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Moran, Nicola Elizabeth orcid.org/0000-0002-6219-0394 (2014) Different models of best practice for transition to adulthood and adult services. In: Transitions for Children and Young People with Autism Conference, 16 Jan 2014, Holiday Inn City Centre.

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Different Models of Best Practice for Transition to Adulthood and Adult Services

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16 January 2014

Definitions

- ◆ Transition:
 - ◆ The transfer of responsibility from children's to adult services in health, social care and education;
 - ◆ A life stage: transition to adulthood encompassing a range of different processes, including leaving home, entering further education and employment, and taking more responsibility for health, nutrition and finances.

Background: Transition for YP with ASC

- ◆ Lack of statutory services to support those with HFA/AS in transition and in adulthood
- ◆ Additional difficulties coping with (multiple) transitions
- ◆ Evidence of poor outcomes for adults with autism
 - ◆ failure to realise full potential and achieve the so-called markers of adulthood: employment, independent living, fulfilling social lives and 'adult' relationships
- ◆ Existing research focuses on YP with LD

Study Aims

- ◆ To investigate transition pathways and the extent of statutory and non-statutory support during transition and into early adulthood for young people across the autistic spectrum, particularly those with HFA and AS;
- ◆ To explore young people's and parents' experiences of planning for transition and making the transition from children's to adults' services or adulthood;
- ◆ To highlight any areas of good practice.

Methods

Five research sites (local authorities) across England, 2010-11

- ◆ Interviews with managers and practitioners, n=68
- ◆ Postal survey of young people with ASC and their parents
- ◆ Interviews with young adults (18 – 24 years) with HFA and AS, n=18
- ◆ Interviews with parents/carers of young people with ASC (aged 16 – 24 years), n=36

Findings: Transition for young people with ASC and learning disabilities

- ◆ Eligible for transition service/support in all sites
- ◆ Clear transition pathways across all 5 sites
 - ◆ Children's disability team ⇒ transition team ⇒ adult learning disability team
 - ◆ Eligible for adult social care and adult mental health services
- ◆ But, query suitability of adult LD services
 - ◆ Appropriateness, awareness of sensitivities
 - ◆ Loss of a key worker at time of great change
 - ◆ Reactive, not proactive, impact on parents

Findings: Transition for those with HFA or Asperger's Syndrome

In contrast, young people with HFA and AS:

- ◆ Often ineligible for transition service/support and thus lacked a statutory transition pathway
- ◆ Ineligible for adult social care support
- ◆ Limited access to adult mental health services
- ◆ Limited community-based services
- ◆ But, some evidence of good practice...

Transition Support

- ◆ 2 sites offered only Connexions support to 19
 - ◆ In the other 3 sites Connexions offered 'adult guidance' to those with HFA/AS up to age 25
- ◆ 2 sites offered social care support:
 - ◆ C: Adolescent Outreach Team worked with many young people with HFA or AS
 - ◆ E: Transition team provided low-level service to those not open to the children's disability team, including those with HFA/AS, for YP aged 14-25.
- ◆ 1 site had a specialist Asperger's Team offering transition and post-transition support

Innovative practice/service 1

- ◆ Asperger's Team
 - ◆ Set up in Adult Mental Health Services
 - ◆ Focus on transitional issues: support/access to FE, HE, employment, independent living: "Try to bring the Asperger's context to wherever they are going"
 - ◆ Open to all with HFA/AS (IQ>70)
 - ◆ Origins: gap in services for young adults with AS
 - ◆ 8 initial sessions, then may apply for funding to provide outreach support
 - ◆ Offers training to other professionals
 - ◆ Becoming a cradle to grave service

Adult Social Care

- ◆ YP with HFA/AS not eligible for adult social care in the absence of additional needs; fall in the gap between adult LD services and adult MH services
- ◆ Thus no adult services to transition to...
- ◆ YP reported feelings of isolation and anger at the lack of support from services; extra burden on parents
- ◆ Concern amongst practitioners: call for inclusive 'vulnerable adults' teams offering low-level support

“One of the saddest things is they don’t need an awful lot of money spending... that is what kills me, we’re not asking for massive great big packages. £60/70 quid a week would make all the difference”.

(Social Worker)

Adult Mental Health Services

- ◆ General under-funding of AMH services
 - ◆ Lack of funding for low-level support services
- ◆ Support from community mental health teams
- ◆ Outreach support
- ◆ Specialist Asperger's teams (2 sites)
 - ◆ **B**: Not transition focused, countywide, stretched
 - ◆ **D**: Focused on (post)transition issues, time-limited

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- ◆ Loss of MH support
 - ◆ unmet mental health support needs
 - ◆ feeling uninformed and 'let down' by professionals
 - ◆ Negative impact of interrupted MH support
 - ◆ YP feared that any progress made in children's services was in danger of being lost or reduced
 - ◆ Importance of early and adequate information
 - ◆ YP reported feeling largely comfortable with her transfer as this had been discussed with her and she knew where future appointments would be

Limited community-based services

- ◆ Patchy community-based outreach support
- ◆ ASC specific social groups and leisure activities
- ◆ YP with AS reported valuing day services and peer support opportunities/groups specifically for people with AS, helped them to feel ‘normalised’ – but only existed in two sites
- ◆ Funding, capacity and sustainability worries widely reported by ASC specific organisations
- ◆ Autism specific outreach service in one site...

Innovative practice/service 2

- ◆ ASC Outreach Service
 - ◆ Open to all ASC aged 16+, focus on those not open to adult services (HFA/AS)
 - ◆ Pilot - became the area's autism specific service
 - ◆ Advice, information and signposting for individuals, families, colleges, etc.
 - ◆ Wide-ranging practical support: crossing the road, going out, accessing voluntary work or college
 - ◆ Link/joint work with other agencies if eligible
 - ◆ Support services/therapies for families
 - ◆ No time limit on support/interventions

Conclusions

- ◆ Young people with HFA and AS:
 - ◆ Often ineligible for support during transition
 - ◆ Typically ineligible for adult SC and MH services
 - ◆ Invisible to strategic managers and commissioners
- ◆ What is needed:
 - ◆ Access to transition services/support
 - ◆ Better mental health support during transition
 - ◆ Provision of timely and accurate information
 - ◆ Inclusive 'vulnerable adults' teams in adult social care
 - ◆ Specialist autism/Asperger's teams in adult mental health services
 - ◆ Asperger's specific outreach services

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- ◆ Changing policy context: Autism Act and Strategy may have led to increased awareness and inclusion of those with HFA/AS
 - ◆ However, the Autism Strategy is explicitly for adults
 - ◆ Query the impact on transition services

 - ◆ Need for further research:
 - ◆ into the costs/benefits of low-level holistic support during transition and into adulthood for YP with HFA/AS
 - ◆ Into the impact and effectiveness of the Autism Act & Strategy

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 - ◆ <http://bit.ly/TranASC>
 - ◆ <http://www.york.ac.uk/inst/spru/>
- ◆ Funding/Disclaimer:

This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are those of the authors and not necessarily those of the Department.