Conference or Workshop Item

Title: When puberty strikes – developing training for parents and professionals

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When puberty strikes – developing training for parents and professionals

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Content of presentation

- Why did we develop this training?
- What did we need to include?
- How do we present it?
- What is it – examples?
- Key issues from having presented it many times
Thanks to...

- Jayne Almond - who presents this training with me in the UK, and who can’t be here due to family illness
- The other members of the Autism Family Advisory Team, examples of whose work is shown throughout this presentation
Autism Family Advisory Team

- Teach parents how to use structured teaching approaches and visual supports in home and community
- Direct work delivering interventions
- Support across home and school settings
- Clinic sessions
- Parent/professional training

(see Preece, D. & Almond J. (2008) Good Autism Practice, 9 (2) 44-53)
Why did we develop this training?

- **So many** parents asking for help
- Dealing with same issues in 1:1 work
- Parents using visual supports in other areas but **not** transferring use
- Same issues impacting in care and school settings
- Ineffectively addressed in ‘curriculum’ – insufficiently individualised
What did we need to include?

- Body modesty and privacy
- Self-care
  - Washing
  - Toileting
  - Deodorants and grooming
  - Dressing / managing underwear
  - Managing menstruation
- Sexuality and masturbation
How do we present the training?

- Staged approach – begin with less challenging issues
- Make consistency of approach and links to strategies used re other issues explicit
- Present visually – with REAL examples
- Stress individualisation – multiple examples at different levels
Examples from the training
EXAMPLE

Focus of session

- Suggests how visual supports can be used to help teenagers on the autism spectrum in dealing concretely with
  - typical issues regarding the challenges of puberty
  - issues regarding sexuality
EXAMPLE

Why use visual supports?

Culture of autism

• Visual learners
• Sensory difficulties
• Information processing problems
• Engagement
• Connecting and sequencing
• Social perspective problems
How do visual supports help?

- Help the adolescent on the autism spectrum to understand
- Help them be calm
- Help them learn better
- Structure and visual supports = “prosthetic devices” that helps them achieve independence and manage their behaviour
EXAMPLE

“But my child’s really able…”

• Remember, most people on the autism spectrum (and many others) are VISUAL learners.

• At times of stress, keep things simple – knowing what they need to do shouldn’t be a test!

• …and adolescence IS stressful enough!
“I was able to understand words better when they were written down on paper than when they were said out loud.”

- “I just tended to feel frustrated because words were so confusing and people expected me to understand speech.”

Therese Jolliffe, PhD (researcher into autism, University of Cambridge – and individual with autism)
EXAMPLE

“But he’s still a child…”

• Individuals on the autism spectrum:
  – lack social understanding
  – are good at creating routines
  – dislike change

• What’s cute as a toddler can be problematic or increase vulnerability as an adolescent and adult
Underlying principles (1)

- Use the same visual strategies that are used to teach other skills (e.g. play, work, etc) – schedules, work systems, etc…
- Consistency of approach helps the person with autism
- Put your own (non-autistic) judgements, prejudices or issues aside – these may be meaningless to the adolescent on the autism spectrum
EXAMPLE
Underlying principles (2)

• Be clear:
  – **what** you are trying to teach
  – that what you are doing is pitched at the right **level**, and is **meaningful** for the individual
  – focus on **independence** – they’ll soon be an adult
Body privacy and vulnerability

- Body privacy – crucial issue in adolescence, both with regard to
  - safety of adolescent with ASD
  - rights and happiness of other family members
EXAMPLE

Body privacy and vulnerability

• Vital issues

- **Who** can see me naked?
- **Where** can I be naked?
- Where is ‘**private**’ (for the person with ASD and others) – other family members have sexual/privacy needs too!
- **Where** do I sleep?
- **Who** can I kiss /touch… and how?
EXAMPLE

Body privacy and vulnerability

<table>
<thead>
<tr>
<th></th>
<th>Kiss on the lips</th>
<th>Kiss on the cheek</th>
<th>Hug</th>
<th>Shake hands</th>
<th>Say Hello</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mum</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
</tr>
<tr>
<td>Dad</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✗</td>
</tr>
<tr>
<td>Lucy - my sister</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>My granddads</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>My nans</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Mrs Reynolds - my teacher</td>
<td>✗</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sally - my best friend</td>
<td>✗</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Jack - my Cub leader</td>
<td>✗</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Any other children</td>
<td>✗</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Any other grown ups</td>
<td>✗</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
EXAMPLE

Body privacy and vulnerability
EXAMPLE
Self-care skills

• Being able to take responsibility for their own self-care
  – Increases independence
  – Reduces vulnerability
  – Increases opportunities for developing relationships
EXAMPLE
Self care – *think about*…

- Can the young person physically manipulate the equipment?
EXAMPLE
Self care

Put on deodorant

1
2
3

1
2
3
EXAMPLE
Self care
EXAMPLE

Self care – *think about*…

• Can a new skill be added to an existing routine?
EXAMPLE
Self care

- Wash arm pits
- Dry arm pits
- Deodorant on
- T-shirt on
EXAMPLE
Self care
EXAMPLE

Self care – prepare…

• Make sure everything needed is available close at hand
EXAMPLE
Self care
EXAMPLE
Self care – *clarify*…

• Minimise uncertainty
EXAMPLE
Self care
Menstruation

• How do I know if I need to change my sanitary towel?

• Where do I put my bloody sanitary towel?
EXAMPLE
Menstruation

Check towel

If its clean
- pull up knickers
- wash hands

If its bloody
- take towel out of knickers
- put it in the bin
- stick clean towel in knickers
- pull up knickers
- wash hands

FINISHED

FINISHED
EXAMPLE
Menstruation
EXAMPLE

Menstruation

• How do I put my sanitary towel on?
EXAMPLE
Masturbation

• For concrete learners, and at home, this generally concerns teaching:
  – where and when to masturbate
  – where and when not to masturbate
  – what to do
EXAMPLE
Managing masturbation

• Picture sequences/visual supports showing what to do
• Visual supports showing where is appropriate (own bedroom)
• Visual supports showing where is not appropriate
• Consistency
• Language (‘private time’)

EXAMPLE

Managing masturbation – where is appropriate

Luke
Places for Private Time

No
No
No
No
No
Yes
EXAMPLE

Managing masturbation – where is appropriate
EXAMPLE
Managing masturbation – privacy
EXAMPLE

Managing masturbation – what to do
EXAMPLE

Managing masturbation – what to do

SUSAN’S PRIVATE TIME

• Put ‘DO NOT DISTURB’ on door
• Private time
• Clean up
• Get dressed
• Go back downstairs

REMEMBER: Private time is special and private. Don’t talk about it.
EXAMPLE
Managing masturbation – what to do
Final thoughts 1

• Approach teaching these new skills in the same way as you would any other.

• Leave your embarrassment and personal judgements at the door.

• Teach as a rule.
  – (Don’t worry about trying to explain the social reasons ‘why’ unless the young person asks you.)
Final thoughts 2

• **Don’t** assume the young person will generalise the skill to different environments
  – they may need to be taught an appropriate place for ‘private time’ at Nan’s too!

• **Don’t** assume the young person will be able to internalise the skill
  – it’s **OK** and **normal** if they always need the visual supports
Key issues (1)

- Stress that the issues being dealt with are typical and normal
- Presentation style – matter of fact, no embarrassment or ducking issues
- Do not discuss own personal judgements and values
- Careful use of humour – enough to relieve tension, but focus on teaching
Key issues (2)

- Be careful about assumptions regarding what parents/professionals are expecting from adolescents
- Be confident **NOT** to have answers, but to show problem-solving technique
- Show low-tech approaches: not all Boardmaker and Google Image!
What’s missing?

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