Tackling Common Issues for Adults with Moderate or Severe Autism

Introductions

• My name is Tessa Phillips.
• I have worked for the NAS for over 5 years.
• I began in a position as an Activities coordinator for the Surrey adult services and worked across two day services.
• I was based mainly in a centre for adults who had moderate to high-functioning autism or Asperger’s syndrome (a form of autism). Many of these were extremely complex and had high needs.
• I also had the opportunity to see other services through our internal quality monitoring system.
• I now work as a Family Support Worker to families caring for a child with autism or a related condition.
Outline of the workshop

• The presentation will focus on common issues for adults with moderate to severe autism. The word autism has been used to describe all autism spectrum disorders.

• Behaviour is a common difficulty. We will look at how the impact of this can change when a person moves into adulthood.

• We will link to the main areas of difficulty and how this affects adult life, remembering that children with autism grow into adults with autism.

• We will look at the option of caring for an adult child at home that many parents take and the dynamics of this.

• There will be time for questions at the end.
How Are People with Autism Affected?

- It is important to remember the main areas of difficulty for those on the spectrum:
  - Social communication
  - Social interaction
  - Social imagination
  - Sensory processing
Social communication

- Many people with moderate or severe autism have communication difficulties into their adulthood.
- Some adults remain non-verbal for their entire lives.
- Some adults develop speech but are not able to communicate in a meaningful way.
- Interpretation of non-verbal communication is often impaired.
- Expressive communication style may not be typical.
- Challenging behaviour is often a form of communication or a response to the frustration of communication difficulties.
- Communication is more important than ever when a child becomes an adult, as they need to make their own decisions.
Social Interaction

- Social interaction skills may not have developed.
- Others perceive adults differently and may not be prepared to accept unusual social skills, as autism is ‘invisible’.
- Adults may not be aware of their own emotions and may have unique ways of expressing themselves.
- Others may not understand difficulties with empathy and theory of mind.
- Adults can become more isolated once they have left education.
- Difficulties such as knowing appropriate behaviour and conversation skills can lead to trouble, potentially with the criminal justice system.
Social Imagination

• Many adults still need a high level of structure and routine and may not be able to put this in place independently.
• Adults may want to engage in repetitive behaviour for a large amount of their time in the day, to bring about predictability.
• Local authorities may feel that a person should work, but they may not have the skills or flexibility to find and maintain employment.
• The transition from childhood to adulthood is a major change and people with autism often find this extremely difficult to adjust to.
• Adults have the right to be in control of and make choices about their own lives and need support to cope with this.
Question:

• How are your own children affected as adults?
Behaviour

• Some children ‘grow out’ of behaviour or learn more appropriate strategies as they become older.
• Some people won’t have an understanding of appropriate behaviour for their whole lives.
• Some adults develop co-morbid mental health problems in their adulthood, most commonly anxiety or depression. This can lead to a change in behaviour, not solely caused by autism.

• What are the types of behaviour that challenge seen in adults?
Challenging Behaviours

- Behaviours resulting from difficulties communicating; grabbing, biting, shouting
- Behaviours linked to anxiety; withdrawal, self-harm, running
- Behaviours linked to sensory processing, such as smearing, hair-pulling or other stimming behaviours.
- Aggressive or violent behaviour
- Repetitive behaviour
- Behaviour due to poor understanding of consequences, such as dangerous behaviour or hurting others.
- Does anyone experience any challenging behaviours they would like to share?
Problems linked to adulthood

- Managing aggressive or violent behaviour from a full grown adult can be more difficult and dangerous than a smaller person.
- Adults are responsible for their actions and answerable to the law.
- The general public perceive adults differently.
- The consequences are different for adults but those with autism may not understand.
- Because autism ‘invisible’ people may not always understand when someone responds or communicates differently.
- Adults may want to be more independent, but may be vulnerable in their community.
Preventing challenging behaviour

• **Think carefully about how the behaviour is linked to autism.** This may help you to understand the root causes of behaviour.

• **Make notes to identify triggers, cues and patterns of behaviour.** This may help you avoid triggers or implement strategies before a behaviour has occurred.

• **Use a low arousal approach** – more on this later!

• **Be aware of sensory processing differences** as this can be a trigger for behaviour and point to helpful strategies.

• **Improve communication.** Many strategies to improve communication, such as PECS, Makaton or visual support, reduce the need to rely on challenging behaviours.

• **Reduce anxiety,** as this is often the real cause of challenging behaviour.
The low arousal approach

• Creating an un-stimulating (low arousal) environment can help to manage anxiety and meltdowns:

LESS LIGHT  Quiet!

Lots of personal space

No strong smells

Accept difference. Not indifference.
The low arousal approach

- Using a low arousal approach can help to prevent and de-escalate challenging behaviour.
- It means making sure the environment is not over stimulating for a person with autism.
- Not bombarding someone with demands or verbal information
- Using a quiet, calm tone of voice and avoiding sudden movements
- It can help someone to calm down if they are anxious or angry and also maintain this.
The Low-Arousal Approach

• Having more control of or reducing sensory stimuli can help:
  – reducing light or brightly decorated environments
  – minimising background noise for that person
  – giving someone plenty of personal space
  – avoiding strong smells in the environment
De-escalating Challenging Behaviour

• **Stay as calm as possible.** Showing someone you are stressed will only increase anxiety.

• **Reduce stimulation.** If the person can be directed to a safe, calm space support them, if not change the environment they are in:
  – Move others away
  – Reduce light, noise and other stimuli
  – Reduce verbal information
  – Avoid restrictive interventions
De-escalating Challenging Behaviour

• **Keep yourself and others safe.** Plan safety strategies like a safe place for you to go and keeping dangerous objects locked away.

• **Use consistent strategies** that the person is familiar with.

• **Distract and re-direct.** Be aware of favourite or calming activities that person can easily be directed to.
One of the questions many parents consider soon after diagnosis is “Will I need to care for my child when they are an adult?”

Many parents are willing and able to do this and there are a number of advantages:
- Consistency in approaches is easier to maintain
- There is less change to deal with such as moving house or introducing new carers
- You can have peace of mind you know your child is well cared for

There are a number of things to consider, though:
- Your child has the right to choose how they live their life
- What are the options for support and respite from your caring role
- How will your family be affected financially
Caring for an adult child yourself

• Person centred approach
  – While you will have a great deal of influence in your child’s care throughout their life, it is more important than ever that they have their say.
  – People with autism often struggle with choice. They will need support to make important decisions, such as what care they want to receive, how they spend their money, what risks they would like to take.
  – Communication is an issue and support to improve communication and help others understand your child must continue.

• Your child has the right to be as independent as possible. This may mean that they want to rely upon you less and the people around them need to support this.

• It can be hard to help someone understand the responsibilities they have as an adult.
Caring for an adult child yourself

Helping your child make their own decisions

• Use of visual support can help your child to make informed decisions:
  – Using PECS, pictures and symbols can help to communicate choices
  – Social stories or similar written or visual documents can help understanding of difficult concepts and give information to make informed decisions
  – Circle meetings are a good way for a person to be involved in planning their own care

• Resources and groups available can help them to understand appropriate social behaviour and other life skills, like money management or safety in the community.
Caring for an adult child yourself

Increasing independence and safety in the community

• Resources and groups available can help with understanding life skills, like money management, social skills or safety in the community.

• A step-by-step approach can help to increase independence whilst building skills for staying safe and managing anxiety.

• Employment can seem an impossible scenario, but people can be supported to gain experience through volunteering or work part-time doing a job they enjoy or are particularly interested in.
Financial support

• You may find yourself managing your child’s finances or supporting them to do this for themselves.

• **Adult social care** may be able to provide financial help for the additional things your child needs, like carers or access to activities during the day.

• Some individuals receive **direct payments** so they can choose their own care. **Surrey Independent Living Council (SILC)** can help you understand how to do this.

• Don’t forget the **Citizen’s Advice Bureau**, as they can offer information about your child’s rights and entitlements.

• Your local **carer’s support** can also help with benefits, local information and support services.
The positives of being an adult

• Families may find that there are many positives when their child become an adult.
• Adults have more choice which increases motivation and fulfilment.
• Funding can be less restricted, for instance can be used towards leisure, educational or care activities.
• Some previous behaviours may reduce as the person grows older.
• Educational provision is still available post 18.
• Often people with autism are happier in their adulthood, because their wants and needs take priority.
Questions?

• Thank you for listening, I hope you have found this workshop informative and interesting.

• If you have any questions I am happy to answer them now.

• Contact me:
  Tessa Phillips
  Family Support Worker
  Surrey Autism Resource Centre
  Tel: 07436261163
  Email: tessa.phillips@nas.org.uk
Sources of help… www.autism.org.uk

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What’s out there?

• National Autistic Society Surrey Branch
  – [www.mugsy.org](http://www.mugsy.org) Tel: 07423 435413
  – The branch runs lots of support groups for parents and has a website with lots of information and advice

• Surrey Autism Resource Centre
  Tel: 01483 521743
  – This is part of the National Autistic Society and runs many children and youth groups, adult life skills and social groups and a signposting service
  – They also run training for parents and carers and have information about autism and where to get support