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Whose research is it anyway? Tensions and difficulties in research that tries to include the 'hard to research'

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Introduction

In this paper I will consider some of the tensions and problems that can arise, and that need to be addressed, in attempting to undertake research with hard to reach groups of 'subjects'. In terms of my research this specifically relates to studies undertaken families that include children on the autism spectrum (including the children on the spectrum themselves) as well as children with multiple disabilities and visual impairment (MDVI). I begin by summarising my work experience and how this has shaped my research interests before moving on to discuss studies I have undertaken with the 'hard to research'. I outline the research studies and the process of the studies before moving on to look at the issues arising. Finally I identify seven key factors regarding this type of research.

My background

Before moving on to consider these issues it is necessary to give some detail about my own personal, background, as this has shaped my experience, and thus my expectations and 'pre-understandings' (Usher, 1996) regarding my areas of research interest.

I studied Medieval History at undergraduate level, before undertaking a Post-Graduate Certificate in 1979. At this time there was a great shortage of teaching posts (and also, to be honest, I was not particularly keen on teaching) and my partner and I were under threat of eviction from our flat. In order to get a job (and a guarantee of a newly-built flat) I began working as a nursing assistant in a long stay hospital for people with severe learning disabilities. This was to be my introduction to the field in which I have spent my working life.

After 18 months working as a nursing assistant and subsequently as a student nurse at the hospital, I moved to better paid employment as a residential social worker with the local authority. I worked in residential homes and respite care (later referred to as 'short breaks') services for adults with learning disabilities, children with physical disabilities, children with severe learning disabilities and children with challenging behaviour. I undertook qualifying training in the field of social care in the mid-1980s: subsequently I worked in management positions in local authority services. During the 1990s I developed and managed residential, short breaks and parent education services for children with autism and their families. By the end of my local authority career I managed all direct local authority social care and education services for disabled children and their families within the county where I worked.

For the last 15 years of this time, however – from 1997 to 2012 – I was not just a practitioner but an active practitioner/researcher. Having been *'bitten by the bug'* of autism (Peeters & Jordan, 1999) I completed my MEd in Special Education (Autism) at the University of Birmingham in 2001. In 2003 I started my doctoral research at the Autism Centre for Education and Research (ACER) in the School of Education at Birmingham. At the same time I began working as a part-time visiting lecturer and regional tutor on ACER's web-based and distance education autism courses. More recently, in 2012, I moved into a full-time academic position at the University of Northampton, initially within the Special Educational Needs and Inclusion Division and currently in the Centre for Education and Research (CeSNER).

So what?

Why does any of this matter? In what way is it relevant to this paper? I outline my work experience, and the times in which I worked as a practitioner, as these informed and shaped my research interests and provided the context in which my understanding of these areas of interest was situated.

In the mid-1990s I managed services for children across a wide range of disabilities and their families. At this time there was a strong imperative – in legislation, policy and good practice guidance – to include the views of disabled children and young people in planning and service delivery across social care, education, health and leisure services (e.g. Department of Health, 1991, 1998; United Nations 1983). A body of literature was emerging with regard to consultation with disabled children (e.g. Morris 1998; Ward, 1997). However I felt that though much was written about values and principles, there was little guidance as to exactly how such consultation should be carried out, especially with children like the ones I worked with. Consultation focused on those with whom the process could most easily be carried out So the reports and articles I read emphasised the experience of teenagers and young adults – not younger children; children with physical and sensory impairments – not those on the autism spectrum; those with moderate learning disabilities – not those whose difficulties were severe or profound.

This failure to address the experience of these children in research was mirrored in practice. Time and again I read review reports where social workers wrote that the child had not been consulted or involved in the production of the review report as they were *'unable to communicate'* or because *'their views could not be obtained'*. Social workers carried large and diverse caseloads; few could communicate through British Sign Language or Makaton, let alone take the time to learn the subtle communication methods used by some of their 'clients', or to be able to infer meaning from the behaviours of more profoundly disabled youngsters. Staff working hands-on with such children in residential homes and schools were more skilled, but even there the children's voice was often little heard, and parents views and wishes were paramount.
But it was clear to me that parents and children often held conflicting views. For example a parent might express a desire for their child to attend a respite care centre, while the child's behaviour when at the respite care centre demonstrated that they did not want to be there. And my daily work experience also taught me that when social workers spoke of consulting with 'the family' or 'the parents' this generally meant mothers. They were around in the day (when social workers visited) and were usually the child's primary carer. But a moment's thought must make it clear that it was possible that fathers, brothers and sisters may hold differing views. Who was talking to or listening to them? What about the perspective of the whole family?

My research

All of these work experiences, and my interests and developing understanding about families (all members) and their interaction with services (education, social care, health, transport, etc.) shaped and informed the research that I have carried out. This has included:

- My MEd research, which focused on consultation with children with autism and learning disabilities about their experience of social care services, and which described and discussed the barriers to consultation inherent in autism (and some strategies that could be helpful in addressing these issues) (Preece, 2002)
- My PhD, which investigated whole families' experiences of living with autism and of social support. This research included:
  - a large-scale quantitative investigation of factors associated with use or non-use of support services (Preece & Jordan, 2007a)
  - an investigation of social workers' understandings of autism (Preece & Jordan, 2007b)
  - an investigation of parents' conceptualization of quality in social care services for children with autism (Preece, 2009)
  - an in-depth qualitative investigation of the experience of children with autism (Preece & Jordan, 2010) and that of their mothers, fathers and siblings (Preece, 2014a) based on in-depth interviews with 14 families.
- Research into effective strategies for teaching children with autism and visual impairment (Howley and Preece, 2013) and those with Multiple Disabilities and Visual Impairments (Taylor & Preece, 2010)
- Investigating problems surrounding providing parent education in physical interventions and positive behaviour support to parents of children with autism and challenging behaviour (Preece, 2014b)

A few words about approaches and paradigms

My areas of research interest, and my perspective on these topics, have been informed by, and are consistent with, my realist epistemological position (Bhaskar, 2008; May, 2001; Sayer, 2000). Realist social scientific research seeks to identify the structures and mechanisms of the social world, to "*uncover the structures of social relations in order to understand why we then have the policies and practices that we do* (May, 2001, p12)". This social world is viewed as complex and stratified and it is the role of a realist research study to engage and address these different layers of reality.

Realism asserts that the knowledge and understanding that people have of the social world in which they live affects their behaviour (May, 2001). Moreover, though people's understanding about the social world may be incomplete or partial – and indeed they may not be directly aware of the underlying mechanisms of the social world – these mechanisms nevertheless affect and shape their experiences. The task of scientific enquiry is to develop theories to explain the real world, to seek to test these theories by rational criteria, and to explain how actions and mechanisms, within specific contexts, produce events.

However, whilst I strongly believe that a key purpose of social research is to bring about change and improvement, I would stress that I do not consider myself to be carrying out '*Inclusive Research*'. In part this is due to what I feel are overly restrictive definitions of the term, which often seem to narrow its meaning down to research carried out by

teams that include individuals with learning disabilities (e.g. Nind & Vinha, 2012; Walmsley & Johnson, 2003). While I certainly would not preclude my undertaking this sort of research in the future, I feel that 'inclusion' means more than just learning disabilities – the voices of many others are also excluded. I am also mindful of the fact that 'the disabled' (or 'the learning disabled') are not a homogeneous group, and I am also concerned that many of those whose views I am eager to identify could not participate as active researchers.

Key questions in undertaking research
Rather, I have a number of key issues points and questions that I ask myself when thinking about research topics and when I try to identify how I should go about designing and undertaking research. These can be summarised as follows:

- How do I differ from those whose experience I am researching?
- What pre-understandings do I hold about the phenomenon I am researching?
  How might these differ from:
  - the 'researched'?
  - other researchers?
- How can I ground my research within:
  - the experience of 'the researched?
  - the literature?
- How can I best capture the reality of the researched?
  - in the tools/process?
  - in the findings?

In the remainder of this paper I will move on to discuss some examples how I have sought to operationalise these questions in my research.

Designing and piloting a research tool with parents of children with autism
At the start of my PhD studies I wanted to survey the experience of as close to the whole population as possible of parents of children with autism in a rural English county. I decided to use a self-completion postal questionnaire as the survey tool; and – due to my desire to capture the reality of the research in the tools – I did not want either to use a pre-existing questionnaire or to design the tool by myself.

The process
The literature suggests that such groups should be similar to the research sample, but should not come from the same population. I therefore made contact with an autism society in a county was comparable to that which I was investigating in that it was of a similar size and population, it had a mix of autism-specific and generic services, and the TEACCH approach (Mesibov, Shea & Schopler, 2005) was used in education and social care services for children on the autism spectrum. I explained the purpose of my research, and the organisation gave me its support, not only with regard to this initial design phase, but also in piloting the survey and (potentially) with involvement in future data analyses.

Ethical considerations were important concerning my involvement and interaction with these parents, particularly with regard to raising parental expectations or causing distress. I wrote to parents, defining the focus group's remit (to ensure the survey focused on issues that were really relevant to parents) and explaining the purpose of the

research. This was stated explicitly to ensure that parents realised that participation in this process would not lead to service development or any changes within their county and to prevent raising false hopes. This letter was forwarded to a random selection of parents. I subsequently met with a group of 10 parents and the overall structure and areas of questioning were identified. I compared these with the literature and designed a first draft of the questionnaire.

I took this draft to a further meeting of parents for pre-testing. This meeting was larger than the previous focus group, with about 15 parents present, most of whom had not been at the earlier meeting. The group considered each question regarding its wording, clarity and potential responses, and amendments were suggested, as were changes were regarding the coding of responses. Subsequent to these amendments the pilot questionnaire was posted out to a random sample of 30 families.

The tensions
This description of the process, whilst factually accurate, does not identify or acknowledge the tensions that were raised in the process of designing the survey and negotiating the piloting process. On returning home after the initial focus group meeting, I wrote in my research diary of the tension and discomfort I experienced as a practitioner/researcher. I went to the meeting as a researcher, seeking support and advice in the development of my research tool. However, the parents' perception of me was based upon my professional role – as a manager of services for children on the autism spectrum, and I was introduced to them as 'an expert'. As such, they were eager to question me about my professional role, seeking advice and information, particularly where they were in conflict with their local authority. I was openly seeking their support and advice for my study, but could not offer the same level of support and advice in return. As a result I had at times felt profoundly uncomfortable, especially when asked by one parent, 'So why should *we* help *you*?'

Further tension arose immediately before the pilot study questionnaires were posted out. I had agreed that the anonymous information gathered in the pilot study would be shared with the autism charity, so that they could use it to highlight issues within their local authority. This seemed an acceptable and appropriate trade-off. However, the society's officers wished to select which families would comprise the pilot study sample, to maximise response and to get a 'stronger' message from the data. I had to stress that this would invalidate both the information (for them) and the pilot study (for me); and a random sampling method was finally agreed – and a random sample was obtained in my presence. However the society's officers' lack of research awareness and desire for change – and my insistence on a rigorous approach, and on being present when the sample was chosen – again caused significant tension and an amount of ill feeling.

Consulting with children on the autism spectrum about their experience
Experience of residential short breaks
In this study (undertaken for my MEd) I sought to identify the experience of attending a short breaks (respite care) service of three youngsters on the autism spectrum who attended an autism-specific residential short breaks service. Children across a wide range of abilities attended the service, and so I wished to consult with 3 children reflecting the diversity of this range, from a non-verbal child with severe learning

disabilities to a more able youngster. Most of the children attending the service were aged 7-14, so this was also the age range of my sample.

Impact of autism on consultation

Autism can impact on the consultation process in a number of significant ways. These are discussed at length elsewhere (Preece, 2002; Preece & Jordan, 2010) but some of the key issues are as follows:

- the social impairments and differences inherent in autism can impact on the process
- the communication impairments and differences inherent in autism can impact on the process
- people with autism may lack person insight and have a poor personal event memory
- people with autism have a concrete understanding of the world and may find it hard to conceptualise future wishes, hopes and aspirations
- people with autism like predictability – therefore they may dislike novel experiences simply due to their novelty
- all of the above factors may lead individuals with autism to seek to 'give the right answer'.

The process

A crucial issue therefore was who should carry out the consultation. The literature identifies that people carrying out research with disabled children should be known, familiar and trusted (Beresford, 1997; Russell, 1998). However, to ensure that children did not feel pressured into giving positive responses about their experience, it was important to me that the interviews were not undertaken either by professionals involved with the short breaks service (including me – I was the manager) or by their parents (who clearly had a vested interest in the service). I considered getting the children's social workers to carry out the interviews; however they too could be considered to be stakeholders in the short breaks process; and moreover they lacked the skills required to effectively consult with the young people. Therefore I decided that the consultation should be undertaken by children's class teachers, who were people who were skilled at communicating with/interpreting the communication of the youngsters, but who were not involved in the short breaks process.

This decision immediately limited the potential sample to those children and young people whose teachers were willing to participate in the study. Having whittled the number down, I selected 3 different settings and set about designing the consultation process. Although 'consultations' carried out by the teachers were central to the study, multiple methods of data collection were in fact used, as outlined below.

- I carried out semi-structured interviews with parents and teachers to establish the rationale for the study, to ensure access and consent and to clarify how the individual consultation exercises would be carried out.
- I observed the children in their classrooms and short breaks settings before the consultations and made contemporaneous field notes.
- In 2 cases, the teachers carried out 'structured interviews' with the young people. One child's interviews were recorded, supported by contemporaneous notes made by the teacher. The other did not want to be recorded, so the teacher made contemporaneous notes only.
- In the case of the non-verbal youngster, his teacher observed him at various times (morning, evening, weekend) in the short breaks setting. These observations were

contemporaneously recorded under the same headings used in the structured interviews.

- After each consultation exercise, I met with the teacher to share and discuss notes to ensure accuracy: to identify, discuss and problems identified in the consultation process; and to identify possible solutions/revisions to the process. I recorded these meetings.
- After each session I also met with the child's residential key worker in the short breaks setting to compare information gathered through consultation with the observations of staff in the service, noting points of congruence and differences.
- Finally I referred to a range of documentary evidence, such as daily notes and children's files.

The tensions

Again, his description of the development and consultation processes smoothes out the issues that arose. Developing 3 separate, individualised ways of asking the same set of questions of 3 youngsters was time-consuming, as was preparing the teachers to carry out the consultations and the level of triangulation required.

Teachers described experiencing role-conflict. Those interviewing identified that it took a 'mental gear-shift' to move from teacher to researcher. The teacher observing the non-verbal child spoke of her frustration at observing without intervening or taking charge, especially when his attempts at communication were unnoticed or ignored. This was exacerbated when on occasion the child would approach her seeking to get his needs met.

I too felt frustrated at a number of points during the process. The research was taking place during the second half of the autumn term and problems arose due to timetable changes to accommodate Christmas concert rehearsals. I often felt powerless and lacking control in my own research.

Experience of family life and social care support

The process

In the latter stages of my PhD research I carried out a number of interviews/consultations with whole families (mothers, fathers, siblings and the children with autism themselves). In total 44 interviews and 2 observations were carried out with 14 mothers, 8 fathers, 10 siblings and 14 youngsters on the autism spectrum. By this time I was no longer involved in the direct day-to-day management of the residential short breaks service, and also had the time that came with undertaking a part-time PhD. I therefore decided to undertake all of the interviews and observations myself.

Following the model used in the initial survey, the research tools were developed, trialled and piloted with parents and families. The interview schedule was trialled with the mother of a child who had previously attended short breaks before moving for educational reasons to a residential school. Piloting was undertaken with a family comprising a mother, father and two sons (one with Asperger Syndrome and one with classic autism)

The issues
All the issues identified earlier regarding the problems inherent in consulting with children with autism again impacted in this study. Additionally, a whole new set of issues came into play. Multiple introductory letters had to be developed, taking account of recipients' ages and reading abilities. Interview privacy had to be negotiated – or in some cases not. Where possible I wished to interview children privately, but found that (as Mauthner, 1997, p18) points out, many families do not share '*mainly white, middle class researchers' conception of children's rights to privacy, confidentiality and autonomy.*' So while I carried out individual interviews with 10 children, a further 10 children were interviewed with at least one parent present, and 3 parents were interviewed with their children with autism in the room.

As in my earlier study I endeavoured to develop individualised consultation tools and processes for the children with autism: and one of the many questions I asked myself during this time was '*How do you pilot an individualised tool*?' Getting to know the individuals on the spectrum, and spending time before the interview date talking with them, playing with them and developing rapport with them were crucial in developing the tools, as was working in conjunction with their mothers, fathers and siblings to develop them.

Parental presence in the interviews definitely impacted upon the data collected. On some occasions parents would answer for their children. On others the child would seek to get their parent to answer for them, or acquiesce and defer to their perspective. A further issue was raised by 4 parents' refusal to allow visual supports to be used during the interviews, as they considered them unnecessary. These were young people who used visual supports at school and for whom they would almost certainly have been a helpful support. I was aware that the data I was obtaining was more limited than it might have been but had to accept the situation.

Finally the interview process produced over 180,000 words of data. Transcribing, coding and analysing this took many months.

Using TEACCH with students with MDVI
This study (Taylor & Preece, 2010), which investigated the use of the TEACCH structured teaching approach (Mesibov, Shea & Schopler, 2005) to develop educational and communication tools for students with MDVI, further identifies the need for extended timescales when researching those who are hard to research. The project took well over a year to plan and implement. There was close collaboration and regular discussion between the academic researcher, the class teacher/researcher and the whole staff team in the class, as well as with parents, other professionals and other school staff. Due to the severity of their impairments, progress was slow and students' learning was negatively impacted by seizures, ill health, issues at home and staff changes. It was fortunate that this was a more informal study, undertaken without funding, reporting or submission pressures. Had such pressures existed, there would probably not have been the freedom to experiment and to develop tools as occurred.

Final thoughts – seven things to remember
So what are the key messages that I've learned on my journey in research and practice, and that I wish to pass on? They are summarised in the following 7 points.

- Differing agendas and perspectives will cause conflict. Accept, expect and plan for it.

- It is down to the researcher to negotiate and manage this conflict to maximise the input of the researched without compromising the integrity of the research.

- Consulting and collaborating with 'the researched' on research design does not mean unquestioning acceptance of their suggestions and wishes. Rigorous research should be based upon the perspective of the researched, the knowledge base within the literature, and the expertise, experience and perspective of the researcher.

- An ethical and rigorous stance may reduce the willingness of participants to collaborate or participate. Again, plan for this and clearly identify the trade-off that are acceptable and where you draw the line.

- Some role-discomfort is probably inevitable, especially if you are a practitioner/researcher. Again, this needs to be acknowledged and owned.

- Researching the perspectives of the hard to research requires individualisation, imagination and collaboration. It is time-consuming and needs clear and effective planning.

- Finally, this is important stuff. It must be done, and done as well as you can do it.

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