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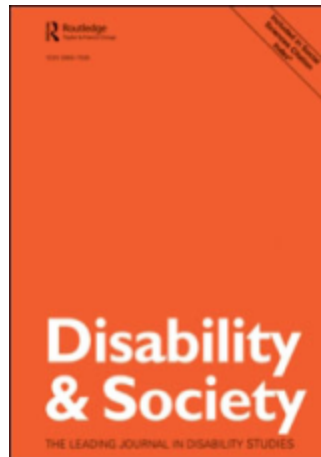
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**Learning disability imagined differently: an evaluation of interviews with parents about discovering that their child has Down's Syndrome**

Journal:	<i>Disability &amp; Society</i>
Manuscript ID	CDSO-2019-0378.R2
Manuscript Type:	Original Article
Keywords:	Learning disability, parents' experience, belonging, Down's Syndrome, language
Abstract:	<p>This article presents findings of a qualitative research study evaluating interviews with eight parents about their experience of discovering their child has Down's Syndrome. The article presents five themes emerging from a qualitative research study using Interpretative Phenomenological Analysis (IPA) as an evaluation method. The themes comprise what it is that makes a life worth living, the loss of an illusion, the language we use to speak about learning disability, the myths that surround it and wider issues of belonging. The diagnosis of a child with Down's Syndrome confronts parents with neoliberal values, that are underpinned by the idea that happiness and fulfilment are derived from independence, success and economic productivity. As a learning disabled child is welcomed into the family, an opportunity is presented to question our assumptions and beliefs about learning disability, to re-evaluate what we mean by normal, to challenge neoliberal values and to imagine disability differently.</p>

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## Points of interest:

- This article illustrates the complex issues that arise for parents on the diagnosis of a baby with Down's syndrome.
- The arrival of a learning-disabled child in the family is an opportunity to challenge neoliberal ideas that equate happiness and fulfilment with independence and economic productivity.
- The interviews illustrate how an experience of welcoming a child with Down's Syndrome into the family can offer opportunities for personal growth.
- It can be hard to find a language to speak about learning disability and the language available to us reflects a complicated history of how learning disability is perceived.
- Listening to the experience of loss shared by parents of children with Down's Syndrome can help us connect to the uncertain futures of *all* children in a precarious world.
- To imagine disability differently involves perceiving difference itself as an opportunity to discover new ways of participating in communities.

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**Title:**

Learning disability imagined differently: an evaluation of interviews with parents about discovering that their child has Down's Syndrome

**Abstract**

This article presents findings of a qualitative research study evaluating interviews with eight parents about their experience of discovering their child has Down's Syndrome. The article presents five themes emerging from a qualitative research study using Interpretative Phenomenological Analysis (IPA) as an evaluation method. The themes comprise what it is that makes a life worth living, the loss of an illusion, the language we use to speak about learning disability, the myths that surround it and wider issues of belonging. The diagnosis of a child with Down's Syndrome confronts parents with neoliberal values, that are underpinned by the idea that happiness and fulfilment are derived from independence, success and economic productivity. As a learning disabled child is welcomed into the family, an opportunity is presented to question our assumptions and beliefs about learning disability, to re-evaluate what we mean by normal, to challenge neoliberal values and to imagine disability differently.

**keywords;**

Down's Syndrome, learning disability, parents' experiences, language, belonging

**1. Introduction**

This article presents the findings of a qualitative research study that evaluates the experience of parents receiving the news that their child has Down's Syndrome. The study involved a thematic analysis of eight semi-structured interviews using interpretive phenomenological analysis (IPA) as a methodological framework.

Throughout the article, I will be using identity-first terminology i.e. learning disabled people, as mandated by the social model of disability on the basis that 'people with impairments are disabled by society, not by their bodies.' (Shakespeare 2013,19). It can also be seen to be a way of reclaiming disability identity, demonstrating an allegiance to disability culture (Andrews et al, 2019; Vaughan and Super 2019). Language around learning disability can be problematic and arises as thematically significant in the research central to this article. Sinason (2010) discusses the complicated history of language used to describe learning disability, noting how '(n)o human group has been forced to change its name so frequently' (39) and she suggests that the struggle with terminology is linked to a wider discomfort about the inconvenient truths of discrimination and oppression that this group of people experience. This history includes a debate around the use of person-first versus identity-first language (Andrews et al, 2019) and this struggle to establish a language has been part of my own personal and professional endeavour to foster emancipatory and inclusive, rather than hostile environments in relation to learning disabled people.

I locate myself in this article as both as a critical thinker and also a first-person subject entangled in, and impacted by, this research. I position myself within a

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3 research assemblage that includes the subject who researches and the individuals  
4 researched as 'entangled in multiplicities of matter interconnecting, co-influencing,  
5 individuating and always becoming new.' (Hargraves 2016; 541). As I enter these  
6 interviews, I am a professional wanting to understand and to find meaning in the  
7 particular lived experience of these parents. At the same time, I am engaging as the  
8 fellow parent of a learning disabled daughter, empathising with the challenges,  
9 dilemmas and opportunities that they share, immersed in an excavation of the  
10 human condition.  
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14 In that place of immersion, I will begin this article with a prelude to set the scene,  
15 offering a small window of my own experience some thirty years ago. This  
16 experience was a turning point for me, in my quest to explore narratives that can  
17 empower learning disabled people. As the mother of a then young learning disabled  
18 daughter, I began to shift into an awareness of our collective responsibility to  
19 campaign for disability rights.  
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22 I'll then outline the aims of the research, the research methodology and the data  
23 collection, before evaluating the themes that arose. These themes include measures  
24 of worth, the loss of an illusion, the challenges of finding a language to speak about  
25 learning disability, the myths that prevail and the issue of belonging. I aim to keep  
26 the voices of the parents central to the writing, emphasising the individual and  
27 nuanced lived experience of each family. I will conclude with a discussion about the  
28 significance of the findings in relation to broader meta-theories of disability politics,  
29 contributing to the discourse about disability rights and a vision for alternative ways  
30 of being together in the world. To protect confidentiality, names and other identifying  
31 information have been changed.  
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## 34 **2- Prelude: All means All**

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36 It was the early 1990s and my daughter with Down's Syndrome was about five years  
37 old. I travelled up to Manchester with two other parents to attend an inclusive  
38 education conference.  
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41 The speaker drew our attention to an image on the screen. Three children were  
42 laughing together, one in a wheelchair, her hair blowing in the wind and her twisted  
43 limbs braced in excitement as she was pushed at speed along a tree-lined path by  
44 another child. A third child ran beside them clutching a ball. The speaker challenged  
45 us:  
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47 *'What do you see?' .... three regular children playing, or a disabled girl with*  
48 *her carers?'*  
49

50 In the next image, a group of young men were standing in a bar. One was leaning on  
51 the counter, his hand cupped around a glass of beer, as he listened intently to a man  
52 with Down's Syndrome. The presenter provocatively repeated:  
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54 *'What do you see; a group of close friends out for a drink? Or a disabled man*  
55 *with a carer? And who do you think has the greatest needs?'*  
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58 My mind shifted to my latest battle to find a school for my daughter. The local school  
59 said her needs were too great. I looked back at the screen. **All means All** was  
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3 highlighted in bold print, striking at the heart of my struggles with an educational  
4 system that, on the one hand, espoused the idea of integration and, on the other  
5 hand, resisted change. I glanced around, imagining other parents entangled in  
6 similar battles, like wild plants trying to exist in neatly cultivated gardens. I felt  
7 trapped between the theory of inclusion and the painful lived reality of exclusion. I sat  
8 between the optimistic ethical conviction of 'All means All' along with possibilities of  
9 imagining disability differently (De Schauwer, E. et al 2017; Fritsch 2015) and the  
10 despair about 'experiences of injustice, exclusion and prejudice.' (Watermeyer 2009,  
11 100) that can weave their way into the lived reality of learning disability.  
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14  
15 This experience has been emblematic for me in a personal and professional quest to  
16 explore the notion of inclusion in relation to learning disability. As I reflect on my own  
17 battles for equality I identify as a parent-scholar (Vaughan and Super 2019), weaving  
18 auto-ethnographic reflections through critical theory and practice. This immersion  
19 has been a way of navigating the labyrinth of joys and injustices that pepper the  
20 parenting of a learning disabled child with a view to seeking 'alternative narratives to  
21 the ones that were available' (1108).  
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### 24 **3- Methodology**

#### 25 **Aims of the research**

26  
27 The overarching aim of this research study was to gain insight into the first-hand  
28 experience of parents as they discover that their child has Down's Syndrome. I  
29 aimed to explore the conscious and less conscious messages received by the  
30 parents from their own internal worlds, from family and friends and from professional  
31 services supporting these families at the moment of diagnosis.  
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33

#### 34 **Recruitment**

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36 I selected participants through purposive homogeneous sampling (Smith et al 2012)  
37 using referrals from relevant organisations and through existing contacts. I chose to  
38 interview parents of children who were at least of school age, so that the experience  
39 would not be so immediately raw as to provoke distress. In selecting participants, I  
40 was cautious that those participating were sufficiently robust to recall their  
41 experience.  
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44  
45 Out of eight participants, five were mothers and three were fathers. Participants were  
46 given information in a digestible format about the purpose, methods and intended  
47 uses of the research and the nature of their participation. It was explained that any  
48 data would remain anonymous and secure. Ethical approval was obtained from  
49 Goldsmiths, University of London.  
50  
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#### 52 **Data gathering**

53  
54 I facilitated semi-structured interviews in participants' homes, with one exception via  
55 Skype. Interviews were audio recorded and transcribed. I conducted the interviews  
56 myself, drawing on my skills as a teacher, therapist and mother, inviting conversation  
57 without leading the interviewee in any particular direction. My interventions tended to  
58 be statements rather than questions, seeking clarification and bringing a focus to  
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3 particular elements of the content, with an attitude that the reality is whatever the  
4 interviewee perceives it to be (Brinkmann 2015). Although I was confident that I had  
5 the professional capacity to contain emotion that arose within the interview process, I  
6 also made available contact details of local and national support networks and  
7 helplines.  
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10 As well as providing data for the project, the interview process itself provided  
11 participating parents with an opportunity to reflect on and share a profound, life  
12 changing experience. One mother commented:  
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14 *'When I heard about this opportunity, I thought: yes, yes, yes! because you*  
15 *never really have the opportunity to talk about these things.'*  
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18 Another mother commented:  
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20 *'It's nice to have this space to remember, because all the time now we're just*  
21 *fighting in the jungle. You know, managing this; managing that; this*  
22 *appointment; that appointment. It's just practicalities all the time. Back then it*  
23 *was much more (she paused and looked out of the window) more like; oh!*  
24 *she'd just arrived from the stars and here she was, this different little person.'*  
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27 Each time we retell our stories and have those stories witnessed by another without  
28 judgement or advice, the experience can begin to make a little more sense. This  
29 opportunity was a chance for these parents to slow down and remember those early  
30 days.  
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### 33 **Data analysis**

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35 IPA was a good methodological fit for the task of data analysis (Smith et al 2012). It  
36 provided a framework by which I could remain open to the parents' accounts of their  
37 lived experience and explore the underlying meanings of the narratives within a  
38 frame that is dynamic and non-linear. This method enabled me to focus on the  
39 unique particularities of each interview, whilst remaining mindful of the context of the  
40 wider metanarratives of contemporary social systems. I concentrated my focus on a  
41 small number of cases to allow room for depth of experience, with enough  
42 participants to identify similarities and differences in relation to the experience being  
43 investigated.  
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47 I immersed myself in the reading of the interview scripts, allowing meaning to arise  
48 from notes that I'd made on the emotional charge, the pauses between the words,  
49 the non-verbal communication and the more-than-human environment, all as  
50 'mediators of the social encounter' (Brinkmann 2015, 120). New-materialist  
51 frameworks were helpful in challenging and disrupting binary thinking, through which  
52 individuals are categorised as *either* able-bodied *or* disabled. I wanted to be open to  
53 'fluid movements of differentiation' (De Schauwer et al 2017, 277) that enable us to  
54 imagine disability differently. In the analysis of the transcripts I was concerned with  
55 the specificity of each unique experience as well as key emergent themes across all  
56 interviews.  
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59 I will now outline the themes that arose, illustrating them with quotations from the  
60 interviews.

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#### 4- Findings:

##### A life worth living

All the parents who I interviewed spoke of pre-natal screening, either as a medical intervention, or as a question from friends and family. Implicit in the screening process is the idea that some lives are more desirable than others. Parents found themselves caught in a place in which learning disability is an inconvenient truth that can be avoided by medical intervention. These parents made informed decisions to continue with their pregnancy on the basis that their children would have lives well worth living.

On receiving the news during pregnancy that Down's Syndrome might be a possibility, one mother recalls her experience of the news being delivered. She said:

*'I went for a scan and they said that the nuchal fold around the back of the neck looks a bit thick, but don't worry. We didn't really think much about it, but then they called us into a little special room. It looked like one of those rooms where they're going to give you bad news. There's a box of tissues and, some kind of special person came in and said to us about this measurement and that this can be an indication of heart problems or Down's Syndrome. On one level, we were quite shocked and on another level part of me was thinking, yes; that's probably right. I remember being really practical and asking whether if I have the test and it clarifies something, will that mean you can do anything to improve the baby's health? They said no, so I said I didn't want it.'*

The powerful message implicit in the 'little special room' immediately suggested commiseration rather than celebration. The mother asked if the discovery of the diagnosis would lead to enhancing this baby's health and the negative response implied that the only reason for the screening was the opportunity for termination. The idea that learning disability can be screened out of our lives as an undesirable category is illustrated by one mother, who described how:

*'My friend said 'oh: didn't you do the test then?' People were worried about why I didn't do the test.'*

The same mother went on to explain how she didn't feel pressurised one way or the other from her consultant, who gave her balanced information:

*'My consultant had been very professional; she'd given me all the information. When I got the leaflets, I read them and I decided I'm not going to do an abortion. My partner agreed and so did his mum. I was shocked when she said that the risk of miscarriage was about 1 in 100.'*

However, another mother's story illustrated how a particular medical agenda defined Down's Syndrome within categories of humans that are undesirable:

*'When I was three months pregnant, the doctor found something that wasn't right. He thought that maybe my baby had Down's Syndrome and he tried to make us consider an abortion. We told the doctor we didn't want to; we were*



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*ready for whatever this baby was bringing. He seemed upset with us. It was terrible for me. We then changed doctor, finding one who accepted our decision and supported us and I had a really good pregnancy. '*

This mother demonstrated resistance to the idea that the world would be a better place without her baby. No doubt the doctor considered that he was acting in the parents' best interests in advising on a termination.

Another mother remembers seeing the scan:

*'It was a beautiful scan...the baby looked great, she was kicking away. They told us it was a little girl because we wanted to find out so that we could either prepare our other children for a brother, or reassure them that she was going to be a sister and at that point the nurse actually said 'Oh no; she's absolutely fine; she looks absolutely fine. Don't worry at all'. And I just thought. Oh; OK, well that's that then. I remember we looked at each other and it was like, ah! we're going to have a daughter.'*

There is perhaps a veiled message in this exchange, with an inference that this 'beautiful' baby is not disabled. The repeated reassurance that the baby is 'absolutely fine', arguably serves as a code for 'not disabled' and the parents are told 'don't worry at all. Learning disability, it seems, would be a worrying turn of events, if not a catastrophe.

### Loss of an illusion

Loss arose strongly as a theme. On one level, nothing has been lost. A beautiful baby has been born, yet the feelings of grief were evident in all the interviews. One mother expressed this poignantly:

*'...in those few days afterwards, it was a real distress. I used to cry day and night. I stayed in the hospital for five days. The first two nights I was in the ward with lots of babies. I think it was about thirteen.... Oh; I cried so much. I was so upset.'*

She continued, remembering her sense of isolation:

*'I remember; while I was in the ward with all those babies making a noise, I was completely isolated. Nobody came to talk to me. All the other mothers were chatting about things and laughing and I was completely alone.'*

What was lost, it seemed, was this mother's sense of entitlement to belong to the group of mothers who were 'chatting about things and laughing' as they stepped into a shared notion of motherhood. Tabatabai (2020) suggests that under neoliberalism, cultural expectations of good parenting are met by raising independent children, who will ultimately become economically productive. This mother's sense of isolation perhaps reflects her sense of diminished motherhood.

The words of another mother illustrated how her hopes for the future were fundamentally challenged:

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*'There was a kind of dawning of acceptance of what that would mean wouldn't be happening for our daughter. I remember at the time the things that seemed important were like, oh.....will she get married and I remember thinking for my partner, oh, he's not going to be going to his daughter's graduation. It felt like in the early days there were always more and more things to let go of at the time.'*

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It is as if all that can be imagined is a future of limitations and lack of opportunity, yet in reality, no parent can know if their child will become economically productive, get married or graduate. Similarly, one father spoke about letting go of the idealised child and the desire for a utopian future. He needed time for the information to make sense as he struggled to accept the reality. He said:

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*'It was a very confusing time because as I'm thinking back on it, I'm looking back on my kind of idealistic picture of, you know, the dream girl or child, whatever, that might have meant to me at the time and then thinking, no, it's going to be different. She's going to be like...well, I don't really know what. I know that you've probably got Down's Syndrome, I thought, but I just can't relate to it. So, it was very confusing and then the extra added layers of that was the stigma of telling people that...that you've got a child who is not normal and all that kind of thing.'*

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This father needed time to adjust to the reality of learning disability as an immediate lived experience. A study by Halberg et al (2010) indicates how important it is that parents have the space to process this news at their own pace. This same father articulates how an important part of the process of making sense of the difficult feelings of loss was, in his words, *'to feel met by another man'*. At the hospital he had been told that only a blood test could confirm Down's Syndrome and the message he had received was *'let's all hope it's OK'*; with 'OK' being a euphemism for 'not disabled'. He describes how a trusted friend, who was also a doctor, visited, looked at the baby and told him gently and directly that the baby clearly had Down's Syndrome. These two men stood together in tears and at that moment this father felt completely met. He went on to say:

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*'Those particular moments really stay with me...of being seen or being touched in an emotional way by that guy. You don't like to show your vulnerability. Recalling it now, I feel quite emotional again.'*

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This sense of being met by another was an experience of being received and listened to without judgement as he experienced the feelings of loss. Parents highly valued the capacity of another person to remain alongside them with openness and availability.

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From the mother who senses that she has lost her entitlement to join a shared notion of what motherhood means, to the father who needs to readjust his vision for his daughter's future, illusions about the future have been disrupted on hearing the diagnosis of learning disability.

Watermeyer (2009) offers a perspective on the notion of loss in relation to disability:

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4 *'Claiming loss, human loss, has the potential to disrupt this cycle of silence in*  
5 *a manner which repositions disabled experience where it belongs, amongst*  
6 *the universal ups and downs of real life.'* (101)  
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9 As a parent is told that their infant is learning disabled, the fragility and precarity of  
10 the human condition breaks through the surface of that *'cycle of silence'*. It seems  
11 that this sense of loss experienced by these parents is related to an existential reality  
12 that belongs to us all. Listening to the experience of loss told by these parents can  
13 help us reimagine the loss as an anxiety shared by all of us, either consciously or  
14 less consciously, about the uncertain futures of *all* our children, notwithstanding their  
15 level of ability, in a complicated and precarious world.  
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### 18 **Finding a language to speak about disability**

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20 It was evident in the interviews that it could be a struggle to find a relational language  
21 that allows us to think and talk about disability. The term Down's Syndrome carries  
22 with it a very particular stigma and this experience might be the first time that these  
23 parents are confronted by the concept of learning disability. There is an  
24 interdependent relationship between the language that we use about learning  
25 disability and the way we perceive it, or not, as an issue that is part of our common  
26 humanity. One impacts on, and shapes, the other and the terminology that we use  
27 has enormous socio-cultural implications (Andrews et al 2019).  
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30 One mother remembers the paediatrician's objectifying language in describing the  
31 medical diagnosis of Down's Syndrome. This was then followed by a reluctance to  
32 provide any space to consider the emotional impact of the news. This mother said:  
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35 *'She (the paediatrician) said you can tell by the facial features, possibly lines*  
36 *on the palms, and there's a thing called sandal toe, where their big toe is*  
37 *further apart from their other toes, as if they were born to wear sandals. I*  
38 *mean she was very light-hearted and jolly. And we said oh; we've got to go*  
39 *away and get our heads around this. And she said 'oh, no, don't be so silly.*  
40 *It's always traumatic having a child. You just need to get home and get on*  
41 *with it. Don't worry.'*  
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44 The identification of physical features objectifies the baby's condition and then, in  
45 complete contrast, the *'light-hearted and jolly'* demeanor dismisses the issue of  
46 disability as significant. These polarised positions close down the possibility of  
47 dialogue, even though the parents have expressed a desire to get their heads  
48 around the idea. Parents are confronted with 'the dissonant and frighteningly  
49 unknown phenomenon of disability' (Watermeyer 2009, 93) in that moment of the  
50 diagnosis.  
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53 However, in contrast, one father described how the news was delivered directly and  
54 gently, without judgement and following the news, the consultant opened a space for  
55 reflection. This father said:  
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58 *'The consultant who delivered the news was a very nice guy. He appeared in*  
59 *the room and explained gently that he was going to examine the baby. He*  
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3 *said 'ah yes I think your baby has Down's Syndrome. We won't know for sure*  
4 *until we've done a blood test. Then he just sort of stayed with us for quite a*  
5 *long time. He answered any questions that we had'.*  
6

7  
8 This consultant had the capacity to remain alongside the parents, to let them take in  
9 the news and to create a relational space for dialogue.  
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11 Parents reported that, along with managing their own mixed emotions, they also  
12 needed to manage the feelings of close family and friends, with whom they needed  
13 to find a language to speak about learning disability. One father stumbled over his  
14 words, communicating this difficulty in the immediate interview. He says:  
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16  
17 *'So it was very confusing and then the extra added layers of that was the*  
18 *stigma of telling people that...well; telling people that you've got a child who*  
19 *... well.....you know, then you have to .....there's all the beginning of all that,*  
20 *like handicapped, not functioning normally, not normal and all that kind of*  
21 *thing and I found it much more difficult to tell my family about that.'*  
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23  
24 At this point, the only language that this father can find refers to deficit, measured  
25 against benchmarks of normality. He hesitantly draws on the language that is  
26 available to him, tending to problematise learning disability.  
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28 Another mother, who already had experience as a professional of working in the field  
29 of learning disability, anticipated the difficult conversations that might ensue, and  
30 wrote a preemptive email to everybody. She says  
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33 *'I said (in the email) that our baby has Down's Syndrome. I reckoned that if*  
34 *you read something you can take your time to take it in and to think what*  
35 *you're going to say or do. And then speak to me. But when you tell the news*  
36 *directly, everybody is in shock.'*  
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38  
39 Professionals and parents sometimes struggled to find a way to speak about  
40 learning disability and to hold the complex range of emotions and issues that it  
41 carries.  
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### 43 **Myths about learning disability**

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45 There seemed to be all kinds of myths that emerged as parents navigated their initial  
46 experience of discovering that their child has Down's Syndrome.  
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49 For example, one of the first issues that all parents confront is how their baby will be  
50 fed. Many mothers wish to breastfeed, some don't. Some mothers who want to  
51 breastfeed find that it problematic, others find it easy and some mothers choose not  
52 to breastfeed, whether or not their baby has Down's Syndrome. Yet, the idea that  
53 babies with Down's syndrome will not be able to breastfeed emerged in several  
54 interviews. One mother said:  
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57 *'I wanted to breastfeed, but I was told that babies with Down's Syndrome*  
58 *don't latch on very well, so I was surprised to find that breastfeeding wasn't*  
59 *difficult for my baby.'*  
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Another mother said:

*I was determined to breastfeed and I was told at the hospital that my baby wouldn't breastfeed because she has Down's Syndrome. I got really upset. Later, a midwife came in who was very gently spoken, asking me why I was so upset. She told me how beautiful my baby was, she encouraged me to breastfeed and made me realise that things weren't that bad.'*

Similarly, the issue of bringing up a child to be bilingual brings the imposition of seemingly unfounded advice about limiting opportunity. One mother's first language was Portuguese. She remembered the speech and language therapist hearing her speak Portuguese to her baby. She said:

*'The speech and language therapist looked at me and said 'do you know your child has Down's Syndrome? You can't speak Portuguese to her; we don't even know if she's going to speak English'. At that time, I was so shocked and scared about everything, I just listened; I couldn't say anything. But when we looked at the research, it was very clear. Children who learn two languages do better, and that seems to be the same for all kids.'*

One father recalls how he needed to confront the superstitious myths about learning disability that existed in his family. He talked about the language that he had heard his own father use:

*'...because where he (his father) comes from they're.... a bit, yeah, different you know there's a different attitude. There were various...what did my dad call them? You know....a few people who, you know, were away with the fairies. My dad had someone who lived down his lane.... Someone's daughter who had learning difficulties. It was considered to be really bad luck... you know, there'd be a whole series of other associations and stories about misfortunes that linked to learning disabilities. Those things would all be there. They were superstitious....but also very, very open-hearted....definitely an interesting mixture of things. Kind of just open hearted and accepting, along with the stories of misfortune.'*

This father was reflecting on the superstitions and unfounded fears of misfortune that are connected with learning disability, that, in his experience of his father's community, sit alongside open-heartedness and accepting attitude. These contradictions demonstrate the complex nature of the concept of learning disability and the misapprehensions that can pervade community values.

### Issues of belonging

As parents unpacked their experience of shock and grief, it seemed that one of the central fears was that of not belonging. Dalal (2015) talks about 'the paradox of belonging' (188) proposing that the state of belonging requires there to be something outside of that thing to which we do or don't belong, or from which some are excluded. Yet, at the same time, he says, we '*cannot not belong*' (Dalal, 2015, 188) as we are all members of the human race. The notion of belonging is socially,

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3 politically and psychologically constructed and this manifests in power and privilege,  
4 imbalances and asymmetries. All parents expressed a fear of not belonging on some  
5 level.  
6

7  
8 One mother said:  
9

10 *'I started thinking what am I going to do? What if my son never learns to*  
11 *speak? Nobody's going to accept him. And when I'm not going to be here*  
12 *what is going to happen to him? Is he going to work? Will we be able to travel*  
13 *in a plane with him?'*  
14

15  
16 This mother was expressing her anxieties about anticipating a hostile environment  
17 and limited opportunities.  
18

19 A father remembered his sense of isolation and his desire to find others who had  
20 similar experiences. He said:  
21

22 *'For a time, it felt very alone. You know; isolated. I went on the internet and*  
23 *found what I could. And I rang the professional association. We then got*  
24 *together with six other parents. We felt we had to do something because I felt,*  
25 *well, there's no-one to talk to who is in a similar situation as us.'*  
26  
27

28 The same father described how:  
29

30 *'When we took her to the GP first of all he said well, we've never had a patient*  
31 *with Down's Syndrome in the practice and apparently the average GP will*  
32 *only have one patient who has Down's Syndrome during their entire career.'*  
33  
34

35 The interviews revealed the complex nature of this sense of belonging. One mother  
36 spoke about how initially, she felt welcomed into the heart of the community when  
37 the baby was born. She said:  
38

39 *'Unlike my other daughter, who I really felt was born to me, there was this*  
40 *feeling like that my daughter had been born to the community. It felt really*  
41 *powerful. It was like the moment she was born, she was of great interest*  
42 *and big part of the community. I used to get on the bus and hand her over to*  
43 *the driver to hold. And everyone was really interested. I mean, we had very,*  
44 *very positive responses from everyone about her. We had no negative kind of*  
45 *feedback like 'oh she's different' or this is sad or anything like that.'*  
46  
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48

49 However, later in the interview, this same mother reflected on how, as time went on,  
50 her daughter challenged community systems and it was less easy to feel a sense of  
51 belonging. She said:  
52

53 *'She was an absolutely perfect baby, but then turned into a total liability as*  
54 *soon as she could walk (the mother laughs as she remembers) at which point*  
55 *I tried taking her to the local parent and baby group, which was very reverent*  
56 *and quiet. My daughter just ran in there and caused complete mayhem. I*  
57 *thought, this is crazy what am I putting myself through and I stopped going.*  
58 *Later, when trying to find a school in the community, they'd said no, they*  
59  
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3 *basically said no we can't handle her as the member of the class. We haven't*  
4 *got the resources. Which was a bit of a slap in the face.'*  
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6

7 When her daughter began to challenge the 'very reverent and quiet' atmosphere of  
8 the local parent and toddler group, she was made to feel that she didn't belong. It is  
9 not untypical that children whose behaviour challenges a system can lead to  
10 exclusion, either circumstantial or official. The consequent isolation of child and  
11 parent contributes to parental stress. This form of discrimination locates problems  
12 within individual pathologies, rather than within an inflexible system that fails to  
13 accommodate differences.  
14

15  
16 One mother recalled how she had wanted her learning disabled daughter to attend  
17 the same school as her other children. She says;

18  
19 *'Basically the school said no, we can't handle her. We haven't got the*  
20 *resources. I found it really difficult, not least because of the way it was*  
21 *delivered. I think the woman at the school was very stressed and had had*  
22 *many requests from families with a child with special needs. I knew it wasn't*  
23 *going to work if they didn't have the patience or the time to be nice about it.*  
24 *But it's a massive hole in that system.'*  
25  
26

27 Along with stories of feeling excluded, all parents told moving accounts of finding that  
28 they had become a magnet for kindness, compassions and a sense of community.  
29 The importance of finding connection and affiliation through shared experiences  
30 stood alongside, and in contrast to, feelings of isolation and exclusion.  
31

32  
33 For example, one mother told of the heartening reception that she received from her  
34 family. The announcement that her daughter was learning disabled brought out the  
35 community spirit as her brothers and their families arrive 'like knights in shining  
36 armour'. She said:  
37

38  
39 *'My family were brilliant. My three brothers turned up straight away with loads*  
40 *of gear. They've all got little children, so they brought all their old gear with*  
41 *them. They were fantastic. They'd bought beef burgers to get my blood levels*  
42 *back up. Yeah it was fantastic! They were like these knights in shining*  
43 *armour arriving and they were really wanting to show that they were*  
44 *welcoming the baby. They might not have all come together like that as if I*  
45 *hadn't had a child with some kind of special needs. So that was that was very*  
46 *heartening.'*  
47  
48

49 The experience of discovering that one's child is learning disabled can be profoundly  
50 unsettling (Linnington 2014), triggering a feeling of not belonging to a mainstream  
51 idea about parenthood. However, it was clear from these interviews that the  
52 experience also brings with it opportunities for compassion and humanity that are  
53 transformative. In the long term, family bonds can become strengthened, as can  
54 emotional resilience (McConnell et al 2015).  
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## 58 **5- Discussion**

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3 The themes that emerged from these interviews with parents of children with Down's  
4 Syndrome comprised the question of what it is that makes a life worth living, the loss  
5 of an illusion, the language we use to speak about learning disability and the myths  
6 that surround it, along with the wider issue of belonging.  
7

8  
9 These parent-participants all related how they had been asked to engage with  
10 conversations about pre-natal screening, with an implication that a baby with greater  
11 cognitive and physical capacity is more desirable than one diagnosed with less  
12 capacity. As we have seen, one mother is taken into a special room (away from the  
13 central activity) where there is a box of tissues to hand (anticipating grief) and where,  
14 as she says, one might expect to receive bad news (an assumption that the news is  
15 unwelcome) from a special person (as distinctive from standard professionals). The  
16 delivery of the news of learning disability is therefore framed within an atmosphere of  
17 catastrophe, otherness and segregation. Fritsch (2015) suggests that it is an 'ableist  
18 failure of imagination' that renders disability 'a deeply and profoundly undesirable  
19 category of being.' (44).  
20  
21

22  
23 Yet, as these parents reflected back on their experience, they all did so with a sense  
24 that their child had a life well worth living, despite the struggles that one mother  
25 described as '*fighting in the jungle*' as she manages the practicalities of supporting  
26 her child.  
27

28  
29 On receiving the news, parents might have had vague ideas about learning disability  
30 that are 'quietly shaped by literature and the media.' (Gothard 2008, 2) in a way that  
31 projects stereotypes of tragedy and vulnerability onto disability, or else idealises the  
32 achievements of disabled people as courageous and/or inspirational (Andrews et al  
33 2019). Learning disability is othered by these perceptions and Watermeyer (2009)  
34 points out how:  
35

36  
37 '*...public discourse about and media representations of disabled people*  
38 *remain firmly attached to the construct of disabled life as incomplete and*  
39 *lacking, with a constant awareness of what has been lost or was never had.'*  
40 (91).  
41

42  
43 The reactions of loss and grief expressed by parents as they are confronted with the  
44 diagnosis can be seen as a response to cultural constructions, in which '(d)isability  
45 becomes known as a malfunction of ability' (Goodley et al 2019, 986).  
46

47  
48 The reality is that all life involves disillusionment, disappointment, loss and grief. The  
49 mother who sits alone in the hospital with her baby, feeling isolated, as, in her words,  
50 '*other mothers were chatting about things and laughing*' illustrates two worlds side by  
51 side; one world in which a parent is anticipating disappointment, lack and  
52 imperfection and another world in which parents are anticipating potential,  
53 opportunity and success. Neither position presents the whole reality, as exclusive  
54 representative experiences in themselves, and both positions are true for all of us at  
55 some level.  
56

57  
58 Perhaps what becomes lost on the birth of a learning disabled child, then, is an  
59 illusion of our entitlement to neoliberal values of independence, self-sufficiency and  
60 economic productivity that underpin contemporary notions of good parenting



(Tabatabai 2020). Happiness becomes equated with these values and learning disability as a concept struggles to find a place in this narrative. Fritsch (2015) asserts that these measures of disability 'are deeply embedded in neoliberal processes of individualisation and the economisation of life.' (48) and it is these values that can define the relative worth of individuals. Unless, of course, we can find a way of imagining disability differently (Fritsch 2015; De Schauwer et al 2017). To imagine disability differently involves thinking differently about ability and disability and perceiving difference itself as an opportunity to discover new ways of participating in communities.

Ideas concerning whose lives are worth living, and the feelings of loss that accompany the diagnosis of learning disability, to some extent shape and are shaped by the language we use. It was clear in these interviews that it can be hard to find a language to speak about learning disability and the language available to us reflects a complicated history of how learning disability is perceived.

The social model of disability shifted our focus from the medicalised language of remedial interventions that located deficits in individuals, to broader processes of enquiry into structural and systemic oppressions (Shakespeare 2013) and this has been supported by legislation, for example, the Equality Act 2010 (Equality Act 2010). However, language around learning disability can still reinforce discrimination, particularly derogatory language referring to cognitive impairments that are freely used as insults, and language that reinforces 'problematic stereotypes' (Andrews et al 2019, 113). The reality is that people don't fit into binary categories of identity (Slorach 2016) and a representation of disabled people as a single homogenous group misses the subtle and nuanced experience of individuals.

At that inclusive education conference that I attended in the 1990s, I gleaned an optimistic message about 'disability rights replacing the sympathetic charity tins' (Ryan 2019, 2) and the language used about disability reflected this shift. At the time, disabled activists had been campaigning for the Disability Discrimination Act and benefits such as the Disability Living Allowance (DLA) enhanced the quality of life for disabled people. A growing interest in inclusive education brought creative practices of including children with disabilities, such as Down's Syndrome, into mainstream schools and other community services. With the financial crisis in 2008, the tide began to turn on these developments. By 2013 the DLA was replaced by Personal Independence Payments (PIP), with a tightened criteria that began to deprive many disabled people of adequate support. At the same time, welfare reforms brought about the abolishment of community care grants and crisis loans. A hierarchy of needs determined that 'it was no longer enough to simply be disabled, you had to prove you were 'disabled enough' (Ryan 2019, 30). By December 2017 nearly half of the disabled people assessed via PIP had their support 'either cut or stopped entirely.' (27). The austerity agenda impacted adversely on issues of inclusion, exclusion and quality of life in relation to disability in British society.

The experience of having a child diagnosed with learning disabilities confronts parents with cultural values that place an emphasis on the idea that happiness is derived from acquiring independence and productivity (Tabatabai 2020). These values become evident in the language that we use and in a Western capitalist culture the term learning disability is not neutral (Acharya 2011). In order to imagine

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3 disability differently we need to create a relational space for dialogue about the lived  
4 experiences of individuals who have lives well worth living. Learning disability brings  
5 the gift of diversity (Snow 1994), that challenges us with the creative potential of  
6 figuring out different ways of being together and different ways of thinking about what  
7 it means to be human.  
8  
9

10 In that struggle to find a relational language to speak about learning disability, it  
11 became evident during the interviews that there are prevailing myths that underpin  
12 attitudes that are 'othering'. For example, the message that babies with Down's  
13 Syndrome can't breastfeed, or will have difficulty with breastfeeding. Breastfeeding is  
14 a symbol of maternal holding and nourishment and this message is perhaps a less  
15 conscious communication about learning disability as a life (not) worth living and,  
16 hence, a life (not) worth feeding and in whom it is (not) worth investing. Other myths  
17 included that of raising one's child as bilingual and also superstitions that linked  
18 learning disability to misfortune. These myths distance the notion of learning  
19 disability as *other*, impacting on the sense of belonging of these parents. As they  
20 imagined their child's future, they anticipated hostile environments and restricted  
21 opportunities.  
22  
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24  
25 Parenting is no easy task, whether or not a baby has an impairment, and the role  
26 involves many challenges as well as joys. The reality is that families with learning  
27 disabled children have a greater likelihood of living with financial hardship due to  
28 higher living costs, for example heating, extra washing, transport, amenities, support  
29 services, healthcare. (Hallberg et al 2010; Hollins and Sinason; 2000, Inman 2019;  
30 McConnell et al 2015; Merin Rajan et al 2018; Ryan 2019; Slorach 2016). These  
31 parents can find themselves '*fighting against a headwind to get what they thought*  
32 *was best for their child*' (Hallberg, et al 2010, 273).  
33  
34

35 However, welcoming a learning disabled child into the family is also an opportunity to  
36 develop new ways of relating to the world. The expression of disappointment and  
37 grief is perhaps the beginning of this opening, in a process of letting go of  
38 assumptions and beliefs that determine who we think we are.  
39  
40

41 The parents who I interviewed clearly loved their children with Down's Syndrome and  
42 valued them as much as they would any child. All parents alluded to encounters with  
43 discrimination and all had found ways to navigate this and to advocate for the needs  
44 of their children. The impact of including a learning disabled child in the family can be  
45 transformational in terms of personal growth, resulting in 'deep and lasting changes'  
46 (McConnell et al 2015, 30) and all the parents alluded to this potential.  
47  
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## 49 **6- Afterword: A deeper kind of knowing**

50

51 One particular moment from the interviews stayed with me. It didn't seem to fit with  
52 the emergent themes, yet it hovered persistently in my orbit of awareness, akin to  
53 what Maclure (2010) describes as research data that glimmer and call our attention,  
54 as they take on 'a kind of glow' (282). The moment was characterised by a disruption  
55 that opened a channel to think about humans as just one part of a wider ecology. In  
56 that ecology, disability is a gift that expands our thinking.  
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3 The night before going to meet one mother, I had a dream in which a horse had  
4 given birth to a very strange foal. All those who saw the foal were confused, not  
5 knowing how to relate to it, having never seen one like it before. I awoke with a  
6 sense of curiosity, as well as sadness for this foal, for whom those around her had  
7 no place in their minds.  
8  
9

10  
11 That day, I was listening to a mother remembering how she told the older siblings  
12 about their new baby sister having Down's Syndrome. She said:

13 *'It didn't seem to mean much to them. I remember that her older sister was*  
14 *really into horses at the time and she asked 'do horses have Down's*  
15 *Syndrome?' I thought, what an interesting question! I began to wonder if there*  
16 *are animals with special needs?'*  
17  
18

19 I was reminded of my dream the previous night and at this point in the interview, the  
20 cat, who had been asleep on a chair, jumped up onto the table and demanded  
21 attention. As we tried to resume the conversation, the cat stood between us and  
22 nuzzled into my shoulder. It seemed that we were being reminded to think differently  
23 about the place of humans as just one species in a wider ecology of beings.  
24  
25

26  
27 The sequence of events, including my dream, the mother's reference to her  
28 daughter's question and the cat's capacity to shift our dialogue, was a timely  
29 reminder to engage with the emergent possibilities of differentiation which are  
30 'mobile rather than static, and are multiple, rather than singular.' (De Schauwer et al,  
31 2017, 277). It helped me to remember to widen my perspective about what it means  
32 to be born with Down's Syndrome and to remain open to ways of thinking that  
33 dislodge fixed ideas about normality.  
34  
35

## 36 **7- Conclusion**

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39 The stories of the parents of children with Down's Syndrome who participated in this  
40 research project illustrate how, despite the struggles they encountered in navigating  
41 the experience of parenting a disabled child, they were able to identify a depth of  
42 experience that had enhanced their lives. Some of the parents interviewed had made  
43 a conscious choice to proceed with their pregnancy in the knowledge that their child  
44 would have Down's Syndrome, often against medical advice. Resources have been  
45 directed into expensive and highly sophisticated medical interventions that identify  
46 and screen for learning disabilities, yet these interviews indicated lack of  
47 sophistication in our capacity to speak about learning disability in a way that is  
48 relational and balanced. Fritsch (2015) suggests that:  
49  
50

51 *'it seems to be easier to imagine the elimination of disability through*  
52 *expensive techno-scientific solutions like genetic therapies, invasive*  
53 *surgeries, or other medical interventions than to imagine desiring disability*  
54 *differently' (65).*  
55  
56

57 In Iceland, for instance, the birth of infants with Down's Syndrome has practically  
58 been eliminated (Maclean, 2017).  
59  
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17

In desiring disability differently, I begin to imagine what it would be like if the birth of a baby with Down's Syndrome was celebrated as a life well worth living and an opportunity to perceive life differently. Confronted with 'ableist norms' (Vehmasa & Watson 2016, 5) that exclude those who fall short of normative expectations, the stories shared by these parents help us to find ways to deconstruct the old narrative and 'imagine disability differently' (45).

This research evaluating the welcoming of a child with learning disabilities into the world, is part of a wider movement of disability emancipation (Slorach 2016). The parents in these interviews found themselves on a path leading to a deeper kind of knowing about what it means to be human and the potential to bring 'forth new worlds' (Fritsch 2015, 55).

I will give the last word to one of the interview participants, as a reminder that a life with learning disability is a life well worth living. She said:

*'At the end, I want to repeat that if I had the opportunity to get the time back, I would choose the same family and the same life. I'm my son's biggest fan! And whatever happens, I'm going to give him the best.'*

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