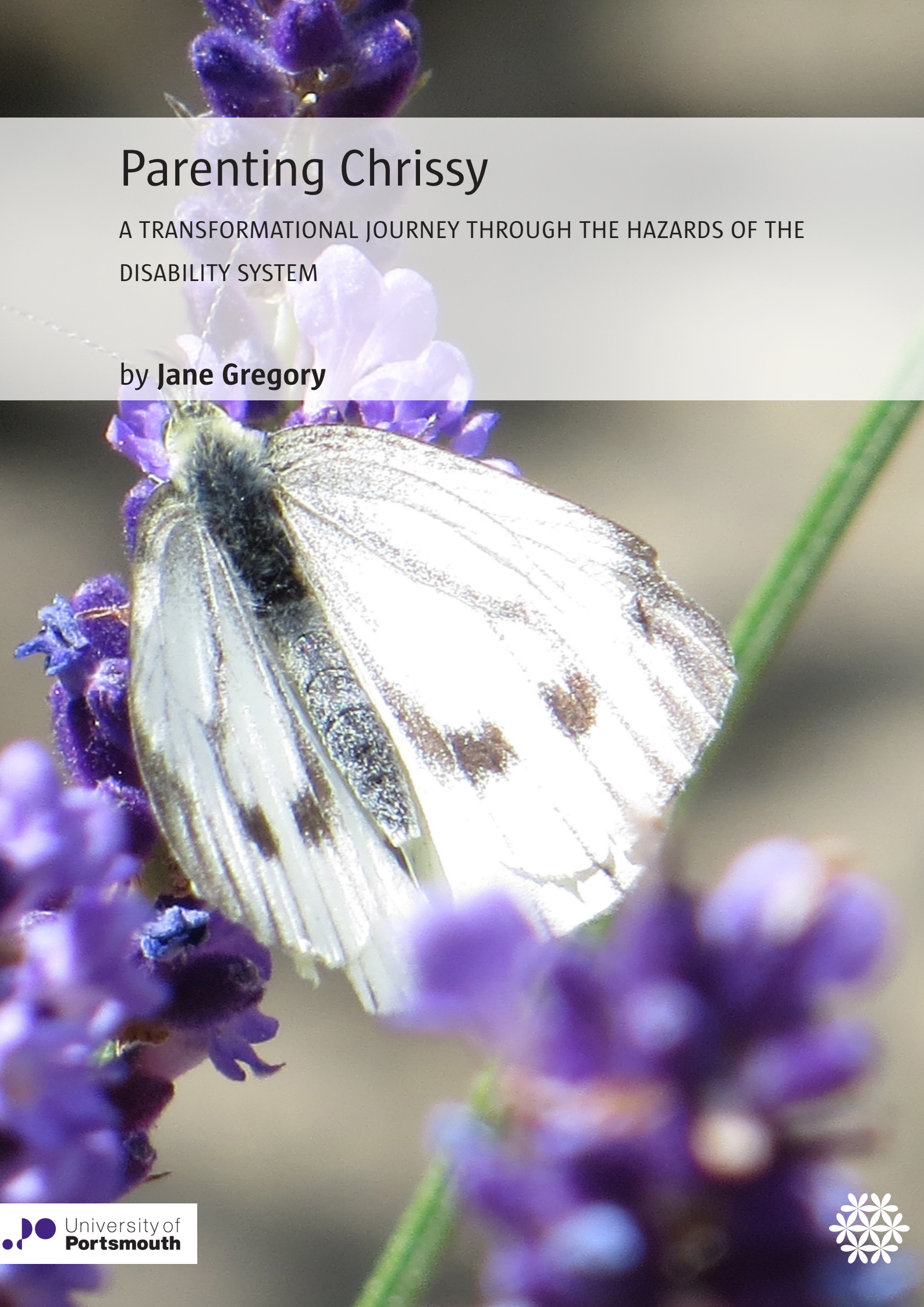

Parenting Chrissy

A TRANSFORMATIONAL JOURNEY THROUGH THE HAZARDS OF THE DISABILITY SYSTEM

by **Jane Gregory**

University of Portsmouth

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About the author:

Jane Gregory has been working as a freelance journalist, writing about learning disability and health issues, among other things, for the past 18 years. She has had articles published in national magazines and newspapers including the Daily Mail, Mail on Sunday (Health) and Community Care.

Jane has written a self-help book *Bringing Up a Challenging Child at Home* and a 'parent's perspective' chapter in *Genetics of Mental Retardation* about her experiences with Chrissy, who has a rare genetic disorder that was not diagnosed until she was 21.

As well as teaching basic skills to students with learning disabilities at an FE college, Jane has worked as a Critical Reader on Mencap's information leaflets for families. She has written and delivered trainings and talks about rare chromosome disorders, learning disabilities, challenging behaviour and communication to healthcare professionals, geneticists and other parents. Jane is very interested in epilepsy, autism and challenging behaviour and shares her thoughts on her blog Sharing Stories.

More recently, Jane was working as an Expert by Experience with the CQC and was involved in producing the CQC's Expert by Experience newsletter. Last year, she gained a Distinction on MSc Applied Psychology of Intellectual Disabilities at Portsmouth University.

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Foreword

by Mark Haydon-Laurelut and Karl Nunkoosing, University of Portsmouth

I (Mark) met Jane when she was considering signing up for the MSc program. Jane had been a parent to Chrissy for decades, navigating the health and social care systems and had written a book about parenting her daughter. Jane briefly recounts our meeting in her essay, wondering about whether against the backdrop of this learning that not possessing 'A levels' may have stood in the way of entering academia. It didn't.

I am glad Jane chose auto-ethnography as her methodology. Auto ethnographies attention to autobiographical accounts in the context of cultural and structural factors enables a nuanced description of the intertwining personal and political. It resists the idea that personal experience (an authentic knowledge of a survivor's experience) cannot be a valid form of knowledge. Taking account of this kind of work will be critical to any service provider who wishes to enact the values of partnership, co-production and collaboration.

What are the hazards to Chrissy and Jane in this story? In no particular order they include long periods of waiting (for services to decide who is responsible for supporting Chrissy and her family, for a diagnosis) marginalization and dehumanization; as the parents voice and the needs of the person who should be at the centre become a battleground over budgets and egos. We see these processes, akin to a kind of carving up of a life, placing strain on the family.

'When Chrissy was in hospital after developing seizures, I asked a pediatrician: "Is she going to be mentally handicapped?" "There's a possibility she could be retarded, yes," he replied briskly. Before I could ask him to elaborate, he turned on his heel and left to continue with his ward round.'

These kinds of critical episodes, where one imagines identities can be made and remade and life courses set out anew, are powerful and one hopes, but cannot assume, that contemporary medical professionals would be better educated in communicating with patients and families. In this 'behind the scenes' quote we really feel we get to know the terrain faced by Jane and Chrissy. Here the GP notes:

'Mum says is miserable at home. Throughout this long consultation, Christina was happy and playing in the room. Looks well. Further reassurance.'

The account of the mother is framed as that which, a non-medical professional says and is juxtaposed with what a medical professional sees and knows

Accounts of disabled family life may appear are skewed towards a particular bias of the authors, most often the tragic, on occasion the joyous. In this paper we see growth, transformation and struggle:

'Chrissy's two siblings were forced to grow up more quickly than their peers because I expected them to make allowances for her. Being younger, they saw odd behaviours and extremes of emotions that they could not understand. It scared them and, as they grew older, they resented her, and were embarrassed and bewildered by her behaviour.'

This story of struggle includes the endeavor to receive an accurate diagnosis for a daughter. The passages on this search for diagnosis are particularly interesting, for example in their reflecting on diagnosis in the context of time:

'I wondered if I would have enjoyed Chrissy more when she was little had I known that she had learning disabilities, autism and a rare chromosome disorder.'

'However, discovering the cause of Chrissy's difficulties so late in her life is not as important to me now as it would have been in the early years when support was scarce and I had fought to get health professionals to even acknowledge Chrissy had a learning disability.'

The autism industry (Runswick-Cole, Mallett & Timimi, 2016) harries parents to seek new 'treatments' for their children; instilling the notion that one can never be quite good enough a parent. There is always something one hasn't tried… The child has failed to attain the ableist ideal (Campbell, 2009) of the narrowly defined economically productive independent, enterprising, resilient and flexible neoliberal citizen and so by association has the parent. The sheer desperation experienced can lead to unproven treatments being tried as the paper notes:

'A third of parents of autistic children have tried unproven alternative treatments in their search for a cure and one in nine has used what medical experts class as a potentially harmful approach.'
(Levy, Mandell, Merhar, Ittenbach & Pinto-Martin, 2003; Gregory, 2010)

In sum

We do not have to wait for the large funded studies - the randominsed control trials and proclamations of privileged institutions to create and share new knowledge about disabled lives:

'New psychological knowledge about people with learning disabilities and their families emerged from this study, which contributes a more contextual exploration of our taken for- granted assumptions about the lives of parents of children with learning disabilities, and explores self-emancipating possibilities.'

However, in the journey from asking 'why?' to knowing, chasing after 'fixes' and then discovering the possibilities of policy changes the word 'psychological' somehow seems inadequate; too small a thing, too individualizing, certainly too apolitical to encompass what the paper describes. In this paper we are shown the complexities and struggles of a real life. A real life example of how systems can nullify policy made with good intentions, yet how policy terms such as 'inclusive', 'person centered' and 'personalised' really do matter and can make a difference to the lives of person with intellectual disabilities and their families. The paper is a journey through the hazards of the health and social care systems, the standoffs between agencies and egos, the hazards of the psychiatric profession – its diagnostic categories in flux and the medication handed out with such seeming ease and certainty - as well as the profiteering providers of services such as Assessment and Treatment Units and the autism industries parental prescriptions and ever changing 'cures'.

The journey described is both unique and reflects experiences and structures that are not new to those of us who work in services. We know of them. We know that change is required. We know that parents and their disabled children are often struggling in confusing and bizarre bureaucratic systems on the one hand and pressured by the disability cure industry on the other. For those us working in these services this paper walks us through this landscape giving us a deeper insight into what kinds of experiences we are fostering.

Summary

This autoethnography explores my journey as a mother of a woman with intellectual disabilities whose complex needs and behaviour has presented significant challenges to services. My biographical accounts include the experiences of receiving my daughter's diagnoses of a rare chromosome disorder and autism in her adulthood. The former allowed a unique story which emerged from phenomena that is being swept in by the tide of the technological revolution in the detection of gene mutations and structural genomic variations causing learning disability.

Within the theoretical frameworks of critical disability studies, social constructionism and family systems approaches, I weave 31 years of autobiographical accounts with cultural and structural factors that influence the experiences of parents of children with learning disabilities.

Included in the investigations were the uncovering of new knowledge about the culture of intellectual disability and an examination of the events leading up to my daughter's four-year incarceration in an institution. Evidence of oppressive, dehumanising social policies and practices intersect with new themes, including the journey from asking 'why?' to knowing, and chasing new 'fixes' to the liberating possibilities of policy changes and transformative validation.

Introduction

The life history approach is being adopted by many researchers to explore the socio-political circumstances and historical context in which our professional life and work is located (Short, Turner and Grant, 2013). A researchers search for the generalisable and the universal runs the risk of relegating the unique experiences of families to the status of marginal knowledge. Individuals with learning disabilities and their families should be considered experts on their own lives and, as a qualitative research method which is often used in disability studies and family studies, autoethnography lends itself to reaping new knowledge from their personal narratives. Moreover, autoethnographical methodology confers validity to our experiences in terms of their cultural situatedness and offers a challenge to mainstream qualitative research practices, which can be characterised by normative assumptions and oppressive institutional rules (Short et al, 2013).

Autoethnography gives my daughter and I voices within the disability research process (Muncey, 2010) and allows someone who has frequently been bureaucratised by disability services and experts into invisibility (Short et al, 2013) to be seen and embodied within the theory and research. It has the potential to expand on and challenge existing themes in learning disability studies, i.e., parental satisfaction with services (Law et al., 2003), stress (Willingham-Storr, 2014), family adjustment (Goodley and Tregaskis, 2006; Helff and Glidden, 1998), disappointment and fear of 'letting go' (Zibricky, 2014), pioneering families (Mansell, 2010), grieving (Bristor, 1984; Greene, Neal, Newey, Wraith and Vellodi, 1992) and coping (Kenny and McGilloway, 2007; Feldman et al., 2007; Zibricky, 2014), and to contribute towards freeing the thinking and practices of professionals that work with people who have intellectual disabilities from the old binary of medical-social model. Autoethnography adds to the methodology of disability scholarship; however detractors view it as self-indulgent, superficial and navel-gazing (Muncey, 2010). Proponents suggest that autoethnography allows evocative and emotionally resonant connections between the researched, researcher and readers to replace the privileging of the distanced spectator and disinterested 'objective' instruction (Bochner, 2001; Short et al., 2013) and cultivates learning and growth from reflexive storytelling (Berry and Patti, 2015).

Locating my narratives within theoretical frameworks of critical disability studies, family systems and social constructionism opened up the possibility of questioning our taken-for-granted assumptions about the lives of families like ours. Critical disability studies (Goodley, 2013; Meekosha and Shuttleworth, 2009) allowed critiquing their oppression and marginalisation, an examination that was enhanced by contextual

exploration of the wider networks from which Chrissy and I hail by threading in family systems theory (Haydon-Laurelut and Nunkoosing, 2010; Galvin, Dickson and Marrow, 2006; Yerby, 1995). The additional challenge to traditional psychological theories that assume 'facts' can be collected through neutral objective observations (Rapley, 2004) was offered by the alternative psychological research and theoretical approach of social constructionism. However, viewing people with learning disabilities through the lens of their family members may be restricted by our own social constructions. We each get in the way when we develop hypotheses about why something is happening in a person's life; perhaps, thereby, as parents, we may protect ourselves from the pain of really knowing what our loved one is experiencing. Davis's (2000) paper addresses the issue of ethnographic researchers in disability studies privileging their own knowledge claims over that of disabled people and explores complementary ways in which additional research strategies can contribute to the conditions within which self-emancipation flourishes.

I am one of a growing number of parents who contribute to understanding of the lives, experiences and support needs of families who have members with intellectual disabilities by writing biographical accounts of their experiences for book publishers, i.e., Moore (2012) and Daly (1992). "When it comes to human lives, storytelling is sense-making," succinctly describes the power of biographical accounts to family identity and meaning making (McAdams, Josselson and Lieblich, 2006, p. 76). My stand-alone narratives about challenges only faced by families that include someone with a disability have been published during my writing career, which include a self-help for parents book (Gregory, 2000), a chapter in a medical journal (Knight, 2010), a blog and magazine/newspaper articles (Gregory, 2013), and a campaign report (Mencap and the Challenging Behaviour Foundation, 2012).

However, this study aims to move beyond personal experience in order to comment first-hand on the larger social, cultural and structural factors that influence the experiences of parents of children with learning disabilities. As such, this autoethnography may play a role in promoting political enquiry (Short et al; Denzin, 2006; Ellingson, 2006; Ellis et al., 2007; Spry, 2001) and informing new ways to support families of individuals with complex disabilities whose behaviour presents a challenge to services, and put my experiences, as a parent, and Chrissy's experience, as a daughter with complex disabilities, at the centre of family and disability research.

Method

Here I outline some of the key elements that make up the method applied to this research.

Ethics

There were no significant ethical issues in this study and I dealt with any routine ethical issues in accordance with the British Psychological Society's Ethical principles for conducting research with human participants. In considering the ethics of involving someone who lacks capacity to give or withhold consent, I concluded that, for someone who will never be able to express herself in a way that others can understand, this study was Chrissy's best chance at having a voice. This research was approved by Portsmouth University's Department of Psychology's Ethics Committee.

Materials

The type of data collection included the use of relevant content from my book about my experiences of bringing Chrissy up, my chapter in a medical journal, book reviews, my blog (including my other daughter, Alex's, blog post about life with her sibling), health and social care records, correspondence from solicitors, MPs, learning disability charities and professionals who have been involved in supporting Chrissy and I, emails from other parents of children with disabilities, personal emails and journals, a transcript of a personal interview with my Project Supervisor, Chrissy's person-centred plan and behaviour guidelines, and magazine/newspaper articles that I have written (Gregory, 2000; Knight, 2010; Gregory, 2012, Gregory, 2013, Gregory, 2014).

Design

Drawing on my other non-academic writing and examining it with a research gaze produced a richer, more nuanced perspective from the one I was accustomed to in my persona as a journalist. The research design and methodology allowed a detailed analysis of my personal accounts and enabled the meaning I derived from them to be captured as it was without attempts to influence outcomes from the emergence of experiential themes that were explored. Furthermore, the interview by my Project Supervisor allowed recursive and open-ended questions to enable expansion and clarification of information that I had already provided and responses that revealed new, original topic areas which I had overlooked or not considered.

Procedure

From the data collected, I compiled a chronology of narratives, stories and reflections which I felt were most relevant to the aims of the study. To analyse the data I used qualitative research methods of Thematic Analysis (Braun and Clarke, 2006) because it is flexible and responsive to capture the meaning of, or simply to understand more about research participants' lived experiences. Braun and Clarke show how thematic analysis can tell an interpretive story of the data collected and give examples of good research policy principles. Thematic analysis allowed me to compare and contrast each narrative in its own right. To keep an open mind and to minimise the risks of deriving data and weak themes from pre-conceived theories, I wrote a reflexive journal and drew from the literature on families and parents who had a member with an intellectual disability.

Findings and Discussion

New psychological knowledge about people with learning disabilities and their families emerged from this study, which contributes a more contextual exploration of our taken-for-granted assumptions about the lives of parents of children with learning disabilities, and explores self-emancipating possibilities. Due to word count limitations I will focus on the themes that reap the most new knowledge from analysis of the personal narratives included in this study: the journey from asking 'why?' to knowing, and chasing new 'fixes' to the liberating possibilities of policy changes and transformative validation.

The journey from asking 'why?' to knowing

The theme of the long wait for a diagnosis and the difficulties resulting from delays in a child receiving this diagnosis is examined in this study and is reflected in Bourke, Snow, Herlihy, Amor and Metcalfe's (2014) qualitative exploration of parents' experiences of having a child with a common genetic condition.

As a young, first-time mum, I fought to get medical professionals to take my concerns about Chrissy's general health and the possibility of her having learning disabilities seriously. In infancy, she struggled to draw milk as her suck was weak, and she vomited after feeds. Chrissy was labelled at her six-week baby clinic check as 'failure to thrive.' During her first year, I was also told that she had 'head lag' and 'delayed development.' These were three of many confusing terms that professionals used then. I had no idea how significant these early signs were – just a gradual, chilling realisation that something was wrong.

Over time, such jargon became part of my daily vocabulary; the more complex a person's needs, the more jargon attaches itself to that person, like excess baggage. Jargon is discourse that tells us something about what (and how) these authorities think about people who depend on their competencies. It relates to the deficit model of disability, which conceptualises people with learning disabilities in terms of their associated conditions (Goodley, 2007) and is reinforced by the different identities and labels that they may acquire over time. Three decades ago the labels 'mentally handicapped' and 'retarded' were used to describe Chrissy. Since then she has acquired a host of others, including 'complex needs,' 'active but odd autism,' 'trunkal obesity,' 'moderate to severe learning disabilities and 'challenging behaviour.' However, despite the stigmatising implications of labels (Goffman, 1968), when Chrissy was a child I constructed that her impairments could be amended with a diagnosis, which (I perceived) would also dispel the ambiguity around her developmental potential.

When Chrissy was in hospital after developing seizures, I asked a paediatrician: "Is she going to be mentally handicapped?" "There's a possibility she could be retarded, yes," he replied briskly. Before I could ask him to elaborate, he turned on his heel and left to continue with his ward round. My bewilderment extended to Chrissy's seizures; it was only when I scoured the library for information on epilepsy that I learned they are usually self-limiting – no interventions were needed.

Furthermore, the associated non-physical features related to our child's condition are often not picked up (Bourke et al., 2014). When I saw our GP about Chrissy's behavioural outbursts that were so at odds with her 'other' charming, sweet-natured side, he wrote in his notes: "Mum says is miserable at home. Throughout this long consultation, Christina was happy and playing in the room. Looks well. Further reassurance" (Gregory, 2000, p. 14).

My feelings of frustration at not being listened to and confusion over ambiguous answers persisted throughout early communications with healthcare professionals. Now I can understand their 'wait and see' approach. What if they got it wrong?

My search for answers kept hope alive but it contained disempowering elements for Chrissy because it focused my gaze on her impairments instead of her qualities and strengths. I constructed a 'warrior mum' identity (Daly, 2014), which may have been my way of expressing grief over the loss of my "dreamed-of infant" (Bristor, 1984, p. 25). My grief was not so much from having a child with a learning disability but the suffering and difficulties that Chrissy experienced as a result of it.

I perceived that Chrissy's lack of a medical label was unusual and that other mothers I met knew what had caused their child or children's disabilities. Furthermore, while I recognised the wide disparity between abilities and characteristics of children whose learning disabilities originated from an identifiable cause, I envied parents who could join support groups specific to their child's condition and constructed that they would feel less isolated due to a sense of belonging and solidarity with other parents. Giving a name to your child's condition may also give an indication of how your child may develop and help you to explain to others what is wrong (Gregory, 2000). I felt like an imposter. I did not feel as if I fitted in with mums who had typically developing children either. Although until Chrissy was around six years old, she did not 'look' disabled, only younger than her years, all her developmental milestones were delayed, particularly her language development.

Around 40 per cent of all disabled children have no diagnosis for their condition (Smellie and Gregory, 2012). However, the diagnosis of a genetic condition has relevance for the wider family and it is natural to want to know the cause of your child's disability (Menday, Partridge and Shelley, 1997). Grief starts from the moment of diagnosis (Greene, Neal, Newey, Wraith and Vellodi, 1992) and, without a diagnosis, you can feel in limbo, trying to come to terms with what is happening and unsure about what the future holds for your child and the rest of the family. Parents often worry that their child will be deprived of appropriate services because they have no medical label.

The identity deficiency construct that I attributed to the absence of a diagnosis resulted in me feeling 'blamed' by others (professionals, family and other parents) for Chrissy's behavioural difficulties, which included unpredictable behavioural 'meltdowns' that could last up to two hours at a time. Galvin, Bylund and Brommel (2004) describe a sibling's account of his brother's school teachers attributing his genetically inherited hyperactive behaviour to his parents' discipline style. This highlights a limitation with systems theory, which tends to overlook individual issues, such as the biological components of problem behaviours, and attribute them instead to troubled family relationships (Broderick, 1993; McCroskey and Meezan, 1997). However, theorists argue that systemic approaches can be aided by individual approaches that recognise such underlying neurobiological traits (Beatty, McCroskey, and Heisel, 1998). The power/knowledge promise that lies behind the practice of medical classification confers identity and provides legitimacy for the challenges that Chrissy's behaviour presented with (Foucault, 1965; Gregory 2000). The parents' relief when a diagnosis confirms that their concerns were not unfounded is also a finding in Bourke et al.'s (2014) study.

At one point during my journey I sank into depression. I was divorcing my children's father and my own father was diagnosed with premature Alzheimer's disease at the age of 50; for a time, my extended family and I were too depleted by our own challenges to offer each other much support.

Families do not exist in a vacuum or as individual components; they are part of a wider context of interconnections, or an ecosystem, that influences their life course (Galvin, Dickson and Marrow, 2006; Yerby, 1995). When Chrissy was a child we experienced failings in the older models of family support which only considered component parts in isolation from the family system as a whole, for example, the need for respite care so the rest of the family could have a break with no consideration given to offering positive behavioural support to help with the challenging behaviour that had brought the family to breaking point. From a systems perspective, "decontexted individuals do not exist" (Minuchin, 1984, p. 2). In McGill, Papachristoforou and Cooper's (2006) study, respite services are rated as the most helpful forms of support for families with a member who has behaviour that challenges services but, as Chrissy grew bigger and it proved more difficult to cope (Kenny and McGilloway, 2007), her respite allocation shrank. The number of hours I received to help me at home with Chrissy during school holidays were halved when we moved to another county; the council said they did not have a big enough purse. It was not my first experience of the postcode lottery of care (Watson, Townsley and Abbott, 2002).

I strived to make everything look good on the outside but it got harder to take Chrissy out in public as she grew, which took the spontaneity out of family life. Outings and simple shopping trips often ended in chaos. People's stares were the least of my worries – I got used to it. Chrissy's two siblings were forced to grow up more quickly than their peers because I expected them to make allowances for her. Being younger, they saw odd behaviours and extremes of emotions that they could not understand. It scared them and, as they grew older, they resented her, and were embarrassed and bewildered by her behaviour.

During my two subsequent pregnancies I had no concerns about having another baby like Chrissy because there was no suggestion of a genetic cause to Chrissy's disability. At the time. I attributed Chrissy's difficulties to my protracted labour, although the birth itself was relatively uncomplicated.

Both children quickly caught up with Chrissy in terms of size and development. I was in awe of what babies do naturally. When Chrissy was four and her brother, Jamie, was two, they were frequently mistaken for twins. Many people were amazed when I said that there were 19 months between them.

After Chrissy was diagnosed with a rare chromosome disorder when she was 22 years old, then with autism a year later, I felt guilty that I had responded to her difficult behaviours similarly to those of her siblings - as naughtiness. The altering of parenting strategies after a diagnosis – how they treat some behaviours differently because they know it is not just their child being naughty is another story that emerged from Bourke et al.'s (2014) study. I wondered if I would have enjoyed Chrissy more when she was little had I known that she had learning disabilities, autism and a rare chromosome disorder. "Individuals make sense of their experiences through reflecting on their specific circumstances and in line with the expectations through prevailing cultural norms" (Furedi, 2007, p. 237). If I had expected less perhaps I would not have pushed so hard to influence the progression of Chrissy's development to fit her into my idealised constructions of family life.

I first explored the possibility of Chrissy having autism with her paediatrician when she was eight years old. He said: "She doesn't have autism - she's verbal and autistic children can't speak." Two years later, I queried it again and was informed that there was "no evidence of autistic features in her social communication and interactions."

Chrissy received an autism diagnosis from a clinical psychologist in her Community Learning Disability Team, which was confirmed by Lorna Wing at the National Autistic Society. Her autism was categorised as 'active but odd' (Bonde, 2000). Three years later, a consultant psychiatrist from the Maudsley Hospital used what he described as "the gold-standard test for the developmental features of autism spectrum disorder" and confirmed that Chrissy had 'childhood autism' (Schopler, Van Bourgondien, Wellman and Love, 2010).

Chrissy is unable to describe her experience of autism first-hand but Hughes (2012), an autoethnographer with Asperger's Syndrome, allows us to gain an insight of what it is like to live with its lifelong effects. His exploration of his 'Asperger's Self' includes examples of his confusion around communication 'rules' in social situations and how he viewed the syndrome as "an annoying person that never leaves you alone" (p. 96).

Views of the nature of autism have evolved and changed since Kanner (1943) published his first description of a unique and specific autism spectrum syndrome that bears his name (Wing, 1988). Over the past six years there has been a rise of an estimated 78 % in the rates of autism diagnoses. Greater awareness (including the heightened influence and availability of the internet) and improved screening and detection may partly explain this finding. However, whether there has also been a true increase in the incidence of autism is unknown (Baron-Cohen et al., 2009; Dawson, 2013; Pellicano, Dinsmore and Charman, 2014; Lilienfeld, Marshall, Todd and Shane, 2014), not least due to limitations of epidemiological research. For example, both Pellicano et al. (2014) and Baron-Cohen et al. (2009) recognise that their methodologies made it difficult to generalise findings to the wider community of people with autism. I attributed Chrissy's late diagnosis of autism to changes in the diagnostic criteria (Wing and Potter, 2002).

After years of searching, I had resigned myself to never discovering a cause for Chrissy's difficulties. Indeed, writing my book (Gregory, 2000) had helped me to value Chrissy's uniqueness and made her feel even more special to me. Her genetic diagnosis came via a letter from the Genetics Unit of one of the world's leading children's hospitals, Great Ormond Street in London, stating that they believed Chrissy's problems were caused by a de novo (not hereditary) microdeletion of chromosome sub-band 1q21.1. Findings from a research project we had taken part in while she had been a patient there had belatedly yielded results via new genetic testing technology. I was excited about the possibility of finding answers and relieved that there was no change in the recurrence risks. However, Chrissy's microdeletion has such variable effects that no prenatal genetic tests could have predicted the severity of her problems; they only became increasingly apparent as she grew older.

A medical label conferred in adulthood would only have made a significant difference in Chrissy's life if it had indicated a predisposition to a serious health problem that could be treated or prevented by early intervention. The research findings did lead to Chrissy having ultrasound scans to check for heart and kidney abnormalities on the advice of her geneticist; the results were normal. The findings made a difference to my life in terms of getting in touch with other parents to share experiences. I have met other families whose children have rare chromosome disorders through the support group, Unique (www.rarechromo.org) (Gregory, 2012; Gregory 2013). Unique put me in touch with other families worldwide whose children had the same genetic condition as Chrissy. We share information and take part in research projects whose aims are to broaden existing knowledge about this newly identified rare chromosome disorder, and I set up the Facebook group, '1q21.1 microdeletions and microduplications.' My story about our genetic breakthrough ran in the Daily Mail newspaper on Boxing Day 2006. Furthermore,

10 years after my book was published (Gregory, 2000), I was able to reflect on ways in which my view of our experiences had changed. My 'Parent's Perspective' was the opening chapter in a medical journal (Knight, 2010) and I started blogging about life with Chrissy http://jgregorysharingsstories.blogspot.co.uk/

Discovering the cause of Chrissy's problems gave me closure after all the years of wondering. It also helps me to tell people that she has a rare chromosome disorder – and what that means for her; 1q21.1 microdeletion is linked to neuro-psychiatric problems, which, added to her autism diagnosis, helps to explain why her behavioural challenges remain so resistant to interventions. Now, we have a better idea of what we are dealing with, it may ultimately help us to understand her complex needs better and more information may emerge as research on 1q21.1 microdeletion progresses. However, discovering the cause of Chrissy's difficulties so late in her life is not as important to me now as it would have been in the early years when support was scarce and I had fought to get health professionals to even acknowledge Chrissy had a learning disability.

> *"Leave off that excessive desire of knowing; therein is found much distraction. There are many things the knowledge of which is of little or no profit to the soul." (Thomas à Kempis, 1842, p. 5).*

The findings that emerge from this theme demonstrate the importance of good quality medical, psychological and social support that places the person with learning disabilities and their family at the centre of decision-making. Moreover, increased detection of rare genetic disorders improves the possibilities of diagnosing previously unexplained causes of learning disability (Firth and Wright, 2011). These findings suggest the theme requires further exploration and a more in-depth examination in studies with an appropriate sample of parents.

Chasing new ‘fixes’

The theme of chasing ‘fixes’ for Chrissy’s impairments emerges from the previous theme of the ‘journey’ in terms of always looking for new ways to help your child. A parent’s experience of always looking out for something she could do to help her child is another one that is referred to in Bourke et al.’s (2014) study.

Examples of new ‘fixes’ that drew my attention were the gluten-free and casein-free diet, which held the promise of fixing my child ‘naturally’ without toxic drug treatments. I also wasted time researching treatments including vitamin therapies, special diets and environmental medicine in the hope that it might help her but, as Chrissy has a history of adverse reactions to several mainstream medications, I feared alternative therapies could cause more harm than good.

A third of parents of autistic children have tried unproven alternative treatments in their search for a cure and one in nine has used what medical experts class as a potentially harmful approach (Levy, Mandell, Merhar, Ittenbach and Pinto-Martin, 2003; Gregory, 2010), i.e., chelation therapy - injections intended to purge the blood of heavy metals, a treatment which resulted in the death of a five-year old boy with autism, Abubakar Nadama from Somerset in 2005 (Calman, 2008). It is easy to get sucked into the huge autism industry that feeds on families like ours, and seductive fad autism treatments and psueudoscience can give parents false hope (Lilienfeld et al., 2014).

I often felt guilty that I wasn't doing enough to help Chrissy, and badgered her doctors to review her medication. A medication overhaul that Chrissy received in hospital when she was 14 years old transformed her behaviour and her quality of life. However, a decade later, life-threatening side-effects that affected Chrissy’s blood-platelet count prompted further medication changes, which resulted in her psychiatrist prescribing antipsychotics. The side-effects from antipsychotics included drooling stupors that stripped away Chrissy’s personality, a worsening of her behaviour and epilepsy, and acute dystonia. Her psychiatrist told me that the side-effects I listed were just ‘Chrissy.’ I disagreed and reported that Chrissy had suffered from similar side-effects when antipsychotics were prescribed during her early teens. Nevertheless, he defended the ‘newer,’ ‘safer’ antipsychotics Chrissy was taking.

For the next five years, Chrissy’s epilepsy and behavioural ‘meltdowns’ deteriorated to such a point that her quality of life was non-existent and she was forced out of two group homes within a year. She was denied the psychological support that her psychiatrist had referred her for due to a complex five-year funding dispute involving National Health Service (NHS) Continuing Healthcare and three local authorities – until I approached the local press with the story. Not only was the ‘ordinary residence’ issue being disputed (Gregory, 2012; Faulkner, 2011) but also whether Chrissy’s behaviour was of a ‘nature, complexity, intensity and unpredictability’ that warranted a primary health need (Gregory, 2013).

Atkin (2010) describes the complexities involved in reaching agreement on eligibility criteria for continuing healthcare funding for people with learning disabilities. The NHS continuing healthcare stakeholders vacillated between constructing ludicrous counter

arguments (i.e., that Chrissy's behaviour was predictably unpredictable) or simply ignoring my communications. I never knew where I was with them. Behind the premise of 'not us!' each party (who professed to be caring) constructed knowledge claims about Chrissy based on their own self-serving agendas. Chrissy was discussed as a financial burden that the Primary Care Trusts wanted to unload. A disabled person had become a battle ground for their egos and vested interests; they each took opposing 'taken for granted' positions; the NHS continuing healthcare fundholders polemicised 'the problem' from the social model (broken society) of disability (Oliver, 1986) and the local authority polemicised it from the medical model (broken person) (Shildrick and Price, 1996). Both these models have disempowering implications for practice because they seek to explain disability universally in a way that excludes its complexity and the important dimensions of disabled people's lives (Corker and Shakespeare, 2002). Moreover they do not take into account the needs of the individual, as described in Valuing People (Department of Health, 2001 and 2009).

These events raised concerns about the extent to which our practices promote the status quo rather than seeking to promote social justice (Nunkoosing, 2000). They fit with the materialist world view that the professional is exonerated from responsibility if an individual with learning disabilities fails to engage with, or live up to, professionally determined strategies (Oliver, 1999) and that the professionals only view behaviour positively if it fits with their perceptions of reality (Oliver and Barnes, 1993).

I was desperate for Chrissy to be safe and constructed that the life-transforming 'fix' from the two-week hospital stay during her teens could be replicated by her incarceration in an assessment and treatment unit (ATU). To an extent it was - except it took four years longer to achieve. ATUs may be run privately or by the National Health Service (NHS) and provide interventions in a therapeutic environment for people who have a learning disability and behaviours that are deemed too challenging to be assessed and treated safely in community based settings.

Chrissy was eventually assessed as needing an emergency admission to hospital but, in order to disentangle the bureaucratic web of different agencies and their respective responsibilities, we had to find a suitable ATU ourselves and engage a solicitor to secure her admission.

The ATU was happy to sell me a dream, just as Chrissy's previous group homes had, but then I was willingly seeking this dream - that professionals there would work together to sort out her medication. However, like many other 'fixes' that I chased, it came with its own set of problems. The ATU was neither person-centred nor family-centred (Law, Hanna, King et al., 2003), nor did it facilitate inclusion (Department of Health, 2001 and 2009; Mencap, 2014). People with learning disabilities and challenging behaviour are frequently treated out of area (Vaughan, Pullen and Kelly, 2000; Vaughan, 1999; Kearns, 2001; Reed, Russel, Kiriakos et al., 2004). Moreover, the ATU employed disempowering practices typical of total institutions (Goffman, 1968), such as restrictive, undifferentiated environments aimed at containing those who presented with the greatest risk. Individual needs are not taken into consideration in ATUs. Chrissy was on a locked ward and had to use plastic cutlery despite the fact that she was not sectioned, is not an 'escaper' and uses metal cutlery safely. Some rituals, like eating, have to be 'just so' in Chrissy's world, and such general service-led issues intensified and triggered her challenging behaviours (Gregory, 2011). Furthermore, Chrissy received unexplained bruising on her neck there, which prompted a safeguarding investigation. As a result the ATU came under scrutiny. However, Chrissy's injuries were eventually attributed to self-injurious behaviour.

A year after Chrissy left, the ATU came under fire in the press for failing all the standards set by the Care Quality Commission, including the one to prevent abuse (Care Quality Commission, 2012).

However, despite its problems, the ATU, paradoxically, empowered Chrissy by removing the disempowering funding agendas and professional vested interests that had been in place (Nunkoosing, 2000). The taken-for-granted knowledge that professionals had constructed about Chrissy during the years preceding her incarceration had maintained their professional dominance (Foucault, 1965) but now this was being challenged by another group of professionals. The knowledge gained in an institution enabled Chrissy by informing a discharge plan that provided indisputable evidence of her complex support needs, unclouded by funding agendas.

Undercover filming in a BBC 'Panorama' television programme revealed a pattern of abuse at an independent hospital called 'Winterbourne View.:

> *"I watched the programme through my hands in some parts, and switched off in tears when it panned in on a vulnerable young woman left shivering outside on the ground after being repeatedly doused in cold water by her so-called 'carers'" (Mencap and the Challenging Behaviour Foundation, 2012, p. 19).*

In his article about what went wrong at Winterbourne View, Oakes (2012) tells men and women like Chrissy: "You are never to be beautiful and certainly must not become powerful" (p. 2). So what are our assumptions about this sub-group of people with intellectual disabilities that makes us want to contain them and pretend they do not exist, who not only look different to us but who also display behaviour that we may find repellent?

The answers may lie within wider studies about the appearance of disability in contemporary Western culture as 'trouble' (Michalko, 2009). We have a sense of what is a socially acceptable range of human variation, the process of 'norming' (Davis, 1995). Myers, Ager, Kerr and Myles (1998) question the notion of the 'normative' as a "desirable goal and a measure of achievement" (p. 5). Amado (1988) cited by Chappell (1992) states: "We try to fit people into existing structures, rather than evaluate what is wrong with a social system that does not accept someone as he or she is" (p. 10). We have expectations about what we, ourselves, and other human beings should look like and how we should act. Society's most disabled people, which includes people with profound and multiple disabilities, as well as those with learning disabilities and behaviour described as challenging, reflect extremes of that normative spectrum. I suggest that they are therefore more 'trouble' for us than other people with learning disabilities that 'play along,' who, Oakes says: "will always dance for the powerful ones."

As Winterbourne's legacy continued, Chrissy's experiences in an ATU were validated by media reports that uncovered the extent to which people with learning disabilities and behaviour described as challenging were being detained in these units (Woolf, 2014). Those with the most complex needs who require the most specialised services are at greater risk of experiencing crisis situations that result in admissions into ATUs (Mansell, 2006). Furthermore, the government's pledge to discharge people with learning disabilities who remained inappropriately in secure hospitals by 1 June 2014 was not honoured. The Winterbourne scandal shone a light on some of the practices that go on behind the locked doors of ATUs. These units are run as total institutions, similar to the long-stay hospitals that were closed during the 1980s, which was meant to herald a new era of social inclusion for people labelled as learning disabled. The resulting gap

in the market provided a lucrative business opportunity and a number of independent hospitals financed by private equity companies were set up. A report commissioned by NHS England (2014) calls to an end for the system where these independent hospitals are financially incentivised to keep patients in for as long as possible. However, despite levying charges of up to £3,000 a week per patient, basic standards of good practice are proving remarkably difficult to maintain in many of these services (Oakes, 2012). Another report commissioned by NHS England (2015) concerns the widespread inappropriate use of antipsychotics and other drug treatments used to treat mental illness that are prescribed so routinely for people with learning disabilities (Gregory, 2010). This report validates my arguments against the one-size-fits-all use of antipsychotics for individuals with learning disabilities.

The funding dispute continued while Chrissy was in the ATU, which made it difficult to move forward as no one would take responsibility for discharge planning. We engaged another solicitor - plundering the public purse to get Chrissy into an ATU as well as out of one.

Mencap and the Challenging Behaviour Foundation included Chrissy's story in their Out of Sight report (2012). They were interested in why she was stuck in an ATU and the claim by the Primary Care Trust, which was funding her incarceration 'without prejudice,' that there was no local provision which could meet her needs.

This theme reflects the personal tragedy approach to disabilities that had underpinned much of social policy and practice up until the 60s and 70s (Oliver, 1986). However, the 'fixes' that we seek as parents also need to be considered in terms of attempts to relieve our child's suffering rather than 'norming' (Davis, 1995). Parents want to do whatever they can to help their child. The ATU was Chrissy's best chance and sometimes that is all any of us have. The interventions and support Chrissy needed should have been available in her local community but they were not. From a family systems perspective, improvements resulting from the individual component 'fixes' I had chased were short-lived; wider networks of person-centred, interconnecting support offered something more robust and enduring that liberated her and her family.

Liberating possibilities of policy changes

The Government's personalisation agenda offers people with a learning disability and their families greater choice and control over their lives, which include more opportunities for community-based living. Chrissy had previously been denied these citizenship-promoting policy changes as she had been expected to fit in with the services that were available. However, she faced considerable barriers in taking advantage of the new policies. As well as the discharge planning delays, we were told that there was insufficient funding to staff the supported living service she needed and a lack of suitable housing.

I went to battle again, lobbying MPs and contacting learning disability charities. Due to experiences in my early life, I had developed a 'stand up for yourself or be crushed' approach to challenges, which undoubtedly helped me to advocate for Chrissy. While I am fortunate to have had so many opportunities to write about our experiences with Chrissy, where my writing has been most prolific has been in my never-ending struggles to find her good, safe, compassionate care. In 2010 Raising our sights (Department of Health) Mansell states that only by the efforts of their pioneering families, who had to overcome discrimination, prejudice, and low expectation, did we start to hear about how people with more complex and severe disabilities manage to make the most of the opportunities presented by the government's personalisation agenda. Policy makers and academics ignored people with more complex needs due to a lack of understanding about what can be achieved and to assumptions that they could not make decisions or live empowered lives (Mansell, 2010). Moreover, barriers that people with learning disabilities in general encounter, such as prejudice and difficulties with communication, are amplified in people with more complex needs.

Thanks to our campaigning efforts, stakeholders eventually shelved their funding differences long enough to act in Chrissy's best interests to plan her discharge. A person-centred plan (PCP), in all its rich, pictorial and anecdotal detail was developed to give Chrissy a 'voice' (Department of Health, 2009; Gregory, 2011). The PCP also informed decisions to be made in Chrissy's best interests that, due to the inter-related complexities of her mental and physical health, she needed to live on her own.

However, Chrissy's local area proved too expensive to be viable for the home ownership schemes that were left after Government cuts in benefits, grants and services, which Duffy (2013) suggests cost people with severe disabilities 19 times dearer than most other citizens. Government cuts have further reduced the already limited housing options of people with intellectual disabilities. Social housing via the local council was Chrissy's last hope; they eventually agreed, after further campaigning, spearheaded by her family, that someone who needed accessible housing to allow a discharge from hospital is counted as

having an exceptional housing need. In March 2014, Chrissy moved into social housing near her family, where she now lives alone with full-time support.

Moving into her own home has indeed allowed Chrissy more autonomy and self-determination. Furthermore, she receives important benefits from living alone in that, for the first time in her life, her support is completely personalised. She can have all her own things around her and any autism-related needs can be met, i.e., the need for her own space. Crucially, given her history of residential placement breakdowns, she has the long-term security of her own tenancy.

Our struggles to empower Chrissy to lead as settled a life as possible have been worthwhile. She now receives pro-active, personalised, collaborative and strength-based approaches that fit with the needs of her family (Gregory, 2014). My Jane-led, normalising agenda that had boxed me into bringing Chrissy home for weekly overnight stays so she could experience 'family life' changed after she moved into her own home. Instead of 'meeting her needs,' I take her out and enjoy her company for shorter spells, which each of us can tolerate more easily. Chrissy is now a right-sized part of my life. When she gets the right care and support, Chrissy can be a delight – funny, joyful and loving, with a great sense of the ridiculous.

Nevertheless, these changes were hard-won and could not have been achieved without the efforts of Chrissy's family. I had been in danger of taking the generalisations and normalising agenda (Redley, 2009) in Valuing People (Department of Health, 2001 and 2009) too literally. I felt they were politically-correct concepts (Jingree and Finlay, 2012), to socially construct a form of 'normalcy' for all people with learning disabilities based on universalist philosophies and that they minimise the brutal reality of having a learning disability for some people. However, I now recognise the liberating effects of citizenship-promoting policy changes.

Transformative validation

While the transformational outcomes of having Chrissy represented 'true' deep and lasting changes (Scorgie and Sobsey, 2000) in some areas of my life, I am not sure that I would describe them all as positive or inherently negative (Ferguson 2002; Goodley and Tregaskis 2006; Helff and Glidden 1998; Risdal and Singer 2004; Gregory, 2013). Some parents may ascribe greater benefits to having a disabled child as a coping mechanism but I suggest that causes of parent-reported benefits are not mutually exclusive; it is human nature to look for meaning and hope in difficult times.

Focusing on our blessings brightens our outlook on life, thereby achieving real and lasting positive outcomes. I believe that I have become a stronger and more compassionate person (McConnell et al., 2014) as a result of having a disabled child but any benefits that I perceive to have gained could equally be attributed to having a child without learning disabilities, or be ascribed to other non-related challenges. However, as Folkman (2008) suggests, in terms of stress-processing, it makes no difference if reported benefits are real or imagined. With regard to the wider family, while I would recognise some benefits over time, i.e., my youngest daughter, Alex's, career path as a trainee Educational Psychologist in autism education and acceptance on a doctorate course, Alex may have made equally gratifying choices if Chrissy had not been disabled.

Moreover, I can only report the benefits of having Chrissy, not just 'any' disabled child. There is a huge disparity between disabled children and generalising about positive or negative impacts, even by using variables, is limited by the variables used and the study's focus (McConnell et al., 2015). Furthermore, most learning disability research focuses on mothers.

Families are made up of interpersonal subsystems and each subsystem needs to be considered if we are to understand the functioning of the whole. Chrissy's step-father, Ian, belongs to an even more neglected group in learning disability research than biological fathers who live within the family home (Gavidia-Payne and Stoneman, 1997; Carpenter and Towers, 2008; Towers and Swift, 2006). Siblings are neglected by researchers too, and their experiences tend to emerge via their parents (Grant, 2015; Hames, 2008; Knott, Lewis and Williams, 2007). However, siblings were quoted in a paper by Sykes (2010), one sibling blogged about her experiences (Gregory, 2012) and Jones's (2014) autoethnography is a sibling's investigation of disability. The experiences of grandparents are only now emerging in the research (Miller, Buys and Woodbridge, 2011). Furthermore, much research on families tends to focus on those who have younger children; i.e., Willingham-Storr's (2014) study about the life-transforming benefits of

parenting a child with an intellectual disability only includes families who have a disabled member aged under twenty years. Voices from families who have an older member with an intellectual disability demonstrate that the need for professional support does not diminish over time (Suelzle and Keenan, 1981) and McConnell et al. (2014) suggest that new parent-carers would benefit from meeting and learning from experienced parent-carers about the positive impact their disabled child has had on their lives.

Notwithstanding the childcare challenges of Chrissy's early years, later on in my life having a disabled child opened up exciting career opportunities. As a journalist, I covered a range of subjects but gravitated towards investigating the experiences of other mums who had fought to get effective support for their child with learning disabilities, and women's struggles in life generally, particularly those who had been misunderstood or defied convention in some way. My personal growth from young, disempowered mum of a disabled child to acceptance into the world of academe can be tracked through my public narratives about life with Chrissy. However, when I embarked on the MSc course, I felt like an imposter again, as I had nearly three decades before around the other mums who all seemed to have a legitimate reason for their child's learning disabilities – comparing myself on the inside with my own construct of how others appeared on the outside? Most academics (and journalists), I believed, had entered higher education after leaving school. My taken-for-granted assumptions about higher education were that it was beyond my reach – especially as I reached my fifties. When I told a friend about this MSc (The Applied Psychology of Intellectual Disabilities at Portsmouth University) she encouraged me to apply based on my life experiences. "How can I?" I asked. "I don't even have A-levels." When I was accepted on the course, I asked my soon-to-be tutor: "Don't I need to write an essay to prove I'm up to it?" "No," he said. "You've written a book!"

Further education has validated my experiences with Chrissy and empowered me. I now have a different voice than the one I had in my professional writing career. My Project Supervisor replied to an email I sent as I worked on this study:

"Jane – I note with glee that you are acquiring the language of ethnography, e.g. 'cultural situatedness.' I love it!"

As a method for creating disability and family scholarship, autoethnography overcomes obstacles, such as the tendency to generalise the experience of disability, which impede other sociocultural explorations; the experiences of families who have a member with an intellectual disability are influenced by multiple factors, such as the type of disability, ethnicity, age and family structure. Furthermore, a wealth of narrative data can be drawn from the letters that parents receive from professionals which document our child's deficits.

My advice to other novice autoethnographers is to explore the autoethnography literature to see how each different researcher approaches it. Resist the urge to rant, name and shame or indulge in any narcissistic gut-spilling (or do it for catharsis then edit ruthlessly); consider instead the cultural situatedness of each story. Do not get distracted into the story itself but do show off your own messy humanness if it produces a relevant finding. In terms of transformative validation, the autographical process of exploring and reframing past experiences can be painful but the learning and growth that ensues is worth it. Allowing yourself to be interviewed will introduce another person's perspective into the research process, which expands on its possibilities.

The findings in this study demonstrate that people with learning disabilities can grow and change, and that emancipating possibilities from Government policy changes do exist

and it is possible to overcome the barriers. Chrissy was constructed as 'trouble' (Michalko, 2009) because she had failed to adjust to prevailing disabling practices. However, she has demonstrated that she can lead a settled life now that she is getting the right support, which liberates me to move on with my own life with greater tranquillity. No more fears about 'what next?' It is about getting the best out of how Chrissy is now. Moreover, many of my fears common to parents of disabled children about 'what happens when I'm gone?' have now been allayed.

The autoethnographical approach has allowed a move beyond personal experience to provide a contextual exploration of the wider factors that affect the experiences of parents of children with intellectual disabilities. Therefore, the findings have the potential to add to existing theoretical knowledge about the experiences of such parents and their families. The themes that have emerged may be expanded on in future learning disability studies and they put the experiences of families who have a member with learning disabilities, including those with complex needs and behaviour that professionals label 'challenging,' at the heart of family and disability research.

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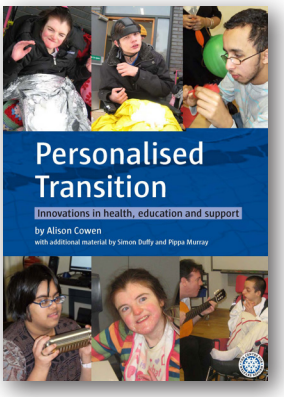

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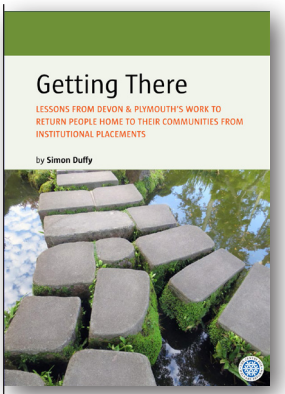

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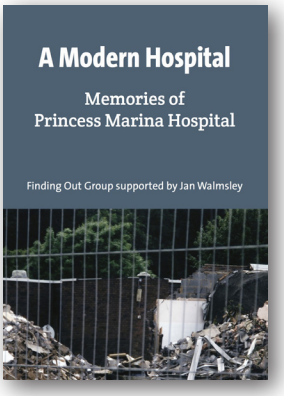

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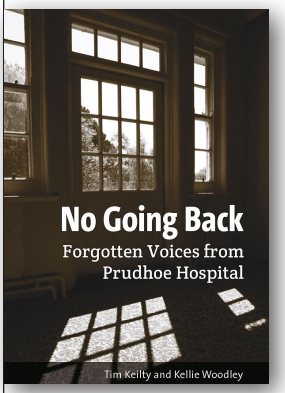

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