Autism in Adulthood and Evidence Based Guidelines for Intervention

Patricia Howlin,
Jim Mansell Lecture
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Why do we need more research into adulthood??
1. Vast amount of research on children - far less on adults

- But autism does not disappear at age 18!!
Reviews of papers on adults with ASD

Mukaetova-Ladinska (2012) 18,000 papers on ASD: 1946-2011

Shattuck et al. (2012) Of 11,000 studies on ASD (2000-2010) only 23 on interventions/services for adults

Bishop- Fitzpatrick et al. (2013) Review of 1217 papers on adults (1950-2011) only 13 on psycho-social interventions meeting adequate experimental criteria

Intervention stops here
2. Social outcomes in adulthood generally poor
Adults with ASD in UK (Adult Psychiatric Morbidity Survey, 2012; 2007 Brugha et al.)

Prevalence:

- Total population 1.1% (2.0% males; .3% females) N~ 400,000 in UK

• As a group (including those of normal IQ)
  - Socially disadvantaged; unmarried, living on benefits and in social housing
  - Educationally less well qualified
  - Under-supported by social, educational, welfare and health services
  - In the lowest quintile for social deprivation

• Life time cost of autism £3.1million per higher functioning person; £4.6m for lower functioning; Knapp et al., 2007 ($3.1 m in US; Ganz 2007)
Transition to adulthood: Positive aspects

- Overall reduction in autism symptomatology from child-adulthood (majority show < scores on ADI; only minority worsen)
- Decrease in repetitive and stereotyped behaviours in older adults (22-50 years)
- Improvement in social reciprocity in adolescents/young adults (10-21 years)
- Decrease in problem behaviours: some follow-up studies = 30 to >40% of participants show marked improvements in late adolescence/early adulthood
  - Kanner, 1973;; Howlin et al., 2013; Mawhood et al., 2002; Farley et al., 2009; Seltzer et al., 2009; 2010
Several follow-up studies show decrease in ADI symptom severity (though specific areas differ)

<table>
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<th>Study</th>
<th>Main improvement:</th>
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<tr>
<td>Howlin et al 2013 (young-older adult)</td>
<td>Repetitive behaviour</td>
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<td>Shattuck et al 2007 (adolescent to adult)</td>
<td>Repetitive behaviour (then Communication &amp; Social)</td>
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<td>Seltzer et al (2003; child to older adult)</td>
<td>Communication; less in social &amp; repetitive</td>
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<td>Starr et al.2003 (children)</td>
<td>Communication; social worsened; repetitive no change</td>
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<tr>
<td>Piven et al., 1996 (child-adult)</td>
<td>Social &amp; communication; repetitive no change</td>
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Transition to adulthood: Negative aspects

- Low rates of employment (~60% in sheltered workshops/day activity centres) even compared with individuals with ID or other developmental disorders
- Adult day activities lower quality than educational activities in school
- Adults of normal IQ significantly LESS likely to have a structured day time activity than those with intellectual impairment
- Difficulties post school persist into later adulthood (i.e. not just a short term problem)

Howlin et al., 2013; Magiati et al., 2014; Roux et al., 2014; Seltzer et al., 2009; 2010; Taylor & Mailick, 2012
Transition to adulthood: Negative aspects

Increase in mental health diagnoses (mainly depression & anxiety)

USA: 58% of adults (total n=4069) on one or more psychotropics (58% for psychiatric problems; 13% challenging behaviours; 13% for both; Tsiouris et al., 2013)

UK: 22% developing new psychiatric problems (mainly in late teens/early adulthood (Hutton et al. 2009)

Increase in use of medication with age (in USA 18% of adolescents, 49% of adults on 3+ meds)

Once begun medication unlikely to stop (Seltzer et al., 2009/10)
Systematic reviews of adult outcome studies (Howlin & Moss, 2012; Henninger and Taylor, 2013; Magiati et al., 2014)

Despite improvements in intervention and educational programmes for children few improvements in adult outcomes over recent decades
Adult follow-up studies: overall outcomes (Howlin & Moss, 2012)

23 studies 1967-2010
Sample size: mean n= 68 (range 11-197)
Age: mean = 25 years (range 16-60 yrs )
Child IQ: <30 to >130
Outcomes:
  Good/very good: mean 22% (range 0-69 %)
  Fair : mean 31% (range 11-75%)
  Poor/very poor: mean 46% (range 12-78%)

% 0 5 10 15 20 25 30 35 40 45 50
Poor/Very poor Fair Good

1960-1999 2000+
40 year follow-up study- (Howlin, Moss, Savage & Rutter, 2013; 2014)

- 60 individuals; all PIQ≥ 70 in childhood
- Mean age first seen= 6.6 yrs (3-13 yrs)
- 1st follow up- mean age= 29 years (16-45 yrs)
- Current follow-up- mean age 44 years (29-64 yrs)
- Diagnosis confirmed with ADI/ADI-r at follow-up
Employment

• Jobs: (ever)
  – 15% in professional/skilled non-manual work
  – 13% in unskilled or manual jobs
  – 17% sheltered employment
  – 55% never worked
Social relationships

• Current friendships (own age group)
  – 7% ≥ one reciprocal relationship
  – 10% some friends but limited reciprocity/duration
  – 77% no specific friendships

• Close sexual relationships (ever)
  – 9% close relationship/marriage now or in past
  – 15% close relationship but limited duration/reciprocity
  – 77% never had close reciprocal relationship
Independence

- 13% living independently
- 13% in semi sheltered accomm/ at home but high level of autonomy
- 17% at home - little autonomy
- 20% residential unit – little autonomy
- 33% autism unit
- 3% hospital care
Changes from early to later adulthood
IQ:
Generally stable

% cohort

- No clinically significant change
- Clinically significant decline
- Clinically significant increase
Language

- 70% good use of phrase/sentence speech but
- only 20% above 18-19 year ceiling on tests of expression and comprehension
- No significant difference between expressive and receptive language
Autism symptomatology decreases (ADI:ADI-R changes)

*Based on same items at each time point
Fewer improvements in independent living, work & relationships

- Semi/independent
- With parents
- In work
- Has friends
- Ever close relat/ married

Mean age 29
Mean age 44
Predictors of poorest outcome/ significant loss of skills (tho’ even these cases show decrease in ADI scores)

- Continuing severe deficit in language post childhood (language regression regression not specifically related to outcome)
- Very poor social skills in childhood
- Severe behavioural problems (e.g. aggression)
- Epilepsy
- Long-term hospital care
- Gender (but n females small)
Great individual variation

Male – 55 yrs old; child PIQ 80 (no verbal IQ score); Adult PIQ 113; VIQ> 130
As child treated as in-patient for some time
No other specialist intervention;
Educated in Intellectual Disability & mainstream schools
As adult- MSc degree; employed for many years, married in past; has group of friends

Female - 47; child PIQ 87. Age 30 yrs PIQ 57. Current IQ VABS only (IQ equivalent 20)
As child limited language ( ? Regression)
Educated in specialist autism provision
As adult- private residential home; little autonomy. Never worked; no friends
Donald T- first child ever diagnosed with autism in 1943- born in Forest Hill Mississippi- still lives in Forest Hill Mississippi

Placed in institutional care at age 3 because parents unable to cope

Later returned home though described by mother as “hopelessly insane”; little special help while growing up-

Now 77 years old; lives independently- drives his own car (fascinated with registration plates) plays golf daily. Somewhat repetitive (“Way to hit that ball, Kenneth!” “Way to hit that ball, Lori!” “Way to hit that ball, Elk!” ) but others happy to partner him and he is appreciated in the local community
3. Poor quality of intervention research
Recent reviews

National Institute for Health and Clinical Excellence (NICE) Guideline on Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum (>9,500 studies)

www.nice.org.uk

Agency for Healthcare Research and Quality (AHRQ) Lounds Taylor et al. Interventions for Adolescents and Adults with ASD. Comparative effectiveness Review No 65 (>4,800 studies)

www.effectivehealthcare.ahrq.gov.
Very small number of studies (30-50) meeting basic research criteria:

- Clear specification of population
- ASD diagnosis, age >15 yrs
- Clear specification of intervention, outcome
- Comparison group/treatment
- RCT (if none then quasi experimental or case series design)
- Minimum sample size (≥10)

- Most of these rated as low/very low quality (high risk of bias; inadequate controls; small effect size; inconsistent findings etc.)
For example: studies of behavioural interventions

Search results and sift

Total sift = 9522

Total psychosocial papers = 654

Behavioural therapies papers = 80
Behavioural studies (RCT’s/quasi experimental)

Number included : 1

Number excluded : 79

Reasons for exclusion:
– Mean age <15 years
– Sample size < 10
– Not primary data
– Not ASC

Generally no high quality psychosocial studies, most low/very low quality
NICE treatment recommendations:

- Mostly cautious: “consider …”
- Many studies extrapolated from child research or interventions in other groups (mainly people with ID)
a) Psycho-social interventions
1. Core autism deficits
   Social problems

   Social skills training
   Adolescents (Hillier, 2007; Laugeson et al. (UCLA PEERs project), 2009/2011; Tse et al., 2007)
   Adults (Verhoeven et al., 2011)

   Theory of Mind
   Adolescents (Begeer et al., 2011)
   Adults (Bölte et al., 2002; Faja et al., 2012; Golan et al., 2006).

   Cognitive Behavioural
   Adolescents - social skills (Bauminger, 2003); social anxiety (Beaumont & Sofronoff, 2008)
Evidence inconsistent:

- Programmes very variable; mostly higher IQ groups; little generalization or impact on wider emotional understanding; some studies = positive impact on social skills, others = no effect. No studies of functioning in real-life settings (Burgess & Turkstra, 2006; Rao et al., 2006; White 2004).
• *NICE Recommendations:* “for individuals without intellectual disability *consider* group based or individual social learning programmes” - including modeling, peer feedback, discussion & decision making; explicit rules specific strategies for dealing with difficult social situations
2. Core autism deficits-

Communication problems
Ritualistic and Stereotyped Behaviours

No adequate group comparisons or RCT studies
But- large number of single case/small group studies indicating the effectiveness of behavioural strategies
3. Adaptive skills

• Most studies of individuals with intellectual disability (1 RCT; 2 non-RCT)

• Some improvements in daily living skills using structured training programme (Matson, 1981); weight control (Harris, 1984); use of Personal Digital Assistants (iphones; Gentry et al., 2010)

Limited evidence for impact on challenging behaviour
3. Adaptive skills

- **NICE Recommendations**: “consider a structured and predictable programme based on behavioural principles”
4. Cognitive Behaviour Therapy (CBT)

- Adolescents: number of randomised control trials – mainly for social anxiety (Chalfant et al., 2006; Sofronoff et al., 2005; Sung et al., 2011; Wood et al., 2004)
- Adult RCT’s:
  - OCD (Russell et al. 2009);
  - Anti- victimisation (adults with intellectual disability; Khemka et al., 2005)
  - Mindfullness training for anxiety/depression (Spek et al., 2013)
- Non- RCT’s (adults with ID) : anti- victimisation (Mazzuchelli et al., 2001; McGrath et al, 2010); anger management (Lindsey et al., 2004; King et al., 1999; Rose et al., 2005; Taylor et al., 2005)
Several studies indicate success in mainly non-clinical settings. But:

- Short term follow-up only.
- Outcome measures rely on parental reports/analogue measures, self reports show less change.
- No real life assessments- do participants do better in the play-ground/ office etc.?
- Huge range of intervention strategies- which are most effective?

Reviews, Moree & Davis, 2010; researchautism.net
CBT

NICE=

• Some weak evidence for impact on mental health problems
• Some impact on anger management and anti-victimization training.

• **NICE Recommendations**: "consider adaptations of standard CBT techniques for adults with autism"
Modifications to CBT needed because of:

| Lack of awareness of actions on self or others |
| Motivation & cognitive deficits            |
| Problems in forming therapeutic relationship |
| Communication deficits                     |
| Stereotyped language; discrepancy between verbal expression and comprehension (misleading for therapist & patient) |
| Difficulties in expressing feelings        |
| (even of severe physical pain).             |
| Difficulty modulating emotional responses  |
| *(everything fine or disastrous)*           |
| Rigidity of thought processes/beliefs      |
| Poor generalization                        |
5. Leisure programmes

- 2 RCTs (Garcia Villamisar et al., 2010-2011)
- Positive impact on quality of life and emotion recognition.

**NICE Recommendations:** “consider group based leisure activity programmes, or individual programmed if group based work inappropriate”
6. Supported employment

- No RCT’s; 6 non-RCTs (Garcia Villamisar et al., 2000/02/07; Howlin et al., 2005; 2008; Lawer et al., 2009; Mavranezouli et al., 2013)
- Improvements in:
  - job finding and job retention
  - quality of life
  - cost effectiveness (compared with non-specialist schemes or standard care)
6. Supported employment

- **NICE Recommendations**: “for individuals without severe intellectual disability consider a supported employment programme”
Outcome of supported employment scheme for adults with ASD: No & types of job found, 1996-2003 (Howlin et al., 2005)

Total jobs=203

Computing/technical 57%

Other 23%

% in employment – specialist scheme vs generic employment services

- % finding jobs
- % in admin, computing
- % in manual jobs

Supported group
Control group
b) Bio-Medical Interventions
1. Antipsychotics/anti-epileptics for behavioural management.

- Mostly extrapolated from studies of children or people with intellectual disability. (15 RCTs; 3 non-RCT). Research quality poor; evidence inconsistent
  - **Risperidone** - limited impact on irritability and aggression; some impact on repetitive behaviour; adverse effects = sedation & weight gain.
  - **Haloperidol** - no evidence of positive effects
  - **Clopenthixol** - limited evidence for impact on challenging behaviour (in people with ID)
  - **Olanzapine** - limited impact on behaviour.
  - **Anti-epileptics** - ? some impact on irritability
2. Other drugs for core autism symptoms or behavioural management.

- Drugs affecting cognition (e.g. galantamine/memantinome as used in Alzheimer's/Parkinson's disease) – (2 RCTs; 4 non-RCT’s) - not recommended for routine use

- Hormonal interventions
  - ACTH (2 RCT’s) - no recommendations
  - Secretin (3 RCT’s) – do not use
  - Oxytocin (4 cross-over studies) - do not use
  - Melatonin (3 non-RCT’s) – no recommendations
    - Children aged 3-16 years gained little additional sleep on melatonin (fell asleep faster but woke earlier); no improvements in child behaviour/family functioning
3. Medication for co-existing conditions (ADHD, depression).

- Most data extrapolated from studies of child autism or specific conditions
  - Stimulants: (1 RCT)
  - Anxiolitics (no studies meeting criteria)
  - Anti-depressants (2 RCTs; 2 non-RCT’s)

- For existing disorders follow NICE guidelines for the specific disorder
Pharmacological interventions for behavioural management.

- **NICE Recommendation:** Do not use to manage core autism symptoms or for behavioural management.
- For challenging behaviours first line of intervention should be environmental/psychological interventions.
- If medication needed, prescribe by specialist; monitor regularly; discontinue if no response in 6 weeks.
c) Other interventions

- Most data (if any) from child autism studies
  - Exclusion diets, vitamins, minerals and supplements
  - Chelation
  - Hyperbaric oxygen therapy
  - Testosterone regulation
  - Facilitated communication

- **NICE Recommendations**: Do not use for management of core autism symptoms

- **NICE**: Do not provide Facilitated Communication for people with autism
Conclusions- AHRQ (2012)

• Given the number of individuals affected by ASD, there is a dramatic lack of evidence on therapies for adolescents and young adults

• Families have little in the way of evidence-based approaches to support interventions capable of optimizing the transition from adolescence to adulthood.
Conclusions- AHRQ (2012)

- Most studies poor quality
- Behavioral, educational, and adaptive/life skills studies typically small and short term but suggest some improvements in social skills, functional behavior & occupational outcomes
- Few studies address the possible harms of medical or psycho-social interventions for adolescents and young adults.
More things we don’t know

- How to reliably diagnose autism in adults
- How do men and women differ?
- How to prevent and/or develop interventions for mental health problems
  - (how to modify CBT/Mindfulness programmes; use of adjuncts to therapy – e.g. oxytocin)
- We know even less about physical health problems and access to medical care
- How to increase *rates* of participation in employment, leisure and other social activities
- How to develop standardised outcome measures
• Cognitive trajectories in later adulthood- patterns of cognitive decline or relative preservation (e.g. memory skills?)
• Criminal justice system- rates of problems; treatment within the CJS; prevention; intervention
• Adults with autism among disadvantaged groups
• Impact on carers- social, economic, psychological (elderly parents; care staff)
• What happens when parents unable to care?
• Piven et al (2012) : Need systematic studies on the characteristics (behavioural, neuropsychiatric, and medical) associated with ageing in autism, and potential interventions, both individual and societal, that may improve outcome and quality of life.

• If the advances in comprehensive treatment programmes for very young children can be applied across the life span, then children with autism now growing up may face a more positive future.
No matter how good, or how widely accessible, diagnostic and intervention services for very young children become, unless educational, health and social services for older individuals improve, the outcome for many adults with autism will remain bleak.
Aims- to redress the balance in autism intervention research