information may prompt (Kessler, 2013). This is in line with taking a person-centred approach; acknowledging the entirety of the person as an individual, with different experiences, morals and desires (Rogers,2012).

### ***Strengths and limitations of the review***

This review included studies with parents from the Netherlands, United Stated of America, Denmark, Israel, Australia and Canada. Each of these countries has different governmental policies and legislation relating to maternal healthcare. Further to this these countries differ in their religious beliefs and laws about termination of pregnancies. Therefore although links can be drawn between their experiences, it is important to acknowledge how societal differences could impact their opinions. Specifically of the studies included in this review: the study conducted in Israel included parents who practiced 'ultraorthodox' Judaism; the studies conducted in the USA where healthcare is not free at point of access. However it may have been more beneficial to complete separate reviews by country of origin to understand the impact of policies and how this could affect parents' opinions.

Further to this, this review included data from both qualitative and quantitative surveys. As the researcher only included the qualitative statements from the survey data some information may have been lost from the surveys statistical analysis.

### *Clinical Implications and Future research*

This review did not include any research on opinions of parents who are living in the UK. Future research could focus on their opinions and experiences of prenatal tests within the National Health Service provision. Additionally, future research should seek to understand the opinions of individuals living with Down's Syndrome on prenatal testing, to learn of the impact the knowledge of these tests may have on them emotionally. There is a negative social narrative explored within the current review, however some of the studies date back to 2013, it may be that opinions on Down's Syndrome have changed following increased media coverage and potential change in legislation. Future research should revisit wider societal opinions on Down's Syndrome as a diagnosis alongside prenatal testing.

The findings within this review show how healthcare services can support women throughout the screening and diagnostic process, by focusing on person centred care. Although the findings are across different countries many parent reported difficulties with their healthcare professionals not explaining the tests, giving unsolicited opinions and assuming the desired care pathway. This information should be used to ensure that appropriate care and attention are provided to these parents, removing both physical and perceived barriers to testing, in delivering results of tests, and any suggestion of further medical procedures, such as termination. Additionally, these findings highlight the need for understanding and knowledge of Down's Syndrome in a wider social context. This knowledge as a society is needed in order to provide necessary support to parents and remove the negative societal narrative surrounding Down's Syndrome.

## **Conclusions**

This review demonstrates the opinions on prenatal testing from the perspective of parents who have children with Down's Syndrome. There is a wide range of both positive and negative opinions on testing overall. Some parents advocate for prenatal testing to allow choice and awareness and others disagree, with fears of the societal impact on how their children or other children with Down's Syndrome may be treated. Further to this parents explain that the attitude of the professionals involved in their care impacts their experience of pregnancy with a child diagnosed with Down's Syndrome. Overall this review highlights the need for each prospective family's care to be tailored to them, their religious beliefs and overall opinions.

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# Part Two: Empirical Paper

This paper is written in the format specified in the journal

*Journal of Intellectual Disabilities*

Please see Appendix K for submission guidelines

**Word Count: 8,411 including tables and figure captions**

# A qualitative study into the lived experience of personal growth in individuals with Down's Syndrome

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## Abstract

**Background**: The current research aimed to provide an understanding of the opportunities and experiences of personal growth of individuals with Down's Syndrome; focusing on their lived experience and exploring how society can both help or hinder these individuals.

**Method:** Six individuals with Down's Syndrome were recruited through social media and specialist support groups. Semi-structured interviews were conducted and analysed using interpretive phenomenological analysis.

**Results:** Four superordinate themes were identified: 'Awareness of Down's Syndrome and the Difference that may be Present', 'Opportunities for Growth', 'Social Impact on an Individual's Growth' and 'Individuals Sense of Self and Diverse Personalities'.

**Conclusion:** This research highlighted the opportunities and ability for individuals living with Down's Syndrome to experience personal growth, a marker of quality of life. It also highlighted the need for further acceptance and provision of diverse opportunities within society for individuals with Down's Syndrome.

## Introduction

Trisomy 21 or Down's Syndrome is a genetic disorder which causes varying degrees of intellectual disability, with physical features caused by the genetic material on chromosome 21 (World Health Organisation, 2020). According to the World Health Organisation, some of the physical characteristics of Down's syndrome are decreased muscle tone, irregular shaped ears and a flat face. Every one in 1,000 babies born will have Down's syndrome and overall it is estimated that there are around 40,000 people currently living in the UK with Down's syndrome (Down 's Syndrome Association, 2020).

Trisomy 21 is considered, medically, as a severe foetal abnormality (The Abortion Act, 1967). One of the options that is given by health care professional in cases of severe foetal abnormality is termination. In regards to Down's Syndrome, termination of the pregnancy can be carried out after the usual cut off periods of twenty-four weeks or in exceptional circumstances twenty-six (The Abortion Act, 1967). This means foetus' with Down's Syndrome can be terminated up until point of delivery under current law. Women are offered screening tests for trisomy 21 usually by 14 weeks of pregnancy and an ultrasound at $20^{+6}$ weeks to identify structural features of the foetus. This is available in order for a decision to be made regarding termination of the pregnancy (Royal College of Obstetricians and Gynaecologists, 2010).

A common psychological approach to the study of disability is that of positive psychology. Positive psychology focuses on positive features that 'make life worth living' including subjective experience and positive individual traits as opposed to a focus on pathology (Seligman & Csikszentmihalyi, 2014). In 1992, there was a shift to a social-ecological approach to disability (within multiple disciplines including medicine and health psychology) in order to understand environmental factors alongside pathology (Buntinx, 2014). This movement continued in 2010 to a non-pathological concept of "human functioning" and a more positive view on disability (Buntinx, 2014). The aim of this approach, within research into disabilities, is to shift the focus from the study of resilience of the individuals, to an acceptance of disability as more an aspect of human functioning which can inform positive development and growth, particularly by adopting a strength-based approach (Shogren, 2014).

The concept of quality of life is composed of the same factors and relationships for all people, including individuals with learning disabilities. It is a multidimensional construct with both subjective and objective components (Verdugo et al., 2012). Quality of life can be split into eight different domains: Personal Development (or Personal Growth), Self-determination, Interpersonal Relations, Participation, Rights, Emotional wellbeing, Physical wellbeing, Material wellbeing (Verdugo et al.,2012; Schalock & Alonso, 2014). The importance placed on these domains is likely to change, subjectively, between each individual including those with disabilities (Schalock & Alonso, 2014).

As well as quality of life, when using a strength-based approach, it is important to include adversarial growth in order to get a holistic view of individual experiences. Adversarial growth or post-traumatic growth is a qualitative change and adaptation, where a person endeavours to find meaning in highly stressful life circumstances, usually occurring as an individual attempts to cope following a trauma (Tedeschi & Calhoun, 2004). However, Kim et al.

(2019) reframed the idea of posttraumatic growth to be that of personal growth, in their study of the changes couples developed following a diagnosis of multiple sclerosis. The experience was not viewed as traumatic but rather as a life experience, which enabled growth. This view allows positives to be drawn from an otherwise adverse and potentially negative situation.

Personal growth is a term that is not clearly defined within psychological literature, as it is often a subjective construct. Broadly, it refers to a process of becoming a 'better self' in a personally meaningful way (Vittersø, 2014). However, it is suggested that current theories of personal growth are nonrelativistic, with some growth trajectories in life being seen as better than others (Vitterso & Straume, 2020). Holding this in mind one could begin taking a relativistic approach to personal growth, focusing on individuals perceived growth without reference to an absolute comparison. This would allow greater inclusivity of individuals whose growth may not be the norm or comparative to others growth outside of their context, for instance people with a intellectual disability, but is just as meaningful and important to them.

Ryff (1989) described somebody who is high in personal growth as one who *"has a feeling of continued development; sees self as growing and expanding; is open to new experiences; has sense of realizing his or her potential; sees improvement in self and behaviour over time; is changing in ways that reflect more self-knowledge and effectiveness."* (p. 1072)

To date, research has mainly focused on the opinions of carers and parents and their personal growth through their experiences with someone living with Down's Syndrome (Counselman-Carpenter, 2017; Young et al., 2020).

Similarly, parents and carers have been asked to report the experience of quality of life and adoption of positive psychology approaches, on behalf of the individual with Down's Syndrome. For example, Haddad et al. (2018) used a third-party approach to investigate the determinants of quality of life in individuals between the ages of 16-31 living with Down's Syndrome. Lyons et al. (2016) explored parental perspectives of the effect of participation in everyday activities, such as interaction with peers, in children with Down's Syndrome and the effect this has on their wellbeing. Further to this, Shields et al (2018) also focused on parent-reported quality of life in individuals with Down's Syndrome.

Studies involving people with Down's Syndrome tend to be focused on health-related quality of life as with those that are from parents and carer perspectives. At the time of writing, there has been no other research into opportunities Down's Syndrome provides for personal growth in an individual. A Down's Syndrome diagnosis could be described as an adverse experience, based on social constructs, and could therefore be an instance in which personal growth is possible.

As personal growth is noted as one of the aspects indicative of quality of life - demonstrated through activities of daily living, choices and decision and personal goals (Schalock & Alonso, 2014) - the ability to experience personal growth would imply life with down syndrome does not equate to a life full of "suffering" and that a quality of life is achievable negating the aforementioned idea that The Abortion Act (1967) is based upon.

The most commonly adopted model of disability within both academia and wider society is the medical model. This model focuses on the restrictions of the disability rather than an exploration of the diverse experiences of each individual (Marks, 1997). Further, this model often has social implications and is readily associated with social exclusion and increased vulnerability (Isaac, 2010). In contrast, the social model of disability proposes that having a medical condition is not 'disabling' in itself; it is the social stigma, functioning and structures in society that makes the world inaccessible to those with such conditions (Shakespeare, 2006).

Intellectual disability historically has been highly pathologised but in more recent years there has been a move towards a more positive, person centred approach, focusing on the disability as an aspect of human functioning (Buntix, 2014). This aspect of human functioning can promote development and growth of an individual (Shorgen, 2014). However, despite Down's Syndrome being one of the most common genetic causes for intellectual disability (Bittles et al., 2007), little research has been conducted to give an insight into the lived experience of the growth and development opportunities of individuals living with Down's Syndrome.

This research aims to gain an understanding of the challenges a diagnosis of Down's Syndrome brings for an individual, and how positive life changes and personal growth are experienced. The focus will be shifted away from physical health, towards the wellbeing and lived experience of an individual, providing an insight for clinicians, into the impact of the diagnosis and the ways in which positive psychology could guide care.

## Method

### *Design*

This study used a qualitative design in order to explore the experiences of people living with Down's Syndrome. The data was gathered using semi-structured interviews, following an interview schedule that included both closed questions, to aid understanding, and open-ended questions to illicit more detailed experiences (See Appendix E). The design and questions were created using a positive psychology lens, focusing on enabling participants to discuss their positive emotions and traits, and places that support their development of these (Seligman, 2002)

The data was analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009).

### *Procedure*

Ethical approval was provided on 21st December 2021 by the Ethics Committee at the University of Hull as part of the Doctorate in Clinical Psychology. (See Appendix F)

Prior to use, the interview schedule was reviewed by a peer, by an individual with learning disabilities and also the Down's Syndrome Association. Feedback was given and alternative wording sought for a small number of proposed questions.

Participants were recruited through Down's Syndrome Scotland, Facebook groups and the Down's Syndrome Association. A recruitment poster was shared to these groups and on social media, which included the researcher's contact details (See Appendix G).

Potential participants were asked to email the researcher to register their interest in the study. Following this, these potential participants received further information about the study's aims, methods and participation requirements before agreeing to take part. This information was provided in the form of an information sheet (See Appendix H). The information sheet was either emailed to them or posted, based on their preference, along with a consent form (See Appendix I). Participants were able to email the researcher with any further questions or queries pertaining to the research. Participants were also asked if they would like any support from their parents or carers during the interview. Following this they were asked to sign and send back the provided consent form via post or email, if they wished to take part. Parents or carers, if participant wished them to be at the interview, were asked to sign the consent form too. This allowed them to be audio recorded if they needed to speak during the interview.

Following receipt of the consent form, the researcher contacted the potential participant via email, to arrange an interview via video call or telephone. Interviews were not offered in person due to shielding guidance of COVID-19. The interviews ranged from 30 minutes to a maximum of one hour. Each was conducted and audio recorded on an encrypted laptop. Following the interview, the researcher gave the participant a leaflet listing sources of support for any of the topics discussed (See Appendix J).

Interviews were transcribed and the original recordings deleted afterwards. These transcriptions were saved separately to the consent forms and given a pseudonym to ensure anonymity.

### *Participants*

The participants in this study were individuals who identify as living with Down's Syndrome. All participants were aged between 18-50 years approximately, able to communicate through spoken English and had the capacity to consent to take part. Four women and two men took part in the study. All but one of the participants requested their parent of carer be present for support. No individuals were excluded based upon any other extraneous variables including race, sexuality, or any other medical diagnosis or conditions. As these variables were not part of exclusion criteria they were not directly collected during the research procedure. Participants needed to have a suitable level of spoken communication, therefore individuals who could be described as having a more profound intellectual disability who have difficulties comprehending or communicating through spoken English were not able to take part.

### *Data Analysis Procedures*

The transcripts were analysed using IPA, following the methods and guidance for this technique outlined by Smith, Flowers & Larkin (2009). The data analysis method of IPA was selected as the methods have an ideographic focus, offering an insight into an individualised context of a phenomenon. This analysis method was chosen to explore the phenomenon that is living with Down's Syndrome, understanding the individual meanings participants assign to their individual experiences.

During analysis the researcher first read and re-read the transcripts to familiarise themselves with the content. Using NVIVO 1.7 1 (released in October,2022) line-by-line analysis of the transcripts was conducted, with exploratory comments being created alongside codes. This was done case by case. Following this, these codes were grouped into similar themes within the cases. These themes within cases were then synthesised and organised into larger emergent subordinate themes. After the creation of subordinate themes, these themes were then organised further into superordinate themes.

### *Researcher Perspective*

Due to the chosen analysis and its interpretive nature, the researcher's position should be acknowledged recognising the researcher is not independent from the social context of the study (Taylor, 1994). The first author is a white British female and a trainee clinical psychologist from North West England. The researcher had personal experience of working with individuals with intellectual disabilities, and a close family friend whose child was born with Down's Syndrome.

As recommended in qualitative research (Elliott, Fischer & Rennie, 1999; Yardley, 2000), the researcher used supervision and a reflective diary to acknowledge personal reflections and preconceptions during the research process. The impact of societal narrative and how this may impact the researcher was also reflected upon in supervision. Please see Appendices A and B for an extended reflective statement and epistemological statement for further context.

## Results

The analysis conducted produced four superordinate themes and ten subordinate themes (see Table 4). Quotes from the transcripts are embedded within the results sections to ensure the themes are representative of the data and the participants' experiences.

*Table 4. Superordinate and Subordinate Themes*

| **Superordinate Theme** | **Subordinate Themes** |
|---|---|
| 1. Awareness of Down's Syndrome and the differences that may be present | • Opinion on Down's Syndrome<br>• Awareness of wider societal opinions of Down's Syndrome<br>• Medical impact differences |
| 2. Opportunities for Growth | • Learning and development within an academic setting<br>• Opportunities and the need for understanding of capabilities |
| 3. Social impact on an individual's growth | • Positive social circle<br>• Making relationships and building a sense of social importance<br>• Opportunity to build awareness |
| 4. Individuals' sense of self and diverse personalities | • Sense of self<br>• Future hopes |

### 1. Awareness of Down's Syndrome and the differences that may be present

This superordinate theme explores how the participants understand their Down's Syndrome, and their acknowledgement of the potential differences that come through having the condition. This includes their own opinions on having Down's Syndrome, their acknowledgement of wider societal opinions, and an awareness and acceptance of medical issues that come through having Down's Syndrome. Acknowledging difference or adversity allows the possibility of personal growth, through this difference.

### *1.1 Opinion on Down's Syndrome Underlying Personal Growth*

All participants held positive opinions about having Down's Syndrome themselves providing potential opportunities for growth, through acceptance of the diagnosis. Liv explained her developing opinion about her diagnosis:

"*Actually its not bad because as I've realised having Downs Syndrome is ok because it means that you're special and you'll always have it, its like your own special thing being unique because everyone is special in their own way and I'm cute in my own way."*(Liv).

Similarly, Liam explained that he can find some things difficult but overall, he thinks having Down's Syndrome is a positive thing for him:

*"I think it's a good thing…people with Down syndrome they have life challenges, but that can be a good thing too…. Because when people have Down Syndrome sometimes they find things quite easy and sometimes quite difficult too."*(Liam)

Participants acknowledged the potential worries that prospective parents may have about having a child with Down's Syndrome and offered some advice from their personal experience. Sophie did not acknowledge any difference between having a baby with the condition or not: *"No it's not (something to be worried about), it's a baby and a baby is a good thing."* (Sophie). Hannah shared similar thoughts: *"It's the best thing that anyone or any new mum can have."* (Hannah).

Further to this a few participants acknowledged there may be some difference between having a baby with Down's Syndrome or one without the condition. Liv did not think that this should be seen as a negative:

*"I would say like if they've got any symptoms if they are different like small or have the crease in their hands and small feet or their eyes are different like mine… they shouldn't be worried at all because its just a part of who we are and I think everyone should know that people with Downs Syndrome would have a happy life."* (Liv).

Liam also implied there would be a difference when having a baby with Down's Syndrome but in his opinion, this was a positive: *"I would say, keep relaxed, keep calm. And if you love babies you are going to love having a baby with Down's Syndrome because they stay baby longer."* (Liam).

### *1.2 Awareness of wider societal opinions of Down's Syndrome*

Some participants spoke about their experience and awareness of discrimination and 'hate crime'. They provided their opinions on how this may affect themselves or others, both providing learning opportunities to develop their sense of self or hindering their opportunities for growth. One participant spoke on his experience of discrimination by his school with regards to his education choices, mirroring the negative narrative of Down's Syndrome being a severe learning disability. Due to the held idea, by his school, that he would not be intelligent enough to go to college to study his chosen subject, the school would not allow him to attempt the entrance exams: *"I'm one of still a marginalised group. They say 'we allow other groups in as long as their smart. And therefore we are leaving you people with intellectual disability out of the university system.'"* (Liam). Liam experienced an impact on his future choices as a direct result of potentially incorrect assumptions by those in the education system. Not allowing him to take the necessary exams, based on the assumption he would not be intelligent enough to pass, resulted in Liam not being given the opportunity to take the tests and either pass or fail to find out his capabilities for himself.

Liv spoke about her feelings about hate crime against those with Down's Syndrome. Suggesting that individuals who commit these crimes lack sufficient knowledge and understanding of the condition:

*"It can be upsetting especially Downs Syndrome hate and disability hate crime. They need to learn that people with Downs Syndrome need to be heard and need to be alive…people need to know more about it and get to know someone"*(Liv).

Further explaining her point Liv acknowledged that Down's Syndrome is a disability but that this does not negate her feelings or right to not have crimes committed against her or others: *"We are all disabled but most people, if they've* *got a disability, they should be proud of it… I feel everyone has rights and they definitely deserve to be heard… be kind and don't spread any hate"*(Liv)

### *1.3 Dealing with Medical Challenges*

A further theme that explores difference is that of the potential medical issues that arise through having Down's Syndrome. These are often the things the general population are made aware of in relation to the condition, such as heart difficulties or eyesight and hearing problems. The acceptance of these challenges and adapting to still thrive with medical problems, gives an opportunity for personal growth. Liv explained the medical support both her and her friend with Down's Syndrome have to help with their ongoing health issues: *"He has the same as me so we have speech and language, we both have a visual impairment, we both get physio. He also has hearing aids and I used to wear hearing aids when I was little. I also wear glasses due to my cataracts. I've got two double ones and I wear these to help."* (Liv).

Amelia spoke about how medical check ups and monitoring are part of her having Down's Syndrome: *"I do have to have check ups for like, my hearing and my eyes. I go to the doctors."* (Amelia). She also spoke about having heart problems that needed an operation when she was a baby, her mother helped her to reflect on this as she did not remember:

*"Tell Lottie about the doctors. It's not always been easy. When Amelia was little she had to have heart surgery … obviously she didn't know anything about it. But that*

*was really difficult for us. (Amelia's Mum) Yeah, it's quite a big operation. (Amelia) "* (Amelia & Mother).

Similarly Sophie had to have heart surgery as a child, but she doesn't see this as something that negative impacts her life now, although monitoring this is still part of her life:

*"Like when I was little I was poorly (and had to have heart surgery) But I don't remember it. I just have check up's now."* (Sophie).

Further to this due to medical issues they experience, during the initial outbreak of COVID-19, participants had to shield because to their vulnerability to the virus. This naturally had an impact on participant's wellbeing and highlighted the physical differences to them. One participant in particular spoke about the impact COVID-19 had and continues to have. Hannah explained that COVID-19 significantly changed her life because she has Down's Syndrome:

*"COVID has impacted my social life and my mental health was really bad. I felt like I couldn't cope in November 2020.... we were shielding as well... It was very very difficult yeah."* (Hannah)

## 2. Opportunities for Growth

This theme explores the different opportunities experienced by participants which enabled growth. The topics touched on by participants were, specific learning and development opportunities, school and adjustments made to enable participation. These opportunities naturally prompt growth and can lead to a sense of life fulfilment and self worth in participants.

### *2.1 Learning and development within an academic setting*

Many participants spoke specifically about learning opportunities at school and college, including courses and placements. Some participants went to a specialised school to help their learning and development. Through this they were given the chance to develop life skills alongside some core subjects of their choosing. Sophie explained the sort of educational activities she partakes in:

*"Uh, cooking, quite a lot of cooking. And photography. I like taking a big basketball 'cause that's my favourite…. I did my social studies and I do a bit of French and Spanish as well…. and maths with a great teacher….ICT as well and cooking and gardening"* (Sophie).

Similarly Amelia is developing life skills with the support of her school:

*"I do drama and science and English. I also do makaton and basic living skills and we go out and do things like catching buses and exploring the wood. We planted some trees."* (Amelia).

Not all participants went to a school specialised for people with learning disabilities, instead they attended comprehensive schools and colleges alongside their peers. Hannah spoke about how she had recently completed a course in 'early years child care'. However she noticed that it was hard for her to get more than one placement in a work setting to better help her prepare for a future career:

*"It's been right difficult to get a placement when I have Down Syndrome.... I haven't got a placement at the moment....The class was for schoolchildren (previous placement)"* (Hannah).

Liv attended a regular comprehensive school and completed her qualifications; this has lead to her recently being accepted on to a place in college to continue her progression in Makaton and British Sign Language to become a teacher:

*"Besides drama I do maths, of course mathematics and English, erm, three sciences biology physics and chemistry and also I did the welsh baccalaureate…so I did a lot of GCSE's… And when I'm older I want to be a qualified Makaton teacher. I went to college today and had my interview and now I have a place in college. I will be doing Makaton and BSL"* (Liv).

Liv looked back on her time at school and reported her school being "really supportive" of her becoming a "young adult", providing reasonable adjustments including a 1:1 assistant who scribed for her during her exams.

### *2.2 Opportunities and the need for understanding of capabilities*

Outside of specific classes and subjects many participants had further opportunities for growth. Peter explained that one of his teachers helped to push him into a project to support him to become a coach, as he enjoyed sports. From this he continued on to get a job in coaching and now is involved in other vocations too:

*"He tried to get me to get work experience and coaching… I do coach rugby, I do that for my job as well… I am playing football coach and goal keeper… got a job at*

*the café … I am a café assistant… I work part time as a trainee baker and I do swimming, I am part of the swimming squad…and I am a model"* (Peter).

Other participants spoke about varied extracurricular activities including sports and drama clubs:

*"I actually do other sport and things besides doing drama…I do judo and I'm an orange belt…besides doing judo I'm actually a swimmer and I was meant to be going to the Paralympics."* (Liv).

Liv also explained how she was head girl and the responsibility this holds: *"So I've been head girl ever since. I've been to a lot of meetings for the school council and governor meetings."*(Liv).

Conversely alongside the positive opportunities some participants noticed the differences that come from a lack of understanding or lack of provision. Liam spoke about how people can be confused that he is able to play an instrument. Highlighting the lack of understanding about people with Down's Syndrome and their capabilities:

*"Well, sometimes when I'm busking um… people sometimes do double takes on me when they see that I have Down Syndrome. They, they see the fiddle. And they are trying to put it all together in their heads. Thinking how is that possible? And I suppose my message that I'm telling them. It is possible. Anyone with Down Syndrome could be an on an artist or a musician. "* (Liam).

More specifically Hannah expressed her belief that Down's Syndrome will hinder her chance at getting a job, and that the current opportunities she has received for work and placement were aided by colleagues understanding:

*"(Do you think that it's harder for a person who has Down syndrome to get a job?) Yes …Well, I did do a placement in a little shop and they were very understanding."* (Hannah).

Overall participants had many different opportunities for growth, Many of these opportunities required wider society to understand their needs and capabilities without prejudgment.

## 3. Social impact on an individual's growth

This theme explores the impact of participant's social context and how this can potentially impact their growth and development within society. This includes a promoted positive narrative about Down's Syndrome or an individual's characteristics, the importance of positive friendships and opportunities to build wider awareness of Down's Syndrome.

### *3.1 Positive social circle*

Individuals who took part in the study often spoke about their family and friends' thoughts about Down's Syndrome alongside their own. No negative opinions from their close social circle were reported. It can be seen that the positive language used within an individual's close social circle can impact their own thoughts about themselves and the condition, and through this their personal growth.

Amelia and her mother explained how other people's opinions impact her view of her own Down's Syndrome:

*"Good. My family think it is a good thing and so do the people around me It's no different... (Amelia)* Hannah also explained her family's views: *"They said it's very special to have the condition… it's fantastic"* (Hannah) and this prompted her to see her Down's Syndrome as something that is "perfect". Liam explained his parent's views on Down's Syndrome and hypothesised why they might hold these thoughts:

*"They did think that it was a good thing. That's what you guys said actually. It well, my. It's because I guess I'm unique. People like me with Down syndrome are unique people in the world."* (Liam).

Likewise Liv explained how her mothers view's impact her own: *"My mum always tells me and I feel like every child with Down's syndrome should be proud of who we are I am proud of who I am and I've achieved everything in my life"* (Liv).

Further to this, participant's parents, who were allowed to support them during the interviews, often commented on the positive impact that the individual has on their close social circle. They attributed this to their children's personalities and the difficulties their families had faced through the diagnosis of their child, leading to their own personal growth in the face of adversity.

### *3.2 Making relationships and building a sense of social importance*

Many participants prided themselves on their relationships and how they interact in their social circle. The development of lasting relationships and recognition of the importance of relationships indicates social growth. Peter thought that having Down's Syndrome specifically helped him to make relationships in his life, including his girlfriend. Liv also expressed that having Down's Syndrome has helped her make friends through the group she attends:

*"Everyone in youth club has got a disability most of my friends there have got Tourette's, autism, downs syndrome so it's just a massive youth club really and I've got so many friends...it is amazing and the best part of my life"* (Liv).

Two participants made reference to building up friends over their lifetime. Amelia spoke about making friends as a child and then building more friendships throughout her schooling:

*"I have friends I met at school. I went to (school name) and I made friends when I was little. I made friends with (names of friends) at primary school. Then I made more friends when I went to a different school."(Amelia).*

Liam also explained how he has maintained friendships from his school years but has developed adult friendships with other people living with Down's Syndrome living in different locations to him:

*"Uhm, sometimes friends from school. And sometimes like my friend (name) in (place name) and (name) in (place name) both of which have Down's Syndrome like me."* (Liam).

Further to this, participants stressed the importance of their personal qualities within their relationships. Both Sophie and Liv expressed that being “caring” and “looking after” someone is a necessary quality of being a friend to someone. Liv also expressed other qualities she thinks are important:

*“I’m trustworthy, you definitely need trust because is very important if you don’t have trust then you wouldn’t be a friend would you? Being a good friend is definitely important using kind words respect and being helpful I am extremely helpful…. I am very good at making sure everyone’s ok and happy. Having listening skills and just be amazing really. Definitely be kind trustworthy and respectful.”* (Liv).

### *3.3 Opportunity to build awareness*

Further personal growth and development was shown through participants taking part in activities that raise awareness of Down’s Syndrome. One participant in particular spoke passionately about how he uses his own life experience to raise awareness in a formal setting:

*“I have tutorial videos up… And I'm teaching, teaching social care work students how to, how to look at people with Down syndrome actually…. I was attending The European network …. as the Council of Europe for a whole week…. I'm doing more of like policy and advocacy rather than self advocacy”* (Liam).

Further to this Liam also explained that he has set up a social enterprise. He explained it’s three goals:

*“The goal is to help me have a great life. The second goal is to share our story. And to help other people like me to live the own version of what a great life looks like*

*for them. And the third and last goal of the social enterprise goal is to change and heal the world."* (Liam)

Liam advocates that people with Down's Syndrome should be seen as the "boss" and allowed to have similar opportunities to those who do not have the condition, which he understands is not currently the norm.

Similarly, although they did not overtly describe this as the reason, other participants engage in activities that raise awareness of Down's Syndrome. For examples Liv spoke about her swimming and how her talent in this meant she was selected for the Paralympics, an overtly public setting which promotes the acceptance and inclusion of people who may be seen as 'different':

*"I'm actually a swimmer and I was meant to be going to the Paralympics…. I love swimming, I swim all the time I do it in school and I do it outside of school I compete in other various competitions and I've got all the medals and trophies."* (Liv).

## 4. Individuals' sense of self and diverse personalities

This superordinate theme explores how participants have grown and developed, within the context of having a diagnosis of Down's Syndrome, into diverse individuals with distinct personalities and sense of self. This includes individual's narrative about themselves, their likes and dislikes, subjective interactions with the researcher and individual hopes and goals for the future.

### *4.1 Sense of self*

All participants perceived themselves to have a unique collection of characteristics, which defined them, showing a sense of self and identity. Peter described himself as “kind” explaining how he shares skills in Makaton to teach people around him:

*“I am kind, erm, I do makaton as well and I do it in school and then I try to teach staff at school and other people and friends”* (Peter)

Similarly Amelia defined herself as “caring”:

*“I’m caring, I like to take care of my friends and my family.”(*Amelia)

Sophie understood her unique ability to empathise with other people and how this aids her in her relationships:

*“Empathy means like feelings…. I notice if people are in pain or something… like with (friends name) they get seizures quite a lot. It was in assembly and I turned around and saw they were having a seizure. So I felt really sorry for her and hold her hand as well.”* (Sophie)

Liam described himself as “gentle” and “optimistic” he continued expressing his personality by explaining his likes, dislikes and talents which add to his sense of self. Giving a clear example of each participants uniqueness:

*“I like to travel, more than like, I love good food….I also love wildlife. I have a vast library of books on wildlife and sometimes I go a bird watching… My favourite kind of movies I like to watch is horror…. I am a visual artist. I mostly do paintings, but I am interested in drawing and stitching and sculpting too.”* (Liam)

Similarly, Hannah described herself through her unique talents and preferences, indicating an understanding of herself:

*"I'm also a very girly girl. I always get my nails done and my make up done and them kinda things… I also plan weddings as well."* (Hannah)

Overall each participant expressed a distinct awareness of who they are as an individual. A few of the participants showed their personality through interactions with the researcher. This was mainly through the use of humour and 'poking fun' at themselves.

When speaking about whether she was currently in a relationship Hannah quipped, prompting laughter in both her mother supporting and the researcher:

*"Not yet. Not yet. I'm free and single the way I want to be."* (Hannah)

Liam used sarcasm when describing himself, this seemed to be mocking other people's perceptions of his condition in wider society:

*"I am also a very frightening person too. *laughter*"* (Liam)

Liv was another participant who used humour throughout her interactions with the researcher, showing her "bubbly" personality:

*"I'm cute in my own way *laughter* my mums laughing in the background… I'm a chatterbox as you now know Lottie so I chat all the time and my mum would agree anyway so… I do love my mum but she can be a little bit embarrassing when she dances *laughter*"* (Liv)

The use of humour in novel situations such as interacting with the researcher, whom they had never met before, shows the confidence of participants. Well-placed jokes and humour in the conversation shows an understanding of complex social cues indicating of social growth and understanding.

### *4.2 Future hopes*

Having future hopes in itself shows an individual's capacity for personal growth towards a desired outcome. All participants expressed different hopes for the future regarding romantic relationships and getting married.

Amelia acknowledged the potential need for support with regards to her hope of the future:

"*I want to get married, I have a boyfriend and it would be nice to marry him and maybe move out, but I would need a bit if help from my mum and family."* (Amelia)

Peter shared similar views of what he wants his future to look like:

*"And with my girlfriend I've been with her for seven years. I want to get married to her. And do buy a house together."* (Peter)

Alongside romantic relationships, one participant expressed a desire to have her own children:

*"I want to get married I've got a boyfriend ...we've been together for quite a while and I love him but he doesn't have down syndrome...he is autistic... I want babies"* (Liv)

Although Sophie had a similar goal to get married and have a house, she also acknowledged other goals working towards independent living needed to facilitate this change:

*"Right now if I go to the dentist I've got to have my mum. But in future, maybe I can go by myself…. like going to hospital meeting like if I need to get a blood test or check up maybe I could go by myself, just be more independent."* (Sophie)

Three participants spoke specifically about potential career goals. Hannah and Liv were sure about what they wanted to achieve. Hannah expressed a desire to work in a caring vocation, within in childcare or in a nursing home.

Liv also wants to work with children, but through teaching:

*"I want to teach kids because I like kids and yea working with kids who are deaf I could be an interpreter to so being a teacher, a qualified one, to teach around schools .So yea it would be my dream to teach makaton and BSL."* (Liv).

Liam also spoke about wanting a future career, but explained his uncertainty about what this would be and how he is trying to 'figure it out':

*"Well, I'm still exploring that every day, I still ask the question of the talented people of what they love about their lives. Well, I ask that question because I'm actually interested in filmmaking and music and all the other interest like zoology so talking with some, with wildlife experts and visual artists is a way to learn more about what I would like to have in my life."* (Liam)

## Discussion

This study highlighted that personal growth and development can be achieved in the context of the unique, and potentially adverse circumstances, individuals with Down's Syndrome find themselves in.

Within the context of positive psychology the three pillars; positive emotions, positive traits and positive institutions (Seligman, 2002), can be seen through the personal attributes and contexts that these participants demonstrate and comment on.

Participants all spoke about their positive emotions in direct relation to their diagnosis of Downs' Syndrome and through their attitude about aspects of their life such as friendships, day to day living and their purpose in society. Further to this participants illustrated their own positive traits through their achievements in education, pursuing their individual career aspirations and developing personal skills in sports, music and communication such as using Makaton.

Within the context of positive psychology, positive institutions refer to an individual's social context, such as family or educational systems, that facilitates the development of positive emotions and traits. Participants expressed different experiences of social support. This was often linked to an individuals education and opportunities provided for skills development. Furthermore the parents, who supported the participants to take part, often expressed their own positive outlook on their children's lives with Down's Syndrome. Social learning theory (Bandura & Walters, 1977) suggests that individuals develop and learn from the behaviour of role models such as parents. A supportive and positive environment, provided by family and their close social circle such as educators and peers, could facilitate the development of the positivity expressed by the participants.

When one looks at the medical model of understanding intellectual disabilities, such as Down's Syndrome, the focus is the physical and intellectual impairments of people living with a disability, and the subsequent negative impact this has on both the person and their families. However, in opposition to this, the social model of disability shifts the focus to the negative impact of discrimination, limitations and exclusions by society and its effect on persons living with intellectual disabilities. It has been argued that disabled people can thrive and have a quality of life when provided adequate support (Bailey, 1996; Oliver, 1996; Larson, 1998; Asch,1999). Further to this, positive psychology shifts the focus away from pathology to the individual's subjective positive experiences and development (Seligman & Csikszentmihalyi, 2014).

Participants actively acknowledged a number of the societal limitations and differences that they face as individuals living with Down's Syndrome. In some cases these exclusions, due to difference, resulted in lack of access to higher education, or inadequate provision of placements within courses. Participants also highlighted a perceived lack of understanding by the general population about Down's Syndrome, and individual's unique capabilities. These finding are congruent with the social model of disability's understanding of how stigma and inaccessibility of society limit an individuals opportunities and sense of self (Shakespeare, 2006).

Within Down's Syndrome literature there is a concept of 'wrongful life' which is defined as *"a life full of suffering because of a handicap while the child was not supposed to have been born but is born anyway because of a negligent act by the doctor or assistant"* (Giesen, 2009, p259). This concept is often used alongside arguments that individuals with disabilities, such as Down's Syndrome, have a decreased quality of life (Bringman, 2019).

The findings of this study are incongruent with the notion that people living with Down's Syndrome suffer, or have a lack of quality of life. Within this study it was found that participants, living with Down's Syndrome, are capable of achieving personal growth, one of the domains indicative of quality of life (Verdugo et al., 2012; Schalock & Alonso, 2014), in spite of their 'impairments'. This was indicated by their self-reported achievements and lived experiences of change and development throughout their lives socially, academically and emotionally. Each person engaged in activities that provided him or her with a sense of fulfilment. Additionally, participants within this study acknowledged some of the medical differences or difficulties they experience as a person living with Down's Syndrome but they did not equate this with 'suffering'. They viewed their medical differences as part of their lives and the same as any other individual who needed to go for medical check-ups and treatment.

A further finding that negates the negative societal perception of Down's Syndrome is that no participant expressed negative opinions of their condition. Instead many participants described themselves as 'special' and the condition as being 'just part of who we are'. Some participants understood that there may be differences in having a child with Down's Syndrome but no participant viewed this as a negative. This is consistent with findings from a study by Skotko, Levine and Goldstein (2011) who found that the majority of their participants living with Down's Syndrome were happy with their lives and liked who they were as a person.

Participants within the current study were seen to be thriving within their lives when provided the necessary support and opportunities. For example being provided the correct support in education, being given the opportunity to have a career and promoting self-advocacy in the wider population. The fatalistic idea of life, is that an individual's life course is inevitable rather than by their will (Maercher et al., 2019). When applied by society to those who have intellectual disabilities, this view can only serve to hinder these unique individuals. It is clear that when given suitable acceptance and individualisation, shifting the focus away from probability to possibility, the participants were able to experience unique and meaningful lives.

### *Implications for Clinical Practice*

Many individuals and families express emotional distress when receiving a diagnosis of Down's Syndrome. Such as fear or worries about what their child's future may be and how it might affect both themselves and their child (Hurford et al., 2013; Nelson Goff et al., 2013; Lou et al., 2020). Further to this there is a belief that some professional's opinions and subsequent recommendations about Down's Syndrome are negative and a perpetuation of stereotypes within society

(Nelson Goff et al., 2013; Kellogg et al., 2014; van Schendel et al., 2017; Lou et al., 2020).

The lived experiences of growth from participants within this study serve to alleviate some of the worries that parents may have about their child's future and what to expect. The experiences of these individuals can be used to promote positivity within clinical practice about Down's Syndrome.

Some parents view information provided by professionals to focus on medical issues rather than social and developmental implications of the condition (Lou et al., 2020). This study provides the latter, and could be used by professionals to provide a more 'well rounded' view on the condition. Acknowledging that all participants do not hold a negative view of their condition and have achieved levels of personal growth living with Down's Syndrome.

Further to this within clinical psychology, when working with clients who have a diagnosis of Down's Syndrome, this research indicates the need for a person-centred approach. Similar to findings by Morisse et al. (2013), the clinician should focus on what is possible, in ways of personal development, in order to provide both psychological and practical solutions, promoting quality of life, to support an individual's mental health.

### ***Future Research***

This research highlighted the need for inclusion and acceptance of people living with Down's Syndrome in society, and provided examples of how a positive environment promotes growth and a quality of life for the participants. Future research into how the education system could better support people living with Down's Syndrome would be worthwhile. Furthermore, there is little literature on the lived experience of individuals living with Down's Syndrome, there is more of a focus on the medical aspects of the condition. One suggestion following this research, similar to Shakespeare (1999), is further investigation into the unique and diverse experiences of people living with Down's Syndrome, focusing on the interactions within their social context and their opinions on themselves. This would provide a more comprehensive picture of the unique aspects of the condition, in relation to the social model of disability.

Findings of the current study were drawn solely from interviews with the participants. In future research it may be helpful to use ethnography (Taylor, 1999) to explore this topic further. Through observations of participants in their unique contexts may provide greater understanding of the positive institutions, referred to as one of the three pillars of positive psychology, that support the positive emotions and traits (Seligman, 2002).

### ***Strengths and Limitations***

One of the strengths of this research is that there was little by way of exclusion criteria, individuals had to identify as having Down's Syndrome and be able to communicate using spoken English. Although individuals who had a more profound intellectual disability that would impact their verbal comprehension and communication were excluded, participants with differing level of intellectual disability were able to participate. Further to this as the research methods allowed for contact online and for interviews to be conducted virtually, participants from all over the United Kingdom were able to participate.

This study used voluntary participation, although the specific focus on positive psychology was not used within the research poster posted on social media, participants were invited to participate if they were comfortable talking about having Down's Syndrome. This may have prompted a certain type of individual with a more positive outlook on Down's Syndrome, or a more supportive social context to want to take part. Therefore the results may capture the more positive opinions and experiences of Down's Syndrome, whilst others with the diagnosis may have more negative experiences that are not captured or explored with the current group of participants. Although this study sought to view the individual experiences of have Down's Syndrome through a positive psychology lens, it is important to acknowledge that this view may not feel accurate for others living with this diagnosis.

Parents were invited to support individuals who chose to take part, in order to aid communication between the researcher and the participant if necessary or to provide comfort to the participants in the unique setting of having an online interview. A further strength of this study is that all questions were directed at the participant and the parents were not seen as the direct subject of the research. The interviews were not conducted as three-way conversations; this was outlined at the beginning of the interview. Parents only spoke when the participants asked for support or to provided clarifying information about timelines or the nature of activities. This enabled the views of the participants to be accurately recorded.

## Conclusions

The individuals with Down's Syndrome within this study had many different experiences of personal growth. Each of these experiences were specific to the individual's personalities and preferences. However some of them described missing out on opportunities that could have provided them more experiences of growth due to their condition. There is already a movement within society towards accepting difference and disabilities. An example of this is more the recent increase in the portrayal of people with Down's Syndrome within mainstream media, such as actors and models. However the findings of this study suggest there needs to be further improvement of inclusion within society, and a further incorporation of these much needed societal changes into everyday life and opportunities for people living with Down's Syndrome. Further to this the findings suggest that using a positive psychology approach when working with individuals with Down's Syndrome may be beneficial. With clinicians focusing on the individuals positive attributes and person-centred problem solving within their social context, to support an individuals mental health.

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# Part 3: Appendices

## Appendix A- *Reflective Statement*

### *In the beginning*

When I began developing ideas for my doctoral thesis, at the research fair in fourth year, I remember feeling incredibly overwhelmed by the idea that in three years I would have created a novel piece of research. I entered into this having no clue what it was I actually wanted to do, except for develop my own understanding of people and help to provide a platform for others to learn. This led me to begin looking at studies involving the 'lived experience' of others.

During my undergraduate years I had worked as a carer and support worker for those with intellectual disabilities. I noticed how, at first, my own lack of understanding led me to be scared of doing something wrong, not knowing how to interact or not being able to communicate effectively with the individuals under my care. However I soon realised I was wrong, and that the stigma and social narrative I had been accustomed to, led to these fears and lack of understanding. The people I worked with provided an insight into what is possible even in the face of adversity. I decided that I wanted to conduct my research with people with intellectual disabilities.

Around this time a family friend gave birth to a baby girl, who was diagnosed with Down's Syndrome. We all knew prior, due to prenatal testing, however there was always an unknown as to what her life would look like (I'd like to mention her life now is pretty great). This is when I decided on my research topic, to shed light on to what is possible for people living with Down's

Syndrome. This idea was further cemented by the media coverage of the campaign to change the laws on termination of foetuses diagnosed with Down's Syndrome.

### ***Recruitment***

After getting my research proposal ethically approved through the University of Hull it was time to start recruitment. I had the support of a few social media groups and assumed that gathering enough participants to complete my qualitative research wouldn't take long. Unfortunately I was wrong.

I felt like all my big ideas of giving people with Down's Syndrome a platform to share their experiences, were not going to come to fruition. I spent time questioning where I had gone wrong and if this research was feasible. Fortunately after a couple of months I was contacted by Down's Syndrome Scotland, who had seen a few of my posts on social media. They asked if they could be of any help and in turn asked if I would be open to supporting them in the future. I was overjoyed and soon I had a number of people coming forward both through their group and through my other recruitment efforts. This late start did however mean that I needed to request an extension for my submission as I was only able to start recruiting in January 2022.

### ***The Interviews***

When I first set out to complete my research I never quite understood the emotional impact some of the stories may have on me. Both positive and negative. I had my eyes opened to a new understanding of what it was like to have Down's Syndrome in society. I felt immense pride in those who I spoke to and what they have been able to achieve with their lives. During this time I also acknowledged that it was far more than I ever imagined. This was something I sought supervision for, from an external source. I needed a place to reflect without judgement and understand my part, within both society and this research. It was also helpful for me to keep a reflective diary during this time, in order to effectively bring all my thoughts and feelings into supervision.

### ***Analysis of Results***

During my analysis I worried that I would not do the views of my participants justice. I knew how important it was to capture their experiences and got caught up in not wanting to generalise anything. However when immersing myself in the research, as recommended in IPA (Smith, Flowers & Larkin  2009),  I focused in each individual account in great detail and realised that there were in fact links between all of them. Despite this I endeavoured to make sure each participant was seen as an individual throughout analysis and write-up. During write up I still worried that I wouldn’t do my participants justice or provide the platform for their opinions in the research, which I very much wanted to push for. I took this to supervision and gathered suggestions as to how to include as many quotes as possible alongside my explanations without making this too ‘heavy’. Reminding myself that my interpretations were acknowledging the participant as an individual helped. I went through the process with this need for individual perspectives at the forefront in my mind and understood I would be acknowledging this throughout both consciously and subconsciously.

During my analysis, although I felt it was going well and I was able to follow IPA and achieve what I intended, I did noticed sadness. This sadness was linked to not being able to conduct the research in the way I would have initially liked, using ethnography (Taylor, 1994). Including observations in my data collection in order to understand an individuals context and interactions within their social system. I think this overall would have helped me to gain a greater understanding of each of the individual in my research and notice my involvement in their social world.

### ***Systematic Literature Review***

I must admit I did not see my review as pressing, in amongst the stressors of not getting the participants I needed as quickly as I wanted. Due to this I struggled to identify what would be an appropriate research question or topic. Whilst completing further background research for my empirical paper I noticed my own thoughts about Down's Syndrome and the media reports coming out about a court case challenging the abortion laws in the United Kingdom. This prompted me to have the idea to gather others thoughts on prenatal testing and diagnosis. I realised from a scoping search that there were many papers focusing on this, so I decided to define this specifically to parents opinions, from those who have children with Down's Syndrome.

Through doing this I also thought it would be a helpful source of information for professionals and parents all in one place. I decided that the review could and should involve papers from different countries, cultures and religions as these are factors that naturally impact one's views on both Down's Syndrome and potential termination resulting from prenatal diagnosis.

When I was analysing the papers included in my review I found it difficult to remain focused on my research question. I wanted to acknowledge both the emotional and factual aspects of prenatal testing from the perspective of parents. But often found myself lost in the emotional experience rather than opinions. I came up with a 'hack' to keep my research questions on a post-it-note and stuck this to my laptop during my write-up.

### *Overall*

Overall I have new appreciation of what it actually takes to complete qualitative research and a new found love for this style. Previously I thought statistics were in the future of my career, but this has definitely changed. This research has taught me so much about myself and how I handle set backs when this research didn't initially go as I had planned. I've learnt to take a step back and accept that sometimes things won't go the way I plan them. I also noticed the emotions that undertaking such an emotive research topic prompted within me, this only made my drive to complete it stronger. Not just for me, but for my participants.

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## **Appendix B-** ***Epistemological Statement***

Initially the method of analysis was collected data was chosen. Interpretative Phenomenological Analysis (IPA) was chosen due to its focus on an individuals experiences of their own world. Allowing detail account to be given by participants on the chosen phenomena (Smith, Flowers & Larkin, 2009).

The epistemological position taken by the researcher is that of Critical Realism. Critical Realism acknowledges that the data collected within research does not constitute a direct reflection of the world, but rather the interpretation of individuals that can be used to further our understanding of the phenomena (Willig, 2013). The phenomenon in this study is that of the lived experience of individuals with Down's Syndrome. This study does not aim to seek one truth but instead to investigate the opinions of individuals to gain knowledge in the field from their experiences.

The two main ontological positions are realist and relativist (Willig, 2008). The main ontological position for critical realism is realist, this is the ontological position taken by the researcher. This ontological position is the belief that there is a reality that exists independent to the view and belief of those living in said reality (Ritchie et al., 2013). However critical realism acknowledges that, despite there being a reality, how we observe this reality is constructed from our perspectives and experiences.

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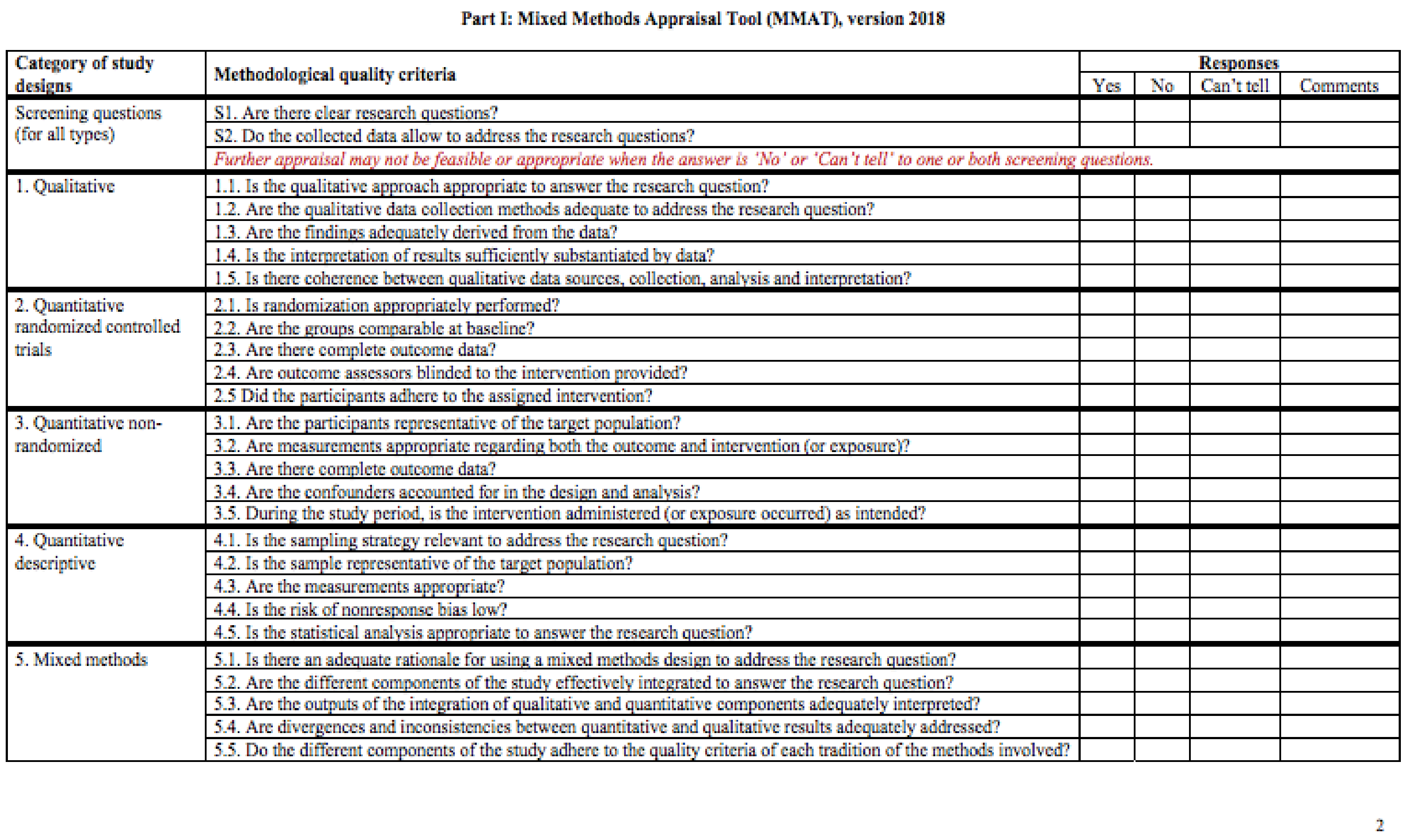
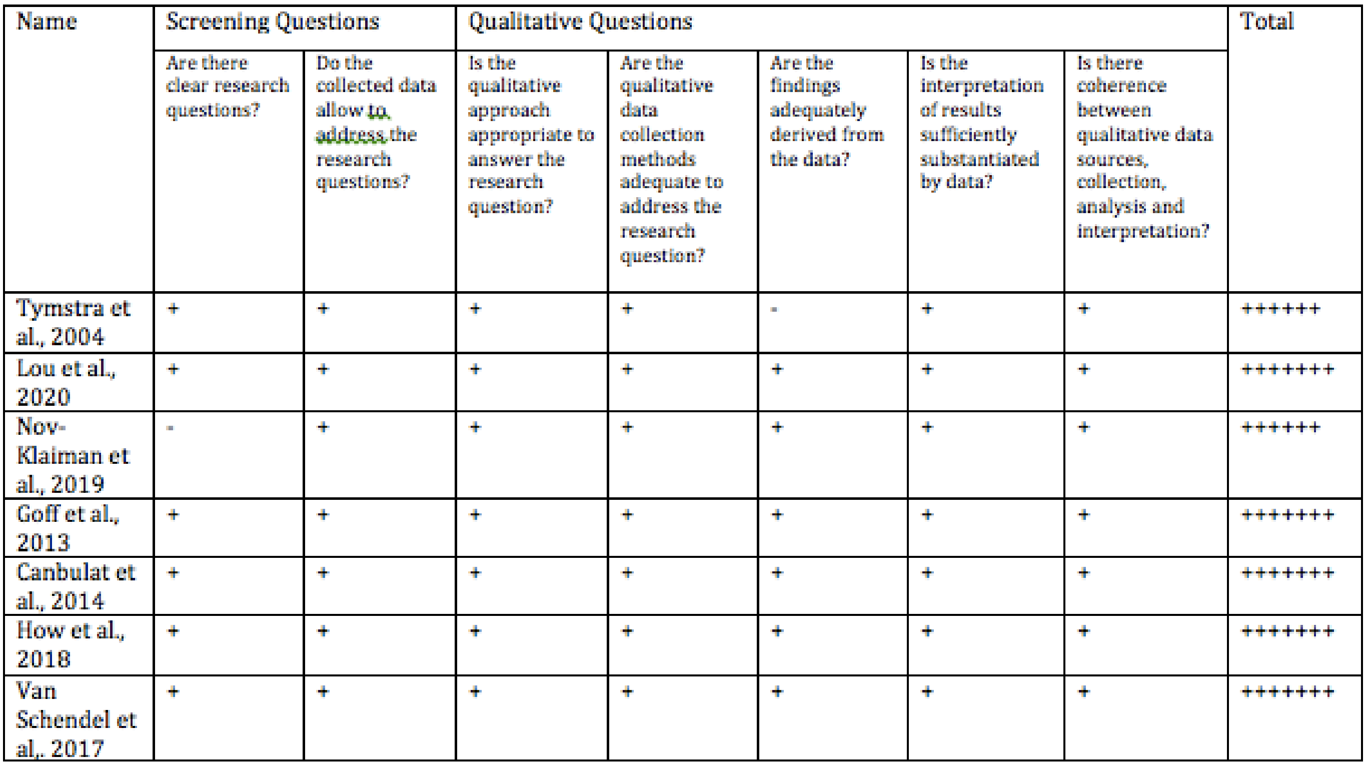
## Appendix C - *Mixed Methods Appraisal Tool, MMAT by Hong et al. (2018)*



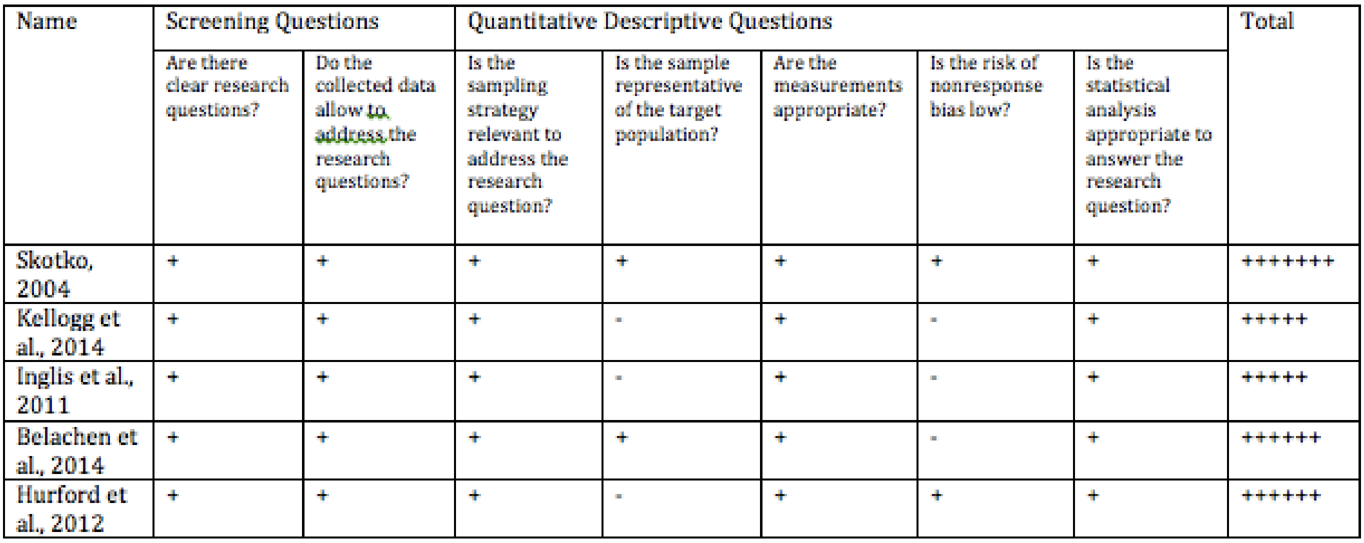
### Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

| Category of study designs | Methodological quality criteria | Responses | | | |
|---|---|---|---|---|---|
| | | Yes | No | Can't tell | Comments |
| Screening questions (for all types) | S1. Are there clear research questions? | | | | |
| | S2. Do the collected data allow to address the research questions? | | | | |
| | *Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.* | | | | |
| 1. Qualitative | 1.1. Is the qualitative approach appropriate to answer the research question? | | | | |
| | 1.2. Are the qualitative data collection methods adequate to address the research question? | | | | |
| | 1.3. Are the findings adequately derived from the data? | | | | |
| | 1.4. Is the interpretation of results sufficiently substantiated by data? | | | | |
| | 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? | | | | |
| 2. Quantitative randomized controlled trials | 2.1. Is randomization appropriately performed? | | | | |
| | 2.2. Are the groups comparable at baseline? | | | | |
| | 2.3. Are there complete outcome data? | | | | |
| | 2.4. Are outcome assessors blinded to the intervention provided? | | | | |
| | 2.5 Did the participants adhere to the assigned intervention? | | | | |
| 3. Quantitative non-randomized | 3.1. Are the participants representative of the target population? | | | | |
| | 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? | | | | |
| | 3.3. Are there complete outcome data? | | | | |
| | 3.4. Are the confounders accounted for in the design and analysis? | | | | |
| | 3.5. During the study period, is the intervention administered (or exposure occurred) as intended? | | | | |
| 4. Quantitative descriptive | 4.1. Is the sampling strategy relevant to address the research question? | | | | |
| | 4.2. Is the sample representative of the target population? | | | | |
| | 4.3. Are the measurements appropriate? | | | | |
| | 4.4. Is the risk of nonresponse bias low? | | | | |
| | 4.5. Is the statistical analysis appropriate to answer the research question? | | | | |
| 5. Mixed methods | 5.1. Is there an adequate rationale for using a mixed methods design to address the research question? | | | | |
| | 5.2. Are the different components of the study effectively integrated to answer the research question? | | | | |
| | 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? | | | | |
| | 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? | | | | |
| | 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? | | | | |

# Appendix D – *Quality assessment summary*

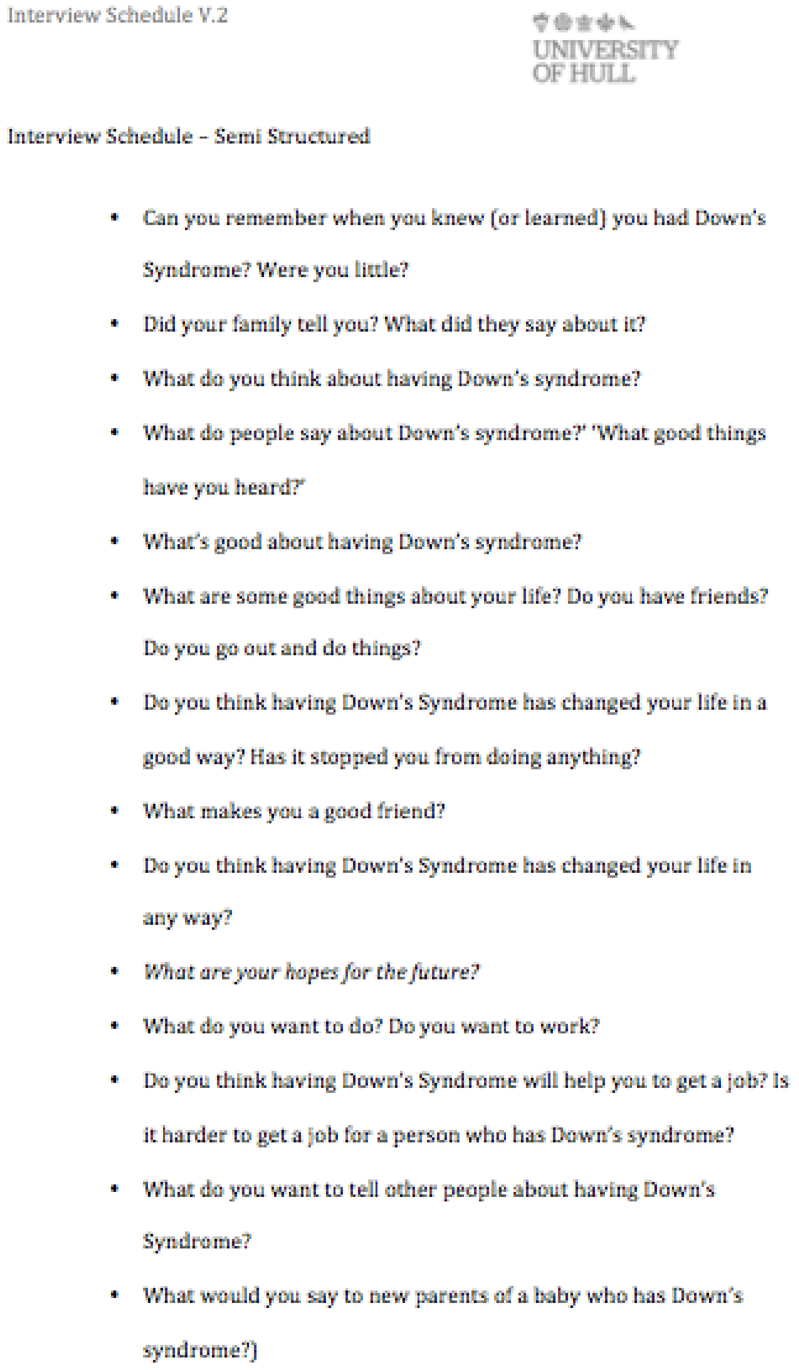


| Name | Screening Questions | | Qualitative Questions | | | | | Total |
|---|---|---|---|---|---|---|---|---|
| | Are there clear research questions? | Do the collected data allow to address the research questions? | Is the qualitative approach appropriate to answer the research question? | Are the qualitative data collection methods adequate to address the research question? | Are the findings adequately derived from the data? | Is the interpretation of results sufficiently substantiated by data? | Is there coherence between qualitative data sources, collection, analysis and interpretation? | |
| Tymstra et al., 2004 | + | + | + | + | - | + | + | ++++++ |
| Lou et al., 2020 | + | + | + | + | + | + | + | +++++++ |
| Nov-Klaiman et al., 2019 | - | + | + | + | + | + | + | ++++++ |
| Goff et al., 2013 | + | + | + | + | + | + | + | +++++++ |
| Canbulat et al., 2014 | + | + | + | + | + | + | + | +++++++ |
| How et al., 2018 | + | + | + | + | + | + | + | +++++++ |
| Van Schendel et al,. 2017 | + | + | + | + | + | + | + | +++++++ |



| Name | Screening Questions | | Quantitative Descriptive Questions | | | | | Total |
|---|---|---|---|---|---|---|---|---|
| | Are there clear research questions? | Do the collected data allow to address the research questions? | Is the sampling strategy relevant to address the research question? | Is the sample representative of the target population? | Are the measurements appropriate? | Is the risk of nonresponse bias low? | Is the statistical analysis appropriate to answer the research question? | |
| Skotko, 2004 | + | + | + | + | + | + | + | +++++++ |
| Kellogg et al., 2014 | + | + | + | - | + | - | + | +++++ |
| Inglis et al., 2011 | + | + | + | - | + | - | + | +++++ |
| Belachen et al., 2014 | + | + | + | + | + | - | + | ++++++ |
| Hurford et al., 2012 | + | + | + | - | + | + | + | ++++++ |

# Appendix E – *Interview Schedule*



Interview Schedule V.2

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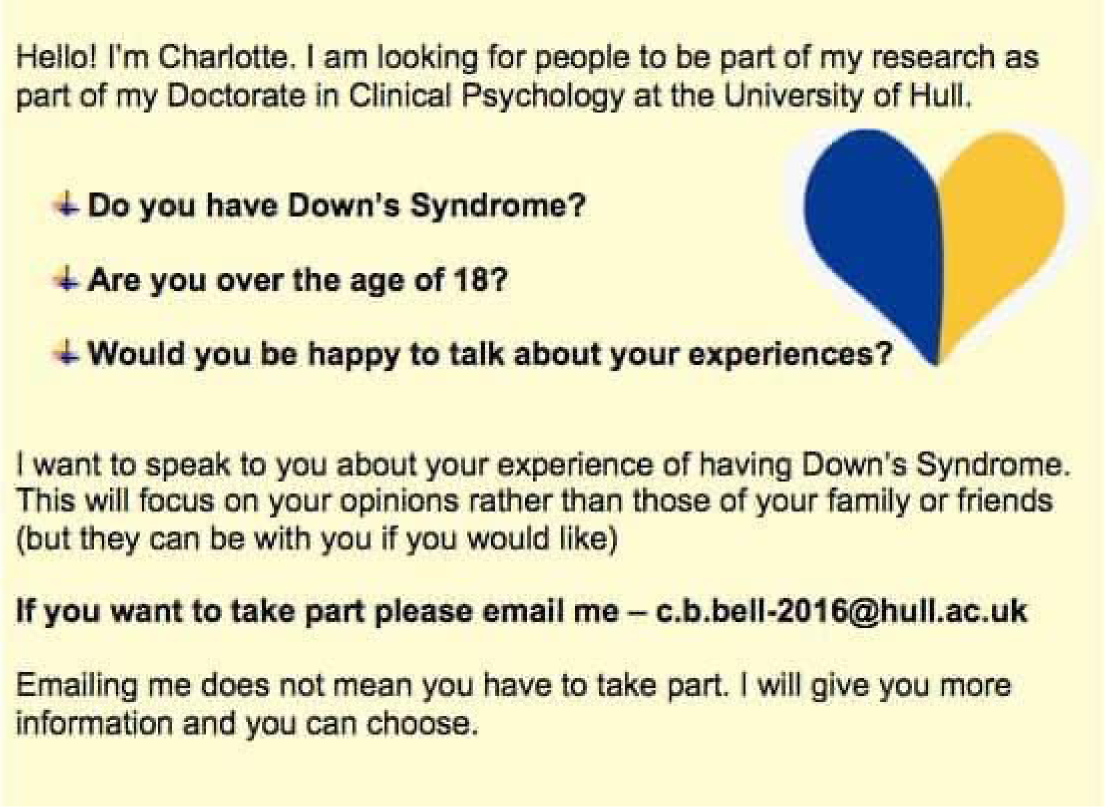
Interview Schedule – Semi Structured

- Can you remember when you knew (or learned) you had Down's Syndrome? Were you little?
- Did your family tell you? What did they say about it?
- What do you think about having Down's syndrome?
- What do people say about Down's syndrome?' 'What good things have you heard?'
- What's good about having Down's syndrome?
- What are some good things about your life? Do you have friends? Do you go out and do things?
- Do you think having Down's Syndrome has changed your life in a good way? Has it stopped you from doing anything?
- What makes you a good friend?
- Do you think having Down's Syndrome has changed your life in any way?
- *What are your hopes for the future?*
- What do you want to do? Do you want to work?
- Do you think having Down's Syndrome will help you to get a job? Is it harder to get a job for a person who has Down's syndrome?
- What do you want to tell other people about having Down's Syndrome?
- What would you say to new parents of a baby who has Down's syndrome?)

## Appendix F – *Ethical Approval Letter*

**-REMOVED FOR DIGITAL ARCHIVING-**

## **Appendix G–** ***Recruitment Poster***



Hello! I'm Charlotte. I am looking for people to be part of my research as part of my Doctorate in Clinical Psychology at the University of Hull.

- **Do you have Down's Syndrome?**
- **Are you over the age of 18?**
- **Would you be happy to talk about your experiences?**

I want to speak to you about your experience of having Down's Syndrome. This will focus on your opinions rather than those of your family or friends (but they can be with you if you would like)

**If you want to take part please email me – c.b.bell-2016@hull.ac.uk**

Emailing me does not mean you have to take part. I will give you more information and you can choose.

**Appendix H – *Information Sheet***

# Participant Information Sheet

The researcher is **Charlotte Bell** and she is a Trainee Clinical Psychologist.

## Title of the Study:

## Qualitative research into the lived experience of personal growth in individuals with Down's syndrome.

I would like to invite you to join this research into Down's syndrome.

I am looking for people who have Down's syndrome to take part.

Before you choose if you want to take part it is important for you to know why the research is being done and what you would need to do.

Please take time to read the information carefully and talk about it with others if you want.

Ask Charlotte if there is anything that is not clear or if you would like more information.

## What is the research about?

Often the opinions of parents or carers of people who have Down's syndrome are researched. But little research has focused on the opinions of people who have Down's syndrome.

I want to focus on the experience of someone who has Down's syndrome. I want to find out about the things individuals have learnt through having a diagnosis of Down's syndrome.

This will help people understand the opinions of some people who have Down's syndrome. It will add to information for parents and for other people who have Down's syndrome.

## What will I be asked to do?

- If you agree to take part then I will contact you to arrange an interview.

- This interview can be either in person or online.

- I will ask you to answer some short questions about yourself like your age and gender.

- I will then interview you about living with Down’s syndrome

.

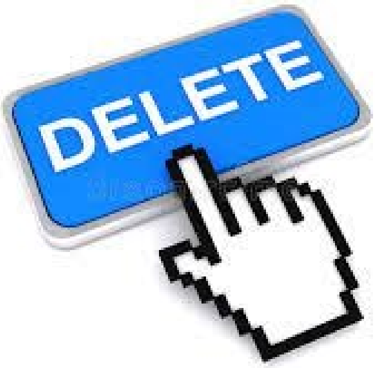
- This should take approximately 60 minutes.

**Your rights:**

- You do not have to take part

- You can withdraw from the study at any point without giving a reason

- You can contact the researcher and ask them to remove your data from the study within 72 hours of the interview



- All your data will be kept safe and cannot be linked back to you

- You have a right to ask questions about the research before and after participating

## What are the possible risks of taking part?

Participating in the study will require 60 minutes of your time and this may be inconvenient for you.

I will ask questions about your life and experiences. If this causes you to be upset I will give you contact details of places and people that may be able to help.

## What are the possible benefits of taking part?

You will not have direct benefits from taking part in the study.

I hope that the information you give will help us to understand Down’s syndrome from your view.

It may also help new parents. It may help people who have Down’s syndrome to understand how Down’s syndrome can affect personal growth.

## What will happen to the results of the study?

The results of the study will be in a written thesis as part of a Doctorate in Clinical Psychology.

The thesis will be available on the University of Hull's online repository https://hydra.hull.ac.uk.

The research may also be published in academic journals or presented at conferences.

If you want to hear about the results of the study you can contact the researcher, Charlotte Bell, who will be happy to provide you with a written summary of the research.

## How will we use information about you?

We will need to use information from you for this research project. This information will include your:

- Name
- Contact details
- Your age

People will use this information to do the research or to check your records to make sure that the research is being done properly.

Some of the things you say in the interview in your own words may be used as quotes in the write up of the study. Your name or names of others you mention will not be used.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Information about how the University of Hull processes your data can be found at https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a ‘task in the public interest’

If you are not happy with the sponsor’s response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner’s Office (ICO) (www.ico.org.uk or 0303 123 1113).

## What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have if this is after 72 hours.

Withdrawing from the study will not affect you in any way.

Your data cannot be withdrawn from the study once the data has been anonymised and analysed.

You have up to 3 days after the completion of our interview to withdraw your data from the research.

If have any questions or want more information about this study please contact me using the following details:

Charlotte Bell

Clinical Psychology

Aire Building

The University of Hull

Cottingham Road

Hull

HU16 7RX

**Email: c.b.bell-2016@hull.ac.uk**

## What if something goes wrong?

If you wish to make a complaint about the study, you can contact the University of Hull using the research supervisor's details below for further advice and information:

**Dr Nick Hutchinson**

Clinical Psychology

Aire Building

The University of Hull

Cottingham Road

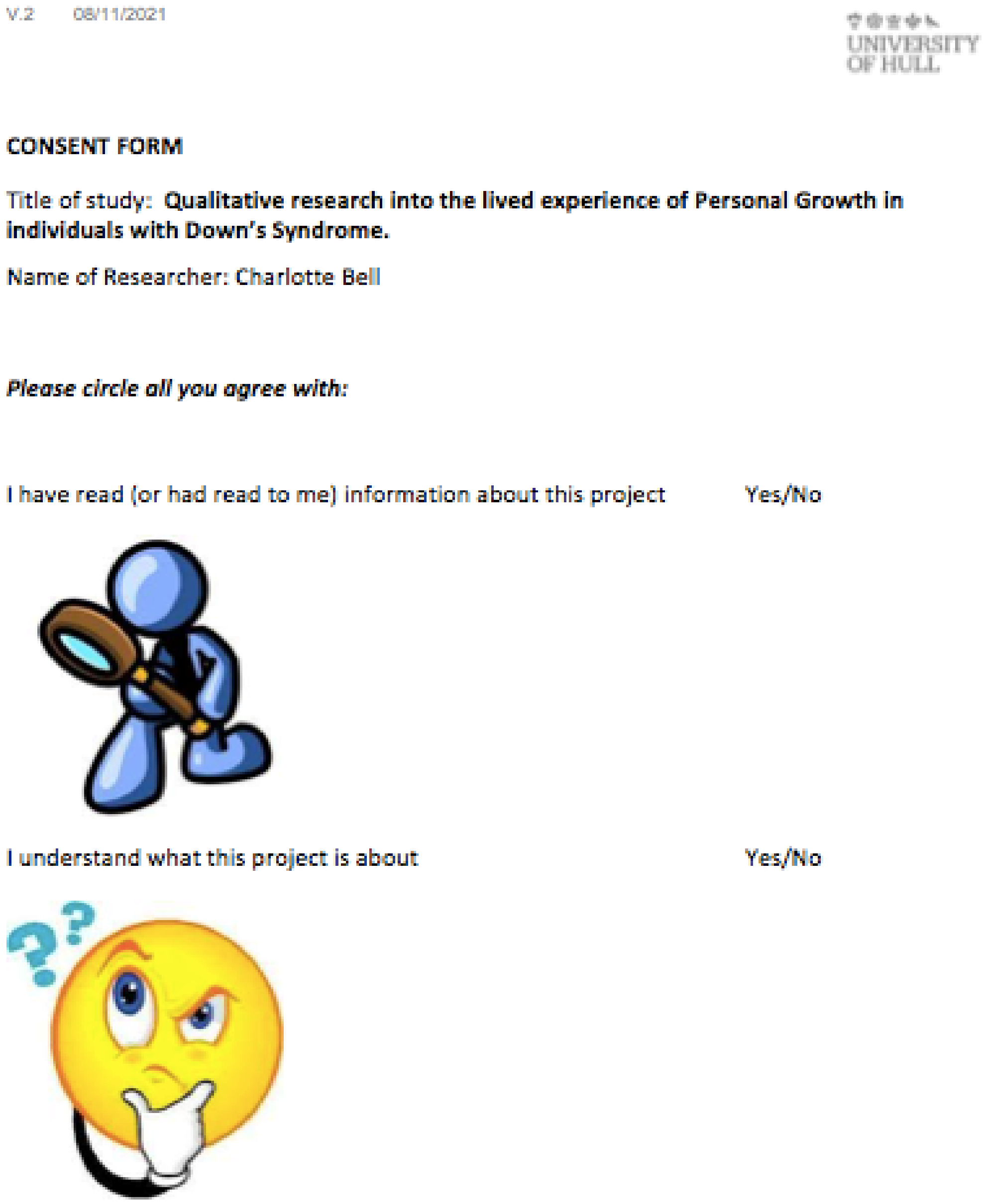
Hull

HU6 7RX

Email address: n.hutchinson@hull.ac.uk

**Thank you for reading this information sheet and for considering taking part in this research.**

## Appendix I– *Consent Form*



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CONSENT FORM

Title of study: **Qualitative research into the lived experience of Personal Growth in individuals with Down's Syndrome.**

Name of Researcher: Charlotte Bell

***Please circle all you agree with:***

| | |
|---|---|
| I have read (or had read to me) information about this project | Yes/No |
| I understand what this project is about | Yes/No |

I understand that I can stop taking part in the interview at any time without giving a reason Yes/No

I understand that I can ask Charlotte to delete what I have said up to 3 days after my interview Yes/No

I understand that my real name or the names of people or places I have talked about will not be used Yes/No

I understand information I give Charlotte will be kept private Yes/No

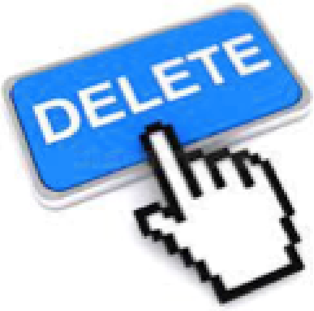
I understand the only people who will have access to information

that says who I am will be the researcher who needs to contact me

and their supervisor Yes/No

I understand my personal details will be destroyed once the

research has been written up in ten years Yes/No



I have asked Charlotte all the questions I want and I am happy with how they have been answered Yes/No

I understand the interview will be recorded Yes/No

I am happy to take part Yes/No

| | | |
|---|---|---|
| ____________ | ____________ | ____________ |
| Name of Participant | Date | Signature |
| ____________ | ____________ | ____________ |
| Name of Person<br>taking consent | Date | Signature |
| ____________ | ____________ | ____________ |
| Name of Person<br>Witnessing consent (if applicable) | Date | Signature |

## Appendix J – *Sources of Support*

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**Sources of Support**

- **Friends, Family or Carers.** If you feel distressed you can speak to someone you trust and share your thoughts and feelings with them.

- **Samaritans** offers a free listening service to help you work through what is on your mind. More information can be found at: https://www.samaritans.org/branches/hull/

  Contact number for a listener: **116 123**

- **Mencap** is a charity that supports both people with a learning disability and their families and carers

  Learning Disability Helpline - **0808 080 1111** or helpline@mencap.org.uk

- **Down's Syndrome Association** is a national organisation specialising in supporting individuals with Down's Syndrome.

  Down's Syndrome Association Helpline – **0333 212 300** (Available from 10am- 4pm)

- **Down's Syndrome Scotland** is a charity that works with people who have Down's Syndrome and live in Scotland.

  Family Support Service - **familysupportservice@dsscotland.org.uk**

## Appendix K - *Journal of Intellectual Disabilities Guidelines*

### 1. What do we publish?

### 1.1 Aims & Scope

Before submitting your manuscript to *Journal of Intellectual Disabilities*, please ensure you have read the Aims & Scope.

### 1.2 Article Types

Your manuscript should ideally be between 6000 and 8000 words long, and double spaced. Please also supply an abstract of 100-150 words, and up to five keywords, arranged in alphabetical order.

Books for review should be sent to: Dr Roja D.Sooben, Senior Lecturer Learning Disability Nursing Research Lead, Room 1F300, University of Hertfordshire, College Lane, Hatfield, Herts AL10 9AB.

### 1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

#### *1.3.1 Make your article discoverable*

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

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### 2. Editorial policies

### 2.1 Peer review policy

Each paper submitted, if considered suitable by the Editor, will be refereed by at least two anonymous referees, and the Editor may recommend revision and re-submission.

### 2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

### 2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

#### *2.3.1 Third party submissions*

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

  Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

### 2.4 Funding

*Journal of Intellectual Disabilities* requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### 2.5 Declaration of conflicting interests

It is the policy of *Journal of Intellectual Disabilities* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'.

For guidance on conflict of interest statements, please see the ICMJE recommendations

## 2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

## 2.7 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

*Journal of Intellectual Disabilities* requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. The editor can also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office.

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## 3. Publishing Policies

### 3.1 Publication ethics

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#### *3.1.1 Plagiarism*

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If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

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## 4. Preparing your manuscript for submission

### 4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guideline page of our Author Gateway.

### 4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

### 4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

### 4.4 Reference style and language conventions

Journal of Intellectual Disabilities does not accept the abbreviations such as ID for "intellectual disability" or NDD for 'neurodevelopmental disability'. This needs to be written in full throughout the manuscript and not abbreviated.

Journal of Intellectual Disabilities adheres to the SAGE Harvard reference style. View the SAGE Harvard guidelines to ensure your manuscript conforms to this reference style.

If you use EndNote to manage references, you can download the SAGE Harvard EndNote output file.

### 4.5 English language editing services

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## 5. Submitting your manuscript

*Journal of Intellectual Disabilities* is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/jnlid to login and submit your article online.

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### 5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities ensuring that their work is recognised.

The collection of ORCID IDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID ID you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID ID will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID ID is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID ID please follow this link to create one or visit our ORCID homepage to learn more.

### 5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

### 5.3 Permissions

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## 6. On acceptance and publication

### 6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate.

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Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

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SAGE provides authors with online access to their final article.

### 6.4 Promoting your article

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