Social and mental health outcomes for adults with autism and Asperger syndrome in the UK

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Most follow-up studies report that 30- >40% of participants show marked improvements in late adolescence/early adulthood.

But from <10% to >30% of participants show an increase in problems over time including:

- rituals, inertia, loss of language and “slow intellectual decline”
From adolescence onwards:

- Clinical studies indicate significantly higher rates of obsessional & anxiety disorders than
  - typically developing,
  - conduct disordered
  - language delayed groups
In adults:

- Significant anxiety and depressive problems in at least one third of adults
Environmental factors

“Regression” frequently coincides with:

- Increased stress (entering university; employment)
- Lack of structure (e.g., when leaving school)
- Disturbances in home/residential life (e.g., loss of parent; favourite staff)
Social impairment also gives rise to:

- Vulnerability
- Teasing, bullying and misuse- leading to anxiety, low self esteem
  - (People with autism/Asperger syndrome more likely to be VICTIMS of crime; not perpetrators)
- Behaviours without apparent cause may be due to stress/ abuse by others
What will happen when parents are no longer around?

> one third of 30 year olds still living with parents
< 20 % in (un) supported residential accommodation
Growing old

?????
New study:

- 93 high functioning adults with autism (Mean PIQ 75) seen when men age ~ 7 yrs and 29 yrs. Now aged 30-60 yrs
- ~ 30 sibs (normal IQ) ascertained as being within broader autism phenotype when younger
- 100 sibs (non-BAP)
For each group: data on

- Outcome:
  - Cognitive
  - Psychiatric
  - Social
  - Employment
  - Marital & family relationships

- Family needs
- Personal experiences
- Service implications
HOW CAN THE SITUATION BE IMPROVED?
Address factors leading to psychiatric and other problems

- Lack of structure & predictability
- Boredom (routines & rituals)
- Low self esteem
- Isolation from peer group
- Improve opportunities for social inclusion

- Especially for work and (semi) independent living
Outcome of supported employment scheme for adults with ASD: No & types of job found, 1996-2003 (Howlin et al., 2005)

Total jobs=203
Job success

- Saving in benefits, significant increase in salary
- High satisfaction - both employers and clients
- Employment rates (70+%): 3 times that in non-supported HFA groups (20%) despite many past failures
- Finding the right job the most time consuming & expensive part of the scheme
Summary of needs

- Improve recognition by social, health and employment services of needs of adults with autism (especially those who are more able)
- Improve options for supported and semi/independent living & removing pressure on parents
- Seek better ways of improving social interactions (social skills groups; befriending schemes)
- Provide for emotional needs especially of more able individuals