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Siblings of Adults with Learning Disabilities: An Empirical Study

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Introduction

Adults with learning disabilities are now more likely to outlive their parents, who are often typically seen as their lifelong carers (Emerson & Hatton, 2008). At this stage, siblings may be called upon as providers of support to their parents in their supportive role (Davys et al 2010). Despite the longevity of the relationship and the fact that most siblings are considered by agencies to be next-of-kin when parents are no longer alive, the relationship between adult siblings of adults with learning disabilities is under-researched. The present study, although only involving a relatively small number of participants in order to tentatively explore possible emergent themes, highlights the need to expand research pertaining to siblings, including taking a life course approach. It is vital that the needs and perspectives of siblings of adults with learning disabilities are understood. This will be of particular interest to organisations such as local authorities (the main funders of social care and support for adults with learning disabilities in the UK), to ensure appropriate levels and types of support are available. Social workers are one of the main professional groups working with people who have a learning disability and understanding the role, perspectives and experiences of siblings is beneficial in order to monitor, inform and enhance practice. Sibling support may have a range of potential benefits: emotional, practical and, not least given the current economic situation, financial.

1 Literature Review

The development of the language associated with 'care' and subsequently 'care-giving' as terms frequently used in social policies and in political terms has meant that a variety of definitions have emerged to categorise and theorise exactly what care is. This paper draws on the ethics of care debate (Tronto, 1993) which highlights a relational and contextual view of care and caregiving. In the UK, welfare reforms and austerity measures have further reinforced the notion of individual and family responsibility to care. Emphasis is on the family to take responsibility for those in need of support. More specifically, in the UK in 2008 a White Paper (DoH 2008) made reference made to 'family carers' instead of 'parent carers'. This highlighted the emergence of a recognition of the importance of family members in the lives of people with learning disabilities (Davys et al 2010). Evidence in the literature relating to adults with learning disabilities and their siblings identifies a number of feelings ranging across a spectrum from ambivalence to enrichment to antagonism (Flaton, 2006; Zetlin, 1986). The current project found that the particularity of the individual's disability had greatest effect on the sibling experience, with challenging/behavioural and difficulties being seen as characteristics that most negatively impacted on the relationship between siblings. This confirms earlier work where the sibling relationship was compared between people with Down's syndrome and Autism (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007). Findings indicate that possibly because of the behavioural challenges associated with being on the autistic spectrum, fewer contacts and lesser input was evident between these siblings than in the group who had brothers or sisters with Down's syndrome. This mirrors other work that

looks at the adult relationship where particular emphasis is on the nature of the disability, including that by Sexton (2009) who explores issues pertaining to siblings of adults with autism.

Additional factors within the literature that appear to influence the experiences of siblings incorporate parental expectations (Bigby, 1997; Greenberg, 1999; Orsmond & Seltzer, 2007) as well as age and gender of the siblings. Previous research has focused on younger siblings (Conway & Meyer, 2000; Moyson & Roeyers, 2012; Rossiter & Sharpe, 2001) and several studies have identified that siblings need relevant and appropriate support that recognises their unique perspective. This is useful as a starting point, although when taking a life course approach, the first 18 years of one's life may be as little as one fifth of the overall life span. Studies that focus on the adult relationship include the work by Taylor et al (2008), which explores later life relationships. For the participants in Taylor's study, with one or two exceptions, there were few negative psychological effects of having a sibling with a learning disability. We know from this work that these sibling relationships were based on care-giving rather than companionship and mutual sharing. The relationship between siblings beyond childhood where one has a disability is an under-researched area. The current research recognised that it is important to focus attention towards the adult years, as relationships alter and there is a reported reduction in sibling involvement as brothers and sisters establish their own lives and families (Bigby, 1997; Hodapp & Urbano, 2007). Although care giving responsibilities fluctuate over time (Kröger & Yeandle, 2013), there are a multitude of ways families make sense of and manage caring responsibilities regardless of the context for care, for example where caring arises as a result of physical disability, age or mental health problems. In these situations the demands placed on family members, including siblings, are no less than those emanating from situations where a learning disability is the main feature. Family relationships are complex at the best of times, there is no one typical form of caring just as there is no one typical form of sibling relationship, any form of caring responsibility is likely to alter the biography of the family in myriad ways which fluctuate over time and space and alters reciprocally (Barnes, 2012).

The literature indicates that for the majority of siblings of people who have a learning disability, anxieties about the future prevail. There is a need for more support, advice and information to be given by professionals, and those professionals working with adults with learning disabilities and their families need a greater awareness of any concerns and particular features of this enduring relationship as often assumptions regarding it may be untested.

2   Aims of the research

The aims of this study were to explore the relationships non-disabled siblings have with their brother or sister with a learning disability. Additionally the study aimed to obtain their views and perspectives regarding the impact any involvement with social workers had on this relationship. The current study invited adult siblings of adults (18 years +) with learning disabilities to tell their stories: by doing this the aim is to discover and explore attitudes, hopes, feelings and fears, as well as capturing the imagination and perspectives of the impact on the non-disabled adult siblings' life. It should not be forgotten that the sibling relationship is generally the most enduring familial relationship, for as Kluger (2011) suggests: children and partners arrive too late, and parents leave too early, whereas siblings are with us for the journey, a theme now emerging much more cogently in the literature (Lamb & Sutton-Smith, 2014; Milevsky, 2011; Whiteman, McHale & Soli, 2011).

3   Data Collection, Method and Interview Schedule

In order to explore, from a sibling's perspective, the issues surrounding having a brother or sister with a learning disability, a qualitative methodology was used (Creswell, 2013), utilising semi-structured interviews as the primary method. Qualitative approaches to research can be seen as a way of rebalancing power in the researcher–participant relationship and encouraging a focus on marginalised groups, understandings and experiences (O'Connor & O'Neill, 2004). One of its strengths lies in uncovering more about people's experiences through the power of narrative and opportunities for explanation and exploration – such a design therefore locates the logic of the research within the frame of reference of the participants (Green & Thorogood 2014). In addition, as both a qualified social worker and the parent of a child with a severe learning disability, the author is acutely aware of the power imbalances present in professional interactions and as such sought to minimise these wherever possible: in this regard, the methodology referred to here achieves this aim.

Semi-structured interviews were selected as the preferred method of data collection as they allowed siblings the opportunity to express their opinions and perspectives in a private and relaxed manner, respecting the need for sensitivity in exploring highly personal issues. Semi-structured interviews also allowed the researcher the opportunity to ask spontaneous questions, recognising and responding to the sensitivities of the situation and the participants need for free expression. In addition, any questions regarding the author's own background were answered in as honest and appropriate a way as possible. In this way, the overall approach emphasised the importance and value of reflexivity, moving some way towards what Flyvbjerg (2001) and Kinsella and Pitman (2012) refer to as phronetic research with its emphasis on the responsive use of both personal and professional knowledge within the research process. As Flyvbjerg points out: "The result of phronetic research is a pragmatically governed interpretation of the studied practices…phronetic research is an analytical project, but not a theoretical or a methodological one" (2012: 140). With the use of reflection and discussion with colleagues throughout the process, due regard was given to equality and fairness. By standardizing the interview schedules, data reliability was enhanced and the possibilities for replication enhanced.

In order to recruit appropriate participants, advertisements and information were posted in several key community areas. The project was also discussed on local radio and an information sheet was distributed to local day centres for adults with learning disabilities and was subsequently included on their newsletters.

A letter that described in detail the process of the study, the objectives and practical contact details was sent to prospective participants when they made contact informally and asked for more information. When they confirmed their willingness to participate, they were sent an interview schedule in order to respond proactively to the perceived hierarchical researcher-participant relationship, and was seen as an attempt to reduce the power imbalance between interviewer and interviewee.

Inclusion criteria referred to potential participants being aged 18 or above and that they self-identified as being a brother or sister to someone who has a diagnosed learning disability.

Topic areas suggested in the interview schedule included:

- o • ¥   'Being' a brother or sister
- 0. • ¥   Their own support network
- 0. • ¥   Social Work and other professional contact - past and present
- 0. • ¥   Feelings about the future
- 0. • ¥   Perceptions of the impact of having a brother or sister with a learning disability
- 0. • ¥   Contact with others in similar situations

By making sure that siblings were aware in advance of potential topics for discussion and emphasising that they were free to ignore those areas that may be too sensitive, allowance was made in a meaningful way to acknowledge and share the power between interviewer and interviewee. In practice, all participants said they were comfortable with all interview topics, and consequently all interviews followed the same schedule. Participants were interviewed separately for between 20 and 70 minutes and, with their signed consent, narratives digitally recorded and transcribed verbatim. Questions were devised by the researcher in conjunction with academic colleagues and were taken to each interview as a prompt/guide for the interviewer.

4   Participants

Following the quest for participants, 15 people made initial enquiries for further information. Ten positive responses were received, whilst 'word of mouth' led to a further 4 participants coming forward at various points throughout the life of the project. Twelve interviews were carried out at the participant's own homes and 2 participants came to the university to be interviewed. Participants ranged in age from 18 -56 years of age.

Participants were reminded at the outset that they were free to leave the interview at any time; in addition, all were made aware of support services, including counselling services that they could access. This was important given the sensitive nature of the discussion. There was no way of knowing if these services were subsequently accessed, although no concerns were expressed or were made apparent by participants either during or following the interviews.

The recordings were transcribed verbatim and then read and re-read. A coding framework was devised to identify salient areas of discussion. This allowed for the identification of elementary thematic patterns and formations and developed the data into a more manageable set of themes. These were then refined and arranged in order to produce more global themes, so as to yield meaningful and useful results. The data was analysed methodically for recurring themes and a thematic analysis in the style proposed by Attride-Stirling (2001) was employed. This involved coding and identifying themes in a web-like network before arranging them as initially as basic themes, then more defined into organising themes and finally into what is termed global themes, which are discussed below.

5   Key Findings and Discussion

The data from the transcripts when coded produced four global themes, which reflected the views of all the participants. The themes were: 1. 'Practical issues and limitations'; 2.

'Concerns for parents'; 3. 'The nature of being a sibling'; and 4. 'Worries about the future and cuts to services'.

5.1 Practical issues and Limitations

This theme covered both positive and negative perceptions that the brothers and sisters had about their experiences of growing up with a sibling with a learning disability. All the participants recognised that their own lives were subjected to a range of limitations not experienced by their peers who did not have a sibling with a learning disability. Twelve out of the fourteen participants talked about how they viewed their experiences with varying degrees of ambivalence, while for the other two it was seen in a wholly positive manner. All participants however, regardless of the nature of their views, noted how there were restrictions which impacted on themselves as siblings and more generally across and on the whole family. The lack of spontaneity in family activities is recognised in the literature (Moyson & Roeyers, 2012; Pompeo, 2009) and was noted by all the participants:

> 'I suppose I didn't notice it until I was older, but we always went to the same holiday centre for our family holidays. Some of my friends went abroad and I would have loved that but there was no way we could have got our Eileen on a plane'.

For several participants, the practicalities of having a brother or sister with a learning disability were described as the norm for their family and life adapted to cope with that:

> 'Well, we always had to buy and cook different food for her; you know she couldn't eat this or that-but you just got on with it.

> 'Debbie could never be left on her own, so that was a real restriction on us as a family, especially after my Gran died but it's like anything I suppose you, just adjust-what choice do you have?'

All the siblings in this study felt keenly the reliance on other family members, particularly Grandparents. Reference was made to the help and support they gave and the importance of that relationship. In many cases, participants saw this as providing them and their siblings with unconditional positive regard.

The difficulties of having a 'less obvious' disability were keenly noted as were the stresses placed on families by difficult behaviour displayed by the person with the learning disability.

> 'I think it's easier if you have a disability like Down's syndrome instead of Autism or Asperger's, cos then people can see and understand-mind you, I don't always think they understand that very well either.'

5.2 Concerns for parents

Findings from the research highlighted how for some siblings a significant area of concern was for their parents, predominantly their mothers. Physically, participants had concerns regarding the mobility and health difficulties of their parent(s). Emotionally, one participant described how her Mother had used anti-depressant medication for years and was prone to anxiety and stress. Financially, three participants made reference to the fact that their mothers had not been able to gain employment, which had a cumulative and compound effect on a lack of savings or pension contributions. The contribution made by welfare benefits was recognised by one participant who gave the example of how her parents would not have a car if the mobility component of disability living allowance were not paid to her brother.

As part of the interview process, siblings were asked about the amount of support their family had received and their feelings about the adequacy of this. Responses given endorsed earlier research, which indicated how emotional support is valued over and above practical support. Some siblings noted that the very fact of having someone to talk to and to listen to affected them in many ways. Feelings of grief, loss, jealousy and envy were reported and were often linked with concern for their parents' wellbeing.

> 'My Mum is in her eighties now and I do worry how long she can go on for, mind you she has my brother with her. He always seemed to be much closer to my Mum than I was-because of his health problems I suppose; they spent and still spend loads of time together. I left home 5 years ago but don't think Johnny will ever leave. Dad's not around so I think my Mum needs him as much as he needs her-they do seem a pair though-with me on the outside.'

Two participants made reference to the fact that their disabled sibling who was still living with their parents was less than ideal, and whilst others also recognised this, they saw it as being a source of company for their parent. This was evident when one participant spoke of her Mother being recently widowed;

> 'In a way it's good he is still there…it's given her (Mother) a reason to keep on going'.

Within the United Kingdom's ageing population, a growing number of adults with learning disabilities are living with elderly parents (Cairns et al, 2014; Emerson & Hatton, 2008;), as they have for many years in spite of the view that institutionalized care was historically the norm (Collins, 2015; Jackson & Irvine, 2013). Older parents of adults with learning disabilities typically experience a range of unique challenges, including combining the management of health and social care with their day to day lives, against a backdrop of limited financial and social support (Bigby & Ozanne, 2004; Walden et al., 2000). This research provided evidence to support the claim that siblings also experience such challenges, many of which related directly to their broader concerns for their wider family. When asked about these in a general way, several respondents said that they 'overlapped' between those for their sibling and those for their parents. Such an 'intertwining' of the lives of parents and their adult children with learning disabilities was seen by some participants as being less than positive.

> 'They are a threesome-if I'm honest, sometimes I do feel a bit pushed out'.

These findings highlight the complexity of ways that siblings make sense of and develop strategies for dealing with the effects of the longevity of their parents care-giving, and their ambivalent relationship with social work and other professionals. Research has illustrated the interdependence that exists between adults with learning disabilities and their older carers (Parker & Clarke, 2002; Prosser, 1997; Walker & Walker, 1998; Williams & Robinson, 2001), and the current study found that for these siblings, this was a notable anxiety.

> 'Well, I think that is one of the reasons I didn't mind living away so much-it is very like Anne and my Dad have developed their own relationship almost as a couple-if you know what I mean, since Mum died. They have their own routine and he'd be the first to acknowledge how she is company for him'.

One participant spoke of her feelings about how she perceived that her parents' lives were 'narrowed' and constrained because of the longevity of their caring responsibilities. She

acknowledged the limitations on her own life and emphasised the reluctance of her parents to share the care of her brother, who needs support throughout the day.

> 'I wish they'd leave him with me when they go out but they won't-Mum says he wouldn't like it because our house is not familiar to him. Well it never will be if we don't start trying'.

5.3 The nature of being a sibling

Findings from this study show that the majority of participants (ten) felt that by being the sibling of an adult with a learning disability they had a greater understanding of the issues relating to learning disabilities per se. Furthermore, participants generally felt that they were more accepting of other people with learning disabilities than their peers might be. Similar findings have been noted and extant research indicates that the non-disabled sibling may also often be more selfless and responsible due to them having a brother or sister with a learning disability (Connors & Stalker 2006; Pompeo 2009). When siblings spoke of care and concern for their brother or sister, it was in terms of being responsible for them. This element appeared to be a heightened and continuous thread, which ran throughout all participants' lives. One sibling reported that she was acutely aware of the negative stigma of being associated with a brother or sister who has a learning disability:

> 'I'm ashamed now to admit it, but at the time I really wished she would just go away and leave me and Mum and Dad to it. When I was younger….. especially when a teenager, I was crippled by the embarrassment of being out with her. She had this noise she would make, like a high-pitched whine and everyone would turn to look at 'us'- it's that notion of a disabled family I suppose.'

Results from this research showed that the most frequent type of support provided by siblings was 'keeping company', followed by helping with chores, sharing mutually enjoyable activities, and providing emotional support for their parent(s). Being a sister or brother to a sibling with a learning disability alters people's lives in many different ways. It has a major significance for personal biographies, as experiences and perceptions are shaped by the cultural and social context in which these siblings lead their lives. Some siblings foresaw a lifetime of caring responsibilities in a similar manner to those of their parents, yet, interestingly, few saw themselves as carers:

> 'Well, its different really isn't it from other sibling relationships? Not in a better or worse way-just different-you just deal with whatever life gives you-I wouldn't see myself as Jane's carer but our sibling relationship is very different from the one I have with my other sister.'

5.4 Worries about cuts to services

A number of siblings described any type of practical planning for the future with professionals as a less-than constructive experience, often with pessimistic future prospects and depressing news about the health and longevity of their brother and sisters being the perceived norm. Professional staff were often perceived as being unhelpful and tied by paperwork and procedural systems they had to follow. However, there was recognition of the positive support offered by staff that worked at a day centre used by three siblings of the research participants. This was however offset by reductions in the availability of the service and its perceived, future demise:

> 'It's ironic - he used to be paid to go to the centre, just pocket money really, but it gave him a sense of worth I s'pose. Then they stopped that and he got nothing, then he even had to pay to go and now, after all that, he can't hardly go at all. It's ridiculous-he hasn't changed, rather it's the system that is at fault, and people like my brother are seen as easy pickings by those that want to make cuts'.

Siblings see support services such as day centres as being vital to the ongoing provision of care for their brother or sister. Characteristics of the adult with the learning disability are seen as significant in determining levels of stress. A higher incidence of behavioural difficulties such as aggression, self-injury and destructiveness are seen as particularly challenging and lead to increasing worries about the future from the perspective of the sibling. It is however important to note that stress for family members can have a multitude of causes, not necessarily to do with the adult with the learning disability. As Mencap (2006: 3) state: 'It's not caused by caring-it's caused by caring without the right help'.

For the siblings involved in this study, many frustrations were articulated. These were mainly due to support services and organisations not functioning as they were expected to, which caused all those involved to feel let down and obstructed. These issues further highlighted siblings' worries about the future:

> 'Well it's getting even worse now with all the cuts…God knows what it will be like for her in a few more years.'

The additional stresses that such experiences bring to the relationship between siblings cannot be underestimated. The enduring worry of financial hardship and the broader implications on the lives of non disabled siblings needs further exploration. Dealings with professionals and with representatives from local authorities were seen as overwhelmingly negative.

> 'Well, one example is that years ago my brother had a support worker who took him to the pub-then they (Local Authority) changed their criteria and said they could no longer take him out as they 'didn't fund leisure'. He hadn't changed but their criteria had'.

Research participants felt there was a lack of viable options available for the future support of their sibling. Some noted the often-temporary nature of support initiatives. One participant gave an example of a social group set up and run by volunteers, and whilst it was believed to be useful, it was only in existence for a few months. The temporary nature of such services was not seen as being beneficial, and similarly, even when statutory services were involved, few participants reported positive experiences.

Worries about future care were frequently articulated, with comments regarding the support given by agencies and social workers commonplace. Examples were given of support staff arriving late or not at all, and of inconsistencies between members of staff:

> 'I remember my Mum and Dad getting ready to go out-it must have been her birthday or something-I was going to stay at a friend's house and Marion was going to stay in the respite unit she went to a couple of times a year-then Mum got a phone call to say they had taken an emergency case and had no room for Marion after all. I can remember her being really upset about that'

The future care of their brother or sister is unsurprisingly an area of major concern for the siblings in this study, although over half reported that they felt their parents had taken the lead

without consultation with themselves or other siblings. There was recognition by siblings that their parents did not always have an awareness of options for the future care of their sibling:

> 'No one tells you anything. I think it is up to Mum to get in touch with a social worker and ask….she seems to think she'll go on caring for him for ever and then I'll take over. I would just like to know what's out there but I'm stuck you see, I can't go behind Mum's back'.

6   Discussion and Conclusions.

This research set out to examine how siblings of those with a learning disability perceived their relationship with their sibling. Each participant had their own unique perspective, and by using semi-structured interviews as the primary method of data collection, the richness and variety of feelings and experiences could be documented.

The centrality of the disabled sibling within relationships relative to the number of children within the family unit was found to be of significance. In particular, these sibling relationships have been shaped by their parents' attitude and approach to the sibling with a learning disability and, as a result, siblings have subsequently adjusted their own expectations of family life across a range of dimensions, not all of which were perceived positively.

The findings build upon and to some extent confirm those of earlier studies where the contribution(s) of siblings to the lives of their brothers and sisters with a disability is not fully recognised, highlighted by their under-representation in the extant literature and by reference to the perceptions of professionals and agencies not seeing this grouping as particularly significant (Burke, 2010; Pompeo, 2009; Taylor et al 2008).

The findings also note the importance of support groups in terms of the broader impact upon supportive sibling relationships, regardless of who organises and funds them. This is a theme articulated elsewhere in the literature (Dodd, 2004; Smith & Perry, 2004), but resonating here with much more acuity given today's 'austerity' climate (Jordan & Drakeford 2013), referred to by several participants. Likewise, this study emphasised that for those siblings who had experienced some type of group work/group care for their sibling, the response was overwhelmingly positive, even if several years had elapsed since the experience. Current socio-economic factors are clearly noted to have the capacity to impact disproportionately on this group of service users and their families, including siblings:

'When I was younger, I went to the Crocodile Club, (laughs) it was good fun - we went on trips-my Mum found out about it-it followed on from my brother getting his diagnosis. This group was just for me.'

Meeting with others who share similar experiences as a sibling provided a functional basis for emotional support and effective advocacy. Although (sibling-) support groups are for many a source of support and information, for the participants in this study difficulties arose even when they had knowledge of the groups' existence. Participants reported encountering practical difficulties in attending, not least because of their own family commitments which for some also included caring for elderly parents who were themselves caring for the sibling with a learning disability. Such complex caring arrangements, often 'taken-for-granted' belie the intense emotional experiences often accompanying these activities such that their import is not fully recognised. A key finding alluded to above was that the often temporary nature of much funding for schemes and support groups meant that for many, such groups are or were

not worth considering because the planning and organizing required was likely to lead to frustrations if the service ceased, thus accentuating feelings of isolation.

These findings have a number of implications for both professional practice and further research. Practitioners and service providers need to continue to develop their awareness and understanding of the unique challenges facing siblings and those factors referred to above that are likely to mediate both current and future responses to the needs of their disabled sibling. This is particularly important where governmental, professional and broader societal expectations are increasingly focusing on the role of the family as the main source of support, with ideologically-driven practices (Jackson and Irvine 2013) such as personalization, currently very much to the fore in terms of overarching service design and delivery structures (Ellis 2014; Lymbery 2014). It is essential that the needs of both the adults with learning disabilities and their siblings are acknowledged, validated and planned for holistically (Walden et al., 2000), but in order for this to be seen and experienced as a meaningful process, assessments and interventions must systematically identify all elements of need. By taking account of the broader range of actors within the caring nexus and the variables likely therefore to impact on plans and interventions, up to date information is essential, but as this can be difficult to obtain, particularly where assumptions regarding the 'known' needs of carers are conflated with the assumption that the needs of siblings are no different or that they do not have unique challenges facing them, increased tensions are likely, but could be minimised.

As services for adults with learning disabilities become more community-based and individualised, the need to identify and support families becomes ever-more pressing. The increasing 'individuality' of service configurations for adults with learning disabilities may prove problematic for parents and siblings who use the traditional day centre as a source of information and as an opportunity to link in with other families. Lack of information leading to feelings of isolation is a key experience shared by many in this research. The findings note that siblings need readily accessible information, and one of the principal ways of obtaining this is from other parents or siblings, or from people who know and understand their situation, by sharing experiences and solutions. An overlooked aspect of the 'modernisation' of services in their efforts to become more community based, autonomous and 'personalised' (Beresford, 2014) is the simple fact that many families rely on day centres and other familiar and trusted (re)sources like this for valuable and 'safe' sources of information. Where these are disappearing, feelings of fragmentation become apparent, and day-centre staff, in many cases having known the adult with a learning disability and their parents and siblings for many years, can no longer be contacted on an informal basis. Such people are an important source of information and support and were seen as a valued service for parents and siblings because their individual caring situations were known and they felt understood, without the inconvenience and possible emotional upset of explaining the situation and history again and again to any number of other individuals and, often, strangers. This is an important theme of particular relevance – the perceived lack of consistency in relation to services, particularly where the commissioning of services from external providers becomes more commonplace.

Siblings of adults with learning disabilities should benefit from mainstream initiatives ostensibly provided for all carers and they need to be recognised by professionals as requiring such. Difficulties can often arise though, as few siblings interviewed actually identified themselves as being a 'carer', which leads to confusion regarding policy documents and initiatives. Despite inroads being made by local authorities to engage with carers and to offer them information and choices, the majority of participants interviewed did not feel this

applied to them or that they had any 'right' to utilise those services aimed at carers. This presents an opportunity for professionals to broaden their understanding of how people perceive themselves, such awareness should be clearly articulated and acted upon – an opportunity for pragmatic responses to have clear and positive effect.

This study highlighted that to improve support for siblings, social work practitioners need to improve upon intra- and inter-agency management and communication, as well as that with parents, siblings and adults with learning disabilities. This could be achieved by developing and utilising a simple and readily available information pack (Rawson, 2012), particularly important at times of transition. The information pack could be used as a tool to signpost siblings to relevant and appropriate services as well as giving them contact details for all those involved in the life of their brother or sister. Inviting siblings to relevant and important meetings would help their understanding of the different roles professionals play and serve to foster confidence and coherency in moving towards workable and successful outcomes.

The many complex factors influencing the relationships between adults with learning disabilities and their siblings as identified in this study, including parental perspectives and hopes, gender, numbers of siblings in a family, geographical distance and other demands on siblings' time, including employment and their own family commitments must be factored into professionals' knowledge and awareness as these have been shown to be of significant import to the participants of this study. Practitioners for their part need time to read and digest research findings in terms of improving practice and extending their knowledge, as good quality practice needs to be both skilled and research-informed. For social workers, the link between theory, research and practice needs to be established and maintained throughout their career, and effective knowledge transfer partnerships can be highly effective in this regard (Farrington et al 2014).

Inequalities and differences characterise the lives of people with learning disabilities and their families, but families need to be seen as co-experts, with their views respected and listened to. This presents a challenge for practitioners to ensure that siblings' views do not obscure the views and wishes of the person with a learning disability or those of their own parents. Balancing the interests of a variety of stakeholders with each other, and with the ever-present constraints of finite resources is an on-going test to the skills of practitioners and a constant source of tension for families. Thus, partnership working needs to be developed not simply to enable carers, be they siblings or parents, to continue caring, but also to promote their broader health and well-being needs, with prominence on giving carers more choice and control over their lives as well as feeling equipped and supported in their caring role.

Despite the above findings and recommendations for policy and practice, it is important to note that a continuing cultural shift in societal attitudes towards both adults with learning disabilities and their carers needs to be more apparent. Some of the greatest restrictions experienced by adults with learning disabilities and, by association, their families are without doubt created by the way that society is organised to exclude them. This includes the negative attitudes expressed by other people and by limited and unequal service provision.

The effects of reduced mortality among people with learning disabilities (Emerson & Hatton, 2008) means that as parents age, more siblings are providing support to their brothers or sisters for an increased number of years. Thus, their needs, currently under-represented in both literature and policy, need to be more prominent. By examining such needs via individual interviews, this research has allowed us to see the differing expressions of siblings'

experiences and their perceptions of their needs, thus mitigating in some small way their under-representation as an important resource. Through this it has been apparent that for this small sample at least, their experiences with professional services raises a number of issues that require consideration and action. It was evident from the research that sibling care was central to the delivery of support and has a key role to play in promoting, supporting and developing the well being and independence of adults with learning disabilities over the longer-term.

This research makes a valid contribution to work with siblings of adults with a learning disability. It provides a snapshot of a moment in time for a particular group of people, enriching our understanding of a unique set of circumstances and experiences. The narratives of caregiving discussed in this paper note and highlight the deeply personal impact these circumstances have on the lives of siblings of adults with learning disabilities. They also articulate 'ordinary lives' situated within 'not-so-ordinary' circumstances, replete with both the trials and tribulations of 'ordinary' family experiences, yet tinged with feelings of loss around what might have been, and trepidation about what the future will look like. For these families, caregiving is an important and normative part of a broader set of relationships infused with mutuality and respect within the day-to-day activities of family life. The findings regarding the experiences and perspectives of siblings need to inform both policy and practice, and with the recent Care Act (2014) opportunities exist to make a more meaningful and functional contribution to the enhancement of wellbeing and human flourishing, notwithstanding contexts of increasing austerity and the politicization of care and social work (Gray & Webb 2013). Care giving has the potential to be a significant tool for individual and collective action, as caregivers and those in receipt of care have an impact on society and therefore the potential to influence policy and practice in informed ways is an opportunity to be exploited, particularly in the context of pursuing a more phronetic turn in such research (Flyvbjerg, 2001). Importantly such research should be fully participatory (Higginbottom & Liamputtong, 2015) and involve siblings themselves.

7   Limitations of the study

This was a small-scale research project limited by sample size, which although varied in age, lacked diversity of ethnicity. This reflects the demographics of the area in which the study took place. A more diverse participant group may have yielded previously unknown areas. This study concentrated on siblings who had a brother or sister with a learning disability, and clearly there may be many similar issues regardless of the nature of the disability that suggests myriad avenues for future research, particularly in ever-changing socio-political and economic contexts. It was not possible in this study to discuss and explore issues relating to siblings experiences that related to their position within the family, for example the number of siblings in a family, age gaps between siblings or gender of siblings, this would be useful to include in a larger study to indicate patterns, make predictions and provide recommendations. Future research might usefully consider the additional use of quantitative analyses of data utilising Q-method factor analysis (Hothersall 2017; Stephenson 1953; Watts & Stenner 2012) ideally suited to the exploration of first-person perspectives.

Footnote

Prior to the commencement of the project ethical approval was sought and granted by the university ethics committee.

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