

Development of ASD Transition checklist & action plan*

Carried out by Watson, R. and Le Couteur, A

Gap & need

- Young people (YP) with neurodevelopmental disorders most likely to fall through the child & adolescent - adult mental health services gap (Singh et al 2010; Birchwood & Singh 2013)
- ~70% children with ASD have additional mental health problems (Simonoff et al 2008)

Guidelines

- The Autism Act (UK Parliament 2009), statutory guidance Fulfilling & Rewarding Lives (DoH 2010), NICE guidelines 170, 128 & 142 (2013, 2012 & 2011)
- Service providers in England to improve access to assessment, diagnosis & services, &
- support the smooth transition to adult services

Previous work

- No published models of transitional care for YP with ASD (Watson et al 2011)

- **NTW funded development of ASD checklist & action plan**
- **Design based on literature review, examples of good practice, clinical & research expertise**

Review/revisions/feedback:

- **Much feedback positive**
- **Many useful wording alterations suggested**
- **Definite need identified amongst professionals & families**

Background & best practice

- Bristol Aspergers Syndrome Service (BASS)
- Birmingham Children's Hospital
- Creating Healthy Futures/ Spina Bifida service (US)
- (Betz & Redcay, 2003; Sawicki et al, 2011)

Review & feedback (draft 1)

- 17 Professionals; CAMHS and LD CAMHS (NE & Bristol)
- 2 Professionals AMHS
- 3 Professionals ESPA, National Autistic Society
- 2 Parents

Revision & feedback (draft 2)

- focus group with 5 parents/carers & 2 professionals on Daslne Committee (NE)
- Focus group with 5 parents and 1 YP (NE)
- ESPA, National Autistic Society

Draft 3 checklist & action plan copyrighted in 2013.

Anonymised action plan based on evaluation interviews

Name:	Andy Smith	Date completed:	20/08/2013
NHS No.:	943-476-5919	By Whom?:	Dr White

Age Band (tick one)
 14-15 years 16-17 years 18+ years

ASD Health Care Transition Action Plan

Domain	Action	By whom?	Review date
Education	• Get back into full time education • Work towards achieving 4 GCSE C grades	Andy	Feb 2014
Employment	• Get more work experience • Develop English skills and basic writing	Andy's teaching assistant to support	August 2014
Leisure/hobbies	• Maintain relationship with dad - playing snooker + watching football. • On waiting list for befriendr	Dr White to keep check on befriendr waiting list	Feb 2014
Independent living skills	• Learn about how to claim benefits (such as DLA/PIP) • Learn about how to use public transport on own • Learn about how to manage money	Parents to support	Feb 2014
ASD related needs	• Refer to disability social services for support with initiating and making relationships. • Attend local group with support to meet people	Dr White to refer Andy to attend group	Feb 2014
Health and mental health	• To have further medication reviews + transfer to adult services • Continue to see physiotherapist with regards to knee problems.	Dr White to review medication and begin communication with adult services.	Ongoing
Community Care assessment	• Young person + parents made aware that entitled to assessments when almost 18.	Revisit when Andy is older	August 2014

Evaluation work

Carried out by Gupta, V. and de Bono, J

Work

- Ongoing evaluation using qualitative methods in 2 NE England NHS Trusts (NTW & TEVV)
- Ethics No - 12/LO/0734

Original plan

- Researcher interviews health professional, YP & parent/carer
- Repeat interviews planned at 6 & 12 months

Current status

- N = 6 complete baseline cases
- Recruitment issues
- Another project recruiting at the same time
- Trust (& NHS) reorganisation
- Checklist & action plan identified as 'research' rather than essential 'clinical' care
- New revised recruitment strategy to target service users direct has just begun

Lessons learned

- **Parents & professionals endorse need to prepare YP with ASD for transition to adult services**
- **Little direct involvement of YP in development work**
- **Initial enthusiasm to structure the various transition tasks via checklist & action plan**
- **Resource constraints/pressures on busy clinicians adversely affected recruitment & evaluation of a potentially useful tool**

"As a family we felt the forms addressed the relevant issues and used plain language. Questions were to the point and not overly long or complicated which can often be a problem"
 Parent

"I think the Checklists will be really useful in helping us conceptualize young people and their families' experience of transition - and for us to think about the gaps in service."
 CAMHS professional

"I work in adult mental health services so have an interest in transition arrangements and services for this client group in adulthood which appear to be relatively lacking to date. These transition checklists seem very good and clear"
 AMHS Professional