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# BPS DECPTEP Conference 2017

# 'Another door into a new world waiting to be explored'

A psycho-social investigation into the transition experiences of young adults with autism using the Grid Elaboration Method.

## **Session Outline**

- Why this? Why now?
- Statistics
- Research question and why this piece of research matters
- Grid Elaboration Method (Joffe & Elsey , 2014)
- Summary of findings
- Implications for EPs/TEPs

## Why this? Why now?

'While nonautistic [sic] parents and professionals might claim that they are best placed to speak for autistic individuals, especially those who find it difficult to speak for themselves, this cannot be accepted on face value. We believe that human dignity requires us to make every effort to access the views and perspectives of autistic people.'

(Milton, Mills and Pellicano, 2012, p.2650)

### Statistics

- NHS (2012) recent estimates suggest there are approximately 700,000 people in England with an ASC, of whom around 100,000 are children and young people.
- Prevalence rate in the UK of 1% with around 82% of those with a diagnosis of ASC being male (Office of National Statistics, 2013).
- There are over 43,000 children with autism in UK mainstream schools, compared with just 10,440 learners with autism in mainstream further education. (Department for Education, 2011)
- Just 15% of adults with autism are currently in full time paid employment (Ambitious about Autism, 2015).

#### **Research Question**

What are the transition experiences of young people on the autism spectrum?

## What did I do?

- 4 participants
- Interviewed using free association Grid Elaboration Method (Joffe and Elsey, 2014)
- Data analysis using Thematic Analysis (Braun & Clarke, 2006)
- Participant feedback incorporated into 'audit trail'
- Dissemination
  - FE college staff
  - EP colleagues
  - Trainee clinical psychologists at King's College
  - EPASIG Study Day (poster presentation)
  - Here today
  - Journal article... (TBC)

#### Free Association Grid Elaboration Method (Joffe & Elsey, 2014)

- Visually-oriented method of data collection
- Based in principles of free association
- "It was good to show people's, like, feelings, if you get them to draw stuff instead of just asking them." (Samantha)
- Use of reflective field notes:

'Being different' and 'difference' felt like pervasive themes...'perseverance' and 'overcoming challenges' and adversity. Challenges of adolescence. Learning to love to socialise? Participant spoke freely about difficult experiences and equally was clear about what had been helpful. Actually felt quite draining to attend to everything. [Participant] spoke with determination; I felt a little intimidated when listening to [their] difficult experiences.

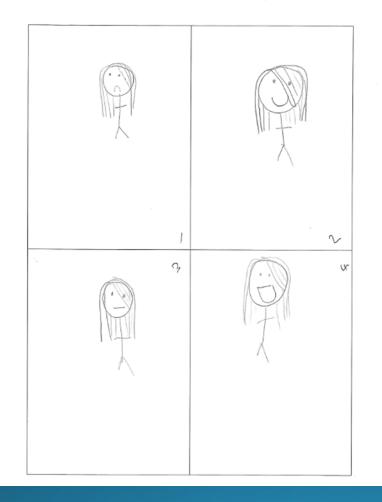
## Example GEM grids (1)

I am interested in what you associate with experiences of transition. Please express what you associate by using images and/or words. Please put one image/word/phrase in each box. Sometimes a really simple drawing or word can be a good way of portraying your thoughts and feelings.

The next stage is another door into a new world just waiting to be explored. Never judge a person When people Say they by their looks + their Can't do anything News needs, we need to Say never. Perservarence Find out What them Give these people extra Will Produce Something time, a little Goost Unexpected. Never Wate OF Considence + reassurance. a human mind

## Example GEM grids (2)

I am interested in what you associate with experiences of transition. Please express what you associate by using images and/or words. Please put one image/word/phrase in each box. Sometimes a really simple drawing or word can be a good way of portraying your thoughts and feelings.



## All about my participants...

Stephen
Ben
Samantha
Jamie

# Findings: Thematic Map

Themes	Sub-Themes
Resilience	Positive attitudes
	Overcoming challenges
Growth and Development	Learning from experience
	Making a positive contribution
Relationships	
Mental Wellbeing	
Agency	External constraints on agency
	Knowing yourself
Understanding Difference	

### Resilience

'And there are some people who said that I couldn't do this...but I've proved them wrong.' (Stephen)

- Positive attitude
- Overcoming challenges

#### Growth and development

'It's exciting...kind of exciting, you know, working with new people, a new classroom, and like learning your way around... it's a bit scary to start off with but you tend to get used to it and you get less and less scared.' (Ben)

Learning from experience

Making a positive contribution

#### Relationships

'Excited! at college, like, meeting new people, teachers understanding you, if you need help you go to them, not to be scared to ask for help.' (Samantha)

## Agency

'I like the fact that college is very good at preparing their students for the next stage, and for the outside world.' (Stephen)

- External constraints on agency
- Knowing yourself

### Understanding difference

'When I was younger everybody didn't understand, I was a stupid retard who didn't understand anything, even people in my family said "oh Stephen, he's autistic, he'll never be able to do that."' (Stephen)

## Mental wellbeing

'Because at the start of enrolment when everyone starts a new course there may be some certain changes to the timetable and things like that, but when I first started here I got really anxious about those changes and I used to get really strange panic attacks and things like that.' (Jamie)

'This college is very good at supporting people with those different needs. And loads of people who need extra time, they offer very good support services.' (Stephen)

## Limitations and future research

- Based on retrospective accounts
- Only one interview per participant
- Parental anxieties and impact on findings
- No psychoanalytic concepts in the data analysis?
- Socio-economic status?
- Further research which explores lived experiences of YP with autism
- Longitudinal research using GEM
- Explore transition experiences of YP with autism at university

## Implications for EPs/TEPs

- Peer relationships may be a protective factor in facilitating a positive transition. This is particularly
  salient when placed in the context of previous research that has highlighted that young people with
  autism tend to have access to limited social networks, fewer friends and lower levels of social support.
- EPs may take up an advocacy role when working with young adults on the autism spectrum and ensure that their voices are heard in relation to decisions which impact on their future and on their well-being.
- The use of the free association GEM with its integrated visual element shows how using 'light-touch' visual support can be helpful in enabling the views and voices of young people with autism to be expressed.
- Empowers EPs to draw upon existing skills in order to develop the EP role and engage with young people with autism in the 18-25 age range, particularly in relation to gaining insight into their experiences and their views.
- **Importance of flexible and individualised transition planning** for young people with autism and of having key stakeholders at the heart of decision making and planning.
- EPs are well positioned to have a key role in facilitating and representing the views of young people at the heart of decision making about their futures. In line with the government agenda of person-centred planning it remains vital to hear from these young people's perspectives and to establish the kinds of support that is most useful to them and the type and extent of support desired.

## Top Tips...

- Aim high...
- Try to hold in mind what drew you to your research area and find the love you have for what you're doing...dig deep
- Peer support
- Positively reframe the viva experience
  - Get on with amendments and get them done  $oldsymbol{\Im}$
- Take heart...there is Life After Thesis

## Acknowledgements

I am grateful to my placement EPS for their support, my supervisors Carol Greenway and Jude Mortell for their guidance and the staff of the FE colleges in which the research took place for their generous support in enabling me to access participants and facilitating the interviews.

I would like to take this opportunity to express my gratitude to all my participants for their time and interest and to acknowledge the contribution that they have made to this area of research. I hope that my participants felt valued and that their contribution will make a difference.

## Useful References

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## Questions?



## Thank you 🙂

You're more than welcome to contact me at Jane.Park@telford.gov.uk

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