

Researching unheard voices: Parents caring for their adult children who have learning disabilities

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Abstract: The intention of this article is to convey the importance of research with 'hard to reach' populations and utilise the outcomes from a qualitative (Doctor of Philosophy) study completed in 2017. Important issues, which involved both social workers located within an adults' multi-disciplinary team (MDT) and parents who supported their (adult) children with learning disabilities, are discussed throughout. The White Paper Valuing People (Department of Health, 2001) is briefly discussed in relation to the impetus towards supporting parents and informal carers. Furthermore, the notion of health and social care integration and its progress is also highlighted, with a focus upon how progress (or not) has had an effect upon parents supporting an (adult) child with learning disabilities. Creative methods of parental engagement are revealed, which highlight the complexities of supporting a son or a daughter with learning disabilities. Stanfield's (2000) Four-level Framework has been utilised as the basis for data generation and the analysis of the findings. The 'lived experiences' of parents who received statutory services are presented as five individual case studies, which discuss their sons' and daughters' support arrangements. The Mental Capacity Act, 2005 has been referred to in this article as the underpinning legislation which brought about changes for the parents and the circumstances of their children. Consequently, the parents discussed their changing relationships with social workers as a result of using this legislation. All the parents (n=5) illustrated the significance of social workers' support and how their input had made a positive difference to their lives. The findings from this research study were shared with social workers and allied health professionals located within the learning disabilities service. The purpose was to present 'new knowledge' about the lives of parents receiving multi-disciplinary services.

Keywords: social workers, multi-disciplinary team, learning disabilities, adults, parents, Mental Capacity Act, 2005

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Introduction

The overall aim of the study was to explore one central theme: the contribution of social work located within a multi-disciplinary team (MDT), in the context of a statutory agency, namely, adults Learning Disabilities Service, in England. The study explored the extent to which social work has a distinctive role to play, as part of an increasing multi-disciplinary approach, in providing targeted services and support for people with complex health and social care needs (learning disabilities).

An additional component and related concept about the nature of social work was the inclusion of parents as research participants, and how their perspectives enlightened the study's outcomes through their lived experiences of receiving MDT services from social workers. Their lived experiences were also affected by the Mental Capacity Act, 2005 which had a bearing upon the outcomes of each story told. Case studies through 'story telling' have been provided to illustrate both the context and experience of parents, who cared for a son or daughter who had learning disabilities.

This article asserts that ensuring an inclusive mind-set provided the impetus to overcome some of the challenges involved when encouraging individuals to become engaged with this study. The terminology 'learning disabilities' has been adopted throughout this article which is concurrent with the author's personal and professional values about people who need support. By this, it is meant that people with learning disabilities are people first, with an emphasis upon what people can do with the necessary support, usually from family carers as, in this case parents. The creation of appropriate research methods, therefore, enabled the 'unheard voices' of parents to be understood and valued by social workers and allied health professionals located within a MDT and learning disabilities service.

Background context

When *Valuing People* was first published (Department of Health, 2001) it was a significant achievement, as the first White Paper about learning disabilities in 30 years. The Labour government's objective was '*to increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively*' (Department of Health, 2001 p. 53). Caring for a family member with a learning disability is a lifelong commitment. Parents (and informal carers) make a valuable contribution to the lives of people, often providing most of the support they need (Department of Health, 2001).

Parents have always been central to the lives of people with learning disabilities, at all ages (Williams, 2013). For many individuals with learning disabilities it is commonly accepted that family members are the basis onto which other support is built (Williams, 2013). Parents are a crucial resource for ensuring that adults with

learning disabilities can live in the community.

The population of people with learning disabilities is increasing across the United Kingdom (UK). There are approximately 1.5 million people in the UK living with learning disabilities (Foundation for People with Learning Disabilities, 2018). Demographic projections suggest that the numbers will increase by 14% by 2021, as many more children born with a learning disability live longer and more fulfilled lives into adulthood, and the increasing adult population of people with learning disabilities grows into older age (Scottish Government, 2015)

Parents in this study were committed to their (adult) children, without whom the health and social care system in their locality would not have been able to function to meet the complex health and social care needs of their children. Since these parents had such a vital role in supporting their children, it was imperative, therefore, to include them within this research study to ascertain their views about receiving social work support via a multi-disciplinary 'model' of service delivery from an adults' learning disabilities team based in England. The model of the MDT team consisted of (1) assistant director (social worker), (2) team managers, (4) experienced social workers, (2) experienced community nurses and (2) development workers (social workers). One development worker linked directly with service users who utilised the MDT services and the second development worker linked directly with parents and informal carers, who supported their adult children either within the home setting or a supported living arrangement – as explained later in the article.

Health and social care integration

The study was carried out during a period whereby there was an increased emphasis upon health and social care integration. Successive governments have used a variety of measures to achieve the closer integration of health and social care, but overall progress has been patchy and limited (Humphries, 2015). Cameron et al., (2012) and Cameron et al., (2014) have also reviewed the research evidence for joint and integrated working. The researchers concluded that a prerequisite for successful integrated service provision is securing the understanding and commitment from staff and, in addition, defining the outcomes that matter to service users, parents and informal carers. Outcomes defined by them may differ from policy and practice imperatives but are a crucial aspect of understanding the effectiveness of joint or integrated services. Romeo (2017) has stated that good progress has been made '*to embed social workers and social care into integrated arrangements through the new care models/Vanguard sites and Better Care Fund*' (Romeo, 2017 p. 10). In particular, positive developments in specific service areas such as learning disabilities have enabled social workers based within integrated settings; (MDTs) to flag up health and social care concerns quickly through access and direct contact with the relevant professional.

This approach is currently being supported through a learning disabilities piloted project: The Named Social Worker Programme. This initiative promotes access to a 'named social worker' who provides professional advice and is the primary point of contact for the 'family' to provide a professional voice across the health and social care system (Romeo, 2017).

Creative research methods: Unheard voices and diffident parents

Ethical approval and informed consent was sought and gained through known sources (University of Salford and agency). This was achieved through protracted negotiations (over one year) with an agency employee, namely the carer development worker (a registered social worker). It was the first time that an 'outsider' i.e. the author, working at a university had initiated this request about parental inclusion in a research study. As a consequence of this, some parents were hesitant to share their knowledge and lived experiences, as many of them viewed their parental and supportive role towards their disabled sons and daughters as something any parent would do, given the same set of circumstances.

It was the intention of the author to dedicate a significant emphasis upon the lived experiences of such parents, to ensure that their important views were incorporated within the research study and to add their 'unheard voices' to the health and social care agenda, given the fact that local people (including parents) had often been excluded from research studies, Cameron et al., 2012; Cameron et al., 2014. Furthermore, it was important to capture their views about the progress (or otherwise) of developments concerned with health and social care integration, in their locality. This was an unknown phenomenon (at this stage) from their perspectives. It was also envisaged that the potential of carers' voices could create 'new knowledge' and inform social workers and allied health professionals located within the MDT, of the outcomes and effects upon these parents. New knowledge such as this was important, given the fact social workers also had access to the Allied Health Team whose members consisted of (1) consultant clinical psychiatrist, (1) consultant clinical psychologist, (1) physiotherapist, (1) speech and language therapist and (1) behavioural support nurse – this last role entailed advice to social workers and allied health colleagues about how best to manage service users who presented 'challenges' to professionals and services, given their complex behaviour(s).

In order to overcome the major challenge of engagement, the author invested time in developing a positive relationship with the carer development worker. This employee had initially volunteered (at an earlier stage) to be interviewed (as a participant) during the data generation phase linked to social work professionals, and their perspectives about the emphasis of MDT working and the health and social

care ramifications involved. Since the remit of the carer development worker included direct contact with parents, supporting them independently from social workers, it was deemed an effective and ‘creative’ method in which to share information about the purpose of the research study with known parents to the learning disabilities service. Consequently, delivering the message (through a familiar face) about the worthiness of their involvement would encourage diffident parents to become research participants, and ensure their contributions would be valued, firstly by the author and secondly, disseminated to a wider audience of social workers and allied health professionals located in the learning disabilities service. Following a twelve month period of discussions with numerous parents (n=45), five parents (n=5) eventually gave their voluntary consent to become research participants.

Research Participants

The participants (see Table 1) agreed to share their lived experiences and therefore the author adopted an open style and approach to elicit the ‘best out of people’ whilst sharing their stories (narratives) in a comfortable way. There was a sense that privileged access (via ethical approval) had been granted to talk to a number of local parents about how they lived their lives with the support of MDT social workers. In terms of the parents, this was in relation to supporting either a son or daughter over a prolonged period of time, this factor being a significant feature of parents who supported someone with learning disabilities:

Families are the only people who will have a continuous relationship with a person with learning disabilities from childhood to adulthood. It is the lifelong nature of their caring commitment that singles this group out from all other carer groups. (Cooper and Ward, 2011, p. 45).

Table 1: The Parents

Parent (Pseudonym)	Age of Adult (child)	Context	MDT
Mrs A	26	Supported son living at home	Social worker
Mr B	23	Supported daughter living at home	Social workers
Mrs C	31	Supported son who was a tenant in a supported living arrangement	Social worker
*Mr D	45	Supported daughter who was a tenant in a supported living arrangement	Social worker
*Mrs E *(married couple)	45	Supported daughter who was a tenant in a supported living arrangement	Social worker

Three parents discussed their experiences within the context of their son/daughter's diagnosed learning disabilities with the exception of Mr D and Mrs E. Their daughter had undiagnosed learning disabilities, and this factor had a bearing upon their responses towards her and the provision of services to her. Mrs A and Mr B supported their children within the parental home, whilst Mrs C, Mr D and Mrs E supported their children living within a supported living arrangement. Since the majority of the parents supported their children in this way, a brief outline about the philosophy of independent and supported living is explained.

The philosophy of independent living was originally inspired by the disabled people's movement. Disability Rights UK (2015) state that:

Disability Rights UK believes that all disabled people should be able to choose to live independent life-styles with dignity. This does not mean that disabled people necessarily need to live on their own or live without any support. In fact, Independent Living empowers you to have greater choice and control in directing your own life, having the same range of choices as a non-disabled person to make informed decisions about any practical support you require going about your everyday life. It is living independently without the dependency created by institutions. (Disability Rights UK, 2015, p. 1)

The philosophy embraces the social model of disability, and is based upon a belief that disabled people should be enabled to live their lives (as far as possible) on as equal terms alongside non-disabled people. It highlights the necessity to ensure they have the support they need to be autonomous and live their lives as fully as possible, and interdependently with others. Beresford (2012) also argued that the 'voices' of service users, parents and informal carers brings new 'experiential knowledge' into the equation, hence the philosophy of independent living and the social model of disability are best-known expressions of experiential knowledge (Beresford, 2012).

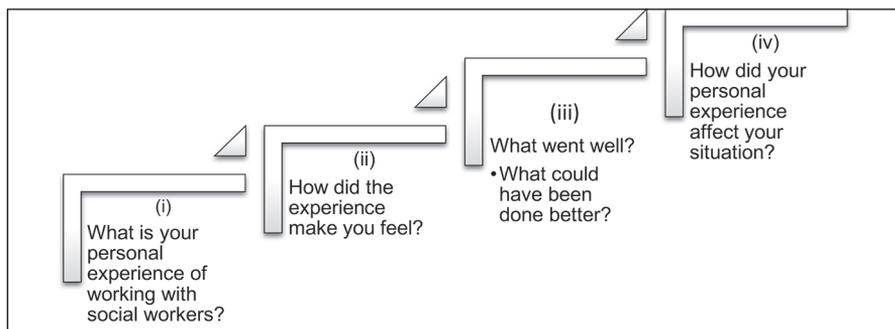
Data generation and analysis: Stanfield's (2000) conversational style

During the data generation phase, it transpired that all the parents felt comfortable sharing their lived experiences through their own story telling, which was significant to them and other people involved in their lives. This development led the author to create a more 'focused conversation' rather than present them with an interview schedule which offered a more structured approach. The emphasis, therefore, was to create a convivial atmosphere (within their own homes) in which to gain access to the 'unheard voices' of parents. All the conversations were recorded and analysed by the author using Stanfield's Four-level Framework as the underpinning theoretical

emphasis. The questions posed to the parents also formed the basis of each case study presented (see Fig 1).

The focused conversation has a Four-level Framework of questions comprising of (i) objectives (facts/timelines); (ii) reflective (personal responses); (iii) interpretative (personal significance and meaning); and (iv) decisional (resolution and future plans) (Stanfield, 2000). There was also acknowledgement that the ‘conversations’ could be emotional and reflective during the meetings. As a precautionary measure, each participant was offered the presence of the carer development worker and assured that the conversation could stop at any point, with no obligation to continue. The sequence of the questions (although used flexibly) during the data generation phase (as demonstrated) encouraged individuals to share their lived experiences which could also offer an evaluative function. This involved relating past events to the present in order to construct the meaning of the present. The focused conversational style of interviewing consisted of the following questions proposed to the participants.

Fig. 1: Stanfield’s Four-level Framework: (original design created by the author)



Findings

Mrs A’s Case Study

Mrs A explained that her son had Williams Syndrome (WS). She further clarified that WS was a genetic condition that is present at birth and can affect anyone. It is characterised by medical problems, including cardiovascular disease, developmental delays and learning disabilities. She spent considerable time talking about the anguish which a delay in diagnosis caused to her and her husband. Her first experience of working alongside social workers was during her son’s childhood

through a voluntary organisation. She praised the social worker from the voluntary sector and said:

As soon as we had a diagnosis (aged 9) we were put in touch with a social worker from (...). She was very good when dealing with his benefits. She helped to sort all that out. We had plenty of information and advice.

Mrs A confirmed that her son had moved around a number of different schools as he couldn't settle in any school. His mother put this down to the fact he had complex health and social needs. Although he was articulate and could communicate well, he would often present as being 'on top of the world' and at times, his somewhat overbearing presence affected how people interacted with him, which often resulted in isolation. His mother and father (to a lesser extent) were often left to explain to their son that some children, young people and adults found him difficult to deal with. Mrs A confirmed that once their son had a diagnosis from the psychology service, this helped them (alongside the social worker) to decide which school would best suit his needs. Once he completed his formal education, he then attended a local college. Mrs A discussed how traumatic this was for them as a family, as change was something her son found difficult. For example, her son hardly slept and he became very anxious that he would be 'taken away' from his parents, although at this stage his living arrangements were stable, as he remained at home. Mrs A shared her concerns about how the demands around her son's behaviours took a toll on her marriage, and as such was aware that at some point in the future, their son would need to leave home. Mrs A confirmed that her experiences working alongside MDT social workers were in the main positive. She commented about the fact that they were easy to contact and offered support if needed. This was also enhanced through the services of the carer development worker, although her presence usually denoted an impending crisis which needed to be resolved. For example, Mrs A found her son's continuous 'problematic behaviours' (her description) difficult to deal with, alongside the fact that she was aware that it also affected her own mental health – resulting in depressive episodes. She said:

I was aware that the social workers from the adult's team were part of a multi-disciplinary team. Whenever we needed help the social workers were always there to provide that help for us.

However, Mrs A did mention that at times there was an underlying tension between her and social workers. This was due to the fact they were all focused upon independence for her son, i.e. his living separately from them. She did agree to respite (but her son was reluctant) as he interpreted this as being rejected by his parents. This situation affected her relationships with social workers. Eventually she was re-allocated a community nurse instead, as she thought there would be less pressure to move her son out of the family home. Mrs A stated that the community nurse (from the MDT) was more flexible in her approach, and was also willing to

look at a variety of options before suggesting her son should leave home, although her own mental health (in the form of depression) had worsened whilst trying to find a solution for her son and a 'best fit' for all the family. At the time of the conversation her son had just moved into a supported living arrangement in the locality, where he shared a house with two older women both of who did not communicate through speech. Mrs A confirmed that her son was doing 'ok' but it still wasn't the best place for him to be, due to the other residents who couldn't verbally communicate that well with him.

Mr B's Case Study

Mr B shared his story in a private room at a local resource centre, which his daughter attended three days per week. He explained that he and his partner had their first child (daughter) when they were 21 and 18 years respectively. He was told a few hours after her birth that she had Down's syndrome. Down's syndrome is a genetic condition caused by the presence of an extra chromosome (21) in the body's cells and occurs at conception (Down's Syndrome Association, 2018). This was their first experience of dealing with a child who was deemed 'different' due to the presence of Down's syndrome, and also their first contact with a social worker. He confirmed that he did not know anything about social workers and they immediately thought that 'they' would take their daughter away from them. He said:

My partner was fearful and she kept asking the social worker if she would take (...) off us. The social worker told us that she was here to help us and not take (...) away.

It was a pleasant surprise to them when the social worker explained her role and was enabling them to keep their daughter, with agreed support arrangements in place. He confirmed that she shared relevant information and also practical matters about feeding and sleeping routines. He was hesitant at this point, but did say that the experience of having both a health visitor and social worker involved left them feeling uneasy and 'watched' in terms of their parenting abilities. In addition to this, he hadn't realised that their daughter would be viewed as disabled by the professionals they would come into contact with in the future. By this he meant the local school, and how difficult it had been to acquire and maintain a place for their daughter in a mainstream school due to her 'difference'. He said:

We had some difficulties trying to get my daughter into mainstream school. The local headmistress wanted us to transfer her to a special school, for disabled children. We refused for quite some time, but our daughter's behaviours gradually got worse over the years –we gave in finally.

Once their daughter had settled in to her new school her behaviours, which

sometimes ‘challenged staff’ (such as low attention to tasks and distracting other pupils through telling jokes at inappropriate times), were less apparent. She also had classroom-based support to help her with her development and social skills. During this conversation, Mr B mentioned that discrimination in his local community was rife. He said:

Kids shout things like ‘mong’. I tell them not to mention that word outside my house. I tell (...) that she can’t use that word either. I just don’t agree with it.

Once she had reached 18 years she then attended the local resource centre through access to an MDT social worker, who undertook assessments of her needs. Mr B discussed how their daughter had aspirations for the future. She was the eldest of seven children and had experienced all of them growing up and beginning to live more independently than she did. This caused friction at home, as she didn’t understand why she couldn’t stay out late at nights, attend party invitations and have a boyfriend. Mr B and his partner had struggled with the idea that she was growing up and she was simply asking to do the same things as her other siblings. He said:

All the way through her adult life we never really had a social worker. They have just been in the background. We asked for a new social worker once, because we felt we needed a better service. We never got one.

His final comments were related to the fact that, whilst he realised that a social worker had helped them acquire a place within the resource centre, he didn’t have much hope for his daughter’s future. By this he meant leading an independent and ordinary life – she would always be dependent upon them.

Mrs C’s Case Study

Mrs C explained that the first time she came into contact with social workers was through a school for deaf children. That was when her son was around 11 years-old; he was diagnosed with autism at that time. She said:

This is because his behaviour is like it is. Nothing was said about autism. In the early days nobody could come up with a diagnosis. I used to think about other people’s reactions to me trying to manage his bizarre behaviours. On one occasion he tried to build a giant tent inside our home.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It includes a spectrum of conditions, which means that,

while all people share certain difficulties, their condition will affect them in different ways. Some people are able to live relatively independent lives, but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over or under-sensitivity to sounds, touch, tastes, smells, light or colours (Autistica, 2015).

Mrs C explained that she had always been wary about working with social workers, in particular. This was related to how her son displayed complex behavioural traits (such as being violent towards her on occasions) when faced with unexpected changes in his life. His unpredictable behaviours (and Mrs C's safety) could have influenced decisions made by social workers as to whether her son remained living at home with his mother, and with access to the local community. A social worker from the MDT did suggest that her son could try a few days respite at a different location, but still within the same locality. Mrs C recalled that this experience was a disaster, as he was placed with other people who had learning disabilities and therefore his needs were not particularly catered for, although he had autism. There were problems with providing enough staff, and no-one spent enough time with her son, to explain to him what would be happening whilst in respite. Mrs C continued to worry about the effects upon her son and also other people he would come into contact with whilst trying this out. In short, this wasn't a break for Mrs C but rather added to the stress of not knowing what was happening to her son whilst away from home. Over time her son's behaviours gradually deteriorated, and he was removed from home through the use of the Mental Health Act, 2007. He was placed in an assessment and treatment unit for a period of seven months. Whilst this was a traumatic experience both for her and also for her son, she knew that he would receive an appropriate assessment of his needs. Mrs C explained that she felt better dealing with medical staff (psychiatrist) and learning disabilities nurses who had some knowledge and understanding of her son's difficulties. Up to this point she had felt that social workers could not offer her the support she needed, and therefore she had no recognition of their value, with the exception of the carer's development worker. Mrs C explained that she had grown to trust her as she was a source of support and had also encouraged her to attend a local support group for carers. Mrs C confirmed that she had 'blossomed' since joining the group and she discussed how she had access to both support and relevant information about autism. Her son spent thirteen years being 'looked after' separately by the National Autistic Society (in a different locality) but by the time he was 40 years old he was offered a more localised supported living arrangement by a social worker from the MDT. She said:

There was a transition period from November until April. It was excellent. It was a planned number of visits, and he could visit the house and get to know staff and other people living there. It's an ordinary house and he's happy. I have plenty of contact and I can bob in anytime.

Mr D and Mrs E's Case Study

Mr D and Mrs E explained that their daughter had undiagnosed learning disabilities, although they were both of the opinion that the cause had been related to a childhood vaccine. They had challenged their local doctor who administered the vaccine, but had had little success in proving a case for negligence. They explained that it happened when their daughter was between eighteen months and two years old. They shared their experiences about their personal hardship and heartbreak knowing that, although she had been born a healthy baby, their daughter would have a permanent disability. They had another son two years older, who went on to become a manager in the 'business world', and were proud of the fact that one of their children could live a lifestyle not encumbered by health and social care professionals. During the early days, they explained how they were left to cope and didn't get any help or advice from social workers. The only contact available was their health visitor, alongside a community nurse, but not a nurse whose field of practice was learning disabilities. Mrs E said:

In the beginning we didn't have a lot of time to deal with social workers. We had to liaise with the hospital all the time, because our daughter had continual epileptic seizures. When she was small we had a social worker from (...).

Mr D also explained how he always adapted his working life and commitments to his job, as he knew that his wife was struggling to cope with the demands of a daughter whose behaviours were difficult to predict. She had no speech and only used utterances to communicate. His limitations around his working life had also had an impact upon his advancement, and therefore offers of promotion always seemed out of his reach. This was a major disappointment to him, as this also meant that finances would always be tough. His wife did not work outside the home. However, they were also proud of the fact that they had adapted their home to accommodate their daughter in the longer term. Initially they had no desire to let her live elsewhere in the locality.

Mrs E confirmed that, whilst their daughter was growing up, most of their support came from the local school. They did have an educational statement about their daughter's profound health and social care needs, and a social worker from a voluntary agency was also involved, but this had come through school rather than a personal request from them to a local authority. Mrs E said:

I was nervous about a social worker coming I mean what do they do? I didn't have a clue about what to expect. There wasn't any information about social workers back then.

Mr D also discussed how relieved they were to discover that the social worker was there to help them and especially their daughter. They had access to respite services which helped to alleviate some of the responsibilities associated with their daughter. During their daughter's adulthood she spent most of her time living at home, her

mother venturing out occasionally with her, but she found this stressful especially as her daughter was a strong and robust woman who could be demanding in her own right. Their daughter did access day services during the week, which gave them a break, and she could meet different people there. Eventually their daughter's complex needs overwhelmed the couple and they therefore asked for residential support, although they did utilise respite services. They explained that a social worker from the MDT had visited them to discuss potential options for the future. They agreed for their daughter to move into a specially adapted bungalow in the locality, with relevant support staff in place. As a couple they appreciated the involvement of an MDT member, and had information about how their daughter would be introduced to her new living arrangements over a period of time. Mr D said:

*We couldn't have coped without social workers, although we have disagreed with them in the *past. During the transition stage, the social worker was great and followed it through. [*The disagreement in the past to which he was referring was related to the paucity of allocated respite they were given during the years their daughter lived at home with them.]*

Discussion

Mrs A expressed her views candidly. Obviously the diagnosis of a learning disability had helped this family acquire services. It transpired through this conversation that it was difficult to reach the diagnosis of WS – due to its relative scarcity. In addition to this, a number of best interest meetings which were linked to the Mental Capacity Act, 2005 had been convened by social workers over the years regarding the future arrangements for her son. Mrs A confirmed that the meetings had affected her relationships with social workers in terms of not being fully in control of the situation, and her limited inclusion in the decision making around her son's future living arrangements. She viewed this as a 'power shift' and realised that her son was now an adult, and her parental responsibilities were minimal. She found this difficult to accept as she was very attached to him.

Mr B's situation was one of a young couple (initially) struggling to come to terms with the news about their daughter. Although support was available from both a health visitor and a social worker, Mr B confirmed that they trusted the health visitor but were always guarded about the involvement of a social worker, regardless of the reassurances given to them during their daughter's childhood. The underlying cause was the possibility of their daughter being removed and placed within foster care, should the needs of their daughter outstrip their capacity to cope with them (as stated in childcare legislation). Once their daughter had reached adulthood, different issues came to the fore. This was related to her financial benefits and how they were managed by her parents. At some point there had also been a best

interest meeting (mentioned by Mr B) about their daughter's capacity to manage her welfare benefits. He gave the impression that he was willing to consider allowing his daughter to have more control over her finances, but he remained adamant that she would always need their support, regardless of her age, and whether she had the capacity to make independent decisions or not.

This mind-set highlighted how there was a reluctance and lack of understanding (to a certain extent) to accept his daughter's rights and her ability to manage some aspects of her finances. At the time of the conversation his daughter received weekly pocket money which indicated that she could not manage her overall benefits and entitlements. This issue was especially relevant given the remit of the Mental Capacity Act, 2005 and the proactive approach towards capacity, but with associated risks. A best interest meeting may have encouraged their daughter to learn about responsibilities in the longer term, enabling her to become more independent albeit within the home environment.

In terms of Mrs C, she had expected to care for her son all his life. It wasn't until life became almost impossible for both of them (for different reasons) that she sought help, mainly from the voluntary agencies. It is also a reminder of the fact that autism (a developmental disorder) was not well understood during the early 1970s or researched by medical professionals, allied health and social care professionals (National Autistic Society, 2015). The Autism Act, 2009 has signified the importance of autism. It did two things: the first was to put a duty on the government to produce a strategy for adults with autism, which was published in March 2010; the second was a duty on the government to produce (by the end of 2010) statutory guidance for local councils and local health bodies on implementing the adult autism strategy (National Autistic Society, 2015). In addition to this, the developments of health and social care integration in their locality had also affected this family. At the time of the conversation, joint funding arrangements for the support of their son became a major issue between the National Health Service and the learning disabilities service. As a consequence of the protracted discussions about the payment of her son's overall care, he was placed 'out of county' in a residential establishment miles away from his locality. His placement was jointly funded through the newly established Clinical Commissioning Group, which consisted of both health and social services senior staff, who were able to make financial decisions on behalf local citizens – in this case, Mrs C's son.

Mr and Mrs E had tried over the years to establish how their daughter had acquired learning disabilities (such as neurological complexities) and the possible effects of a vaccine, but without success. During her adult years (40+) she was living in a supported bungalow with relevant staff. The carer development worker had spent intensive periods of time with Mrs E in particular, talking through issues about her daughter's care. Mrs E also continued to grieve about the fact she had 'lost' her healthy daughter, and she could no longer care for her disabled daughter within the home environment.

Conclusion

All the parents' lived experiences presented complex situations about the nature of their children's learning disabilities. In addition to this, they discussed the necessary support arrangements required in order to help their children maintain the ethos of independent living within a community setting. Parents commented frequently that the ability to achieve positive outcomes for their child was facilitated (in the main) by a contribution from social workers, based within the MDT.

Some tangible examples given by the parents included supporting Mrs A over long periods of time to enable her son to access an independent living arrangement. She commented that she had found social workers easy to contact and that they offered both information and support to her in terms of the provision of respite services. Mr B commented on the value of social work interventions that were linked to an assessment and risk assessment of his daughter's needs. Both Mrs C and Mr/s E also found social workers' contributions invaluable; this contribution was in relation to the transitional arrangements (towards independent living) made on behalf of their children.

However, all the parents expressed concern about how the nature of their initial relationships with social workers (built upon trust) could easily change due to the process of undertaking best interest meetings (on behalf of their adult children) - a process which is enshrined within the Mental Capacity Act, 2005.

Mrs A explained that the change was driven by a 'power shift' over who had the responsibility for her son. Likewise, Mr B was of the opinion that he and his partner were best placed to enable their daughter to access her financial resources and not social workers.

All the parents also mentioned the paucity of appropriate services underpinned by the slow progress between 'joined up' health and social care agencies. These factors had affected the ability to provide the right types of services to meet the complex health and social care needs of their children. Their lived experiences revealed that in some cases, services were not sophisticated enough to provide care for their son's/daughter's complex learning disabilities, resulting in parents having to struggle to provide care and support with limited respite offered to them.

The parents' contributions in this study have highlighted that their lived experiences had been associated with what they needed at any particular time. It was important therefore, that a social worker from the MDT could respond accordingly, albeit within limitations defined by available service provision. The presence of the carer's development worker, (social worker) made an important contribution, in terms of alleviating some carers (Mrs A/C, and Mr/s D/E) of high levels of personal stress.

The main focus of this article was to explain how 'hard to reach' research populations had 'something to offer' in the form of their lived experiences of receiving MDT services from social workers. The 'heard voices' of parents and, therefore, the creation of new knowledge revealed that social workers had made

significant contributions by providing support and services at specific times within the parents' lives. These findings also revealed that social workers had a person centred approach towards individuals, underpinned by a collaborative approach to service delivery. Social workers had made a contribution by undertaking a variety of roles and tasks. These included home visits, completing personalised assessments, creating care plans, arranging personal budgets, negotiating with other agencies (housing and health) and supporting individuals during difficult times judged to be high risk situations. These scenarios were also supported through the provision of best interest meetings reinforced by the Mental Capacity Act, 2005 on behalf of some individuals trying to manage in difficult circumstances.

The limitations associated with this research study were focused upon the low numbers of parents, (n=5) out of a population of 45 who gave their consent to become research participants. The initial recruitment was problematic due to them being 'hard to reach' and deciphering who would be willing to share their lived experiences with a potential stranger (the author). This feature has affected the generalisability of the results, although the outcomes (shared by the author) were valued by the social workers and other allied health professionals located within the MDT and the learning disabilities service.

Finally, all the parents viewed themselves as citizens within their own communities, despite the resource limitations surrounding their lifestyles. They had aspirations to live fulfilling lives supported by people they trusted and social workers from the MDT. They wished to pursue their own interests, in some cases have a job and maintain a caring role alongside this. Social workers as members of the MDT were a part of their complex networks of support. They offered significant contributions, through the provision of a variety of professional services underpinned by a personalised approach at important junctures in people's lives.

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