Transition to adult services for people with neurodevelopmental disorders

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Prevalence issues in child mental health -

- Follow-up of the 1999 Child and Adolescent Mental Health UK survey (Meltzer et al, 2000)
- All those with a disorder in original survey with a disorder (~10%) had questionnaire (at 20 mths) and interview (at 3 years)
- Proportions with Neurodevelopmental disorders at follow up:
  - Hyperkinetic disorder (ADHD) 6%
  - ASD (PDD) 3%
  - [Conduct disorder 32%]
  - [Anxiety disorder 29%]

Tamsin Ford et al, Child & Adolescent Mental Health, 2007
Use of services – reported at follow-up

<table>
<thead>
<tr>
<th>Neurodevelopmental</th>
<th>Other disorders</th>
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<tbody>
<tr>
<td>• <strong>Hyperkinetic disorder:</strong></td>
<td>• <strong>Anxiety disorders</strong></td>
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<tr>
<td>– 34% mental health services</td>
<td>– 17% mental health services</td>
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<tr>
<td>– 15% paediatric services</td>
<td>– 8% paediatric services</td>
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<tr>
<td>• <strong>Autism Spectrum Disorders</strong></td>
<td>• <strong>Conduct disorders</strong></td>
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<tr>
<td>– 33% mental health services</td>
<td>– 24% mental health services</td>
</tr>
<tr>
<td>– 49% paediatric services</td>
<td>– 10% paediatric services</td>
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</tbody>
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Evidence for persistence of NDD and demand on non-CAMHS

*Tamsin Ford et al, Child & Adolescent Mental Health, 2007*
Additional prevalence issues

Current prevalence ASD

• Highly controversial

• 2% boys in USA have an ASD diagnosis

• Baron-Cohen et al (BJPsych 2009) claim only 60% of all cases currently identified

• Provisional prevalence figure in UK of 1.00% with 10% in special schools

Baron-Cohen and Fombonne*

*EBMH, Feb 2010
The hidden proportion of children (and adults) with antisocial behaviour and social-communication impairment

- Severely disruptive children at school - ~5%,

- Donno et al (BJPsych 2010) assessed children 6-13 yrs age from inner-city schools

- 35% met diagnostic criteria for ASD.

- None had previously been diagnosed
Autism Act became law in November 2009

- Autism strategy to be produced by April 2010

- Statutory guidance for local authorities, NHS bodies, and NHS Foundation Trusts to be produced by December 2010
The rhetoric…

• Autism Strategy
• published March 2010

• Key recommendations…

• Increase **awareness** of ASD across services
• Increase **capacity** to make diagnosis (how?)

• Local commissioning of specialist autism teams

• Assess of need
• Provide of specialist support services
• Encourage capacity to work productively

• DH and DCSF (*as was*) is funding a study on transitions to adult services, reporting 2012

• NICE has ‘adult autism strategy’ under development
Statutory guidance for health and social care to support implementation of Autism strategy

- Provision of services
- Identification of adults with ASD
- Assessment of needs
- Planning of services for transition from child to adult
- Staff training
- Local leadership
The reality…

- Around 2% of all boys in USA now have an ASD diagnosis (*Kogan et al, 2009, Pediatrics*)

- We do not know the figure for the UK, but it is sure to be greater than the 0.26% figure derived from the 1999 national survey (*Fombonne et al, 2003*)

- Autism awareness in the UK among adult psychiatrists is likely to be low, except for those working in learning disability

- *Currently, services for adults with ASD focus on those with significant learning difficulties or disabilities*
Improving transitions for young people who move from child and adolescent mental health services to mental health services for adults: lessons from research and young people’s and practitioners’ experiences
Antonio Muñoz-Solomando\textsuperscript{a}, Mervyn Townley\textsuperscript{b,c} and Richard Williams\textsuperscript{b,c,d,e}

- Emphasise the loss to mental healthcare of many children who do not enter adult services
- Neurodevelopmental disorders are at high risk of secondary mental health and other problems
- Evidence base for how best to support children in transition is lacking
- Views of the patients, practitioners and managers are not available at present

Current Opinion in Psychiatry, 2010
What provision for transition is being made by CAMHS?

Key recommendations:

• Young adults who are approaching 18 and who are being supported by CAMHS should, along with their parents or carers

• know well in advance what the arrangements will be for transfer to adult services of any type, following a planning meeting at least six months before their 18th birthday

• be able to access services that are based on best evidence of what works for young adults and which have been informed by the views of young adults

• have a lead person who makes sure that the transition between services goes smoothly

• know what to do if things are not going according to plan

• have confidence that services will focus on need, rather than age, and will be flexible.

2008
New proposals for transitional services...

• **Report recommends:**

  • Developing effective models of mental healthcare which work best for adolescents and young people
  
  • Ensuring new approaches based on evidence and expertise are developed to promote effective transition between services and agencies or jointly provided youth services.
  
  • Surely – *this is merely restating the obvious?*

*December 2009*
Danger of children with neurodevelopmental disorders not making the transition at all

- Adults with autism may present to learning disability service or local mental health team

- BUT for most adults with an ASD it is neither a learning disability nor a mental health problem

Yet secondary mental health issues are common, including anxiety (67%), depression and occasionally psychosis
Issues of transition from child to adult mental health services for neurodevelopmental disorders
Issues of transition from child to adult mental health services for neurodevelopmental disorders
Other anomalies in our transitional services...

- CAMHS currently specifies a transition at 18 years
- Youth Justice covers ages 10-17 years
- LA schools, colleges etc, provide services to 19 years
- Children with disabilities may have LA services to 25 years
- Should CAMHS cover children up to 19 years?
- Should there be young adult services for 16-25 years?
- Is chronological age the best determinant for appropriate service provision?
Planning for transitions with ADHD…

- A series of sensible and practical suggestions
- Re-evaluation at least 6 months before 18 years
- Formal meeting between CAMHS or paediatric services and adult psychiatric services
- Care Program Approach to be used
- Young person involved in planning
- Further re-evaluation of child undertaken after transfer
Care Programme Approach

• Assessing your needs with you, in relation to any given situation.

• Developing a plan with you, in response to the needs identified and agreed.

• Sharing responsibility with you (and others as needed, including family, carers and friends who provide unpaid support), to put the plan into action.

• Reviewing the plan with you and others who provide support, periodically, to see that it is meeting your needs and to agree any changes.

• Includes issues such as a Care Plan, Reviews and a Care Coordinator – but some only applicable in case of complex needs.
Recognition by adult services of neurodevelopmental disorders of childhood?

- NICE guidelines for ADHD have been recommended as model for application to ASD

- BUT
  - The concept of Adult ADHD is a controversial one, not universally accepted by adult psychiatrists
  - High functioning autistic children (e.g. with Asperger syndrome) may be re-diagnosed when they reach adult services
  - What services are there currently for adults with ADHD?
Recognition and treatment of ADHD by general adult psychiatry

- <20% adult psychiatrists treat ADHD
- Prevalence ADHD in adulthood ~4%
- Transitional services for 40% ADHD in Scotland (?20% in England)
- Probable bias toward treatment of those with LD
- Paediatric-adult psychiatry service transition problematic

Adult attention-deficit hyperactivity disorder: recognition and treatment in general adult psychiatry

PHILIP ASHERSON, WAI CHEN, BRIDGET CRADDOCK and ERIC TAYLOR

Marcer et al, Child Care Health, Dev (2008)
Edwin and McDonald, Psych Bull (2007)
Taylor, Fauset, Harpin, ADC (2010)
Recognition and treatment of ASD in general adult psychiatry

- Does the prevalence of ASD in adulthood fall (as appears to be so in ADHD?)

- Are secondary symptoms that require psychiatric management dominant (e.g. anxiety)

- What is the role of medication for the core symptoms of ASD?

- What is the prevalence of forensic complications (violence, stalking etc)?

- What proportion of late adolescent ASD are re-diagnosed (e.g. as personality disorder) by adult psychiatric services?

*Tantam and Girgis, BMB (2009)*
The Economic Case…

• Autism costs UK economy a total of £28.2 billion per year

• Adults with autism cost the economy £25.5 billion per year
  - 59% services
  - 36% lost employment
    - only 15% identified ASD adults are employed)

  - Currently, we do not know what proportion of adults with ASD are receiving psychiatric support

  - Best-performing Liverpool has identified just 14% - *but there is no psychiatrist in this team!*
THOUSANDS OF CHILDREN WITH AUTISM FACE A FUTURE OF MENTAL HEALTH PROBLEMS. NEEDLESSLY.

WE CAN CHANGE OUR CHILDREN'S FUTURE.

Children with autism need:
- the NHS to know how to help them
- the Government to know this can't wait.

NAS, June, 2010