

Making Personal Budgets work for young adults with an ASC in Transition

with particular reference to Asperger's Syndrome and HFA

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The Context - What are the issues about Transition for young people with ASD?

- Micro level transitions
- Macro level transitions
- Why are changes/transitions difficult for people with autism?
- What skills are required by the person?
- What skills are required by their professional supporters?



What is a transition?

- *Transition is all about what the next thing is, and the steps which will take you there'*

Wendy Lawson 2002



What have young people with ASD long been saying about their experiences of transition

- Not sufficiently involved in planning
- Key decisions are being made by others
- Hopes & aspirations ignored or viewed as unrealistic
- Too little information being given
- Being frightened of the unknown
- Being frightened of the known
- Not knowing how I am doing
- Trying to cope with changes 'normally'



Change & Transition – Micro level

- one room to another
- between activities
- these changes require predicability, so consistent support is vital



Transition – Macro level

- 5 years – early years into school
- 11 years – secondary transfer (possibly inclusion in mainstream provision)
- 14 years – UK transition review
- 16 years – Continued/Further education
- 19 years – leaving school
 - further/ higher education
 - adult placement
 - employment
- These changes require predictability so consistent support from carers and professionals is vital, but is often hard to achieve in multi-disciplinary working



Why are changes difficult?

- Difficulty in predicting events
- Dislike of change
- A focus and determination to preserve sameness
- Ritualistic and repetitive routines
- High levels of anxiety
- Lack of flexibility of thought
- Difficulties with choice and decision making
- Needing to keep in control



Why are changes difficult?

- Difficulties in switching from one perceptual mode to another – a micro delay but has an effect.
- Scared of the new and unfamiliar therefore need structured choice
- Dependence on routines “ a situation, a performance, a sentence is not regarded as complete if it is not made up of exactly the same elements that were present at the time the child was first confronted with it.” Kanner. (1943)



Why are changes difficult?

- Difficulties with making 'connections'
- enhanced discrimination and reduced generalisation can result in an inability to recognise similarities between stimuli or sensations
- Everything is experienced as if it were new and for the first time?



Difficulty with Understanding Concepts

- Every change for a person with autism is difficult.
- These will vary in intensity of difficulty according to the stressors in each situation.
- People with ASD have an ‘attention tunnel’ (Wendy Lawson)
- Conceptualising, and anticipating consequences of change is harder if information from only one channel is being processed.



Memory Problems

- Poor 'personal episodic memory'
- Difficulties with 'prospective memory' – remembering to carry out your intentions
- Good rote memory means reliance on this and reluctance to deviate from order in which tasks are listed
- Problems with multi-tasking result – but the content of Macro Transitions are complex
- Problems accessing memories of past experiences
- Can't necessarily draw on past experience to solve problems



Attention

- May have difficulties in ‘switching’ attention
- May have difficulties in ‘integrating’ stimuli from different senses
- May attend to detail and not grasp overall meaning
 - May lead to highly developed skills
 - May not be useful for general learning ability



Transition- what skills are required?

- Problem solving
- Decision making
- Compare options
- Review / Stick to decisions made
- Planning
- Perseverance



Problem solving and decision making

- What is problem solving?
- Why is it so important?
- Difficulties with problem solving.....
 - Choice
 - Comparing options
 - Weighing up consequences
 - Being able to learn from mistakes
- Is it addressed enough in schools?



Making Choices

- Difficulties in making choices involve:
 - Lack of awareness of options
 - so called ‘lack of imagination’
 - Dreams, aspirations, desires
 - Do what I’ve always done
 - Easier not to opt out than make a choice



Person Centred Planning

- A toolkit containing a range of techniques to elicit a person's dreams, expectations and needs for the future.
- A proactive framework to proactively plan for this future, thus maximising outcomes



Why is PCP difficult for people with autism?

- Same difficulties they experience with change
- Decision making, Choice, Problem solving
- Need to be taught these skills
- Need advocates
- Need to be taught self advocacy



Change – How to make it easier for people with autism

Try and provide Structure

- Free choice causes anxiety
- Things must have a beginning, a middle and a clear ending
- The young person should always know
 - where do I have to be?
 - what am I doing?
 - how much do I have to do?
 - when will I know I have finished? and
 - what will I do next?



Change – How to make it easier for young people with autism

Use a variety of means of communication

- Don't rely exclusively on verbal communication -
 - Put it in writing/ picture form
 - Use written plans and timetables
 - Visual schedules
 - Use objects, photo's, symbols
- Build in planned, regular breaks
 - Avoid fatigue
 - Allow people time to 'de-stress' and relax
 - Provide clearly defined breaks between structured activities
 - Balance active and passive activities



Change – How to make it easier for young people with autism

Give clear rules and be consistent

- Check that you have been understood correctly
- Mean what you say and follow it through
- Use language that is clear, precise and concrete, unambiguous
- Always forewarn
 - Tell the young person what to expect
 - Give plenty of notice



Change – How to make it easier for young people with autism

Recognise the stresses involved in transition

Don't crowd - give physical/personal space

Don't overload with information

Allow time for questions to be processed

Be clear and concise

Teach waiting and turn-taking skills

Avoid confrontations



Advocacy and autism

- Interpret, but encourage people to present their own opinions in whatever way works for them
- younger people need ‘mentors’ and role models from other people who have undergone successful transitions previously
- Recognise the ‘dilemmas’ in exercising choice- not knowing what to choose
- Inappropriate choices- lack of cause and effect and sense of consequence: How does your decision impact on others?
- Motivation – Lack of understanding of rights or not wanting to make decisions
- Biggest problem is sufficient advocate ‘time’ in terms of amount of input required to use PCP techniques effectively



Advocacy and assisting Choice

- Presumption of shared values by advocates may cause problems
- People with ASD- Limited experiences = limited choice
- Small-steps process
- Teach the understanding that one can change one's mind
- Professionals and advocates need to accept that some may choose an alternative way of life and have capacity to make 'unwise' decisions.



The key role of parents in transition

- continuity of perspective
- in-depth knowledge of the young persons emotional development
- provide an effective link between all life stages
- enable generalisation of skills in a range of settings
- have often acquired specialist knowledge of their young person's behavioural issues
- research and autism professionals indicate parental involvement helpful



Our experience in NAAT

- We can take referrals from any source whatsoever
 - We then assess and arrange for commissioned services to individuals and carers based on their needs under the Fair Access to Care Criteria; this is done under the Putting People First/Personal Budgets initiative
 - We have been averaging 3 new referrals a week for the past 18 months
 - We have conducted over 300 assessments in total over 30 months, these have led to the team currently supporting around c.180 people on the team's collective case list (5 FTE staff)
 - We already know 10% of the estimated prevalence of Adults with AS in Nottinghamshire after 2 years of operation
- *We look at people's needs in a holistic way based on their Self-Directed Support Assessment, which we have interpreted for them to be as autism-friendly and as Person-Centred as we can*



Community Care Assessments of Adults with AS – what we have learnt

- This issue was summarised in my paper in GAP Magazine – Volume 11 No 2 October 2010 – ‘***How can adults with Asperger’s Syndrome contribute most effectively to their Community Care Assessments.***’
- A very useful practical source of guidance about engaging with people being assessed is – ‘***Saeki.M and Powell.A (2008) Social Care: assessment of need for adults with an autism spectrum disorder.***’ London. **NAS**
- Essential that caseloads of assessors are realistic and they reflect that such assessments may take several visits to complete. Implications for time management and Performance Indicator NI132 deadlines in Local Authorities.



Support Planning for Adults with AS using Personal Budgets – what we have learnt

- Commissioning Support Planning using a Personal Budgets Framework is dependent on the Indicative Personal Budget (Cost Envelope) as determined by the 'Resource Allocation System.' The support package provided must be costed within this
- Both IB's which are either very small or large can be a challenge to be value for money
- Many of our community based individuals have demonstrated they can be adequately supported by 3 hours per day/21 hours per week
- The assessment process must be explained with absolute clarity – this often involves providing explanatory materials and documentation about the available options in having a Personal Budget and their relative merits e.g. Direct payment v a Managed Personal Budget
- Objectives in the Support Plan must be SMART and unequivocal. Only a few should be initially identified, as too many can be intimidating and disappointing if not achieved. They must not be so imprecise they can be misinterpreted – deliberately or otherwise!



Ensuring Effective Transitions – key themes

- Individual planning which is fully Person Centred, despite the time and resources this takes
- STRUCTURE to support transition
- PROACTIVE/ focused approaches
- COHERENT joined-up professional links
- Monitoring and Evaluation at a personal and service level – individual reviews and service data collection
- Pragmatism and creative solutions which are value for money



Making Personal Budgets work for young people in Transition

- Transitions for young people with autism are ongoing for them on both a micro and a macro level
- They will always be a constant source of anxiety
- Good planning reduces stress
- This needs proactive, individualised programmes
- and multi agency collaboration with the fullest carer involvement

Transitions are a process and not an event.....



Case Study A

- W referred in July 2009 by his mother via GP
- Unable to complete his studies in music technology in mainstream college.
- Not wishing to return college withdrawing from interaction with family and peers.
- Spending his days in his room and has no plans for the future or how to resolve his situation.
- Needs to have assistance with benefits



Case study A

- For any PB to be effective need to adapt working style to enable communication and assessment to take place.
- Gain an understanding of and specific knowledge of W to understand how his anxiety was impacting upon his ability to have contact with others
- Consider his belief system, hyper sensitivities and hypo sensitivities are these impacting upon ability to function
- Engage with his family and provide support. Consider if clinical support will be useful
- Consider W's strengths and any available resources – are they appropriate
- Use person centred planning to engage W with support in an incremental way.
- Recognise the need for control for W. Therefore issues of choice and timing of intervention are essential
- Goals must be realistic achievable and regularly reviewed



Case Study B

- A was identified as a transitions case within CLDT. Considered to have AS therefore referral made in December 2009 for assistance with transition of DP from Children's Services to Adult Services. Transitions worker closed the case.
- A's mother had recently died and A was cared for by father who had previously had little contact with care arrangements. Father was struggling with the death of his partner and it was important to consider the carers stress levels.
- A. attained the age of 18 in July 2009. At the point of transition A had limited understanding of his condition and there were very few people around who understood A's needs. A had been reliant upon his mother who had met all his needs
- A had plans to attend mainstream college with support. This was supported by his father.
- Children's Services closed the case identifying that A had no unmet needs. Any needs could be met within the family



Case Study B

- Initial involvement was perceived as necessary for transfer with DP otherwise A and his father were reluctant to engage with services. Needed to respect their wish for independence and hear their voice
- DP used to pay family friend to offer befriending service.
- Strengths were PA had good knowledge of A and he felt relaxed and comfortable in her company. She had a good understanding of the triggers for his anxiety and encouraged him to be part of her family. As a friend of his mothers this was continuation of the norm for A and not a further loss.
- A request for increased payment of DP during school holidays highlighted that father had a poor understanding of the danger his son may experience. Supervision throughout his life had led to a lack of concept of danger for A and his father. Referral for OT was made.
- Mainstream College highlighted problems with behaviour and queried the possibility of Classical Autism. Specialist assessment revealed that good rote memory and specialist interest in reading along with secure environments may have masked behavioural characteristics.
- Attempts to pursue mainstream college failed due to high levels of anxiety
- A was referred to Autism specific college with transitional work to a college for adults with physical and learning disabilities. After one year he has commenced his second year.
- SDSA process has identified a PB which has enabled A to consider a micro provider for autism specific services during school holidays. This is enabling A to mix socially with others in a community environment and begin work on independent living skills. Allows father to continue work and not look at a reduction in working hours. Provide carer support and activity
- Father has recently reported A is loving it and has suggested A did not need his DP for a befriender.
- To make a PB work is it is important to consider pace of intervention and respect the views of service user and families. Think long term in transition and not in the here and now. Encourage environments which support good communication and consider if the persons learning style. Demonstrate what options are available and how the service user can choose these resources, visits to establishments home visits computers leaflets all or a few.ble. Encourage flexibility within resources and no one approach fits all.

