



National Autistic Society: Autism and Anxiety

# Managing Anxiety at Times of Transition

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# Outline

Autism spectrum and anxiety

Transition and anxiety

Research project on transitions to Further Education

Strategies for managing anxiety and making 'reasonable adjustment'

# Autism Spectrum

- Asperger's syndrome
- Sophisticated use of language and comprehension through to receptive and expressive language difficulties
- (Non or) pre-verbal
- Multiple intelligences including specific intense ability through to mild, moderate, severe learning difficulties
- No associated medical issues to a range of co-morbidities including epilepsy, gastro sensitivities, sleep issues etc

BUT Commonality of social communication and interaction difficulties and probably sensory sensitivities



# Autism and anxiety



- *'significantly higher levels of anxiety than in the general population'*
- Physiological arousal and panic which interferes with daily life
- Anxiety and the increased social demands of adolescence (Bellini, 2006)
- More common among those with high functioning autism? (White, 2009)
- Triggers, consequences and strategies (Trembath et al., 2012)



# Triggers for anxiety

1. Everyday environments
2. Interactions with others
3. Concern for others
4. Fearful anticipation
5. Disappointment

(Trembath et al., 2012)



# Manifestations of anxiety



# The challenge of transition(s)

Moving from one activity to another

Small transitions problematic (Sterling-Turner & Jordan, 2007; Hume, 2008)

Crossing thresholds

Moving from home to school

Changes in family relationships

Lack of motivation

May not comprehend all verbal instructions

Difficulty sequencing

Sensory changes

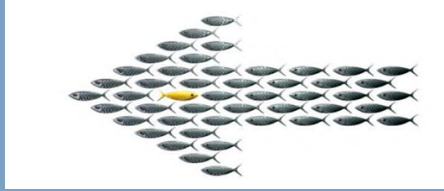


# Transition and ASC

- *'anxiously obsessive desire for the maintenance of sameness'* and a *'dread of change'* (Kanner, 1943, p245)
- Imagining the future
- Challenge of social interaction
- Need for routine, predictability
- Additional learning difficulties
- Young people with autism typically, *'will have the combination of fewer social links, be more emotionally immature and less experienced in 'knowing the ropes' to help them'* (Plimley and Bowen, 2006, p56)







# The research project

## The project:

Fewer than 1 in 4 young people with autism continue their education beyond school? (*Ambitious About Autism, 2011*)

Pupils with autism and learning difficulties in last year of special school planning to go on to mainstream college of Further Education (3 schools, 5 colleges, 3 local authorities)

Followed through young people over the period of one year (interviews with young people, teachers, parents and tutors)

Young people at the centre of the research

# From special school to FE college

Many more people

Peer groups?

Bigger sites/campuses

More staff, less contact

Social areas, social time

No uniform

Getting to and from college

Part-time timetables

Less parental involvement

Transition to adulthood



# Methods

Swimming



I ♥ Maths

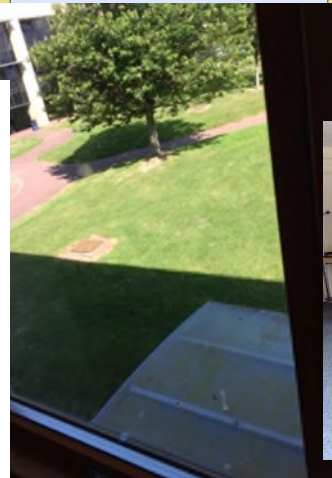
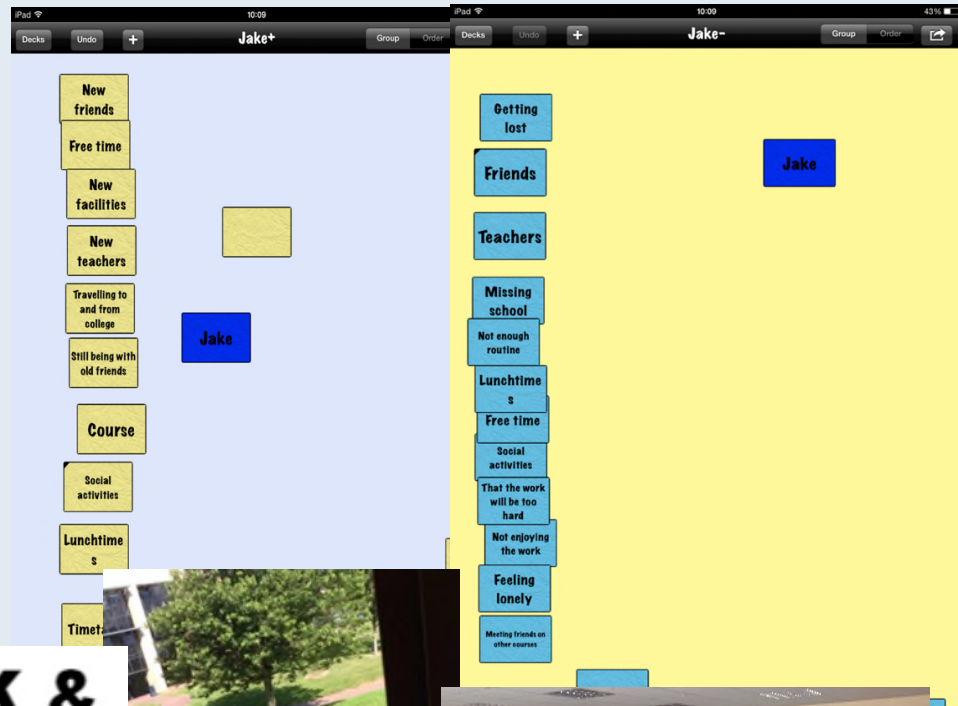
Drama



WALK &



TALK

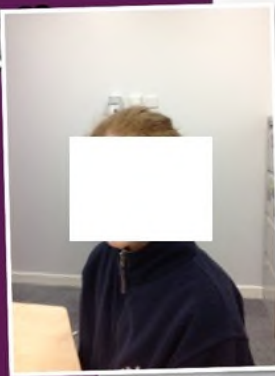


Beth

# Animation


# Media

Socialising  
with  
friends



# Dra

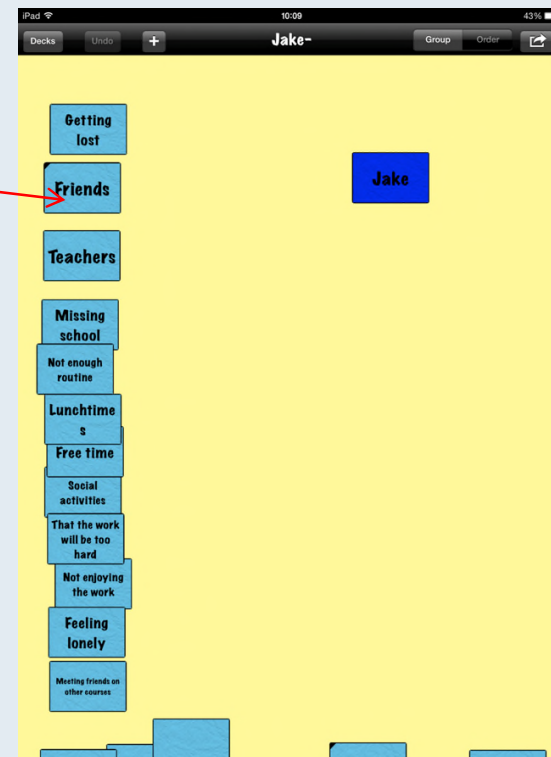
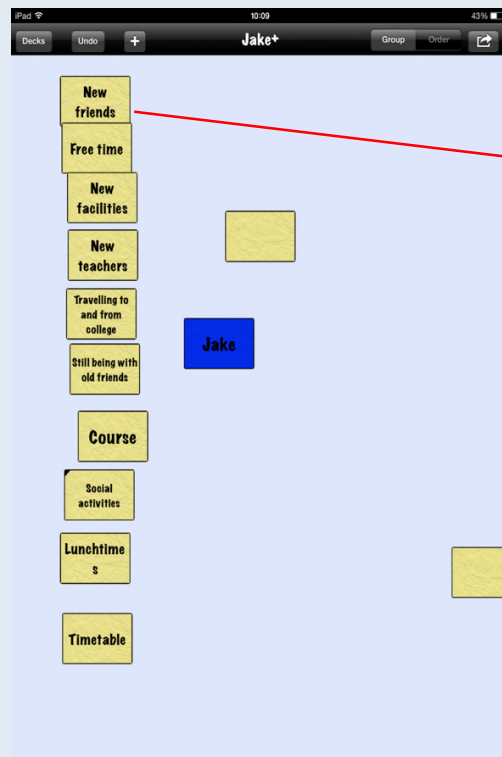


I  <sup>2</sup>  
Maths





# Card sorts - Jake



# Capabilities and interests



- ✓ Chose subjects including ICT, media, cooking, woodwork, maths, music, science and drama
- ✓ Enjoyed swimming, drama and youth clubs; Frankie was in a choir; Beth was a fantastic animator; Eric excelled in his work experience
- ✓ All were sociable, used social media and talked about friendships
- ✓ All talked about living independently and having jobs in the future; they talked about relationships and possibly getting married

# Card sorts - Going to college



## **Looking forward to...**

- Making new friends, having new teachers
- New facilities and having free time
- They were also looking forward to their new courses

## **Anxious about...**

- Making new friends, having new teachers
- Getting lost, missing school, not enough routine
- Feeling lonely, not coping with the work, transport

# Key themes

Anxiety and transition

Academic and social progression

Social interaction difficulties and supporting **social transition**

Managing time

Lack of peer group

Independence and vulnerability

Supporting parental transition

Travel training – emancipation or imposition?





# Challenge of social interaction

**Eric constantly supervised** (Eric's college tutor) College within one corridor

and **Eric and being excluded** *'Someone did punch me in the face once and I punched him back, he got suspended and came back early and I got suspended for weeks and weeks for no reason'*

**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)

**Frankie being bullied** *'some horrible person forced me to smoke'* (Frankie)



# Beth and the social compromise

*'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 during second term at college)



# David and induction day

**JS:** so is there anything else that you think college could have done to make starting here any better?

**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

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**David's Mum:** *The only thing that Michael struggled with was the enrolment day, it was manic, there were just people everywhere and he just had to go off on his own and sit in various classrooms and have talks, there were forms to fill in and he really struggled with having to do that on his own and with all these people around um...and he doesn't really know how to sign his name even so it's quite difficult for him to sit down and do a form like that, it's not something he's ever done before*



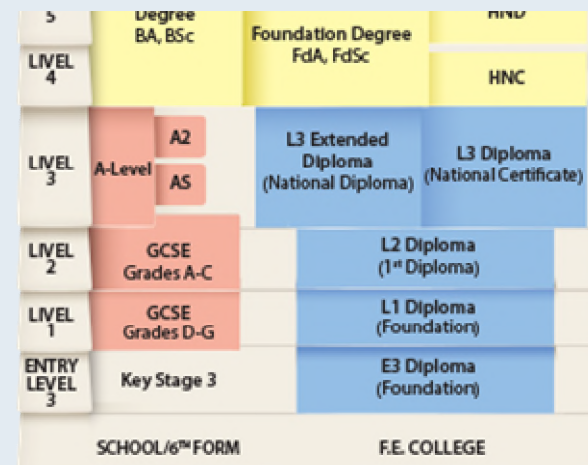
# Jake and the academic compromise

*'we felt that going straight to mainstream from special would have been too much [...] I think he'll probably be a bit bored by some of the options um...but...I think it's a sort of necessary process really'* (Jake's mother)

Jake on whether the work was easier or more difficult at college:

*'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...'*

College tutor: *he's probably the highest ability student I have ever had*





# Managing part time timetables

## College tutor knows that days off are not productive

JS: *And what do you think they do on their days off?*

Tutor: *I know what they do, they all sit around and they play computer games and they don't do anything*

## What Frankie does

JS: *So what do you do in the day if you're not going to college?*

Frankie: *I either go out or stay in and play games or chat with friends on Facebook*

JS: *And that's OK is it? Is it alright on those two days?*

Frankie: *Yeah, sometimes but sometimes I don't have anything to do*

## David handed his coursework in on time so had further time off,

David's mother: *'At the moment he's not doing very much time at all at the college, apparently he finished the coursework and that's it so until the other side of half term now he's not going in any more*

JS: *So he does all day Tuesday and Monday afternoon and that's it?*

David's mother: *And that's it*

Monday	Tuesday	Wednesday	Thursday	Friday
	Introduction to Physiotherapy Practice (Lecture)			Introduction to Physiotherapy Practice (Practical)
			Professional Health Competencies (Tutorial)	
	Introduction to Physiotherapy Practice (Tutorial)		Professional Health Competencies (Lecture)	Human Anatomy and Physiology 1 (Tutorial)
			Human Anatomy and Physiology 1 (Lecture)	
	Population Health and Society (Tutorial)	Population Health and Society (Lecture)		

# Summer holidays

*'I think a degree of anxiety comes into play if there's nothing happening' (Jake's mother)*

David and the summer holidays, *'I would definitely say that David has been quite withdrawn over the summer break and he has not wanted to take part in any activities...to be honest I am a little worried that he might also be a bit depressed' (David's mother, email)*

Frankie's father's surprise at length of summer holidays,

*For three months, it just went on and on and on and so that was bonkers and the other thing was I didn't appreciate the fact that he would be out of school after he did his exams so that was a surprise to me so he was actually sitting on the sofa for quite a long time doing bugger all*



# Eric and ‘vulnerability’

*‘he’s so behind, he’s very socially and mentally behind in his age and that so it’s going to be very, very hard, **it’s like sending a 12 year old to college**, you know, Eric is very immature.’ (Eric’s Mum)*

Reliance on learning support assistant

Not allowed to go anywhere unsupervised even at break times

Relationships with girls

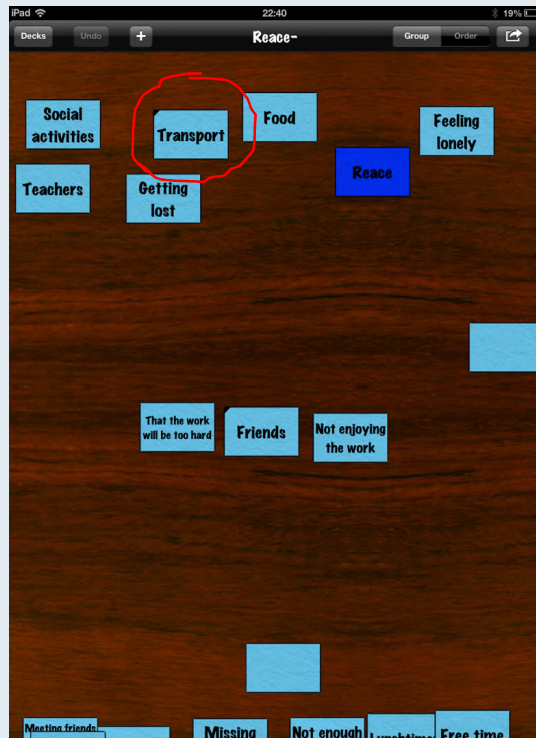
‘Vulnerable’

Lack of peer group

And yet, ready for ‘travel training’...



# Transport: a matter of life and death?



*He [the college travel trainer] was very aggressive to me, the man, he shouted at me. He said parents like you don't want their children to grow up and have independence don't you want him to have a girlfriend and have a job, don't you want him to have a normal life? I said, do you want my son in a coffin? I said his death will be on your shoulders, I said I'm his mother, it's my responsibility is to keep him safe[.....]that man thinks he knows more about Eric than I do and all he's seen of Eric is half an hour through the day...I think it is very dis-respectful and I'm not having it... 'well he's passing, he will have to make his own way to college'. I spoke to someone about it and said I'm not happy about this, Eric is still very vulnerable, he is very vulnerable.*



# Supporting social transition

- Peer links between schools – buddying
- Dialogue between autistic and non-autistic pupils
- Autism awareness in whole school community
- Preparation for school social life and opportunities
- Social progress
- Potential of social media
- Sharing skills and abilities



# Managing 'break' times

- Structure at unstructured times – clubs, sports, games, reading, maths, computing
- Social teaching and learning – peers
- Whole college approach - social spaces, office staff etc
- Peer support and interaction
- Quiet spaces
- Social stories and storyboarding
- No one eats alone day (US)



# Celebrate interdependence

- Acknowledge that restricted peer groups, learning difficulties sometimes mean more reliance on parents (and others) Challenge of social interaction, lack of peer group, spend more time with parents (Orsmond & Kuo, 2011) – involve parents in transition planning *but also in first terms at college*
- Develop independence where possible and timely and support where it is not
- Holistic approach to transition involving peer groups and buddy systems



# Mutuality

**David** could have helped others with Maths, *'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'*

**Beth** and animation workshops *'I really like animation because you set yourself a goal and then you can just kind of get really obsessive with it and just keep on going'*



# ‘Double empathy’ problem

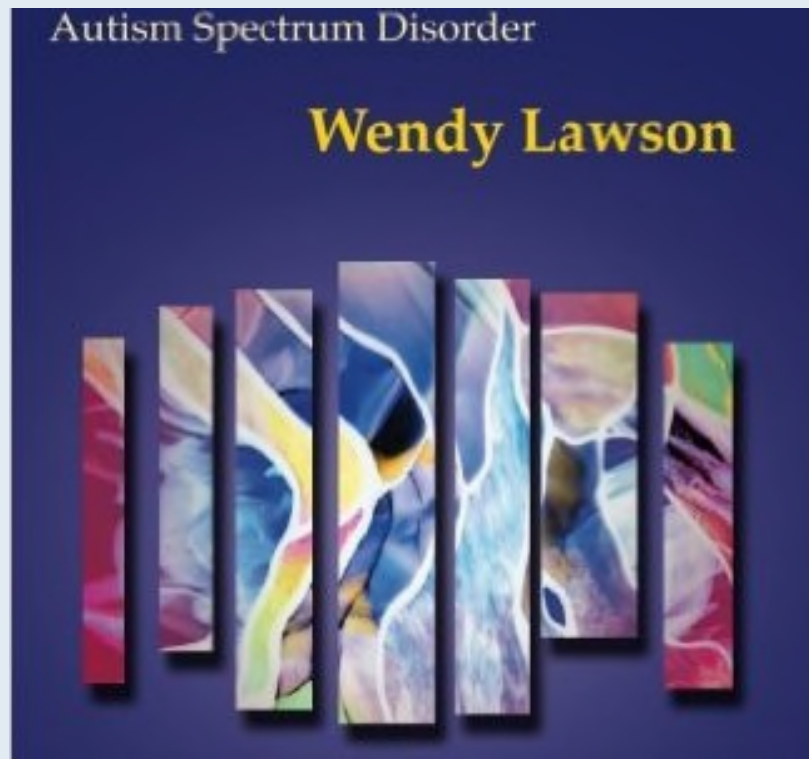
*‘One could say that many autistic people have indeed gained a greater level of insight into non-autistic spectrum society, and more than vice versa’ (Milton, 2012)*





# Making 'reasonable adjustment'

*If things became really bad and I suffer what I call a sensory overload, then I close out all the sounds and noises of the world. I could sit somewhere quietly or put my hands over my ears and enjoy the quieter sounds of life. Somehow to just sit and close off gives me space and time to recover from being anxious. It helps me to calm down. If I cannot find the room to do this, then the overload can build to an explosion! (Wendy Lawson, 1998)*



# Autism and transition & *reasonable adjustment*

Managing change – preparation and planning to help manage anxiety

Small transitions problematic – scripting, visuals

Social use of language – language privileged in education, alternative communications

Social interactions – peer support and understanding

Effective person-centred planning

Imagining the future, flexibility of thought – making it concrete

Need for routine, predictability – what can be predicted? Time management

Special school vs mainstream college – size matters, sensory environment, quiet spaces

Sensory adaptations – alternative sensory environments

# Readiness?



# References

- Ambitious About Autism (2011) *Finished at School. Where next for young people with autism?* London: Pears National Centre for Autism Education.
- Bellini, S. (2006), The Development of Social Anxiety in Adolescents with Autism Spectrum Disorders *Focus on Autism and Other Developmental Disabilities* 21(3) 136-145
- Hume, K. (2008) 'Transition Time: Helping Individuals on the Autism Spectrum Move Successfully from One Activity to Another.' *The Reporter*, 13(2) pp. 6–10.
- Kanner, L. (1943) 'Autistic disturbances of affective contact.' *Nervous Child*, 2 pp. 217–250.
- Lawson, W. (1998) *Life Behind Glass* London: Jessica Kingsley
- Orsmond, G. and Kuo, H. (2011) 'The daily lives of adolescents with autism spectrum disorder.' *Autism*, 15(5).
- Plimley, L. and Bowen, M. (2006) *Autistic Spectrum Disorders in the Secondary School*. London: Sage.
- Sterling-Turner, H. and Jordan, S. (2007) 'Interventions addressing transition difficulties for individuals with autism.' *Psychology in the Schools*, 44(7) pp. 681–690.
- Trembath et al.,(2012) The Experience of Anxiety in Young Adults With Autism Spectrum Disorders *Focus on Autism and Other Developmental Disabilities* 27(4) 213 –224
- White, S., Oswald, D. Ollendick, T., and Scahill, L. (2009) Anxiety in Children and Adolescents with Autistic Spectrum Disorders *Clinical Psychology Review*, 13, 216-229
- Williams, D., (1999) *Nobody Nowhere* London: Jessica Kingsley

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*'Interrupted Interviews': Listening to young people with autism in transition*

<http://exchanges.warwick.ac.uk/index.php/exchanges/article/view/62>



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