**PERSONALISATION, FAMILY RELATIONSHIPS AND AUTISM: CONCEPTUALISING THE ROLE OF ADULT SIBLINGS**

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**ABSTRACT**

*Summary:* Current policy discourses demonstrate a weak connection to broader theoretical debates about family obligation and in particular how family responsibilities become negotiated over time and across the life course. How policy imagines family care can, therefore, be different to the actual experiences of families. This qualitative paper, using semi-structured interviews, explores the experience of a particularly neglected group, adult siblings, who have a brother or sister with autism (plus learning disability). We spoke to 21 adult siblings, met with 12 of their siblings with autism and talked to 11 health and social care professionals.

*Findings:* Our analysis suggests that connectedness and commitment, which remained subject to continuous redefinition by all family members, informed sibling relationships Practitioners, however, struggle to engage with this complexity, thereby undermining the extent siblings’ relationships can be realised.

*Application:* The paper concludes that policy initiatives are at risk of becoming an uneasy compromise, in which the need to offer choice occurs alongside the ‘problem’ of managing family care. Sibling relationships are more than simply ‘being of’ or ‘belonging to’ a family. They are dynamic, subject to contingency and negotiation. Interventions should be formulated to work with these assumptions, without presupposing a definite experienced fixed in time and space. This would not only maximise the disabled siblings’ quality of life, but also ensure a more productive and fulfilling context for family relationships.

**KEY WORDS:** Autism, learning disability, sibling relationships, family caring, personalisation.

Current policy agendas across a range of post-industrial societies emphasise the role of personalisation and person-centred care in empowering people with disabilities (Costigliola, 2010). Understanding the views of disabled people is of primary importance in facilitating these policies, although families are also recognised as having a role in enabling the person with disability to fulfil their potential (Boxall and Dawson, 2009). Personalisation, however, can have a weak connection to theoretical debates about family obligation and in particular how family responsibilities become negotiated over time and across the life course (see Pickard, 2011). How policy imagines family care can be different to the experiences of families (Finch, 2007); and the failure to understand context and contingency creates potential and long standing difficulties, in which neither the needs of the disabled person nor their families are met.

This might seem surprising given how the increasing policy interest in family care has led to a growing theoretical sophistication and an expanding empirical research base (Glendinning, 2010). A potentially misleading impression that we know all there is to know about family carers can, however, lead to complacency. Reading the latest research account can create a sense of *deja-vu*, as we again learn about the difficulties faced by carers; the problems they face in having these difficulties recognised and responded to; and the financial savings they make for the State (see Carers UK, 2010). Such research, although reflecting the realities of caring for many, can sometimes encourage policy and practice to focus on one, individual (and frequently, ‘heroic’) primary care giver - who is usually a parent, spouse or adult child - rather than exploring a more collective and strategic response (see Northhouse et al., 2010). Policy can specifically fail to engage with the diverse experiences associated with family life, where most if not all family members are likely to be involved to some extent in ‘caring’ (Finch and Mason, 1992).

Nearly twenty years ago, Twigg and Atkin (1994) noted how little was known about the caring roles of adult siblings, observing that their contribution was often overlooked by policy. Little has changed since then and the inability of policy to engage with and conceptualise sibling relationships, once beyond childhood, has important implications for current debates (Conway and Meyer 2008). Adult siblings can play an equally important, albeit different role to parents, when offering support to a disabled brothers or sisters. They can, if willing, offer a supportive, long-term relationship, which can assume particular significance for siblings who have difficulties in communication and social understanding and whose social contacts are limited to paid staff. However, UK Government programmes and guidelines, although emphasising the role of family members in enhancing the lives of people with learning disabilities, while advocating the use of ‘whole- family’ approaches in planning and providing care (DoH, 2010), rarely mentioned adult siblings. A concern about older carers of people with learning disabilities as they age and die (Bowey and McGlaughlin, 2007), for example, has not led to a strategic interest in the potential role of the next generation in taking on some of these parental roles (Davys et al., 2010). It is, therefore, not surprising if social care practitioners pay little attention to adult siblings and their potential role in their brother or sister’s life (Mansell and Wilson, 2010).

The neglect of siblings, however, is not simply an expression of policy but evokes a more fundamental theoretical tension – often associated with late-modernity - in how we come to understand family care (Pickard, 2011). Recent policy accounts of personalisation and family combine a concern with a reflexive, autonomous self, alongside a more long-standing, instrumental interest in how individuals ascribe meaning and purpose to what they do, as the basis of enabling the State to manage complex social problems (see Atkin at al., 2011). To this extent, claims to self-actualisation and choice occur alongside the negotiation of normative values and assumptions, which delineate ‘correct’ social and family roles, in ways that support social stability (Bauman, 1996). This is how the self-directing propensities of citizens are connected to a broader set of more collectively defined aspirations (Rose, 1998). Policy statements such as ‘carers are fundamental to strong families and stable communities’ (DoH, 2008, p9); and a recognition that our society ‘depends to a large degree on the continuation (family) carers provide (DoH, 2008, section 1.17) demonstrate such expectations. Individuals, therefore, have to decide what is the ‘right and proper course of action’ (Pickard, 2011, p475) in which their own preferences are negotiated in relationship to their interpretation of broader societal expectations and aspirations (Taylor, 2004).

This is one of the reasons why Janet Finch (2007) suggests that an interest in how families ‘display’ themselves is more analytically productive than focusing on - and trying to define - what families do (or do not do). Consequently, family life is at best considered an adjective rather than a noun (Finch, 2007: p278); understood as a set of activities, which takes on a particular meaning, at a given point in time (Morgan, 1996). Families change and evolve; subject to continuous redefinition and negotiation. Rooting our understanding of ‘doing family’, in a way that captures a sense of connectedness and commitment is, therefore, likely to be a more appropriate starting point for policy and practice (Williams, 2004). Personalisation is a specific part of this connectedness, particularly since it is said to encourage individuals to actively engage with their disability, using personal, family (and community) resources as a means of gaining greater control over what is happening to them (Glenndinning, 2010).

**DOING THE RESEARCH**

Our findings are taken from a nationwide UK qualitative study, which explored siblings’ perspectives on having a brother or sister with autism and learning disability; and in particular explore how their relationships were negotiated and given meaning across the life course. The material generated in answering this broad research question was used to question explicitly the extent to which policy debates about personalisation engage with siblings’ experience. We chose a qualitative methodology because it is particularly effective in exploring complex, sensitive and potentially contested themes, while in-depth interviews enable us to understand how people interpret their experiences (Denzin and Lincoln, 1998).

After gaining ethical approval from a University Governance Committee, we explored the experiences and perspectives of twenty-one adult siblings, aged between 25 and 67, of people with autism plus a learning disability from seventeen families in different parts of England (see table one). We focused on siblings whose brother and sister had severe autism and learning disability because they have some of the highest and most complex support needs. The eventual sample consisted of fourteen women and seven men, recruited through third sector networks, who between them had eleven brothers and six sisters with autism and a learning disability. Apart from two young men still living with their parents, the siblings with autism lived in residential homes or supported living. Siblings varied in how often they met up, from around once a week if nearby, to a few times a year if they lived at a distance.

**[Table one here]**

In focusing our interviews, we used a guide, informed by specific topics, to facilitate ‘guided conversations’ (Fielding, 1993: 144). We wanted to cover broadly similar topics with our respondents, to ensure we could compare their responses, while at the same time, create an environment that enabled them to reflect on their specific and unique experience of autism. We asked adult siblings about their experiences of family life; their current relationship with their sibling and how this had evolved; and their future hopes, plans and concerns for both themselves and their sibling. They were also questioned about their contact with professionals, such as teachers, speech and other therapists, health and social care staff. Interviews took place at locations across the UK, in the respondent’s own home. At the end of the interview, siblings were asked to nominate someone they had met or knew of who had been involved in arranging or providing care to their brother or sister with autism.

This generated a sample of 11 professionals, who we asked about their and their organisations’ experience of working with siblings. Again, we focused our interviews by using a topic guide. We were interested in getting professional to talk about their current engagement with siblings and their views on the extent to which service agencies should work with siblings. We were also interested in asking practitioners to comment on the findings from our interviews with siblings. All the professionals we spoke to worked in social care and included current or past key workers, house, care or day service managers in both residential care and supported living settings or local teams. Practitioners working for care providers represented seven different organisations, five of which offered autism specific support services.

Finally, to gain a better understanding of the sibling relationships from the perspective of both parties, the researcher met with 12 siblings with autism, such as on a picnic or walk or in a café and in all but one instance with their brother or sister present. (The researchers having taken their advice about what sort of meeting would suit the person with autism.) Engaging adults with autism, who have additional difficulties with communication, is far from straightforward, although more visual techniques offer an opportunity to elicit their views, particularly if negotiated with a person who knows them (Mitchell et al., 2009). We, therefore, used family photos to evoke memories, when meeting with both sets of siblings, to generate a discussion about family life. In some cases, siblings made a scrapbook or collage of people and activities that they enjoyed together. This not only generated discussion but provides the research team with some insight in to the disabled sibling’s life. We captured this with written field notes and the use of photographs. The non-disabled siblings showed considerable skill in facilitating these meetings, which demonstrated mutual affection and an individualised communication style, based on long-term shared understanding and family experiences.

All interview material was audio-recorded (with permission), transcribed and organised according to analytical headings using Atlas-ti. Detailed familiarisation with transcriptions and field notes enabled the identification of key themes and relationships between categories. Our interpretation was further assisted through two feedback sessions with twelve sibling participants along with suggestions from the project advisory group. These discussions helped confirm and prioritise themes, in addition to the key messages for policy and practice. In the case of interviews with siblings, we began by identifying themes relevant to an interview, which were then interrogated in relation to each individual account, as means of understanding a particular case; compared across cases by highlighting potential similarities and differences: and finally, related to those characteristics of the respondent that could be reasonable justified as an explanation which mediated experience (see Silverman, 2004). Material from practitioners’ interviews was compared with the themes identified from the sibling interviews, so as to draw out similarities and differences between the two perspectives, in a way, relevant to policy and practice. To this extent, our overall aim was to move beyond a semantic and descriptive account of specific interviews towards a level of analysis in which themes were explicated within existent and emergent theory and debate. Consequently, a constructionist rather than realist or essentialist approach informed the analytical process (see Riseman, 2009).

**PRESENTING THE RESEARCH**

In bringing together our theoretical interests with our empirical material, we offer an analysis, which connects the social meaning of family relationships with the more explicit policy assumptions associated with personalisation. Our intent is to privilege individual sibling accounts and their inherent complexity. To this extent, expressing preferences, while negotiating normative assumptions informing choice and duty remained a legitimate exercise for those we interviewed. This represented the means through which families were displayed. Our account demonstrates the continuity of the sibling relationship. The nature of this relationship, however, is sensitive to time and space: and at times ambivalent. It is also a reflection of siblings’ on-going struggle in ensuring their relationship is recognised by practitioners. In exploring this further, we connect siblings’ experiences with policy and practice, by considering them alongside the accounts of practitioners, with whom they have contact. All names appearing hereafter are anonymous and we have removed any contextual information that could identify respondents.

**Displaying sibling relationships**

Our findings confirmed that sibling relationships were lifelong and reciprocal, often characterised by strong, if ambivalent feelings and loyalties (see also Cicirelli, 1995). This was captured well by one of our respondents, who described having a brother with autism, as ‘the soundtrack to my life’. Siblings often talked of a life-long bond, albeit one highly sensitive to context in which the present was reconciled with the past (see also Gass et al., 2007). This was how reciprocity became balanced alongside an obligated connection, in which duty could be seen as an expression of a loving relationships. The broader literature describes adult sibling relationships as ‘taken-for-granted’ but ‘not indifferent’ (Connidis 1992; p232). This is the normative basis of on-going contact (Whiteman et al., 2011) and one with which the siblings we spoke to could identify. The context of autism, however, created a specific dynamic, which while connecting with these normative assumptions, became mediated by a siblings’ strong sense of responsibility, associated their brother or sister’s disability. They, for example, spoke of their siblings’ vulnerability and of their need to protect them. A brother in his early-forties explained:

I would have said that’s all the way been, been the same all the way through life with her and it probably developed there. But obviously I looked out for her because there was nobody else around and that’s why we are sort of close together.

Siblings accepted their need to care, while at the same time realising how these responsibilities impacted on their lives. This created a potential source of ambivalence, which could emerge at various points, as family relationships evolved. Many siblings recalled how early family life revolved around the needs of the child with autism. Despite the best efforts of their parents, most siblings described family life as ‘chaotic’ and a ‘struggle’. Half of our sample, for example, had sought formal counselling to help make sense of the past, which they associated with a re-occurring sense of depression, low self-esteem or anger. Sometimes these feelings were triggered by an event such as losing a job or the breakdown of a relationship, which caused them to dwell on the past, as a way of explaining the present. Dealing with the ensuring resentment can be an important part of any negotiated family relationship (Cheal, 2002): and one for the siblings we spoke to never quite resolved. Negotiating this occurred alongside the need to normalise their relationships with their sibling (see also Woodgate et al., 2008). A sister, in her mid-forties, explained:

I mean it’s just who you are…It’s normality, isn’t it, for an autistic sibling, that’s your normality, and I would have thought it very strange to have siblings who aren’t autistic.

Maintaining normalcy, however, remained fragile, as constant reminders of difference and loss became reconciled alongside a choice to maintain a supportive and caring relationship. Negotiating independence when leaving home, for example, could pose particular dilemmas. When they first left home siblings often relished their new freedom, but some began to feel guilty and worry about those they left behind. This again made them feel distanced from their apparently more carefree peers. Those who did not leave home, when in their late-teens or early twenties, found it increasing difficult to move out from the parental home, particularly since they were aware of how much their parents and their sibling with autism relied on them. This explains why several siblings said they decided to live close to their parents, so they could continue to help out. In at least one case, a sibling moved back with their parents to help with their sibling’s care. Other siblings indicated that they could only move on with their own lives once their brother or sister had themselves made a successful transition into adulthood. A sister in her mid-thirties explained a frequently expressed dilemma evident in other sibling accounts:

I didn’t really want to leave. There was a lot of guilt. Watching Thomas and, just wanting to be I suppose to be there around to look after him, but not, also at the time perhaps not realising that I needed to start my own, you know, sort my own life out.

A few siblings – including brothers and sisters of those we interviewed - made a conscious decision to move far away from the parental home, thereby creating a sense of distance.

A sense of duty and responsibility, reconciled within the constraints of choice, continued to the present day. Most siblings described and demonstrated a close, affectionate relationship; even those who recalled resentment and anger when growing-up. A brother in his forties said:

I think it’s just nice to spend time with her and being part of her life and she sees me as part of her life…having that bond there.

Many others talked of an enduring personalised commitment, albeit one moderated by the difficulties involved in establishing and sustaining a mutually supportive and reciprocal relationship with a person with autism. Siblings often reflected on the difficulties of juggling their feelings of love and protectiveness for their brother and sister, with their sadness and frustration at the limited reciprocity in their relationship. A sister in her late twenties remarked:

You love him to bits and you have these breakthrough moments that just make everything wonderful, but then a lot of the time you think this isn’t rewarding, this is just hard.

Some specifically expressed a sense of loss at not having a typical, mutual sibling relationship, while others again attempted to normalised this, by saying they knew of siblings, who were not especially close (see also Connidis, 1992). Nonetheless and whatever the level of contact, they saw themselves as peers, of the same generation, who could offer something different from their parents. A sister in her mid-thirties said:

I just have an incredible love for him, that I don’t feel I have for anyone else…Our relationship is unique and maybe it’s just an increased sense of understanding him.

In realising these relationships siblings also had to negotiate other preferences – and assumptions - associated with fulfilling other social and family roles. Forging ties and loyalties were, therefore, played out in and impacted by a unique family context (see also Orsmond and Seltzer, 2007). Connectedness and commitment, which is constantly evolving and subject to continuous redefinition, defined sibling relationships: a negotiation of ‘a never ending cycle of biographical appraisals’ (Williams, 2000: p61), involving active formulation, reconstruction and ‘recasting’, constantly reconciling past, present and future (see Beck, 1995). Typically, for example, sibling’s contact with their disabled brother or sister was mediated by their busy and unpredictable lifestyles; and their family, social and work commitments. These commitments presented a different set of obligations and choice, interceding in their relationship with their siblings. Many siblings found this helpful in establishing boundaries in their relationship with their disabled sibling, which they hoped others would respect. Juggling choice alongside a range of different responsibilities, however, was not straightforward.

Siblings were especially aware of how their lives were sensitive to changing life circumstances. Those beginning their careers, establishing relationships with a new partner, caring for young children had a different set of expectations and choices available to them than say those siblings, whose own children had now left the family home. Indeed these siblings often commented that they now had more time to devote to their sibling with autism. Consequently, relationships were not fixed, but altered over time and according to circumstance. In negotiating this, siblings were equally sensitive to the changing needs of their sibling and parents. All siblings, for instance, expected to take on more responsibilities over time, such as those associated with financial and care arrangements. Siblings were partly motivated by helping gain peace of mind for ageing parents, alongside a need to navigate a potential end to the relationship between their parent and disabled sibling, in a way that would cause least distress to their brother and sister. For some, this meant rekindling or even reinventing their relationship with their autistic sibling. Even when navigating increasing responsibilities, siblings remained reluctant to be seen as formal carer - at least in a way defined by policy – and expressed a continued desire to be seen as brother or sister. This was seen as being more consistent with their sense of family obligation.

**Expectations of social care and personalisation**

Siblings – as we have seen - wanted a fulfilling life for their brother or sister and comparisons with their own lives and the choices available to them were often a source of sadness. A brother in his mid-forties explained:

I think she would have been, she would have loved to have been married and had a family…But I mean she loves my daughter.

Most siblings - whatever their view of their sibling’s care arrangements - were very conscious how support was vulnerable to organisational changes and policy shifts, thereby creating uncertainties for their brother or sister and for their own future responsibilities. Several expressed particular anxiety about the continuity of positive support arrangements in what to them, seemed the never ending re-organisation of social care. Some siblings did see positive opportunities arising from personalisation, while others feared changes, which they believed would be driven by the need to save resources, rather than the needs of their brother or sister. They used previous experiences to support this view. Such anxieties were compounded, by siblings’ uncertainties over their legal status or about the extent they could insist on becoming involved in their sibling’s care.

According to siblings, practitioner support in facilitating greater involvement in their autistic brother or sister’s life remained variable. Examples of good practice although mentioned, remained rare. Most siblings felt they had to be proactive and put themselves forward, while also expressing frustration at being expected to accommodate the limitations of the care system and assuming responsibility for understanding how it worked. This added to the difficulties of evolving a consistent and continuous involvement in their brother or sister’s life. Many siblings commented on how they lacked confidence when engaging with care professionals, a situation sometimes made worse, as several felt unfairly judged by social care staff. Siblings wanted to be supported in whatever role they chose to adapt. A sister in her late-fifties said:

She’s my sister, I love her, but I don’t have the sort of relationship that I have with other people because she can’t understand the way I think and probably I can’t understand the way she thinks. But I’m totally dedicated to her welfare and want her to have as much fun and enjoyment in life as possible and, you know, be happy in herself, and when things go wrong, I will always try and sort it.

In maintaining what siblings regarded as an appropriate supportive role, they were conscious of struggling against policy assumptions that regarded them as a resource (see Twigg and Atkin. 1994). Many siblings remarked that they only seemed to be considered when a problem emerged, with little sense on the part of service practitioners that previous and on-going negotiation, within the context of a sustained family relationship, could make the solving of a current problem a lot easier. Further, negative instances of social care support, could not help but evoke a sibling’s more long standing distrust of service intervention. A sister, in her late-twenties, explained:

I’ve had so much lip service, and I think don’t you dare patronise me, I know far more about this than you do (laughs) when it comes to Jack I sort of think I’m the expert, you know, and we’ve lived with him and we’ve known him all his life, you don’t know him….different ideas come in and out of play, but actually what needs to endure is that the people who have the best interests of that person at heart, need to be the ones considered and have their say.

Several siblings connected the failings of early interventions to their current lack of confidence when dealing with their brother or sister’s difficult and upsetting behaviour; and in developing meaningful communication. Evidence supports these assumptions. Early understanding and explanations of autism help siblings accommodate their brother or sister’s behaviour in the longer term (Ross and Cuskelly, 2006). Siblings argued that being able to make sense of their sibling’s autism - both in coming to terms with condition and in being able to explain it to other – helped facilitate their relationship.

Siblings felt they were able to provide long term and meaningful support beneficial to the person with autism. However, practitioners’ concern for the immediate and fixed, which reflected how they managed complexity, meant many overlooked siblings’ potential contribution. Practitioners’ lack of enthusiasm for facilitating sibling relationships took various forms and is initially driven by what they regarded as their primary concern; meeting the needs of the person with autism. This they argued was consistent with good practice, although it also offered a broader expression of how they conceptualised the broader moral, social and legal standing of sibling relationships, which they saw as offering a weaker form of obligation than say parental relationships (see Horwitz et al., 1992). Consequently, most practitioners, although recognising that siblings could be ‘a lifeline’ for those they supported, particularly as parents aged, did not see it as their responsibility to facilitate such relationships. A few practitioners specifically expressed concerns about pressurising siblings in to maintaining contact. A team leader working in a residential setting explained:

And I think, you know, possibly we could be more proactive and encouraging. But then we don’t want to sort of overstep the line and say, you know, this is what you should be doing for your sibling. We very much leave it up to the individuals and as, as the majority of our service users don’t tend to have very deep connections with individuals, we encourage those connections that are there to, to stay present.

Practitioners were more at ease at dealing with individual relationships – usually a parent - rather than family collectives, where family responsibilities are more fluid and difficult to support. Several practitioners specifically pointed to a lack of capacity to support siblings. They were equally aware of how they needed to make their role manageable. Attempting to balance many different and possibly conflicting demands was seen as creating far too many difficulties, which might prove impossible to resolve.

A more general reluctance to engage with siblings, however, could also disguise a lack of skills on the part of practitioners (also see Dorr & Virgo, 2011). Without appropriate training and opportunities, practitioners were likely to fall back on their own assumptions, values and expectations. This explains why some practitioners felt comfortable making broad judgements about siblings, often without knowing anything about an individual’s life or their previous experiences. Confirming siblings’ suspicions, a few practitioners were critical of those who maintained limited or sporadic contact. One practitioner bemoaned how siblings might become involved during a crisis but then ‘go back to only seeing them once a week’. Practitioners also cited examples of siblings who they regarded as irresponsible or possibly abusive in their relationship, although when probed, they admitted such instances were rare and often cited examples from other practitioners’ experiences. Nonetheless, such views can have a disproportionate influence on how they saw siblings; further justifying their reactive and cautious approach.

Further, aspects of autism might have encouraged a certain detachment by staff. Difficulties in social understanding and ways of communicating make rapport difficult to sustain with someone who has autism. Such impressions could manifest themselves in practitioners’ interpretation of family relationships. One practitioner remarked how people with autism: ‘don’t have very deep connections with individuals’. Another said that people with autism were interested in other people for what they could get out of them. Such attitudes are far from unique among those working in autism and dehumanising attitudes in services may be more prevalent than sometimes imagined (Robinson & Chenoweth 2011). People with autism may need support to enjoy human contact and develop attachments, but there is no evidence that their emotional needs for such bonds are any less than anyone else (Flood and Perry, 2008). Practitioners, however, struggled to facilitate this while such views further justified their lack of engagement in facilitating relationships among siblings (see also Arthur 2003).

**CONCLUSION**

Connectedness and commitment, which is constantly evolving and subject to continuous redefinition, define sibling relationships. Practitioners, however, struggle to engage with this complexity, thereby undermining the extent siblings relationships can be realised. This is despite the broader policy emphasis on ‘whole family approaches’ when facilitating policies such as personalisation. The siblings we spoke to talked of a strong, loving relationship, albeit one characterised by ambivalence. Admittedly we have to accept the intensity of this relationship described in this paper was probably a reflection of our sampling strategy. The siblings we spoke to, wanted to care. Even when there at times in their lives when they struggled to fulfil their sense of obligation, they still had a vested interest in what happens to their sibling. Family relationships, however, do not have the same consistent meaning for all members and while some are supportive, others might not be. This is the challenge facing social care. Variability - often confused with inconsistency - is what practitioners especially struggle to accommodate. Whereas for siblings, variability is a seen as a normal feature of sibling relationships and one with which they felt service delivery should be able to work with.

Returning to our initial theoretical observations, siblings’ experience suggest personalisation is at risk of becoming an uneasy compromise, in which the need to offer choice occurs alongside the ‘problem’ of managing disability and family care (see Sointu, 2005). In the first instance, practitioners tend to assume rather than negotiate preferences. They can sometimes fail to understand how adult sibling relationships are rooted in unique but complicated past experiences and contexts, while at the same being dependent on current and future circumstances. That such a relationship can provide a consistent thread of care, commitment and concern, is balanced against its necessarily contingent nature, which is sensitive to place, time and context. Given the fluid nature of many sibling relationships, practitioners felt it was the responsibility of the sibling to negotiate contact with their disabled brother or sister. This explains their generally reactive approach, which could be further justified by them pointing to the difficulties of episodic contact for the person with autism. Practitioners’ need to engage with the preferences of those with autism should, of course, not be underestimated. Practitioners’ caution, however, could reflect a more defensive position, in which a commitment to a disabled person’s preferences became interchangeable with operational concerns to make the complex simple. We had little evidence, for example that service organisations had attempted to understand what the person with autism wanted: often making assumptions on their part rather than offering genuine choices. Underlying this, were assumptions that those with autism struggled to maintain meaningful and fulfilling family relationships.

Siblings, for their part, expressed frustration, feeling professional practice thwarted their attempts to do what they regard as the ‘right thing’ (see Mayer and Rankin, 2002). This is an example of how policy and practice can come to define families, as much as the individuals who participate in them (see Giddens, 1991). Siblings feel the onus is on them to maintain meaningful contact. While they accept this is an expression of individual preferences, negotiated in consultation with their brother and sister as an end in its own right, they are equally aware of how their involvement can benefit service delivery. Our siblings would like practitioners to establish how each could help the other, in the spirit of ‘co-workers’; alongside identifying the kind of support and involvement siblings would find helpful, more in keeping with the idea of ‘co-clients’ (see Twigg and Atkin, 1994). At an individual level, siblings wanted services to be sensitive to the level of involvement different siblings might want in their brother or sister’s life, while bearing in mind that this involvement may fluctuate over time, depending on other commitments. To some extent, person centred planning offers an ideal opportunity to facilitate this, particularly when new care arrangements are been discussed or individual budgets set up. Such plans could include the sorts of contact siblings would like with their brother or sister; the information held by siblings, such as early activities and other family members; and the support they would like from care providers, such as information about their sibling’s condition and ideas about how best to engage or communicate. What is recorded should be agreed with siblings and – if possible - the person with autism. Person-centred approaches could also help develop wider networks for the person with autism, which could be supportive to their siblings too.

Adult siblings have a wealth of knowledge and experience which can enhance not only their brother or sister’s life, but provide a valuable contribution to service delivery. Becoming more ‘sibling aware’ and recognising, valuing and supporting siblings could, therefore, be a keystone to progress in social care. This would not only maximise the disabled siblings’ quality of life, but also ensure a more productive and fulfilling context for family relationships, which would be particularly beneficial at times of transition. This would also have the potential to save resources, by turning a potential crisis into a more managed and negotiated event. At present, however, siblings feel it is their responsibility to make a success of policy. In facilitating sibling involvement, policy and practice communities perhaps need to question how they define and ‘imagine’ sibling relationships, in a way that enables them to respond to the needs of people without recourse to generalised and fixed notions of family relationships. Sibling relationships are more than simply ‘being of’ or ‘belonging to’ a family, but an expression of a person’s negotiation of multiple identities within different social and historical contexts. In addition to reflexive families able to exercise choice, we also need reflexive practitioners, able to apply critical insight, as they respond to diversity and more specifically, a person’s circumstances and definitions of what they believe their family to be. Policy makers find personalisation attractive and in particular its association with self-empowerment and choice. Nonetheless, to ensure a family engagement which benefits the person with autism, practice needs to accord with the ways in how people ‘display’ families. Debates on personalisation - and an interest in how emotional and social resources enable individuals to counter the more negative effects of disability in a way that facilitates successful coping and greater choice - assume significance in relation to this process.

If we are to re-capture personalisation debates in a way that can benefit the person with autism, we need to engage with the dynamic and complex nature of family life. This enables us to see family experience as social, iterative and dynamic, subject to contingency and negotiation. Interventions can then be formulated to work with these assumptions, without presupposing a definite experienced fixed in time and space. This suggests a more pluralistic response to personalisation and an awareness of how people adapt to their circumstances. Some of the policy literature, especially in long standing conditions, has begun take note of this; emphasising the broader discontinuity between policy and individual accounts, while reminding us of the political nature of such interventions (see Bury et al., 2005). Our account would support this. Policy should avoid imposing generic, standardised and individualised definitions of family caring; and adapt a less instrumental and more contextualised and nuanced approach to family relationships. Personalisation and family life is socially negotiated, defined by the social space in which it takes place. Recognising his would not only benefit the person with autism, but also their family members, thereby creating a more conducive setting in which to enact policy and practice.

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**REFERENCES**

Arthur A. (2003) ‘The emotional lives of people with learning disabilities’*, British Journal of Learning Disabilities* 31(1) 25-30

Atkin, K. Stapley S. and Easton, E. (2010) **‘**No one listens to me, nobody believes me: self-management and the experience of encephalitis’, *Social Science and Medicine*, 71(2), 386-393

Bauman, Z (1996) *Intimations of postmodernity*, London: Routledge.

Beck, U. (1992) *The risk society*, London: Sage.

Bowey. L. and McGlaughlin, A. (2007) ‘Older Carers of People with Learning Disabilities confront the future: issues and preferences in future planning’, *British Journal of Social Work*, 31 (1):39-5

Boxall, S and Dowson, P (2009) ‘Selling individual budgets, choice and control: Local and global influences on UK social care policy for people with learning difficulties’, *Policy and Politics,* 37(4): 449-515.

Bury, M., Newbould, J. and Taylor, D (2005*) A rapid review of the current state of knowledge regarding lay led self-management of chronic illness*, London: National Institute of Clinical Excellence.

Carers UK (2009) *Facts about carers*, London: Carers UK.

Cheal, D. (2002) *Sociology of Family Life,* London: Palgrave Macmillan.

Cicirelli,V. (1995) *Sibling relationships across the life span* New York: Plenum Press.

Connidis, I. (1992) ‘Life Transitions and the adult sibling tie’, *Journal of Marriage and the Family,* 54(4): 972-982.

Conway, S. and Meyer, D. (2008) ‘Developing support for siblings of young people with disabilities’, *Support for Learning* 23(3): 113-117

Costigliola, V. (2010) ‘Healthcare overview: global process of personalisation in medicine’, *EPMA Journal*, 1: 525-528

Davys, D., Haigh, C. and Mitchell, D. (2010)’ Futures planning, parental expectation and sibling concern for people who have a learning disability’ *Journal of Intellectual Disabilities*, 14(3): 167-183

Denzin, N.K. and Lincoln, Y.S. (1998) *The landscape of qualitative research*, London: Sage.

Department of Health (2008) *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own,* London: DoH

Department of Health (2010) *Carers and Personalisation: improving outcomes,* London: DoH

Dorr H. and Virgo L. (2010) *Good Practice in Involving Family Carers in your Workforce Development: the what, why and how*, London: Mencap

Fielding, N. (1993) ‘Interviewing’ in Gilbert, N. (ed) *Researching Social Life*, London: Sage

Finch, J and Mason, J (1993) *Negotiating family responsibilities*, London: Routledge.

Finch, J. (2007) ‘Displaying Families’, *Sociology*, 4(1), 65-81.

Flood A. and Perry E. (2008) Autistic spectrum disorder and attachment : where are we now? *Clinical Psychology Forum* 185, 20-26

Gass K., Jenkins J.and Dunn J. (2007) ‘Are sibling relationships protective?’ *Journal of Child Psychology and Psychiatry* 48(2): 167-175.

Giddens, A (1991) *Modernity and self-identity*, Cambridge: Polity Press.

Glendinning, G (2010) ‘Reforming adult social care: what can England learn from the experiences of other countries?’ *Quality in Ageing and Older Adults*,

Horwitz, A.V., Tessler, R., Fisher. G., and Gumache, G.M., (1992) ‘The role of adult siblings in providing social support’, *Journal of Marriage and Family*, 54(1); 223-241

Mansell, I. and Wilson, C. (2010) ‘It terrifies me, the thought of the future’: listening to the current concerns of informal carers of people with a learning disability’, *Journal of Intellectual Disabilities,* 14(21), 21-31

Mitchell, W., Franklin, A., Greco, C (2009) ‘Working with Children with Learning Disabilities and/or who Communicate Non-verbally: Research Experiences and their Implications for Social Work Education’, *Social Work Education*, 28(3): 309-324.

Morgan, D.H.J. (1996) *Family connections*, Cambridge: Polity Press.

Northouse, L.L., MC Katapodi, M.C., Song, L., Zhang, L. and Mood, D.W. (2010) ‘Interventions with Family Caregivers of Cancer Patients: Meta‐Analysis of Randomized Trials’. *Cancer*, 60(5): 317-339.

Orsmond G. and Seltzer M. ( 2007) ‘Siblings of individuals with autism spectrum disorders across the life-course’, *Mental Retardation and Developmental Disabilities Research Review* 1(4): 313-320.

Pickard, S. (2010) ‘The good carer: moral practices in late modernity’, *Sociology*, 44(3), 471-487.

Riessman, C.K. (2008) *Narrative methods for the human sciences,* Thousand Oaks: Sage.

Robinson S. and Chenoweth L. (2011) Preventing abuse on accommodation services: from procedural response to protective cultures *Journal of Intellectual Disabilities* 15 (1), 63-74

Rose, N. (1999) *Powers of freedom*, Cambridge: Polity Press.

Ross P. and Cuskelly, S. (2006) ‘Adjustment, sibling problems and coping strategies of brothers and sisters of children with autism spectrum disorder’, *Journal of Intellectual and Developmental Disability* 31(2): 77-86.

Silverman D. (2004) *Doing Qualitative Research: A Practical Handbook*. Sage: London.

Sointu, E. (2005) ‘The rise of an ideal: tracing changing discourses of wellbeing’, *The Sociological Review*, 53(2), 255-74

Taylor, C (2004) *Modern social imaginaries*, London: Duke University Press.

Twigg, J and Atkin, K. (1994) *Carers Perceived*, Buckingham, Open University Press.

Whiteman, S.D., McHale, S.M and Soli, A. (2011) ‘Theoretical perspectives on family relationships’, *Journal of Family Theory and Review*, 3, 124-139.

Williams, F. (2004) *Rethinking families*, London: Calouste Gulbenkin Foundation.

Williams, S. (2000) ‘Chronic illness as biographical disruption or biographical disruption as

chronic illness?’ *Sociology of Health and Illness*, 22(1), 40-67.

Woodgate R., Ateah,C. and Secco, L. (2008) ‘Living in a World of our Own: the experience of parents who have a child with autism’, *Qualitative Health Research* , 18(8): 1075-183

**Table 1: Sample of adult siblings**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Gender | Age  | Own Children | Other Siblings | Age and sex of sibling with autism |
| Female | 27 | None | None | 25 (male) |
| Female | 30 | None | None | 28 (female) |
| Male | 48 | Two sons | None | 50 (male) |
| Female | 27 | None | Sister  | 31 (male) |
| Male | 39 | Daughter and son | Brother and step sister  | 37 (male) |
| Female | 48 | Daughter and two sons | None | 46 (male) |
| Female | 28 | None | None | 24 (female) |
| Female | 34 | None | Sister and brother  | 26 (male) |
| Female | 36 | None | Sister and brother  | 26 (male) |
| Male | 49 | Two sons | None | 45 (male) |
| Male | 33 | None | Two sisters  | 26 (male) |
| Female | 25 | None | None | 24 (male) |
| Female | 45 | Three daughters  | None | 40 (male) |
| Female | 50 | Three sons  | Sister  | 43 (male) |
| Female | 51 | Daughter  | Sister and brother  | 45 (female) |
| Male  | 44 | Daughter  | Two sisters  | 45 (female) |
| Female  | 49 | Daughter and two sons  | Sister and brother  | 45 (female) |
| Male | 67 | None | Two half brothers | 65 (female) |
| Female | 33 | None | Sister | 26 (female) |
| Male | 44 | None | None | 47 (male) |
| Female | 57 | Two sons and daughter | Two brothers | 59 (female) |