

Interviews are not the only fruit: accessing the voice of young people with autism



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What was the research?

- ◆ Transitions of young people with autism from special schools to colleges of further education
- ◆ Tensions between special and mainstream education the interface between them
- ◆ Academic and social progress
- ◆ Student centred – lived experience
- ◆ Capability not deficit approach
- ◆ Implications of the new legislation and SEND code of practice - person-centred planning?



Transition and ASC

- ◆ Insistence on sameness *'anxiously obsessive desire for the maintenance of sameness'* and a *'dread of change'* (Kanner, 1943, p245)
- ◆ Challenge of social interaction
- ◆ Social codes and conventions
- ◆ Imagining the future
- ◆ Rigidity of thought
- ◆ Need for clarity
- ◆ Need for routine
- ◆ Vulnerability?
- ◆ Sensory sensitivities/distractions



Person centred planning

- ◆ *Local authorities must consult the child and the child's parent or the young person throughout the process of assessment and production of an EHC plan. They should also involve the child as far as possible in this process. The needs of the individual child and young person should sit at the heart of the assessment and planning process. Planning should start with the individual and local authorities must have regard to the views, wishes and feelings of the child, child's parent or young person, their aspirations, the outcomes they wish to seek and the support they need to achieve them.*

◆ (SEND Code of Practice, 2014)

We need to devise ways of putting the perspectives of people with autism 'at the centre of the autism conversation'

(Ne'eman, 2011)

FOSTER CARERS ANNUAL REVIEW
Form 4(a)

To be completed by Foster Child with Child's Social Worker

This form will be completed when child/young person who has left the placement and/or for a child's current placement at the time of the Foster Carer's Annual Review.

Name of Foster Carer(s):

Your Name:

How long did you live/have you lived in your Foster Placement?

What I like about my fostering placement

What I would like to change

Do you get on with your Foster Carer(s) and any of their children?

Foster Home

1. What do you like and enjoy about school?

maths, computers, the field

1. What would you change about school?

more music lessons

2. How have you changed in the past year?

grown up and talk more

3. What are you good at doing?

counting + reading

What do you still have problems with?

tolerating loud noises

5. What do you think would help you?

practise/ ear defenders

6. What do you want to learn to do next term?

how to take photos

7. Use this space to say anything else about how you are getting on at school.

Who were the participants



- ◆ Leavers from three special schools across three local authorities
- ◆ Pupils with autism in last year of special school 16-17 planning to go on to FE
- ◆ Varying social and communication abilities
- ◆ Tracking transition to further education over 12 months – five different FE colleges
- ◆ Interviews with young people, teachers, parents, careers advisers
- ◆ Six detailed case studies – breadth/depth balance
- ◆ Why and how would they talk to me?

The problem with interviews...

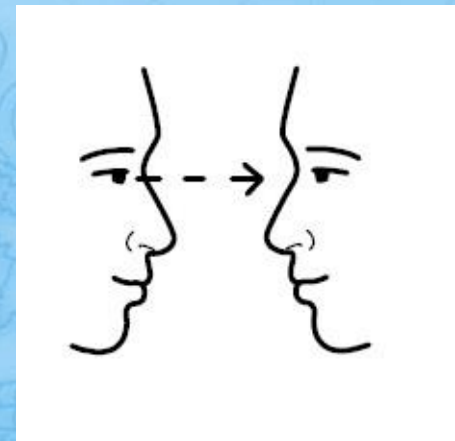


Assumptions

- ◆ 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, p8)
- ◆ Power asymmetry (Kvale and Brinkmann, 2009)
- ◆ Definition of an interview as 'a conversation with a purpose' (Burgess, 1993) and therefore assumption that respondents can focus and be motivated by research on someone else's behalf
- ◆ That respondents can concentrate for relatively long periods of time

And yet...

- ◆ How to privilege young people's voice?
- ◆ '*Nothing about us without us*'
- ◆ Human difference not defect; 'diffability'
- ◆ 'to listen with all our senses' (Rinaldi, 1999)
- ◆ Listening to very young children (Clark & Moss, 2011)
- ◆ More scaffolded approach needed
- ◆ Dignity and respect



Personalising interviews for young people with autism

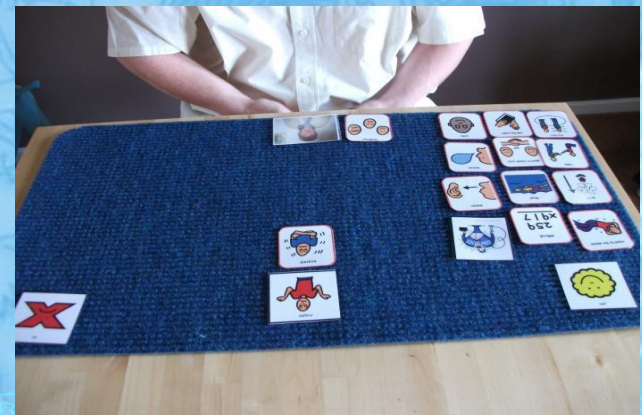
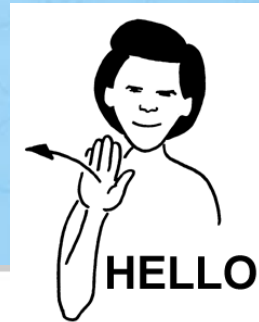
(Classroom Observation, 'Semi-structured' interviews with young people, Semi-structured interviews with parents, teachers, lecturers and careers advisers, field notes, emails and Learning Difficulty Assessments)

- ✓ Focus on abilities, interests and aspirations
- ✓ Concerns and hopes for the future and going on to college
- ✓ Inclusion, college community
- ✓ Involving the young people more in the interview process
- ✓ Use technology?



Exploring 'personalised interviews' with young people with autism

- ◆ Mosaic approach (Clark and Moss, 2011)
- ◆ Participative Rural Analysis (Chambers, 1994)
- ◆ Cue cards (Lewis et al., 2008)
- ◆ Augmentative and Alternative Communication (AAC) (Mirenda, 2008)
- ◆ Talking mats (Murphy & Cameron, 2008)
- ◆ Challenges in the interview process (Preece & Jordan, 2002; Abbott, 2012)
- ◆ Methodological challenges (Nind, 2009)
- ◆ Walking interviews (Clark & Emmel, 2010)



Collages, card sorts and walking interviews



Ellis – Card Sorts

Decks Undo + Ellis+ Order

New friends Free time New facilities New teachers Travelling to and from college

Still being with old friends Social activities Lunchtimes Timetable

Ellis

Course

Decks Undo + Ellis- Order

Teachers Missing school Lunchtimes Not enough routine Transport

Food That the work will be too hard Feeling lonely Friends

Not enjoying the work

Ellis

Meeting friends on other courses Free time Getting lost Social activities



Jake – walking interview



Jake – Walking Interview

JS: I'm going to be completely lost so I'm just going to follow you...[start walking, Jake has ipad] and how's it all going...are you enjoying it?

Jake: Yeah, I had my interview yesterday for my new course

JS: oh, is it ICT?

Jake: ICT BTEC level 2, yes. They said that I'd be the perfect candidate for it [beaming smile]

JS: Oh, well done

Jake: so that's good

JS: so that's what you want to go and do next year

Methods as scaffolding?

To allow processing time and use of pause? (Lewis, 2001)

To use visuals to strengthen communication? (Preece, 2002)

To support language or 'inarticulateness'? (Booth & Booth, 1996)

Adjusting the power relationship? (Lewis & Porter, 2004)

To prompt discussion and provide a concrete record of the interview



Scaffolding?

JS: and what sort of things will you do on that? Do you know what subjects you'll do?

David: mmmmmm...can't remember what I chose now [turns to Mum]

D's mother: have a think... do you remember we went in and spoke to the lady and she had that sheet, do you remember?

David: Yeah know but I can't remember what I chose

D's mother: you can't remember what it was? [pause for David to think]

David: seriously I can't remember

A bit later...

JS: what do you think you might do after college

David: Don't know. Seriously do not know *(from first interview)*

David – original interview

JS: and how was that going to college each week?

David: Yeah, it was alright

JS: do you think...are you going to be taught in the same classrooms that you've visited?

David: Yeah, I think so

JS: right and the same people will be teaching you...?

David: Yeah

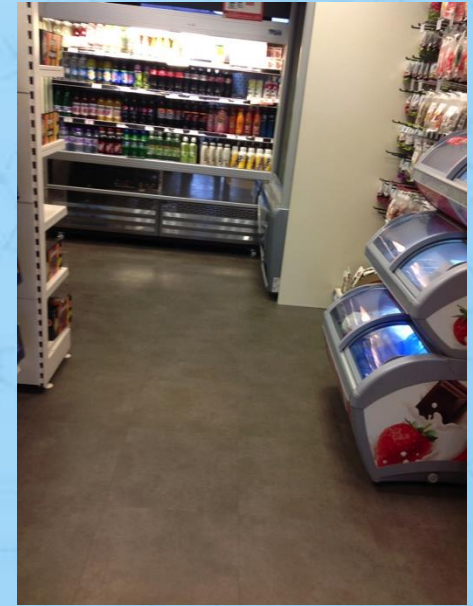
JS: So what do you think it's going to be like your first day at college?

David: I seriously have no idea what it's going to be like

JS: yeah, yeah and you're going to get transport there aren't you so at least that's what you're used to isn't it? Umm, I want to do a little thing on the ipad, are you happy to do that with me?

David: Yeah.

David – Walking Interview



David – walking interview

JS: so is there anything else that you think college could have done to make starting here any better or...was there anything which was just completely confusing when you started....I know it's a while ago now...

David: probably the induction, I don't know...it was pretty good but it's probably like the most confusing thing

JS: was that when you started? Did you have to register and get photos and that kind of thing?

David: yes it was bringing money to do the course, then getting photos so they can give you a student card and stuff like that

JS: so it was all of that bit which once your timetable is going it's OK but it's the first bit - yeah - but it was good they showed you round to the rooms so you could find your way around so if you had to go to other parts of college would you be able to find your way, so if they said to go to construction or...

David: if they told me like, like a room number like this one, then I'd probably be able to find it



JS: this looks like a good room, what do you do in here?

David: this is enterprise which is like arts and crafts and stuff, making it and selling it and stuff like that

JS: so everyone from all over college can come to this café then?

David: Yeah, it's not normally this busy...cos like everyone's in and you actually have to come in on a Thursday if you're on this course so you're going to go in there



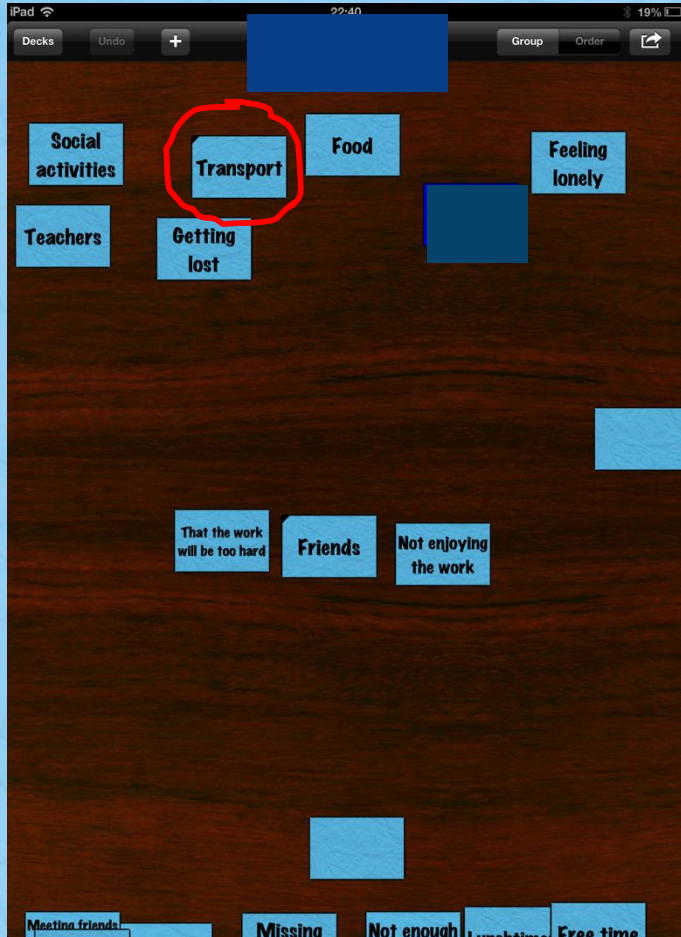
JS: yeah, yeah. Was it Maths you got the GCSE in so you didn't have to...was that just fewer lessons then?

David: yeah. I don't get to do that now cos like the thing I want to do is Maths which I can't do and then I've got English which I struggle to do and I've still got to do

JS: and is that doing GCSE again or is it functional skills?

David: I don't know they say it's entry 3 and level 1 group so probably GCSE *[walking to the carpentry classroom]*

Eric Card Sort



Carol (Eric's mother) : what have you written it on top then? Social activities, teachers, getting lost, transport - what you worried about transport for? Oh the noise of the other children?

Eric: I don't know, I don't know I probably wouldn't be by myself but with other people

JS: so transport would be OK if you were by yourself?

Eric: Cos I might be in the same taxi as those other children what I used to be in and I don't want that to happen. Like, I did like Brad but the other two together really annoys me so I want to be in a different taxi from them lot

Carol: you probably will cos you've got a different course you're going on because the courses might not run at the same time. I didn't know you was concerned about your transport?

Eric: I don't want to be in transport in the first place, I want you or Derek to sort me out

Carol: but you didn't say that because you used to get upset when you couldn't get a taxi because you really liked the taxi and you wanted to go in the taxi. This is just you changing your mind Eric

Eric: I just want you to take me

Carol: well, why didn't you say that? We'll have to sort something out then. You might enjoy it, the thing is me and Derek's not going to be here forever, you need to do things....

‘Putting words into their mouths...?’

(Brewster, 2004)



- ◆ Over-scaffolded responses? How do you choose words/pictures without doing that?
- ◆ More participatory approaches?
- ◆ Could add their own pictures and words but few did

Suggestive

Potentially artificial rank order

Spending longer than the one-off interview – getting to know children and meanings over time (Lewis, 2002)

Putting words into their mouths?



Eric: [on ipad] how do you make it bigger? I want to make it bigger

JS: Like that, if you put two fingers on and spread them out - do you want that one bigger or?

Eric: Yeah. Err, don't do French.

JS: Ok, shall we put French in the bin then?

Eric: umhm...media?

JS: do you do media?

Eric: is it like...?

JS: Films and TV and stuff - yep?

Eric: Is it drama basically?

Confidentiality and Anonymity

Animation

Media

Socialising
with
friends



Dra



I ♥²
Maths



Beth: [laughs] no I don't like cooking

JS: Maths is somewhere in the middle

Beth: Yeah, the thing is like I quite like Maths because some animation does actually involve Maths so I found it quite interesting so it overlaps

JS: Media - cos that's what you're going on to do isn't it? So that needs to be big

Beth: I might put that round there...although...ah there's so much I like [excited]

JS: Yeah, that's good

Beth: Although I really like that I'm going to put it around here just to organise it a bit [laughs]

JS: you can put it down the bottom if you want, if it's big then I'll know it's big so that's alright

Beth: OK. I really do like socialising with my friends, ...ICT...that's going to overlap...just to make some room I'll move that there



Frankie Walking Interview



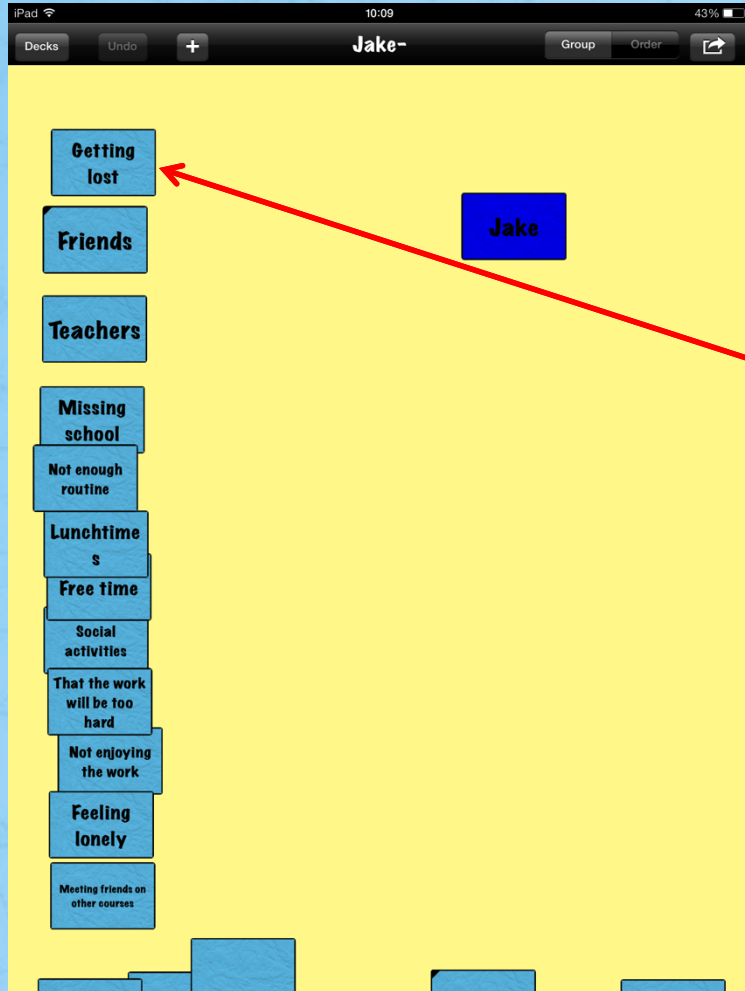
Respect and dignity: the ‘double empathy problem’

- ◆ *‘a disjuncture in reciprocity between two differently disposed social actors...’ ‘double problem’ because both people experience it, and so it is not a singular problem located in any one person’*
- ◆ It is usually more severe for the non-autistic person as it is experienced as unusual but for the autistic person it is more common.
- ◆ *‘one could say that many autistic people have indeed gained a greater level of insight into non-AS society, and more than vice versa’*
- ◆ Empathy thus a two-way street
 - ◆ (Milton, 2012)

Jake's Moving On Plan

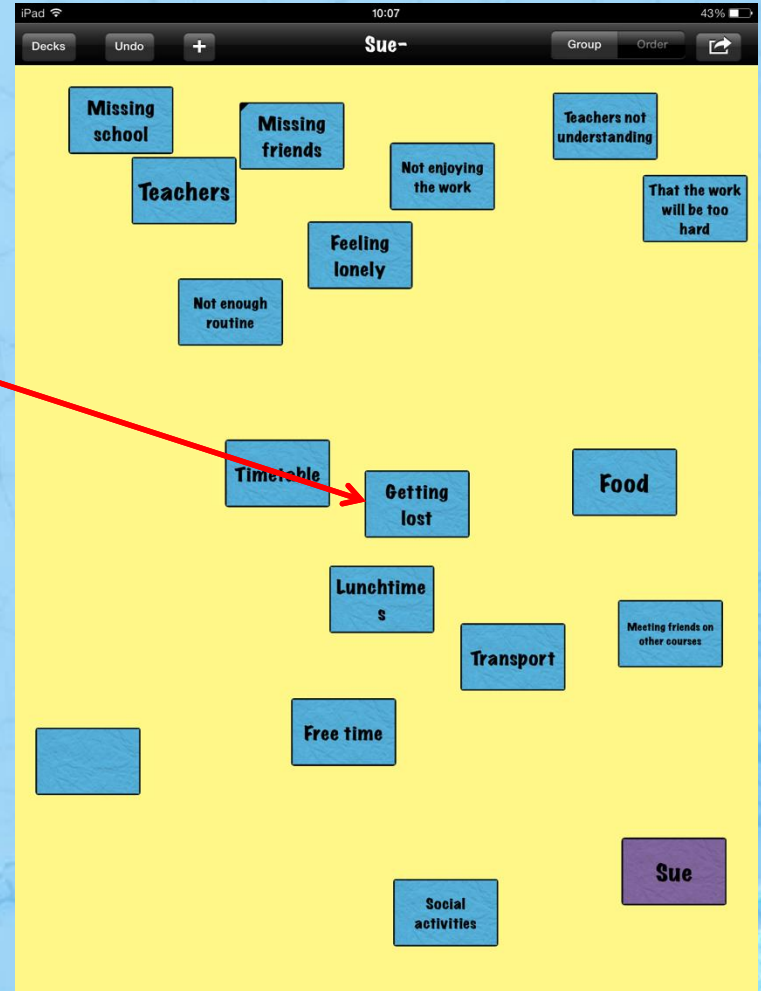
- ◆ Jake has experienced a few difficulties with friendships this year, mainly due to his rigidity of thought. He has been willing to talk about his mistakes and is willing to try hard to learn about them. (*Moving On Plan, 2012*)
- ◆ He [Ellis] wanted to do woodwork and I think that was the only lesson he was going to at Marton School for *[mainstream secondary]* but he ended up leaving even though he'd had someone with him because he kept asking questions. He was asked to be quiet because it was keeping everyone else behind (*Elaine, Ellis's mother*)

Card sorts – Jake and Sue, his mother



This screenshot shows a card sort interface for 'Jake'. The cards are organized into a single vertical column on the left side of the screen. The cards, from top to bottom, are: Getting lost, Friends, Teachers, Missing school, Not enough routine, Lunchtime s, Free time, Social activities, That the work will be too hard, Not enjoying the work, Feeling lonely, and Meeting friends on other courses. A blue card labeled 'Jake' is positioned in the center of the screen. A red arrow points from the 'Getting lost' card in this view to the 'Getting lost' card in the adjacent view.

Jake



This screenshot shows a card sort interface for 'Sue'. The cards are scattered across the screen. The cards include: Missing school, Missing friends, Teachers not understanding, Teachers, Not enjoying the work, That the work will be too hard, Feeling lonely, Not enough routine, Timetable, Getting lost, Food, Lunchtime s, Transport, Meeting friends on other courses, Free time, and Social activities. A purple card labeled 'Sue' is located in the bottom right corner. A red arrow points from the 'Getting lost' card in this view to the 'Getting lost' card in the adjacent view.

Sue

Extract from transcript (Jake and Sue, Jake's mother):



Sue: Hmm....I'm surprised actually *[looking at card sort]*..it's interesting

JS: and let's have a look at the things you might be worried about, concerned about... so top of that list was getting lost wasn't it and new buildings?

Sue: Oh right, I didn't think you'd be worried about that son. Hmm *[very concerned]*

JS: friends, er...teachers, concern about making friends, missing school which was quite a high one, not enough routine, lunchtimes, free time, social activities erm...

Sue: oh right, getting lost and friends. What about teachers, did you mean whether they're going to be nice or not?

Jake: yeah.

Sue: I'm sure they'll be nice *[laughs]*

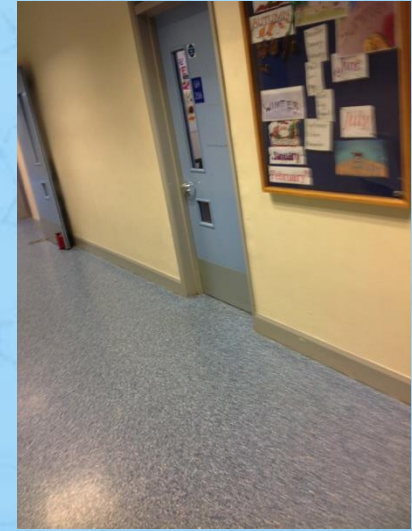
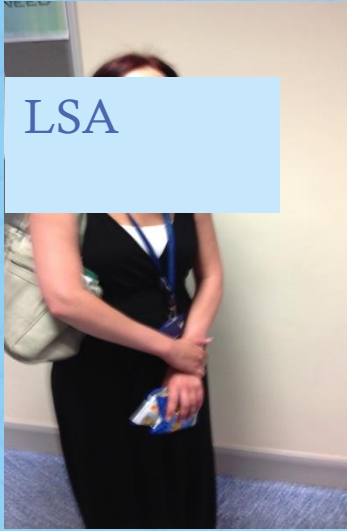
Jake: are you sure?

Sue: yes

Jake: is that it then because I've got to go back and do the weeding?

JS: yes, yes that's it

Eric walking interview



Right of withdrawal/ongoing consent

- ◆ Time out during interviews
- ◆ Checking at each stage
- ◆ Right to withdraw from research
- ◆ Checking on going consent
- ◆ Mental capacity? (Jordan, 1999; Beresford, 1997)

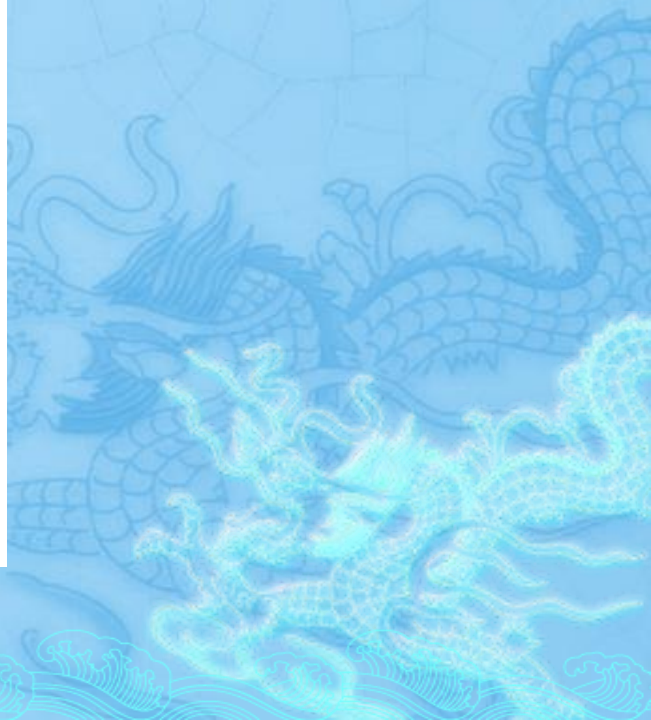
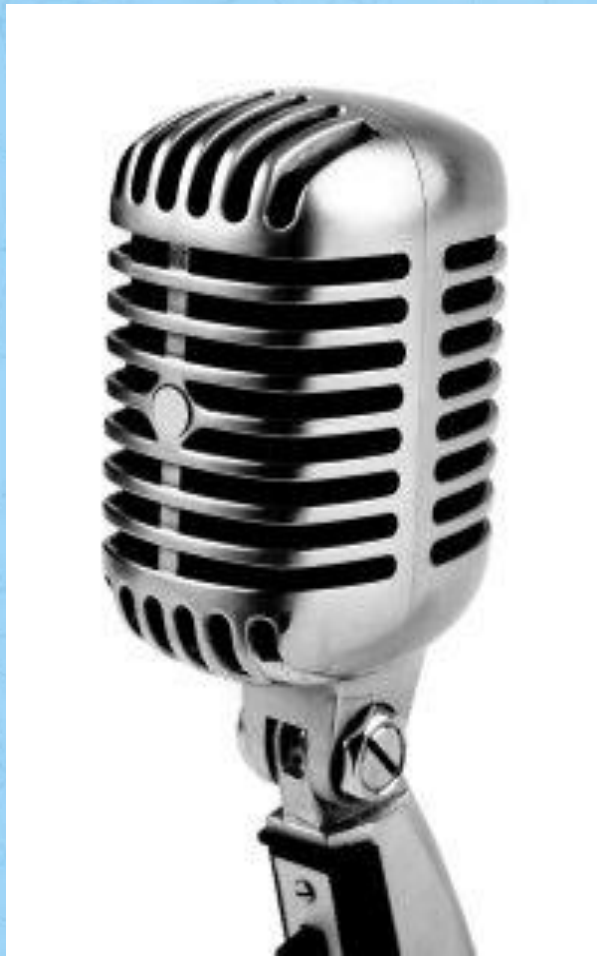


Beth's aspirations

- ◆ Going on to do a level 3 Media course, *“I definitely feel that it’s right, I get a good feeling about it if you know what I mean?”* (Beth)
- ◆ Future plans: *“I think I definitely want to do animation as a career when I’m older so...yeah, that’s kind of set in my head”* (Beth)
- ◆ *“I think college will work, my main sleepless night scenarios are what the hell these kids do after college...Beth is so zoned into wanting to be an animator, I would like to think she could but...I’m not sure, I dunno, it’s frightening that she’s so rigid in her ambition although she’s praised for being really ambitious, what they don’t get is it’s really tunnel vision, that this is what I want, nothing else will do...so I don’t know”* (Beth’s Mum)
- ◆ *“So we said go along [to college] see what you think, try it out and she absolutely loved the media course, and has been back a couple of times since and it’s all been positive”* (Beth’s teacher at school)

Beth's experience at college

- ◆ *It's mostly the social and friends side of things which I'm finding really hard. I keep trying to talk to people but everyone's always in groups and I often feel that they're leaving me out and then I get really worried that I've said something wrong. I feel a bit sad that there's no one like at Meadowlands in my class but I've met a few people on other courses who are really nice so I guess I'm just a bit unlucky with who's in my class.*
 - ◆ (Beth email, 4 weeks in to college)
- ◆ *“things are not going at all well for Beth at college and she's really struggling poor love. She's asked me if you'd mind if we didn't carry on as she's finding everything so stressful” (Mum's text, Spring Term)*



So What?

- Breaks up the interview – less intense
- Helps to access student voice?
- Takes pressure off social interaction
- Creates a space to have discussion with parents
- More concrete and visual record to revisit with student
- Scaffolds thinking processes
- Articulates concerns/abilities/aspirations through forced choices
- Walking and talking helped interview to have a purpose and prompted more discussion
- More control to respondent – where to take the interviewer
To show not tell



Challenges/difficulties

- Being too prescriptive with choices – leading responses, closing down – putting words in their mouths? (Brewster, 2005)
- Walking interviews and photos – intrusive, lack of anonymity? (Clark & Emmel, 2010)
- Location of interview/parental influences (Abbott, 2012)
- Some interviews more successful than others
- Spend more time revisiting and reflecting - develop
- Teenagers with autism
- The stories we can't tell and the right of withdrawal



Questions?

What are the limits to confidentiality and anonymity?

How do we balance the need to support communication without imposing our agenda?

How can we really know about mental capacity?

How do we consider ethics in data presentation and research dissemination?

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