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**'Well the future, that is difficult': An Interpretative  
phenomenological analysis exploring the maternal experience of  
parenting a young adult with a developmental disability**

## **Mothers of young adults with Dev. Disabilities-IPA**

**Background:** The predominant focus of extant literature exploring maternal experience of developmental disability is stress, adaptation, efficacy of interventions and the burden of care. Most studies involve mothers of children, with scant attention given to what life is like later in the life course. This study qualitatively explores the experience of mothers of young adults (aged 19-28 years).

**Materials and methods:** Semi-structured interviews conducted with six women aged 48 to 60 years were transcribed and analysed using interpretative phenomenological analysis.

**Results:** Three themes illustrate how mothers are confronted with their adult children's continuing need for support and how a lack of trust in social care creates anxiety about the future, increasing awareness of mortality.

**Conclusion:** Vulnerability represents a useful concept for understanding these findings theoretically. Galvin and Todres' (2013) conceptual framework for the humanisation of care provides the opportunity to prioritise the needs of individuals by highlighting dimensions of existence which confer meaning.

**Keywords:** Mothers, Young Adults, Developmental Disabilities, IPA

## **Introduction**

The predominant focus of extant literature exploring maternal experience of developmental disability is stress, adaptation, efficacy of interventions and the burden of care. Researchers have largely studied mothers of children as opposed to mothers of young adults who continue to require considerable parental involvement; as a result there is a gap in our understanding of what life is like later in the life course. Normative development generally entails young adults gradually assuming independence (Arnett, 2007) whereas the commitment made by mothers of adults with disabilities often exceeds the typical maternal experience in terms of intensity, complexity, and its temporal unfolding (Burkhard, 2013). Jennings (1987) referred to this cohort as 'perpetual parents', a group who, in contravention of the typical life span trajectory, continue to be intimately involved in ensuring offspring's needs are met.

In a longitudinal study Seltzer, Floyd, Song, Greenberg and Hong (2011) found that 57% of parents of individuals with intellectual and developmental disabilities had co-residing adult children compared to 16% of the comparison sample while Pedrovska (2009) demonstrated poorer well-being for parents, particularly mothers, when adult children continue to live at home. This may relate to the fact that planning for the future of adult children with intellectual disabilities represents a pervasive concern for parents, a factor

attributed to the complexity of the process given the multiple variables influencing each family's situation.

Magill-Evans, Darrah and Galambos. (2011) employed mixed methods in a longitudinal study investigating the parental journey of 21 mothers of young adults with cerebral palsy. Qualitative analysis found that 15 mothers reported challenges to physical and/or emotional health in response to parenting demands. However the majority also believed their experience had positively influenced their views of themselves, disability and life in general. Smith et al. (2010) conducted a diary study of the daily experiences of 96 mothers who co-resided with their offspring (aged 17 to 53 years) with Autistic Spectrum Disorders. The results of their statistical analysis reveals a complex picture of the maternal experience characterised by both positive and negative aspects. Although mothers in the experimental group experienced more stressful events than the control there was no difference in terms of the number of days on which they had positive interactions or participated in volunteer work. This finding garners further support from Burkhard (2013) who adopted a phenomenological approach to explore the lived experience of 11 mothers caring for adolescents or young adults (aged 14 to 22 years) with severe cerebral palsy. Thematic analysis identified the experience had had a profound impact on participants' lives which were comprised of sorrows, joys and challenges.

Green (2007) employed mixed methods collecting survey and interview data. She argued that the tendency to focus on the emotional burden of having a child with a disability as opposed to examining the impact of society's negative attitudes towards disability and the impact of inadequate support has failed to recognise parental experience of benefits. She claimed that the majority of research has emphasised Subjective Burden (emotional distress), failing to fully acknowledge the Objective Burden (socio-structural constraints) as well as any benefits. Post hoc analysis of survey and interview data found participants' lives to be more emotionally complex than existing findings suggest. Green believes the results demonstrate the need for more *nuanced* research examining the burden of care-giving as well as an exploration of the benefits mothers derive from a lifetime of loving and living with their children with disabilities.

It is apparent that there is a gap in our understanding of what it is like to be the mother of a young adult with a developmental disability. The broad aim of the study is to explore this phenomenon using a qualitative method, Interpretative Phenomenological Analysis (IPA). IPA provides the opportunity to focus on how mothers experience and ascribe meaning to parenting these young adult and begin to address an existing gap by providing a rich, nuanced and contextual account. In this paper we focus on one aspect of the overall findings which was particularly salient for the participants, namely maternal conceptions of adult children's future with an emphasis on the provision of care. In this paper we aim to

explicate this from the mothers' unique frame of reference and to discuss the implications for all interested parties including service providers.

## **Materials and methods**

### Methodology

IPA is an interpretative phenomenological method with a commitment to examining how people make sense of *their* experiences (Smith, Flowers and Larkin, 2009). IPA typically employs small participant groups who share experience of a particular phenomenon and aims to elucidate shared patterns of meaning. Fundamentally phenomenology aims to study 'human experience carefully and systematically and to express insights arising out of such study in language that does justice to these experiences' (Halling, 2008, p.3). IPA acknowledges that analysis is an interpretative endeavour and that researchers can never fully put their pre-suppositions out of play. We are interpreting beings and Smith et al. (2009) invoke a 'double hermeneutic' whereby the researcher is attempting to make sense of the participant making sense of different aspects of their experience, for example mothers' understanding of their response to adult children's vulnerability . IPA's idiographic commitment means that researchers privilege the experience of individuals in the context of their lives necessitating small numbers of participants and intensive analytic work.

## Participants

Six white British women, aged 45 to 60 years (see below) were interviewed by the first author. Criteria for inclusion stipulated that each was the mother of a young adult, aged 19 to 28 years, with a diagnosis of a developmental disability. All but one, who is in a long-term relationship, remains married to the father of their children. Participants had at least one other typically developing adult child. Ethical approval was granted by the Ethics Committee of the Department of Psychological Sciences, Birkbeck, University of London. The women were given pseudonyms.

A pilot interview was carried out with a mother known to the first author. The resultant data was not included in this study. The participant provided contact details for a mother she had met through a support group and an interview was arranged. Thereafter snowball sampling was employed allowing for recruitment of a homogenous sample in order to represent a *particular perspective* as opposed to a population (Smith et al., 2009). Below are vignettes for the participants whose data is reported here:

**Mary and Megan:** Mary is 48 years old and has been married to John, 49 years old, for 30 years. Mary works for social services and John is a business manager. They live in a small village in the south of England and recently bought and adapted a large detached house to provide separate accommodation for their daughter Megan and a carer. Megan, 24 years old, has cerebral palsy, is a wheelchair user



and currently receives 24 hour care. Megan's sisters, Helen 28 years old and Maddy 25 years old, have left home.

**Anna and Henry:** Anna is 58 years old and has been married to Mark, 49 years old, for 22 years. They live in a small town in the south of England. Anna retired from social work two years ago and Mark is an engineer. Their son Henry has autism, is 22 years old and lives at home. Henry recently finished college and is awaiting assignment to a part-time job. Anna has a daughter from her first marriage. Phoebe is 28 years old and has left home.

**Jan and Livvy:** Jan and her husband Jeff are 60 years old and the couple are both retired business consultants. They have been married for 32 years and have three daughters. Livvy is 28 years old and has low- functioning autism. She lives in a residential care home in the same London borough as her parents. Rachel, 29 years old, and Lucy, 26 years old, are both married and have their own homes.

### **Data collection**

Participants were interviewed in their own homes with interviews lasting between 1 hour and 2 hours and 49 minutes. Interviews took place between June and October of 2012. IPA advocates the use of semi-structured interviews, asking open-ended questions as a means of accessing an individual's sense-making in relation to a given phenomenon. Questions included 'Just start by telling me about Henry?', 'Tell me about a typical day?', 'Tell me about your experience of support?', 'What are the best things about being

Henry's mum?', 'What are the most challenging things?', 'How does the experience compare to parenting your other child/children?', 'What have you learnt from the experience that you wouldn't otherwise have known?' and 'How do you see the future?' The interview schedule acted as a framework allowing the researcher to seek clarification where necessary, providing the opportunity to explore facets of experience introduced by participants. Interviews were recorded on a digital recorder and transcribed verbatim.

### **Analysis**

In line with IPA's idiographic focus each transcript was analysed individually. The process started with the first researcher reading each interview while concurrently listening to the recording. This facilitated immersion in the data such that the participant became the focus of analysis. During a second exploratory reading, initial notes were made and anything of interest recorded. Next analysis moved to a more abstract and conceptual level. Conceptual coding is more interpretative and demands a shift in focus. This involves moving beyond narrative and descriptive comments and thinking about how the participant is experiencing the phenomenon psychologically and the meaning ascribed to it. Given IPA's commitment to preserving the integrity of the participant's account, the process is necessarily iterative; a synergistic process of description and interpretation. Data were reduced as conceptual codes were clustered into themes and given descriptive labels, capturing initial conceptions of meaning. This was a cerebral and

iterative process demanding sustained effort to ensure that findings adequately represented participants' experiences. The researchers' voices were foregrounded as together we explored the abstract and conceptual meanings disclosed through the analysis while continually checking that they were grounded in the data. Once transcripts had been analysed individually and their themes, with supporting extracts entered into a table, data for the participant group were considered as a whole. Again IPA's epistemological commitment meant that similarities and connections were explored as shared features of the experience were identified whilst the researchers endeavoured to retain and account for the nuance, complexity and texture of individual experience.

### **Reflexivity**

IPA advocates combining "a hermeneutics of empathy with a hermeneutics of 'questioning'" (Smith et al., 2009, p.36). The first author conducted the interviews and took the lead with data analysis. Both authors are mothers of adult children who do not have a developmental disability. Our experience does not mirror that of our participants, but as mothers we are able to identify with many of the thoughts and feelings expressed. Also, both authors have friends with adult children with a developmental disability and at the outset of the study we assumed that we had some degree of insight about what our participants might say. However our understanding was challenged by, among other things, their honesty and the level of anxiety they experienced. It was only in having our

preconceptions made apparent that we became more aware of what they were. We were able to look at the data anew, questioning our prior assumptions in an attempt to ensure that our interpretations were grounded in the participants' accounts.

## **Results**

Analysis of the complete data set identified four inter-related master themes capturing participants' experiences (see Table 1). The first theme encompasses issues relating to participants' overwhelming need to protect their adult children and the way in which the relationship was symbiotic such that participants' affective state reflected that of their daughter/son. The second theme encompasses issues relating to parenting typically developing children including balancing their needs against those of the child with a disability, the way in which typically developing children's development serves as a constant reminder of the limitations conferred by disability and consideration of the contribution they will make to future care, particularly the tension between burden and the need for someone who genuinely *cares* to be involved. The third theme relates to conceptions of social care which are viewed as largely obstructive and inadequate such that participants mistrust care providers feeling that they fail to deliver holistic care. Mothers respond to this lack of trust by maintaining a state of vigilance and they are anxious about a future when they will no longer be able to intervene. The fourth theme illustrates how all of the mothers felt they had been transformed by their experience. The majority

believed they had developed an enhanced propensity for compassion and understanding. Further, 'vulnerability' was established as an over-arching theme which permeated all others. Young adults were perceived as vulnerable to abuse as well as exclusion from many of the opportunities their typically developing siblings had available to them. Intimate experience of vulnerability affected participants' world view with most feeling they had developed greater empathy and compassion.

As a result of the inductive, participant- led approach adopted for this study we garnered a large volume of data relating to various aspects of the maternal experience as outlined above. One area of particular concern relates to adult children's vulnerability, an ongoing need for support and the options available to families in terms of care provision. Given the import of this phenomenon to participants, in this paper we have elected to provide a contextual and nuanced account of three mothers, Anna, Mary and Jan who have each chosen different options for their adult child's living arrangements (reporting of the remaining data set is in preparation). Anna's son continues to live at home. Mary's daughter lives in a self-contained annexe of the family home and Jan's daughter lives in a residential care home. The three participants whose experiences are not reported here have sons who also live in residential provisions. We could equally have elected to include an account of their experiences. However we chose to report analysis

of Jan's interview because she has the most experience of residential provision.

This approach affords the opportunity to detail experience illustrating its shared patterns of meaning at the same time as retaining depth and an idiographic focus. To achieve this we report three inter-related sub-themes from two of the master themes; *'Something inherent that you want to protect'*: overwhelming protective instinct; *'We are very watchful'*: vigilance in response to mistrust and *'What on earth will happen to Henry?'* Facing an uncertain future. Together they provide an illustration of how, in different circumstances, mothers' compulsion to protect their adult children affects their experience of social care in light of the ongoing need for support. Young adults are perceived as vulnerable and participants typically invoke a narrative of mistrust in relation to care, either as a result of personal experience or the experience of others as portrayed in the media with the result that they are ambivalent about relinquishing control. Acknowledging that this need will continue beyond their own lives throws participants' mortality into sharp relief and they are increasingly anxious about their offspring's future. These factors combine to create a situation which is not easily negotiated and uncertainty is a feature of participants' lives as they have no way of knowing how much longer they will be able to maintain their current level of involvement.

## **Themes**

**The three sub-themes as they relate to the participants;**

***‘Something inherent that you want to protect’: overwhelming protective instinct***

Societal conceptions of disability make adjusting to the birth of a disabled child more difficult than necessary. Having a disabled child ‘is one of the most dreaded experiences a family can encounter’ (Gill, 1991, p.624) and society’s values and beliefs are mirrored in the words and behaviours of friends, family and professionals’. Given that wider society considers the birth of a disabled child a tragedy, the revelation that mothers experience intense feelings of love for their children may challenge popular conception. Mary infers this when she says:

*I think somebody did say something to me once it was just after Megan was diagnosed and she actually had a 50 year old son with Down’s syndrome, and she said ‘When you have a child with a disability or special needs, it’s not that you won’t love them, it’s that you’ll love them too much.’ She said ‘It’s so hard.’ And she never actually did manage to cut the strings really and then he was quite bereft when she died. But it’s **true** ...*

Experience has taught Mary that this assertion is true.

Overwhelming maternal love compels her to continue to protect Megan and she cites vulnerability as the factor which defines the difference between her relationship with Megan and Megan’s sisters:

*because of the vulnerability, yes, there is a stronger feeling of protectiveness. I think the others have all the skills they need and if Megan didn't have a learning disability and just had a physical disability I wouldn't be as concerned at all. **At all** because I can imagine how articulate she can be now sometimes and how much she continues. There's a great tenacity about her to keep telling you something if you're not listening.*

Vulnerability is perceived as arising from Megan's learning disability. While her physical disability affects movement, her learning disability limits cognitive function with the result that she doesn't have the 'skills' her sisters have; the skills which allow them to function independently. Mary claims that that it is this aspect of Megan's disability which hinders her ability to protect herself and represents the source of her own anxiety. Paradoxically Mary acknowledges that Megan can be both articulate and tenacious suggesting that she does in fact possess the skills necessary to alert others to her needs. In light of Megan's abilities Mary's response is not entirely rational and in attempting to articulate her reasoning she is somewhat confused by the strength of her anxiety and the influence it exerts on the way in which she parents Megan; ultimately Megan's disability induces a powerful and ineffable drive to keep her safe.

Anna is aware that being over-protective of Henry is a characteristic she shares with other mothers in her social network:



*I think all our mums, I think if we're criticised for anything it's for being a bit too protective and they're all young men now. You know, we're all clucking 'Ooh, have they got something to eat?'*

The image her analogy conveys is of a mother hen staying close to her chick, alert to its every need and always ready to intervene.

Anna recognises the irony of her actions given that her son is an adult acknowledging that her approach is inappropriate; she is '*too protective*'. However while able to recognise this she is not able to attenuate her behaviour. It appears that there is something inherent in the experience of having a disabled child that produces a heightened awareness of that child's physical and emotional state and a concomitant need to respond.

All the women in this study have typically developing adult children. They are thus able to recognise that the protective instinct they describe is characteristic of the experience of having a child with a disability. The psychological pain and anxiety experienced when a mother fails in this quest is reflected in Jan's account of a distressing episode when, aged 18 years, Livvy transitioned from child to adult services;

*She's stopped eating and drinking and a member of staff who was on at the weekend had noticed when she was on the following weekend, that Livvy was severely dehydrated and that she probably hadn't eaten or drunk for five days and she was taken into hospital and put on a drip..... We realised that she'd had **eighteen** different members of staff working with her in one week coupled with these*

*sixteen kids in the house (designed for eight) , total chaos. Now the one thing that an autistic person needs is routine and stability, consistency.*

This incident, so vividly recounted, occurred more than eight years ago and yet Jan still struggles to understand how a provision she and her husband selected with great care failed their daughter from the very start and with such catastrophic results. Jan's perception is that she entrusted the care of her vulnerable child to others and they let her down. Not only did the staff fail to provide the ordered environment imperative to the well-being of an individual with autism, they failed in their duty to meet her most basic needs. Jan's anguish was compounded by the fact that once Livvy was discharged from hospital she was told that bringing her home before the college conceded that they were unable to meet her needs would result in a complete withdrawal of social services funding. Recognising that she would not cope without support, Jan had no option but to concur:

*That was the longest two weeks of my life. It was awful...*

Returning Livvy to a provision described as being in '*total chaos*' was intensely painful as Jan felt powerless to protect her and was terrified of what may be happening. There is a sense of time moving forward at an intolerably slow pace while a mother waited for those in positions of power to concede that they weren't able to meet her daughter's needs.

**'We are very watchful'; vigilance in response mistrust**

While the previous theme relates to the emotional tone of the maternal experience this theme describes the concomitant behavioural response. Lack of trust is a key characteristic of the participant's experience and mothers' perception is that care delivered by care workers is not of the same order as the loving care they provide. Their response is to maintain a state of vigilance, watching over and monitoring the actions of those employed in this role.

Like the other mothers in this study Anna experiences a heightened sense of anxiety because she believes that Henry's autism makes him vulnerable. His condition is such that he is able to go out into the community unaccompanied and this serves to exacerbate Anna's concern;

*I mean you read some **horrendous** stories that make me feel sick about young people with learning disabilities being bullied , and then the whole thing about residential care and horror stories, whether it's people with learning disabilities or older people in care homes I think in this country we're just not up to scratch with our carers...*

Anna is alert to media reports of abuse and they contribute to her lack of trust and anxiety. Thinking about vulnerable adults being 'bullied' induces a somatic response; she feels physically sick. The world is perceived as a threatening place and the mother/son relationship is experienced as symbiotic. Anna feels secure when she

knows Henry is in a safe environment and in keeping him in close proximity, she protects them both.

The fact that prior to retirement she worked as a social worker means that, like Mary, Anna has first-hand experience of care in practice. She is disparaging of provision in England suggesting that across the board carers simply don't meet the requisite standard. 'Horror stories' pertaining to recipients of residential care elicit overwhelming and painful feelings of fear and anxiety with the result that she is not yet prepared to move Henry out of the family home.

Given their close proximity Mary is very much aware of Megan's interactions with her carers and having envisaged her current situation '*through total rose-tinted glasses*', she is disappointed to find that entrusting her daughter's care to others continues to be difficult. Mary's '*inherent*' need to protect means that safeguarding her daughter is of utmost importance and she experiences difficulty in finding staff of high enough calibre:

*I think one of the biggest challenges is finding really good, well-trained staff people who want to make a career and acknowledging that you might only do this for two years and you may be studying, but, people who are willing to keep their training up to date and that it's not just a job to fit in with the kids...*

There is a contradiction in that while acknowledging that people may only work as carers on a relatively short-term basis, Mary wants

them *'to make a career.'* Career suggests advancement, a profession and although delivering personal care is an incredibly important occupation it doesn't receive sufficient recognition and this is reflected in the status and salary it commands. Wanting employees to think in this way demonstrates the importance Mary places on the role. She is entrusting her daughter to their care and she needs to feel that they care for Megan in just the same way she does. In tacit acknowledgement that this is not the case she *'still wants to keep a certain amount of control to ensure she's being looked after properly.'*

At 28 years old Livvy is the eldest of the young adults in this study and Jan therefore has more experience of adult provision than the other participants. As exemplified above, since entering adult services Livvy has been subject to terrible neglect and withdrawn from residential homes on two occasions. The family are currently awaiting the findings of a police investigation into an incident which occurred at her current home and the cumulative effect of these events is that Jan is always *'watchful.'* She uses the example of a young woman in Livvy's care home to illustrate what can happen when there are no family members to monitor her well-being:

*There is nobody watching out for that young woman and she can't talk. We have no idea whether anything has happened to her. All we know is that from time to time her behaviour deteriorates and she can't explain why and there's nobody visiting, nobody. So it's totally dependent on the staff doing the right thing. And that is not a good*

*situation for anybody and of course this is what we're terrified of. Suppose Livvy had been in that situation and there was no family to get her out of it. And the staff are worried about losing their jobs so they don't report it... This is what we're worrying about. We're always concerned....*

The critical importance of family supervision is evident. Given Jan's previous experience of negligent care, being '*totally dependent on the staff doing the right thing*' equates with being at risk of neglect. She implies that carers are afraid to raise concerns relating to other staff members when they are anxious about losing their jobs. This is pertinent at a time when the economic climate is difficult and unemployment high. For Jan the fact that employers and employees have vested interests means that client care may be compromised. In these circumstances the need for vigilance is paramount. Jan's lack of trust means that she exists in a pervasive state of fear that Livvy may one day be in this situation; the distress this prospect engenders is tangible.

***'What on earth will happen to Henry?': facing an uncertain future***

The fact that offspring will continue to need support throughout their lives means that mothers are forced to confront their own mortality, a future when they will no longer provide and oversee care. This is a difficult prospect and there exists a tension between recognition of the need to make provision and a deep-seated mistrust in providers.

While Mary feels compelled to remain involved in over-seeing Megan's care, as an employee within the social care sector she has seen what can happen when a parent has not adequately prepared their adult child to live independently:

*I don't want to ever get to the point, and I've seen it, professionally myself, where, we have the 70 year old mother with the 50 year old learning disability daughter and the 70 year old mother, sadly passes away and the daughter is bereft and been cosseted all of her life*

As she approaches fifty Mary is increasingly mindful of the passage of time and a future when she is no longer able to protect Megan. Experience has shown that it is imperative that she 'let her go'. She describes 'the 50 year old learning disability daughter' as 'bereft.' Invoking feelings of loneliness and abandonment, something she wants to protect Megan from, Mary's inner turmoil is reflected in her struggle to take the requisite step back knowing that in the long term maintaining a high level of involvement will be detrimental. She needs to let Megan 'fly' as her sisters have and yet remains ambivalent about doing so.

Given Henry's continuing need for support Anna recognises the importance of addressing her concern about the quality of care provision and making plans for the future:

*you just assume you're gonna live to be a ripe old age and we don't need to worry about that now. I think I'm more aware of those things than Mark I say 'Look, we have to do the power of attorney*

*thing. If anything should happen to us you know what on earth would happen to Henry?'*

As Anna approaches sixty and contemplates Henry's future she is forced to confront her own mortality. The powerful protective instinct engendered by Henry's vulnerability, existential awareness and misgivings about the care system coalesce to create deep-seated anxiety. Her lack of trust is reflected in the question '*what on earth would happen to Henry?*' There is a palpable sense of urgency and yet Anna has not resolved the dilemma of where Henry will live in the long-term. She knows that a decision must be made but the prospect is distressing and she is not yet able to relinquish her son to the care system.

Jan is more tentative in referring to a future when she is no longer able to oversee Livvy's care. She qualifies reference to a time when she's '*not around*' by preceding the statement with '*if*':

*Well the future, that is difficult. I really don't know, one of the things that we're glad about is through (support group) there's a special section called (name) and that's about life-long advocacy with the idea being that if we're not around to keep a watch on things, whether we're ill or dead that there will be somebody who knows her well who will be keeping an eye on things.*

Jan refers to a charity which appoints advocates to support individuals with disabilities, the idea being that advocates develop long-term relationships with those on whose behalf they act.



Advocates visit on a regular basis developing knowledge and understanding of those they represent. Knowing Livvy 'well' is paramount but ultimately no one will know or care for Livvy in the way her mother does. The maternal bond induces a profound love and her vulnerability an overwhelming drive to protect. What Jan ultimately craves is a proxy mother and recognising that this can never be is almost too much to bear.

The importance of 'keeping an eye', maintaining a constant vigil, reflects Jan's mistrust. Given her previous experiences it is perhaps not surprising that she feels one can never be complacent because situations are subject to change:

*... and you think something's going brilliantly, and it might be brilliant for three or four years and then you get a change of staff and it all goes wrong and it can go wrong very quickly*

Thus far Jan has been able to remove Livvy from potential harm when situations have started to deteriorate. However she recognises that the future is uncertain and is terrified of what may happen in her absence. Awareness of her own mortality is exceptionally painful; it means acknowledging that there will be a time when she isn't able to protect Livvy and this may explain why Jan is tentative in referring to this eventuality.

## **Discussion**

A strength of this study is that it addresses a significant gap in our understanding of *what it is like* to be the mother of a young adult

with a developmental disability; previous studies have typically focused on the child. The findings illustrate the deep anxiety experienced by mothers as they contemplate their offspring's continuing need for support and the fact that, in all probability, they will not always be in a position to ensure these needs are adequately met. Concern is exacerbated by both personal experience of social care and widespread media coverage of abuse perpetrated against vulnerable groups within society. To varying degrees participants mistrust the system and those who work within it. They maintain high levels of vigilance in an attempt to protect vulnerable adult children.

That these mothers are reliant upon English social care may be particularly pertinent as there has recently been a high-profile case whereby vulnerable adults were subjected to significant abuse. The value of this study is demonstrated by the fact that the Department of Health emphasised that 'listening to and involving people with learning disabilities and their families' is more important than ever before (National response to Winterbourne View hospital, 2012).

The participants experienced their offspring as vulnerable, an adjective defined as 'exposed to being attacked or harmed' (Oxford English Dictionary). A corollary of this perception is that participants experience an overwhelming drive to protect. Protecting adult children from possible harm was paramount and as a result they were highly attuned to children's physical and psychological well-being. To this end mothers maintained a state of vigilance and the

prospect of their children being harmed in any way induced feelings of intense anxiety. Maintaining a heightened state of awareness and the psychological distress this engendered meant that mothers were vulnerable too.

These findings could have been discussed in relation to attachment theory (Bowlby, 1969) or parental control (Baumrind, 1967). While these theories both focus on aspects of the parent/child interaction their concern lies more with the resultant relationship and the offspring's behaviour in terms of the ability to form positive relationships (attachment theory) and the ability to lead a successful life (parental control). The data-driven nature of an IPA project means that theoretical engagement is guided by the perspective of the participants, in this case, the mothers. The participants in this study identified the experience of parenting a young adult with a disability as qualitatively distinct and analysis disclosed perceived vulnerability as an important feature of that experience. As a result we aim to demonstrate the usefulness of vulnerability as a concept for starting to understand these findings theoretically as well as providing a framework for thinking about ways in which the difficulties experienced can be addressed.

Vulnerable Child Syndrome (VCS) develops in response to the threatened loss of a child early in life resulting in 'long-term deleterious effects on both parents and children' (Green and Solnit, 1963). In VCS, despite their objective health, parents perceive children as particularly vulnerable and become over-protective.

They may also experience problems with separation due to an inability to trust others with the care of their child. While not pertaining to those with a disability, identification of this syndrome has some explanatory power in that it demonstrates how perceptions of vulnerability can engender protective behaviours and issues with separation relating to trust. All three mothers expressed a lack of trust in the ability of others to provide adequate care. Anna made direct reference to '*horror stories*' reported in the media pertaining to care of the elderly and those with disabilities in residential homes while Mary '*wants to keep a certain amount of control to ensure Megan's being looked after properly*' and Jan is '*very watchful*'. As a result all were reluctant to relinquish control and continue to be intimately involved. However VCS describes an inappropriate response to an objectively healthy child. The young adults in this study really *are* vulnerable by dint of their disabilities. To varying degrees all will be reliant on others for support throughout their lives with the result that their safety and well-being is dependent upon the integrity of those delivering care. Given widespread media coverage such as that relating to criminal abuse perpetrated at Winterbourne View it is not surprising that mothers experience anguish when contemplating their children's future. For participants whose children are already in residential care, vigilance appears to be a rational response to possible threat.

When contemplating the possible abuse or neglect of adult children's needs mothers responded viscerally. Kittay (1999, p.34) described the intersubjective nature of care giving relationships with

both parties identified as vulnerable, albeit in different ways. She highlighted the fact that carers identify with the well-being of their charges such that they empathise with their suffering. In light of the high levels of anxiety participants expressed it appears that they too are vulnerable. They experience intense psychological distress and this is of particular concern given that their role as carer is on-going. Tomkins and Eatough (2013, p.21) point to the fact that familial care, unlike that delivered by professionals, has a long biographical trajectory with the result that 'the care experience meshes the past with the present and the future.' Having nurtured and protected their children since birth, care has become an integral part of participants' lives, both past and present. As they project forwards the prospect of no longer fulfilling this role makes the future a very difficult prospect.

Mothers typically expressed a deep mistrust of those delivering care suggesting that in failing to provide the nurturing care they both want and expect vulnerable adults are not being valued as individuals worthy of respect and this represented a huge source of anxiety, particularly in relation to future provision. Having identified vulnerability as an existential category, Sveinsdottir and Rehnsfeldt (2005) proposed that respecting the patient's dignity represents a fundamental value in caring for another human being. It is evident that mothers do not experience, or anticipate experiencing, care in this way. Rather the data supports Galvin and Todres' (2013, p.1) assertion, supported by extensive survey data, that patients and service users 'do not feel fully met as human persons in the way that

care is organised and practised.’ They propose that a service culture predicated on target- setting and efficiency drives has somehow lost its quintessential *raison d’être*; to deliver meaningful human care.

Galvin and Todres (2013) believe that the current patient/client centred approach to care developed in response to the medical model of illness and by extension, disability. They argue that in attempting to redress this situation by empowering service users, providers have failed to account for individuals’ vulnerabilities in times of need. Further there is a continuing tendency to overemphasise difficulties and attenuate agency. In focusing on decontextualized goals and quantifying the measurement of quality we run the risk of dehumanising practice (Hemingway, 2011). In response to the failings of the current system Galvin and Todres’ (2013) developed a conceptual framework for the humanisation of care which applies to the context of health and social care. Informed by existential- phenomenological philosophy they described a lifeworld-led approach to care. Lifeworld is a Husserlian concept (1936/1970) denoting not an objective world ‘out there’, but rather ‘a humanly relational world full of meanings’ (Galvin and Todres, 2013, p.25). In this approach existential dimensions including intersubjectivity, embodiment and mood, are employed to understand an individual’s lifeworld and used to inform care practises. Within this model they adopt an existential view of being human with the fundamental dimensions of freedom and vulnerability, conceptualised in terms of possibilities and limitations

(Todres, 2007). An example of how this might be applied in practice is exemplified by Jan's experience of Livvy's current provision:

*I don't like some staff think that the easy way is for her to be isolated. They don't have to work on her, building up relationships with the other residents. They each resident is independent and they don't mix. I don't like that and it's not in Livvy's best interests to get into those sorts of habits.*

Implicit in this passage is the notion that Livvy needs structured support and encouragement if she is to reap the benefits of engaging with other people. In shifting the focus away from target setting the framework provides the opportunity to place people at the centre of care practice. It alerts providers to dimensions of existence which give it meaning allowing them to tailor provision to sensitively meet the needs of individuals in ways which recognise both the possibilities and limitations of their condition. It may also serve to alleviate mothers' anxieties in relation to social care, both now and going forward.

### **Limitations and future research**

The study has a number of potential limitations. In the Reflexivity section we referred to how the level of participant anxiety challenged our preconceptions. Reviewers' comments led us to reflect on the way in which IPA's inductive approach elicited predominantly negative facets of the experience given that these were most salient to the participants. In light of this we intend to

return to the data to ask focused questions with the aim of exploring the contexts in which participants enjoy positive experiences.

Criteria for inclusion stipulated that participants were the mothers of young adults with a developmental disability. This describes lifelong disabilities manifested before the age of 22 years and attributable to physical and/or mental impairments. In this paper we report on two participants whose young adults were diagnosed with autism and one with cerebral palsy. Although these two conditions have different characteristics both meet the criteria for a developmental disability. Essentially we were interested in exploring the experience of mothering a young adult whose need for support transcends the typical pattern. Further all of the women were white, lived in relatively large houses and appeared to experience a comfortable standard of living. Their experiences may not relate to those of women from different ethnicities and in different socio-economic circumstances. Willig (2008) acknowledges that while small qualitative studies are not able to make claims for generalisation, in elucidating experience of a given phenomenon we demonstrate that it is available within a society or culture. On this definition we are able to claim that the findings represent one experiential possibility. Research focusing on different participant groups would further illuminate the phenomenon.

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Overarching theme	Vulnerability								
Master themes	<i>'It's not that you won't love them, it's that you'll love them too much'</i>		Parenting the 'others'			'Battling' the system: negative conceptions of care			Transformational experience
Sub themes	<i>'Something inherent that you want to protect':</i> overwhelming protective instinct	<i>'I felt good inside':</i> symbiotic relationship	<i>'It's not just us and Livvy living in a vacuum.':</i> family life	Passing on a 'huge burden'	<i>'A whole different package':</i> constant comparison	<i>'A significant way to go':</i> thinking holistically	<i>'We are very watchful':</i> vigilance in response to mistrust	<i>'What on earth will happen to Henry?':</i> an uncertain future	<i>'It has transformed our lives':</i> positive and negative aspects of change
Anna	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sarah	✓	X	✓	✓	✓	x	x	✓	✓
Mary	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jan	✓	✓	✓	x	✓	✓	✓	✓	✓
Patsy	✓	✓	✓	✓	✓	✓	✓	✓	✓
Helen	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 1: Themes and their prevalence