

## **Whose story is it: exploring autobiographical methods**

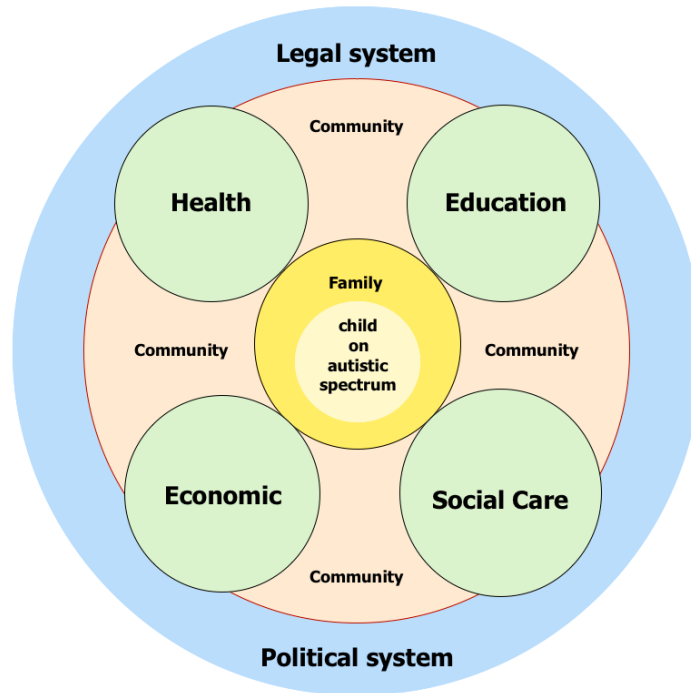
I am the mother of a young man with Asperger's syndrome. Over the past dozen or so years, I have learned far more than I would have ever wanted to about autistic spectrum disorders, child and adolescent mental health provision, educational provision for special educational needs and the criminal justice system. Prior to the birth of my son, I worked for many years in both statutory and non-governmental social service organisations. As I engaged in getting my son's needs identified and appropriately met, I became involved with other parents on similar journeys. I realised that my own background gave me advantages in that I was used to speaking to dealing with bureaucracy, to completing complex forms, and to communicating with professionals in various disciplines. Through my involvement in online forums and co-ordinating a local support group for parents, I have been able both to learn from other parents and to share my own knowledge. I have found it of particular interest over the years to observe how parents, who have initially approached groups needing to glean whatever information they could, have become those who offer support and guidance to other parents.

My research focuses on the learning journeys, or learning experiences, of those involved in supporting and caring for children and young people with autistic spectrum disorders, and I am focusing more specifically on children and young people diagnosed with Asperger's syndrome or high functioning autism. In this presentation, I am focusing on the experiences of parents with children on the spectrum, rather than on the professionals and support staff employed by the various agencies involved in the care and support of these children. I will first describe the autistic spectrum domain and how it is experienced by parents, and then turn to my research methodology.

### **The autistic spectrum domain**

The autistic spectrum domain is complex as shown in figure 1. At its centre are families with children on the autistic spectrum. Those families live in communities which may or may not be supportive of them – it is not uncommon for parents to speak of having been ostracised by other parents and even to tell of parent organised petitions requesting their children should not be placed in the same class as a child with an autistic spectrum disorder.

Families with a child with special needs have far more contact with health professionals than other families (Rogers, 2007; Truss, 2008). The average child is likely to have contact with a health visitor, family doctor and dentist plus occasional visits to the accident and emergency department at their local hospital. The child on the autistic spectrum is likely to have contact with paediatricians, clinical psychologists, speech and language therapists, occupational therapists and may have contact with child psychiatrists and other mental health specialists. In arriving at a correct diagnosis, or diagnoses, the child might be seen by specialists in both the national health service and the private sector and may be seen by some specialists in order to rule diagnoses out. Each specialism has its own systems which have to be negotiated by the family.



**Figure 1 The autistic spectrum domain**

Although there may have been difficulties in school prior to diagnosis, especially so in the case of Aspergers and high functioning autism, where diagnosis might be comparatively late in the child's life, and prior to diagnosis the child may have acquired naughty label, parents often have the expectation that once a diagnosis has been made, provisions will be put in place to support their child. However, diagnoses are made by the health services and educational special needs provision is determined by schools in conjunction with local authorities and a range of specialist staff. Increasingly, the emphasis is on meeting the needs of the child from within the school's own resources, with special needs budgets devolved to schools. In practice, parents can experience the provision as inadequate and will find themselves engaged in a struggle to improve the provision for their children, running the risk of being labelled as pushy parents.

In telling their stories, parents often speak of fighting to get their child's needs met, or refer to the struggle they engaged in (Paradice & Adewusi, 2002). Figure 2 shows words commonly used by parents in describing their relationships with public bodies. Some find themselves engaging in legal action, appealing to SENDIST (Special Educational Needs and Disability Tribunal) when they find themselves in conflict with the local authority.

In any event, as with health provision, parents of children with SENs have far more involvement with education officials than parents of the average child. Again there is a system to traverse and a specialist language to learn.



**Figure 2 Metaphors of struggle and fight**

Some families of children with autistic spectrum disorders will engage with the social care system, although this is less common in the case of Asperger's and high functioning autism. Parents may request an assessment of their child's needs and of their own needs as the child's primary carer. They may also want to know about respite services and other support provision. Although, there is very little support generally available for these children, it can be important to have involvement with the social services department, especially if funding a residential placement becomes necessary.

Some families do not request assistance from social services, but find they have been referred due to concerns about the child. It is not unknown for families with a child on the spectrum to find they are being investigated under child protection legislation. Rather than being supported, such families can experience the caring professions as accusatory and unhelpful, failing to recognise the day-to-day difficulties of caring for a child with challenging behaviour.

Many families with children on the autistic spectrum can experience financial pressures. A parent may effectively become advocate and key worker for their child, limiting their earnings and potential career development. Those parents who choose to make use of the private consultants or engage legal support in approaching SENDIST may find themselves paying many thousands of pounds of their own money. Although most children on the spectrum are eligible to receive DLA (Disability Living Allowance), not all parents are made aware of this, and the forms are complex and oriented towards children with physical needs. Parents who have low earnings and a child in receipt of DLA are eligible to claim a carer's allowance, but again this is not well publicised.

## **Research methodology**

In my research, I am collecting stories from parents, professionals and other carers, relating to how they have learned about autism and about the various support systems available to children on the spectrum. I am conducting a series of semi-structured interviews in which I ask participants to reflect on their experience of the autistic spectrum, how they have learned about autism, and on their knowledge of the various systems available to support children and young people on the spectrum. As a way into the story, I ask participants if they can recall an incident when they can recall learning something about autism. This approach is based on the concept of critical incidents (Flanagan, 1954), but I am adapting the methodology to facilitate story telling. In the

information given to participants, I identify myself as having a son on the spectrum and in the course of an interview refer to my own experiences if appropriate, returning to the participant's story as quickly as practicable.

From my own involvement with the domain, I am aware that although some specialists have particular expertise, most participants in the domain speak of learning by doing. Health professionals refer to learning from their patients, teachers refer to learning from pupils, and parents speak of learning from their child. There has been considerable research which has shown that about 80% of all learning takes place outside of formal education and training settings (Bingham, 2009; Livingstone, 2001). By collecting stories of learning journeys and experiences, I hope to clarify what different participants in the domain know and how they know it. Many decisions about the care and education of children on the spectrum are made in meetings of professionals and parents. Parents can feel marginalised and disempowered at such meetings (Rogers, 2007). By focusing on learning journeys and shared knowledge, it may be possible to enable parents to be more involved and empowered in the decision making processes about their children.

Since the 1990's there has been an ongoing debate about the use of personal narrative in sociological research (Atkinson, 1997, 2010; Bochner, 2001, 2010; Frank, 2010; Thomas, 2010). This revolves around whether such narratives are inappropriately privileged in being seen as giving access to understandings which might not otherwise be available leading to an over-emphasis on content rather than the social construction of such accounts and how they relate to a wider understanding of the societal context of such accounts. Thomas (2008) offers a useful middle way suggesting that it is possible to consider form, content and the wider social context rather than focusing on just one approach. Merrill and West (2009) similarly take a holistic perspective.

A further area of concern is the blurring of roles when the researcher is also a participant within the domain being studied (Rogers, 2003). This raises questions of bias, though as long ago as 1967, Becker suggested that there was nothing wrong in investigating from a known standpoint as long as other positions were both recognised and understood, going on to say: "Our problem is to make sure that, whatever point of view we take, our research meets the standards of good scientific work, that our unavoidable sympathies do not render our results invalid" (Becker, 1967, p. 246).

The use of auto/biographical methodology also raises ethical questions which may not be evident at first sight. We all recognise the responsibility we have to protect our participants and to hide identities. However this is not always straightforward. Merrill and West (2009) make the point that although a number of identifying factors can be changed, it is not possible to hide identity completely from those who know the participant well. Rogers (2007) draws attention to a further issue in discussing her daughter: "there were some occasions where anonymity was impossible: those involving my daughter. I have talked to her about this research and her inclusion (which she agreed to), and I do not apologise for the lack of anonymity here because unlike children in general, many of whom become 'able' adults, she, like many of the participants' children, will never be able to 'tell' her story via this particular medium."

Stanley describes the interaction between constructing one's own autobiography and constructing the biographies of others (Stanley, 1992). My story is made up of other people's stories, just as my story is incorporated in the stories of others. The moment I declare myself as the mother of a son with Asperger's syndrome, my story and that of my son interconnect. As I talk about experiences throughout his childhood, he becomes more

of a person and more recognisable and identifiable. Unlike Chrissie's daughter, my son is in the process of becoming an 'able' adult. For me this is an as yet unresolved issue.

Atkinson, P. (1997). Narrative turn or blind alley? *Qualitative Health Research*, 7(3), 325-344.

Atkinson, P. (2010). The contested terrain of narrative analysis &#x2013; an appreciative response. *Sociology of Health & Illness*, 32(4), 661-662.

Becker, H. S. (1967). Whose Side Are We On? *Social Problems*, 14(3), 239-247.

Bingham, T. (2009). *Social learning and Web 2.0*. Paper presented at the ASTD 2009.

Retrieved from

<http://hosted.mediasite.com/mediasite/Viewer/?peid=6ec314e18ba94dad8e940e08b618cbaf>

Bochner, A. P. (2001). Narrative's virtues. *Qualitative Inquiry*, 7(2), 131-157.

Bochner, A. P. (2010). Resisting the mystification of narrative inquiry: unmasking the real conflict between story analysts and storytellers. *Sociology of Health & Illness*, 32(4), 662-665.

Flanagan, J. C. (1954). The critical incident technique. *Psychological bulletin*, 51(4), 327-358.

Frank, A. W. (2010). In defence of narrative exceptionalism. *Sociology of Health & Illness*, 32(4), 665-667.

Livingstone, D. W. (2001). Adults' informal learning: definitions, findings, gaps and future research. *NALL Working Paper*, 40. Retrieved from <http://www.nall.ca>

Merrill, B., & West, L. (2009). *Using Biographical Methods in Social Research*. London: Sage.

Paradice, R., & Adewusi, A. (2002). 'It's a continuous fight isn't it?': Parents' views of the educational provision for children with speech and language difficulties. *Child Language Teaching and Therapy*, 18(3), 257-288.

Rogers, C. (2003). The mother/researcher in blurred boundaries of a reflexive research process. *Auto/Biography*, 11(1&2), 47-54.

Rogers, C. (2007). *Parenting and Inclusive Education: Discovering Difference, Experiencing Difficulty*. Basingstoke: Palgrave.

Stanley, L. (1992). *The Auto/Biographical I*. Manchester: Manchester University Press.

Thomas, C. (2008). Cancer narratives and methodological uncertainties. *Qualitative Research*, 8(3), 423-433.

Thomas, C. (2010). Negotiating the contested terrain of narrative methods in illness contexts. *Sociology of Health & Illness*, 32(4), 647-660.

Truss, C. (2008). Peter's story: reconceptualising the UK SEN system. *European Journal of Special Needs Education*, 23(4), 365 - 377.