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Mothers perspectives on the lived experience of children with intellectual disability and challenging behaviour

Abstract

Children with intellectual disability and behavioural needs (challenging behaviour) are vulnerable to exclusion from services and communities. The situation is exacerbated by difficulties in accessing appropriate support and services to effectively meet the needs of children and carers. Family perspectives on the 'lived experience' of children can provide insight into how behavioural needs can affect their ability to access everyday experiences. Semi-structured interviews were conducted with mothers of children with intellectual disabilities and challenging behaviours. Phenomenological thematic analysis provided four key themes: finding our way; square services round needs; behavior touches everything and belonging. Experience of inclusion and exclusion were central tenets of the lived experience. Recommendations call for timely proactive and bespoke interventions to identify and support children at risk of exclusion from communities. Early intervention and effective local provision will avoid increased burdens placed on families and services, in supporting children whose needs are currently unmet within child-centered provision.

Keywords

Intellectual disabilities, challenging behavior, behavioral needs, children, lived experience

Introduction

In 2014 it was estimated that there were 40,000 children with intellectual disabilities and behaviours that challenge in England (Emerson et al., 2014). Described by Gray (2006) this population of children has been highlighted as low in incidence but high on impact associated with the need for specialist local service provision that can effectively support them and their families. It is established that children with intellectual disabilities and their families often interface with multiple service providers and agencies (Limbrick 2007). Despite this level of interaction however there is clear evidence that a high proportion of these children go on to experience extreme levels of exclusion from peers, their community and ultimately future opportunities (Gore et al 2014, DH 2017). Inappropriate support results in 'the costs (to the individual, family and society) of problems escalating or becoming ingrained' (Mansell, DH 2007, p9), whilst the link between children with intellectual disability and the development of emotional and or behavioural difficulties in early childhood is well documented (Emerson et al., 2014;Totsika et al., 2011a; Totsika et al., 2011b, Emerson and Einfeld, 2010). The incidence of behavioural needs identified in a child's early years to its prevalence in later life has also been highlighted (Murphy et al 2005).

Families of children with an intellectual disability whose behaviour is described as challenging report experiencing high levels of stress as well as physical and or emotional health problems (Hassall et al 2005, Woodman et al 2014). This situation appears to be exacerbated by the difficulties families have in accessing effective, timely and useful support (Social Care Institute for Excellence (SCIE)

2011). A child's behavior described as challenging or disruptive is cited as a key reason for them to be living away from their family home, often being placed in residential schools as a result of family and service breakdown (McGill et al., 2006, Pilling et al 2007, McGill et al 2010, McGill and Poynter 2012). The removal and consequent exclusion of children from their families and local communities elevates a child's level of exposure to risk, abuse or neglect (Jones et al 2012, Gore et al 2015) and ultimately negates opportunities for the child to engage in usual childhood experiences.

Following the Winterbourne View Expose (DH 2012) the lack of specialist support to meet the needs of people with intellectual disabilities was highlighted. Current service provision is undergoing a major shift in focus via the Transforming Care agenda (NHS England 2015). Recommendations place a firm focus on community and family based provision as opposed to the exclusion of individuals in traditional inpatient facilities. A focus on person centered clinical and cost effective solutions for individuals with intellectual disabilities are recommended with a firm emphasis on the original Valuing People Agenda for people with intellectual disabilities (DH 2001, DH 2009, National Audit Office (NAO) 2015, National Institute for Clinical Excellence (NICE) 2015).

In support of current national agendas associated with the design of support for people with intellectual disabilities a need to consider the experiences, needs and wishes of this group of individuals is paramount. This paper contributes to the understanding of how behaviour can affect the 'lived experience' of children with intellectual disabilities by considering their childhood through the

perspectives of their mothers. The research utilized a qualitative methodology of semi-structured interviews within a phenomenological approach that was designed to elicit rich narratives to further understanding of the impact of behavioural needs on the lives of children with an intellectual disability.

Methodology

Full ethical approval was obtained for the study via Manchester Metropolitan University ethics committee as part of an academic programme of study. The university research ethics process supported the production of participant information sheets, consent forms and interview guides.

Partners in Policymaking a national network that supports families of people with an intellectual disability, (www.partnersinpolicymaking.co.uk 2017) aided the development of the research question, 'What are mothers perspectives on the lived experience of children with intellectual disabilities and behavioural needs?'. The question and methodological approach chosen for the study was designed to enable the mothers of children whose behaviors had been described as challenging to discuss their perspectives on the impact of this on their child's life. As the people closest to the children indepth interviews were used to gain a true understanding of a child's 'lived experience'.

Phenomenology as the methodological approach adopted for the study has been described as a way of considering how an individual orientates themselves within their lived experience (Walters 1995). For the participants it was able to support understanding of experience from their perspective whilst considering the qualities described within those experiences and identifying individual

meanings through interpretative processes (Bogdan and Taylor 1975, Morgan 2007, Balls 2009).

Participants narratives embodied the perceived impact of the child's behavioural needs through the context of lived experience. The process of reflection involved in the retelling of their child's experiences supported the ongoing cycle of interpretation described by Bryman (2008) and supported the aims and methodological approach of the research.

Mothers were invited to take part in an interview. The phenomenological interview is considered to be different from other forms of in-depth interviewing due to the focus on the analysis of narrative (Van Manen 1990, Patton 2002, [Kvale and Brinkmann 2009](#)). Mother's perspectives were gained through personal levels of interactions utilizing open and unstructured forms of communication to stimulate discussion and reflection within a supportive and safe environment (Spradley 1979). The interviewer guided participants through a semi-structured interview format containing open questions which allowed them to reflect on their perspectives of their child's experiences through significant events such as birth and diagnosis, through to usual developmental phases of childhood such as nursery, school and key transitions. Mothers were encouraged to share perspectives on the impact that their child's behaviours had on life events, social interactions and their ability to integrate with peers and their communities. Parents tried to make sense of their child's world, through consideration of the context and phenomena that their children had experienced. The reflective nature of the interviews supported understanding through the

mother's eyes with acceptance of the phenomenon described as part of the iterative process later used in the analysis of data (Bogdan and Taylor 1975, Attride-Stirling 2001, Morgan 2007, Kvale and Brinkmann 2009, Bevan 2014,).

Methods

Information and contact details about the study were disseminated through Partners in Policymaking networks through a presentation of the original research aims at an annual national forum event hosted by the network and also through dissemination of information and contact details through the networks regular newsletter. Parents contacted the researcher directly to receive initial study information and further contacted the researcher if they wished to take part in the study and be interviewed. Ten parents (all mothers) from across England agreed to be interviewed. Inclusion criteria for the study were based on parental disclosure of their child/children's diagnoses of intellectual disability, behavioural needs and special educational needs (DfE 2014). Six mothers reported that their child/children had attended special educational provision.

Interviews took place at a time and venue chosen by participants with the principal researcher. Interview guides and consent forms were disseminated prior to interview to allow participants to prepare, ask questions and withdraw if necessary. Participants were interviewed utilising a semi structured interview format allowing time for them to discuss their perspectives on key events and their perspectives on their child's experiences. All participants consented to recording and transcription of their interview.

Data Analysis

All 10 interviews were recorded and transcribed. Thematic analysis deduced 58 initial codes applied 5685 times across the interviews. Utilising Attride Stirling's (2001) three stages of data analysis, 24 basic themes, 8 organisational themes and 4 global (superordinate) themes were identified.

The model of thematic analysis involves three discreet stages; initial coding to form 'basic themes' (or lower-order premises), grouping of more abstract principles or 'organisational themes' and finally the development of global or 'super-ordinate' themes which depict overarching principal messages. Visual thematic networks are used to illustrate the stages of the analytic process and provide a level of transparency that depicts and reinforces the iterative process (Koch 1994, Attride-Stirling 2001, Morse et al 2002).

Initially transcripts were individually coded and related back to the original research question 'What are mothers perspectives on the lived experience of children with intellectual disabilities and behavioural needs?'. The original identification of codes was established through a process of reading the transcripts, listening to the audios and prolonged periods of reflection to identify the essence of experience contained within the mother's narratives (Pollio et al 1997, Thomas et al 1998, Attride-Stirling 2001, Whitehead 2004, McConnell-Henry et al 2009).

The second stage of analysis involved the identification of experience and common meanings across the transcripts as a whole (Eggenberger and Nelms 2007). Organisational themes emerged from relationships and patterns identified within the data (Byrne 2001, Attride-Stirling 2001).

Finally overarching or super-ordinate global themes were developed to represent the key messages deduced from the data.

Thematic networks are designed to represent a non-hierarchical depiction of data that demonstrates transparency rather than levels of significance (Attride-Stirling 2001).

Findings

Participants

Table 1 provides details of the participants (pseudonyms used), the age of their child or children and a description (as identified by the parent) of their child's diagnoses.

All participants (n=10) were female and described themselves as mothers of the child/children. 12 children were discussed, 2 girls and 10 boys. Age ranges 18 - 7 years, mean age = 13.6 yrs.

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The four overarching (superordinate) themes are represented in Fig 1- Finding our way, Square services, Round needs, Behaviour touches everything, Belonging. Inclusion and exclusion are represented in all four superordinate themes as they emerged as central tenets across all interviews.

Figure 1

Global theme- Finding Our way

‘Finding our way’ represents how mothers discussed their experience of how they and their family managed to support their child. This included consideration of how they negotiated their way through a new situation (having a child with an intellectual disability who also had behavioural needs) and the services they encountered. This theme encompassed two organisational themes of the ‘Child’s Needs’ and the ‘Complex Journey’. Mothers discussed issues associated with their realisation of difference in relation to their child’s progress, potential and eventual diagnosis. Mothers reflected on this:

Denise *‘we realised he wasn’t going to be one of the ones doing all the running round’*

Jane *‘... we didn’t realise just how tough it would be for her to cope with all the changes’*

The ‘complex journey’:

Cathy said of her son *‘...I don’t know this boy because he hasn’t got communication he couldn’t talk and tell me what he wants ...’*

Parents described how they refocused their hopes and dreams and also became parenting professionals in their role and interaction with others:

Gill suggested that *‘...to be a mum with a child like him you’ve got to go out and do your own research ...you’ve got to become a professional in yourself, and go out there.’*

Global theme- Square services, round needs

This theme illustrated the parent and child's experience of services. Discussion focused on how the child often didn't 'fit' into the services that were available to them, with the untimely provision of services a key issue.

Angela: the impact of what's happened and happening, is going to cost more than if you'd put support in, in the first place – proper support into the home that made sense for us as a family. Yes it would have saved so much more money in the long run.....

Mothers articulated a lack of family and child centered provision across services. They struggled to negotiate their child's needs across multiple providers due to issues of communication between services at key transition points in their child's lives. One mother was told it was her responsibility when they moved area to:

'...get in touch with all her consultants. .. to get the service needed.' Kate.

How services perceived the rights and needs of the children was also reflected on in the interviews. Attitudes associated with the abilities and future of their children were perceived by mothers to be negative. Cathy spoke of her young son's experience at primary school: *...they don't care the school. They think in those schools (the children) are animals and we just treat them as animal. The school is just a day care for them and when it's time for them to go home, let them go home. I meanthey don't care what they can be tomorrow or not.*

All ten mothers identified within their interviews one individual professional that had been particularly useful in relation to supporting the family and the child. This was particularly related to the child's behavioural needs. The

individual was discussed in relation to their knowledge and specialist skills which were considered to be different, unique and directly useful to the family in understanding their child's behaviour:

Mary ' *The behaviour nurse was the best thing that ever happened. Hugely intensive I have to say but the advice and time and support that he spent with us as a family, trying to understand the triggers, trying to find the right kind of methods to work with him, was phenomenally beneficial.* '

Global theme- Behaviour touches everything

This theme focused on how behaviour affected the whole families as well as the child's experiences.

Mary ' *...your whole life revolved around his behaviour, what you could and couldn't do. How you could function as a family revolved around his needs.* '

During these periods Mary articulated her son's distress as he ' *... had no idea what was happening until he started to come back down the other side.* '

Crisis periods were identified as particularly difficult times.

Mary ' *.... it took two of us to actually maintain that stability, the behaviour,it would get so violent... it was about safety and nothing else.* '

The impact of the child's behaviour on their ability to access education as well as allow parents to pursue usual activities such as work were discussed.

Emma ' *... I can't go back to work because I had to leave my job through him, I was getting called to the school every day... it could be something quite serious but most of the time it's silly little things, he spent most of time in junior school in the corridor...they just couldn't cope in the classroom...(she was told to)... Take him*

home.'

Global theme -Belonging

The global theme of belonging focused on how mother's perceived that the child and family were included in their local communities. Mothers described the experience of integration as predominantly child centered and associated with service provision. Some families chose mainstream provision where possible and others had chosen to withdraw their child from mainstream services based on their child's experiences. . . One mother spoke of how her child thrived in a mainstream youth club:

Jane '...She had a challenging behaviour when I tried to bring her out of it cos she just didn't want to come home Some of the schemes ...just for children with special needs, I knew it wasn't right...'

Two mothers discussed how they had been involved in the creation of specialist provision or services that they felt were able to meet their child's needs in the absence of any other alternatives. Denise described a play scheme set up by herself and 3 other mothers as there was no local provision to meet the needs of their children

Denise '...we used to take thirty five kids a day, and we had charity status and it was great while it ran.'

The child's experience of exclusion from everyday events and activities due to their behaviours was discussed by all mothers.

Emma '...he didn't get invited to parties... his brother would, but he wouldn't.....he would just sob and sob you know. 'Why can't I go?'...parents had seen the way he had acted up and didn't want him at the party so it was heart breaking.'

Gill '*...I tend to go on my own with him...people don't understand... I'm sick of people looking and they tut... I didn't know how to deal with his behaviour in public. So I suppose I withdraw him and myself from outside community.*'

Discussion

Mother's perspectives of their child and families experiences play a fundamental part in the understanding of 'lived' experience. Mothers involved in the study were keen and willing to take part in the research. Narratives were directly related to the mother's perspectives on their child and families lived experience. Mothers primarily described and reflected on their child's experiences through services such as schools, nursery and within their local communities. Most children (ten out of the twelve discussed) were teenagers at the time of interview. Consequently mothers described their child's experiences across multiple forms of service provision, childhood stages and through key transitional points within their child's life.

Discussion associated with inclusion and exclusion was persistent throughout all the interviews. Examples included perspectives on integration such as inclusive education or specialist provision. All children discussed in the study were reported to have experienced both formal and informal levels of exclusion from services such as special schools, play schemes and respite provision. Ultimately exclusion will affect the range of support and experiences available to the child and family. Significantly mothers expressed that when they were able to make a choice about types of provision for their child these were primarily based on perspectives of their child's past experiences. Where mothers felt that a

provision would not be able to meet their child's needs they were more likely to reflect on previous incidents and interactions that they perceived to have affected their child in a negative way. This ultimately affected the extent to which a child was able to experience integration and inclusion as mothers highlighted the impact of negative experiences on the child's ability and the parents willingness to allow the child to continue to attend such activities. The vulnerability of children with behavioural needs to exclusion has been clearly articulated in the literature (McGill et al 2006, SCIE 2011, Office of the Children's Commissioner 2012, NHS England 2015, DH 2017). In this study mothers directly attributed their child's inability to 'fit in' to situations and environments to the behavioural needs and lack of available expertise within services to meet these needs effectively. For children with intellectual disabilities the multi-factorial elements of exclusion continue to have pervasive effects on their lives and life chances as they move into adult hood (DH 2001,2009,DH 2017).

Mothers perceived that their children experienced multiple layers of stigma. Those associated with the child's intellectual disability were further impacted by their child's behavior. In order to manage this situation mothers described how they often proactively regularly removed their child from situations or services to avoid exclusion, particularly in light of a lack of alternative provision to meet their child's needs. This was particularly discussed in relation to education when parents were afraid that their child would be officially excluded if they did not take their child home when requested. Parents were aware that options for their child were limited and articulated their fears that the child would be left with no resources if they did not manage situations to avoid 'formal' exclusion. The

combination of preemptive 'Informal' management of such situations by parents and informal exclusions associated with behaviour highlighted by the Children's Commissioner (Office of the Children's Commissioner 2012) leaves children and families in tentative and unsustainable situations. Placement in residential schooling for children with intellectual disabilities is primarily related to service and family inability to support the needs of the child in their local area (Enfield et al 2010, McGill et al 2010, Gore et al 2015).

Mothers perceived the experience of supporting children with behavioural needs as very different from supporting children without this level of complexity. Current evidence associated with high levels of stress experienced by parents whose children have intellectual disabilities and behaviours described as challenging supports this (Baker et al 2003, Neece 2014). Mothers articulated their concerns for their child's futures, their need to constantly advocate for their child, and the lack of support available to both the family and the child to affect the negative impact of the behaviour on the child's experiences and opportunities. The complexity of the child's behaviour can be seen to minimise the availability of services to them whilst placing responsibility for their care with those people who have the least amount of support available to them (Holt 2003).

The ability of services to support children effectively was discussed at length by mothers. A range of provisions were included in the narratives with mothers describing the services they had encountered as largely ineffective in supporting their child's behaviour. These views echo contemporary findings associated with a lack of skills and knowledge within services (DH 2017) and recommendations

that call for national standards of training to be made available for those employed to work with people with intellectual disability and behaviours described as 'challenging' (DH 2012). Attempts at strengthening the knowledge base of the workforce and services that support people with intellectual disabilities and behavioural needs post Winterbourne continue across the UK with the introduction of such tools as the Positive Behaviour Support Competency Framework (Skills for Care 2015). Training however remains ad hoc within services with no nationally agreed standard of training to ensure consistent quality for this group of people.

Low levels of motivation and issues associated with the value-base of staff within services were also discussed by mothers in the study. Some evidence suggests that staff who support people with intellectual disabilities report levels of disempowerment and marginalisation (described by Mitchell (2000) as 'parallel stigma') within their own services and professions. A situation of poor skills and training exacerbated by a workforce that appears vulnerable to exclusion within their own services suggests that current provision requires major investment and support in order to deliver good quality support.

Despite mothers' perspectives on the suitability of services for their children being largely negative it was noted that an individual practitioner was often mentioned positively during the interviews. Such individuals (all professionals) were deemed to be unique both in their attitude towards supporting children and their families and their level of behavioural knowledge and expertise. The impact of such practitioners cannot be underestimated in the call for a skilled workforce that can meet the needs of its service users (DH 2012). It must

however be acknowledged that effective behavioural skills as described by Mansell (DH 2007) should be considered as additional to those ordinarily required to work effectively with people with intellectual disabilities. This view supports those shared by the mothers in the study who called for early and bespoke support to meet their child's needs.

The resourcefulness of families in meeting their child's needs due to a lack of appropriate support was also clear in the data. Negative experiences of community integration and services lead parents away from traditional models of service and leisure provision. The perceived vulnerability and protection needs of their child led families to develop their own forms of support that would meet their child's and similar children's needs. As discussed by mothers they were not constrained by bureaucracy, policy or procedure. They were able to identify gaps in provision, recognise need and use practical problem solving skills to support their children and their families. Their motives were philanthropic in nature, which concerned the support of children, and provision of practical solutions to the 'so called' complexity of support for children with behavioural needs at risk of exclusion from services. Interesting that specialist provision may exclude children with this level of need but that parents are able to develop cost effective, child and family centred, appropriate support independently.

Current inclusive practices and integration do not support this group of children. How children with a learning disability and behavioural needs are included and integrated is affected by parental decisions based on perspectives of their child's

lived experience. It could be proposed that current policy and practice associated with this group of children does not support their integration, with an increasing focus on the results of exclusion for children with behavioural needs (Contact a Family 2013, DH 2017, Channel 4 2017). Communities are known to be reluctant to engage with people considered to be different (Harris 2000, Holt 2003). When children are unable to fit into systems they become isolated and vulnerable. This exacerbates their situation and alienates them from their peers. O'Brien and O'Brien (2002) assert that relationships within a local community enhance people's lives and can ultimately protect them. This view was expressed by one mother (Lynn) who felt that integration was the only way to keep her sons safe. Policy and practice that support exclusion negate opportunities for this to happen.

Children with a learning disability and behavioural needs are more vulnerable than their peers (Gray 2006, DH 2017). The interview data highlighted the predisposing factors that made children in this group particularly vulnerable. They experience levels of stigma and marginalisation that place them on the outside of their communities. Communities have historically instigated the removal of people with a learning disability (Wolfensberger 1972, Sibley 1998). Behavioural need is the reason most cited for the placement of children in emergency and residential support (McGill 2007) associated with a lack of appropriate local provision (DH 2007). This type of support is difficult to regulate (Beadle-Brown 2006) and therefore places people with a learning disability at risk of abuse and isolation (DH 2012). Recent exposés, such as that at Winterbourne View (DH 2012) and St Andrews Hospital (Channel 4 2017)

have reinforced fears for families that their child's needs cannot be met, even within what are professed to be 'specialist services'.

Throughout the paper the term 'challenging behaviour' has been used minimally. Terms such as challenging behaviour must be acknowledged as contributing to the marginalization and labelling of people with an intellectual disability (Anderson 2007). Terminology stigmatises individuals and identifies them as unpopular within services as discussed by the mothers within this study. Whilst the term 'challenging behaviour' (Emerson 1995) was originally devised to signify the challenge to services of meeting individual need it has become a powerful and descriptive label (Gifford and Knott 2016). The term is commonly used in current practice diagnostically to describe an individual and their presentation. Currently services commissioned to support people with behavioural needs can be described as 'challenging behaviour teams' for example. The use of language that may deconstruct and challenge negative imagery and descriptions of individuals must be considered in order to redress the balance of judgement applied to people with intellectual disabilities.

Study Limitations

As a group of mothers all participants were articulate and actively involved in the support of each other in voicing their opinions with a view to changing policy. Participants in the study were clearly immersed within the 'phenomena' for study (Sim and Wright 2000). Discussion however associated with the development of bespoke provision to meet the children's needs may be less

evident in a different cohort of carers that may not have access to, or be able to be part of a supportive and proactive network.

The research question was designed by parents. However those parents who volunteered to take part in the study were all mothers. It is not unusual for fathers to be under represented in parental studies (Macfayden et al 2011. Further research considering father/male carers and most importantly the child's perspectives would significantly enhance our overall understanding of lived experience.

The research utilized ten interviews. Although a small sample for research purposes generalisation of findings was not the aim of the study. The epistemology and methodology for the study was designed to elicit rich data that provided the essence of and insight to the child's lived experience.

Conclusion

This study represents an insight into the lived experience of children whose behavioural needs pose challenges to current service provision and local communities. Ten mothers took part in research interviews to share their perspectives and experience on how behavioural needs had impacted on their child's life. Following thematic analysis of the mother's narratives four key themes were identified: finding our way; square services round needs; behaviour touches everything and belonging.

The research has highlighted the importance of considering perspectives of those who live with and support children with intellectual disabilities in the understanding of behavioural needs and its impact on their everyday lives. This particular group of children can be deemed to have discrete and different needs

from their intellectually disabled peers. A child's behavior is associated with high levels of both formal and informal exclusion, vulnerability and stigma from within mainstream, specialist services and their own communities. Families become isolated through their desire to support and protect their children from this everyday phenomena. In light of these factors bespoke provision is required to holistically meet the needs of both the children and their families and ensure that children have the best possible outcomes available to them (DH 2017, DH 2012). Gray (2006) argues that the number of children who require this level of support is low, however the impact of their needs is high, both in respect of an individual's quality of life but also in respect of the financial impact that reactive provision creates whilst serving to further exacerbate the child and families vulnerability to exclusion (DH2012, McGill et al 2006). Child and family centered provision that provides pro-active, evidence-based support that can identify and respond to the pre-disposing factors involved in the development of behavioural needs is imperative. By learning from families and their children we can hope to inform the move towards effective provision of early intervention and specialist services to enable children to stay with their families and communities (DH 2012, Lenehan Review 2017).

In answer to the question of 'what are mother's perspectives on the lived experience of children with a learning disability and behavioural needs?' the data affirms that the children discussed in the research experienced a level of marginalisation that is pervasive and significantly more than that experienced by other children. Children with behavioural needs experience discrimination perpetuated and reinforced by current forms of service provision and lack of

support within their local communities. Within mainstream and specialist services this group of children struggle to fit in and experience disproportionate levels of discrimination and stigma due to their behavior and the inappropriate implementation of integration and inclusion strategies which marginalize this group of children and their families.