'Interrupted Interviews': listening to young people with autism in transition to college

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Abstract *This article examines the methodological approaches used in a research project that investigated the lived experiences of young people with autism and learning difficulties as they made the transition from special schools to mainstream colleges of Further Education.*

A combination of visual methods, using tablet applications and walking interviews were explored in an attempt to develop ways of engaging young people with autism in research and to privilege their voice in their own transition. The effectiveness and limitations of these methods are examined here and illustrated through the experience and responses of one young person in the study and his engagement with the research.

Keywords: transition; autism; special school; further education; visual methods; learning difficulties; walking interviews

Introduction

This longitudinal research set out to understand the experience of transition from the point of view of young people with autism as they left special school and started at mainstream college. Whilst potentially unsettling for any young person at this age, this transition can be particularly challenging for young people with autism, knowing that an 'anxiously obsessive desire for the maintenance of sameness' and a 'dread of change' are likely characteristics of autism (**Kanner 1943: 245**). The focus of this study was on the transition from a small special school environment to one of a large mainstream college. All the young people involved in the study had both autism and a degree of learning difficulty that had necessitated a statement of special educational need and a specialist environment. The research was carried out against the backdrop of a changing policy context where all young people are now expected to stay in education or training until the age of 18 (**DfE, 2008**) and, for young people with a new Education, Health and Care (EHC) plan,

potentially until the age of 25 (**DfE et al., 2014**). This was also linked to an increasing emphasis on giving people with learning difficulties a voice (**UNCRPD, 2006**) and developing more person-centred planning, particularly in relation to transition arrangements (**DfE & DoH, 2014**). With this in mind, the research sought to understand transition for young people with autism through developing appropriate methods to listen effectively to their experiences as well as those of their care-givers and related professionals. The resulting 'interrupted interviews' based on these methods helped to give voice to the individual participants and communicate their preferences and experiences. This article focuses on the methodological approaches used in this project and discusses their strengths and limitations as illustrated by a single case study of one of the young people in the research.

Autism, transition and adapted interviews

While a significant cohort of young people with autism do now progress on to further education (**Mitchell 1999; Breakey 2006; Chown & Beavan 2012**), the 'Finished at School' Report suggested that 'less than 1 in 4 young people with autism continue their education beyond school' (**Ambitious About Autism, 2012: 8**). **Breakey** (**2006**) argued that reasonable adjustments have to be made for students with autistic spectrum condition (ASC) when they make the transition to further education, that pre-access preparation is essential to redress the balance between them and their neurotypical peers and that many autistic students still fail to access further education because of the lack of such provision. While these adjustments have been identified, they do not yet seem to be wholly in place, 'with knowledgeable support there can be an improved prognosis for persons with autism, however, such support is considered to be a rarity in further education at present' (**Chown & Beavan, 2012: 477**).

Representing the experiences of the young people in this project was particularly pertinent to its central core as it sought to focus on the range and diversity of individual young people with autism. Ways in which to do this ethically and constructively have been explored in the literature, although there is no conclusive evidence for the most appropriate method for interviewing people with autism (**Lewis & Porter 2004; Nind & Vinha 2013**; **Palikara et al. 2009**; **Milton et al. 2012**). This area of research is clearly in the process of development although Preece, albeit writing in 2002, could find very little published research that had included the direct participation of children with autistic spectrum conditions.

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While semi-structured interviews were an extremely valuable instrument in gaining the views of the adults in the research, they were not necessarily the most apposite choice for talking to young people with ASC and additional learning difficulties. The diversity and heterogeneity of this group potentially implied that they might not make eye contact, might not have much language, might struggle with social situations, and might be disconcerted or made anxious by the presence of strangers (**Wing 1996**). The young people in this study all had different communication and social interaction capabilities and difficulties so they were not a homogenous group. The premise in much of the research methods literature is about the ability of participants to express themselves clearly, thoughtfully and openly (**Kvale & Brinkmann 2009**; **Gubrium & Holstein 2002**; **Weiss 1994**) and that the 'respondent is someone who can provide detailed descriptions of his or her thoughts, feelings and activities if the interviewer asks and listens carefully enough' (**Gubrium and Holstein, 2002: 8**). These premises do not necessarily apply to the participants in this project. However, there was evidence to suggest that visual stimuli or cue cards (**Lewis et al. 2008**) and 'talking mats' (**Cameron & Murphy, 2002**) could be helpful to support communication with those on the spectrum, 'this is the kind of practical visual complement to open-ended approaches which is seen as particularly useful for participants with autism' (**Nind 2009:10**).

Potential methodological approaches were explored in relation to literature on ASC and on research methods. **Booth & Booth** (**1996**) explored the 'excluded voice thesis' in relation to people with learning disabilities and identified four particular challenges when carrying out narrative research which proved to be useful markers for considering interview research in this project: *inarticulateness* which could relate to limited language skills as well as anxiety in social situations; *unresponsiveness* as they might find it difficult to answer open-ended questions; *concrete frame of reference* which might be characterised by difficulty in generalising from experience and thinking in abstract terms and similarly difficulty with imagining the future, and *problems with time* making it difficult to order past events.

Preece (**2002**) identified very limited research with children and young people with learning difficulties and proposed that consultation with young people with autism had not considered the specific impairments associated with ASCs. He concluded that aloofness, social anxiety, poor memory and the limited and idiosyncratic use of language all impacted on the ability of those with autism to participate in the consultation process and, for this study, all these areas had to be taken into account. While there is little known about which research methods might afford the best opportunities for the participation of young people with autism

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(**Harrington & Foster 2013**), it is incumbent on researchers to consider the individual, common and exceptional needs (**Lewis & Norwich 2005**) of the participants and design, and adapt methods accordingly. With this in mind, 'interrupted interviews' that involved both the use of collages and card sorts on the tablet were developed for the early interviews, and walking interviews around the college environment were planned for the later data collection point.

The research study

This ESRC funded doctoral research took the form of a longitudinal case study approach over a ten month period of data collection from June 2013, when the young people were preparing to leave school, through to March 2014 when they had spent six months in their new college settings. The sample comprised six young people with ASC from three different special schools who progressed on to five different colleges of further education. They continued on to a variety of courses including BTEC, Foundation Learning and other vocational courses at different levels. The data used in this article relates to one student, Jake, in order to illustrate the methodological approaches used and their relative effectiveness and limitations in listening to the views of young people with ASC.

Jake: a case study

Jake is a young man with a diagnosis of autism and moderate learning difficulties, who was in his final year at a special school in the South of England when he was first interviewed. He had had a statement of special educational needs since he started school and had always been educated in special provision. He had good communication skills and was on the higher functioning end of the autistic spectrum as evidenced by his progress at school and his ability to interact well with his peer group and with adults. He was one of the more able young people in the study, and was able to communicate in complex sentences and answer open-ended questions in some depth. According to his Learning Difficulty Assessment (also known as the Moving On Plan) he had difficulty in making eye contact when stressed, difficulty with understanding facial expressions, body language and tone of voice and struggled with words that had several meanings. The 'interrupted interviews' helped to support the interview with Jake and diluted the intensity of the interview scenario.

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Jake was initially interviewed at school, which took the form of a semi-structured interview punctuated by activities that included making a collage and sorting cards into order of preference on the tablet. **Preece (2002)** argued that visually mediated methods strengthened the communication of young people with ASC in the consultation process. The collage task required Jake to organize and select both his abilities and interests in and out of school, as part of the focus here was to focus on his strengths and capabilities. The images of typical school subjects were pre-loaded and he could remove them, make them bigger and smaller according to his likes and dislikes, and move them around. We added the words 'swimming', 'drama' and 'media' because he also wanted to represent those activities that were partly undertaken outside school.
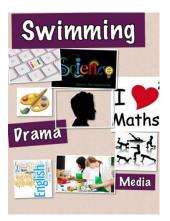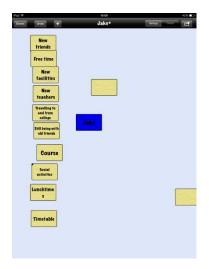
Figure 1. Original Collage **Figure 2. Jake's Collage**

After some more questions about Jake's experience of special school and his preparation for college, a card sort exercise was introduced. The individual cards held a list of pre-loaded words or phrases (with some additional blank cards for adding his own ideas) and Jake had to move the items into the order of perceived importance regarding what he was looking forward to (Figure 3), and what he was worried about (Figure 4).
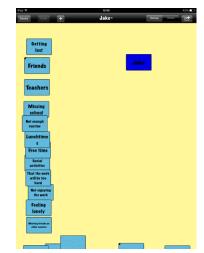
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Figure 3. Jake (looking forward)   **Figure 4. Jake (worried about)**

The second data collection point took place during the Spring Term of Jake's first year of college, and after some interim emails during the first term. Jake was interviewed for 30 minutes at home and then during a 'walking interview' (**Clark & Emmel 2010**) at college. The aim of the interview was to walk around the college environment, led by Jake, to the places where he attended lessons and socialized in order to build a picture of his college experience. He was given a tablet to take photos of places at his college that were significant to him in some way (care being taken not to include identifiable pictures of other students for ethical reasons). An extract from the walking interview is given below (Figure 5) in which Jake indicates how he uses the central facilities at college in his free time between lessons:

Figure 5. Upstairs in the Learning Resources Centre

Researcher: So do you come in here if you have gaps in between lessons?

Jake :   If I have gaps in between lessons, I sometimes come in here…so yeah, take a picture there. Do you want to go downstairs and take a picture?

Researcher: I don't mind. Do you mostly go upstairs or downstairs?

Jake: I go downstairs but I sometimes go upstairs, downstairs is where you can read the books down there...[walking downstairs] ...so you've got the ICT, public services, you've got all sorts of books there

Researcher: Right, that's really good isn't it?

Jake: I'll take a picture there...right that's taken [takes picture of downstairs in LRC]

Figure 6. Downstairs in the Learning Resources Centre

Effectiveness of the methods used

The use of activities on the tablet and also the walking interviews helped to open up the discussion during the interview, especially in the first interview when the researcher-participant relationship was newly formed. Jake showed an interest in the tablet from the beginning of the interview and was motivated to use it. Although his language skills were very good and did not suffer from the 'inarticulateness' **to which Booth & Booth** (**1996**) refer, he nonetheless had some limitations and idiosyncrasies in his use of language (**Preece, 2002**) which manifested as echolalia, for example,

Researcher: Have you got friends at school?

Jake: I have got friends at school...

and

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Researcher: Right so you're pretty fast then? [swimming]

Jake: Yes, I'm pretty fast, yes

Using the activities on the tablet helped to develop the interview into more of a conversation around the subjects that Jake liked and the activities that he took part in outside school. The walking interview also helped to support the conversation about how Jake was getting on at college and demonstrated in a palpable way that he was familiar with the college environment outside the learning support block,

Jake: Yeah. Performing Arts I could show you...there are loads of things to show you...we need the whole day..! If you want to...maybe we should see classrooms first because there's more classrooms

Researcher: So do you know your way around most of college or just this bit near here?

Jake: This part really, I mean we went down to the Lowood bit for the futures fair that was on which is where you... there were lots of organisations like universities there....

The collage activity and the card sort methods required some participant reflection and therefore allowed for silences during the interview involving thinking time or 'use of pause' (**Lewis 2001**), and the ensuing discussion could then be framed around these visual choices. Jake was also able to look at the tablet and move things around while we discussed them,

Researcher: So it's just getting an idea of size so you can have a fiddle with that [silence ...32 seconds... while Jake moves the pictures around]

Jake: I'll put heart maths ....PE is like there ....[pause while Jake moves the pictures around]

Researcher: ICT quite big there isn't it?

Jake: Just trying to fit it all in

Researcher: Yeah. [silence...14 seconds... while Jake continues]

The walking interviews also lent a purpose and structure to the discussion, whereby we were on a 'mission' to take photographs of the college that resulted in the conversation already having a focus. The walking interviews took the pressure off the social interaction required and reduced the need for eye contact and face-to-face talk which some young people with ASC, including Jake, could find problematic. For example, Jake was able to respond in some detail to a relatively closed question that might not have been the case in the intensity of a one-to-one interview,

Researcher: And how are you finding all the work this year? Are you finding it easy, is it easier than school? Is it about the same? Is it more difficult?

Jake: Well I would say it's easier because it's lower quality... but...because last year I was doing GCSEs, this year it's like entry level...but I am doing functional skills 2 in English which is equivalent to a C but I would say it's slightly easier 'cos it's that educational course but...it's gonna be harder when I do my next course because that's more mainstream but I think I should cope well because I know lots of people

The collage method contained visual symbols of the main subjects that Jake was likely to be doing at school presented of equal size and in random order. It was Jake's task to move them around and create an arrangement that represented his main interests in some way. This helped to prompt verbal reactions to certain subjects, and for Jake, to suggest other subjects or activities that were missing,

Researcher: Oh media, did you say media?

Jake: We have done some media. Not sure if media's in there [in the choice of pictures]

Researcher: Shall we add it?

Jake: Yes

Copies of the card sorts and collages that resulted were emailed to Jake after the interview took place so that he could have a visual record of what we discussed in the interview. This proved invaluable at the second

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round of interviews after a six-month gap as it addressed some of the issues relating to poor memory (**Preece, 2002**) by offering a concrete visual representation and reminder of our conversation. Jake was able to look back at the collage from the first interview and articulate the extent to which his interests had changed from the original collage,

Researcher: Do you think anything has changed? Do you think anything has got bigger or smaller?

Jake: I'd probably say that's still the case really now

Researcher: Yeah so those are still the things: swimming, IT, science, Maths are all quite big and these

Jake: Art, drama's quite big, English is about medium-sized, media is quite small sized but I'd say because I do the media um, like a taster in the media, I'd say that has actually, the media has got bigger

All the methods used within the interviews had another purpose in helping to readjust the power relationship between the researcher and participant (**Lewis & Porter 2004**) by sharing the process more with the participants themselves. Handing over the tablet to order the card sorts, to arrange the collage and to take photos all contributed to this changing relationship to the point where, in the walking interview, the participant was literally leading the researcher around unfamiliar territory. The extract below shows Jake leading the way during the interview and really 'owning' the space of his college

Figure 7. Media Corridor   **Figure 8. Outside media classroom**

Jake: The classroom's there and that's T45 and that's also where we do media so I can take it [takes picture of the media corridor onto which the classrooms open]

Researcher: And have you seen where ICT will be next year, have you seen the classroom that will be in?

Jake: I've seen...we went into one of the classrooms where I might go for like my interview so if you want to see where I went, we could go there if you want? We can go down and I can show you the ICT and the um...my normal classroom

Limitations of methods used

One of the dangers of scaffolding the interviews and using collages and card sorts with pre-determined choices is that the results can sometimes be too prescriptive, as Brewster explains, in relation to interviewing people with learning difficulties with little or no speech,

> *"A characteristic many of these methods share is a reliance on pre-selected vocabulary; but how do you identify the specific vocabulary without 'putting words into their mouths'?"*
> (**Brewster et al. 2004: 166**)

Jake was able to add some choices to his collage but did not add any extra cards to the card sorting exercise, and this may have limited the range of considerations regarding the transition to college.

It could be argued the these methods could have been used more effectively if more participation had been sought from the respondents earlier on in the research process. Jake was articulate and would have been able to contribute to ideas about his likes and dislikes at school and his anxieties about college that could have helped to inform the design of the collages and card sorts to help with other participants (**Nind, 2014**).

Discussion

The use of tablet applications during the initial interviews with Jake helped to structure the interview and direct focus away from social interaction and towards the tasks, perhaps making it more comfortable for him. This was particularly helpful at this early point in the research when the researcher was a complete stranger to Jake and was interviewing him on his own in a room at school. The applications also helped to make reflections about capabilities and transition more concrete and that helped to support Jake in conceptualising the future.

The walking interviews in the college environment also afforded a greater insight into Jake's experience in the sense of walking with him in

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his journey around college and also allowed him to take the lead in showing the researcher around his territory, rather than just describing it (**Clark and Emmel, 2010**). He was, at that time, in his second term at college and was already looking forward to moving on to a level two course within the mainstream of college, the researcher was able to witness the learning support corridor of classrooms in one block of the college and was then taken to a busier part of college where Jake would be taught in the following year. It became clear that it had been a transition year within college from learning support to mainstream course and a traditional interview in one fixed place would not have demonstrated this embodied experience of Jake's on-going transition.

Conclusion

The methods used in this research were tentative and experimental but attempted to locate the focus of the experience of transition for the participants with ASC and learning difficulties by ensuring that they had a range of opportunities to express themselves. The methods could also be adapted according to the needs and abilities of different participants, with more use of visual symbols or fewer symbols used to those with a greater degree of learning difficulty. While it would be an exaggeration to claim this research to be truly participatory (**Nind, 2014**), the concept of the 'interrupted interview' does begin to take small steps towards more inclusive research. Challenging ourselves to think creatively about traditional qualitative methods will help to put young people with autism and learning difficulties at the heart of research, and will deepen our understanding as we walk with them in their journeys.

Acknowledgements

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