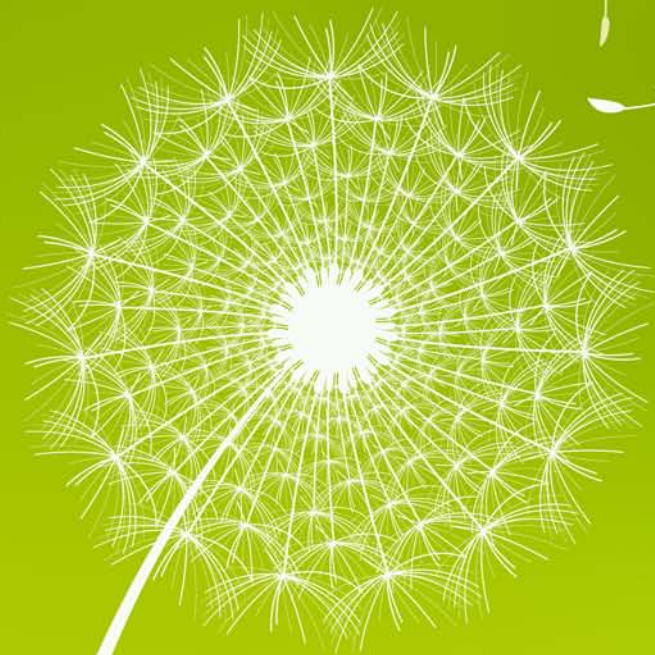


**Developing services to improve the quality of life  
of young people with neurodevelopmental  
disorders, emotional/neurotic disorders  
and emerging personality disorder**



**Occasional Paper OP77**

Developing services to improve  
the quality of life of young  
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Occasional Paper OP77  
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# Introduction

It has long been acknowledged across the UK that too many young people with mental health or neurodevelopmental disorders encounter difficulties when attempting to make the transition from child and adolescent mental health services (CAMHS) to adult services.

However, less commonly recognised is the fact that young people with neurodevelopmental disorders (e.g. autism-spectrum disorder, attention-deficit hyperactivity disorder (ADHD)), emotional/neurotic disorders and emerging personality disorder are those who struggle the most, either because of difficulties in the process of moving from one service to another or because they find that no suitable service exists for them once they reach adulthood. It is these young people that this paper is concerned with.

This paper pulls together research data which starkly demonstrate that, in terms of quality of life, conditions with continuity into adult life such as neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder have as great an impact, or greater, than physical health conditions such as diabetes, hypertension, back problems, Parkinson's disease or rheumatic disease.

The purpose of drawing these findings together is to impress upon commissioners, clinicians and service providers (from all sectors) the high level of disease burden experienced by young people in these three groups and to stress the need for services to be developed to help them.

Guidance on effective transitions for young people across the board has recently been produced by the National Mental Health Development Unit,<sup>1</sup> and the plight of the young people that are the focus of this paper is helpfully highlighted in that document.

However, we feel that it is important, and timely, to devote an entire paper to the needs of young people with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder for the following reasons:

- young people with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder are those who are most likely fall through the care gap entirely;
- reforms to the National Health Service (NHS) and social care (in England, but which will doubtless have ramifications across the UK) mean that an opportunity exists to influence the new commissioning structures which will shape mental healthcare in years to come;
- evidence-based treatments for neurodevelopmental disorders, emotional/neurotic disorders and personality disorder exist but commissioners and clinicians may not be sufficiently aware of them;

- good practice examples exist for neurodevelopmental disorders, emotional/neurotic disorders and personality disorder (see Practice examples 1–3) but commissioners and clinicians may not be aware of them;
- evidence suggests that interventions to treat young people with the conditions that this document focuses on may be cost-effective (see Appendix).

In relation to the second of these points in particular, this Occasional Paper seeks to build on the English Government's mental health strategy which strongly urges those commissioning and providing services that they should be 'focusing on outcomes and improving joint commissioning, to promote flexible services based on developmental needs'.<sup>2</sup>

Commissioners will be held to account for how well they perform in relation to outcomes. Since both the NHS Outcomes Framework 2011/12<sup>3</sup> and the Adult Social Care Outcomes Framework<sup>4</sup> include an overarching indicator regarding 'health-related quality of life for people with long-term conditions' (while the NHS Outcomes Framework 2011/12 also includes an 'improvement area' regarding 'ensuring people feel supported to manage their condition'), we hope that, having read this paper, commissioners of services will be galvanised into designing, or re-designing, services and pathways (which includes the introduction of new providers into the sector, if that is the most effective approach), since it is against such outcomes that commissioners under the new system will be judged.

# 1. Background

## CASE STUDY

I am the carer of a now adult son who has been diagnosed with Asperger syndrome. He was initially diagnosed as having a specific intellectual disability, then as having dyspraxia and finally Asperger syndrome – a process which took many years and involved referrals to a number of health professionals, including an educational psychologist and a CAMHS psychiatrist.

My son's transition into adulthood was a nightmare both for him and for the rest of the family. There was no transition from CAMHS to adult mental health services (AMHS) and there was no clinician in my local health trust with any expertise regarding Asperger syndrome. As my son got older and his behaviour became more challenging, I had to look around for more help.

Even now there are no proper interventions or therapies for someone like my son. I am his main carer and I have had to help him in every aspect of his life, such as preparing him for work (which in the end was unsuccessful) and finding him his own accommodation (as his influence on family life was very negative and challenging). I have come through many crises with him over the years. He is nominally under the care of AMHS currently, but for several years he was completely disengaged from them: apart from being put on a very strong antipsychotic drug to control his anger, calm him down and help him to sleep, no other therapeutic intervention was provided – no counselling, no talking therapies, nothing.

These days my son lives an almost independent life in his own flat, and I have arranged support for him which he pays for from his Disability Living Allowance. However, he is very heavily medicated. I have told my trust that there are evidence-based treatments for neurodevelopmental disorders but my trust will do nothing as they say they haven't the funding to provide such a service. Instead, they treat people such as my son by drug therapy alone which, because of his frustrations and anxiety, helps but is by no means the whole answer. Ironically, it is helpful/positive in one way but negative in another because of side-effects such as weight gain.

I have read of examples of good practice and I think that if my son could have accessed a service such as 'Bridging the Gap' in Brighton and Hove I think he could have benefitted considerably. Unfortunately, no such service exists where I live, so I just struggle on supporting him, looking for more appropriate help, which hopefully in the fullness of time will be there for him.

Although the process of transition is not the focus of this document, it may nevertheless be helpful to describe how young people making, or attempting to make, a transition from CAMHS to AMHS<sup>5,6</sup> and to adult services outside of mental health fall broadly into three groups.

- Those who don't make a transition into adult services – because no appropriate service exists for them or they do not meet eligibility criteria – and fall through the care gap.

- Those who make a transition into adult services but have a poor experience and therefore do not engage with adult services.
- Those who have an optimal transition into adult services and have their mental health needs met.

In terms of quality of life, since young people in the first group do not suffer from transient conditions, it is very likely that their needs are unmet into adulthood and they end up with very poor quality of life. Young people in the second group also have a poor quality of life because of their disengagement from adult services. It is likely that young people in the third group have improved quality of life, although this aspect is currently under-researched.

However, although concern about the quality of life enjoyed by people in the first and second groups has undoubtedly been a factor which has underpinned attempts to improve CAMHS–AMHS transitions,<sup>6,7</sup> it has rarely been the central focus. We believe, however, that the quality of life enjoyed by the young people this paper describes should be foregrounded in future debates, whether these debates relate to transitional issues or to issues of ongoing care.

## 2. Struggling to get help

Young people making, or attempting to make, a transition from CAMHS and other services (such as pupil referral units and youth justice services) to AMHS or other adult services can undergo multiple other transitions at the same time, including leaving home, leaving education and joining the workforce, living independently and becoming a parent.<sup>8</sup> Difficulties experienced in attempting to move from one service to another therefore can – unless adequate support mechanisms are in place – add to what is often already a bewildering and unsettling experience, thus further undermining quality of life. The process is complex even where a good service exists to transition to; if no appropriate service exists (as is often the case for ADHD, autism-spectrum disorder and borderline personality disorder, for example), then the quality of life of these young people is unlikely to improve.

Furthermore – and particularly in relation to the young people this paper focuses on – there are often difficulties regarding eligibility criteria, with many young people unable to access AMHS since they do not meet the criteria for that service (e.g. they do not have a severe and enduring mental illness such as schizophrenia or bipolar disorder).<sup>9</sup>

Although many services have adopted the use of protocols to manage the transition of young people from CAMHS to AMHS, in practice there are significant procedural and structural issues (on both sides of the divide) relating to this process.<sup>10</sup> Readers are advised to refer to recent guidance from the National Mental Health Development Unit for information on how to improve this area.<sup>1</sup>

It is generally acknowledged within the mental health sector that relatively little progress has been made to overcome the issues of both process and appropriate service provision. Indeed, the TRACK study,<sup>10</sup> which evaluated the process, outcomes and user and carer experience of transitioning from CAMHS to AMHS, found that:

‘optimal transition, defined as adequate transition planning, good information transfer across teams, joint working between teams and continuity of care following transition, was experienced by less than 5% of those who made a transition.’<sup>10</sup>

Furthermore, the study reported that:

‘individuals with a history of severe mental illness, being on medication or having been admitted were more likely to make a transition than those with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder.’<sup>10</sup>

This chimes with other research findings, reviews of evidence and policy guidance in relation to ADHD and autism-spectrum disorder,<sup>1,6,11-13</sup>

emotional/neurotic disorders<sup>14</sup> and personality disorder,<sup>15,16</sup> which highlight the lack of adult services that address these disorders.

And since the TRACK study adds: 'following transition, most service users stayed engaged with AMHS and reported improvement in their mental health',<sup>10</sup> the importance of addressing the failure of young people with neurodevelopmental disorders (e.g. autism-spectrum disorder, ADHD), emotional/neurotic disorders and emerging personality disorder to make the transition from CAMHS to appropriate adult services should be made clear.

# 3. Measuring quality of life

In public health and in medicine, the concept of health-related quality of life (HRQoL) refers to a person's or group's perceived physical and mental health over time. Measuring the effects of chronic illness – through validated, self-report questionnaires which look at an individual's physical, functional, social and emotional well-being – is a well-established means of better understanding how an illness interferes with a person's day-to-day life.

This paper presents research data on quality of life published on a range of mental health, neurodevelopmental and physical health conditions. Taken together, these study findings demonstrate that the quality of life of those young people most likely to fail to make the transition from CAMHS to AMHS (or other adult services) is equivalent to, or poorer than, that of people with certain common, long-term physical health conditions.

The research findings presented in this paper are stated in numerical terms (i.e. quality-of-life scores). The following paragraphs however – which relate to the three condition groupings that this paper focuses on – are taken from some of the more extensive studies cited, as they provide a compelling narrative when viewed alongside the numerical data.

## PERSONALITY DISORDER

Soeteman *et al's* 2005 study,<sup>17</sup> which investigated the burden of disease in a large population of in-patients with complex personality problems and personality disorders receiving psychotherapy in specialised units, found that 'these patients experienced a high burden of disease, which was comparable to the burden of disease of patients with severe somatic illnesses such as Parkinson's disease or rheumatic disease.'

## EMOTIONAL/NEUROTIC DISORDERS

Cook *et al's* 2008 study,<sup>18</sup> which aimed to 'compare the burden of disease experienced by people with mental health conditions with people who have common medical disorders', found that having depression, anxiety or emotional problems resulted in significantly lower HRQoL than having back or neck problems, diabetes and hypertension. The authors draw the conclusion that 'an efficient health-care system should consider the relative disease burden of specific conditions when allocating health resources.'

## NEURODEVELOPMENTAL DISORDERS

Kulhtau *et al's* 2010 research on the quality-of-life scores of 286 children with autism-spectrum disorder found that they were 'significantly lower than those of healthy populations. When compared to normative data from

children with chronic [physical health] conditions, children with autism-spectrum disorder demonstrated worse HRQoL for total, psychosocial, emotional and social functioning.<sup>19</sup> Children with autism-spectrum disorder scored as poorly as children with chronic illnesses in the area of physical health.<sup>19</sup> This finding concurs with that of Dankcaerts *et al*, whose systematic review of the quality of life of children with ADHD concluded that the 'impact of ADHD on QoL...is at least as great as seen for many physical disorders'.<sup>20</sup>

## INSTRUMENTS FOR MEASURING QUALITY OF LIFE

There are a small number of well-validated and extensively used instruments for measuring HRQoL. Tables 1 and 2 list scores from two of these: the Pediatric Quality of Life Inventory (PedsQL)<sup>a</sup> and the EQ-5D<sup>b</sup> instrument.

**Table 1 Quality-of-life scores (parent proxy-report) using Pediatric Quality of Life Inventory (PedsQL) of individual mental health conditions compared with physical health conditions**

Condition	PedsQL score (parent proxy-reported)
Healthy population <sup>23</sup>	82.7
Healthy population <sup>21</sup>	82.3
Cardiac problems <sup>21</sup>	79.4
Diabetes <sup>21</sup>	76.6
Obesity <sup>21</sup>	75.0
Gastrointestinal conditions <sup>21</sup>	72.7
Rheumatoid arthritis <sup>19</sup>	71.0
End-stage renal disease <sup>21</sup>	69.6
Asthma <sup>21</sup>	68.8
Rheumatoid conditions <sup>21</sup>	68.7
Cancer <sup>21</sup>	68.4
Newly diagnosed cancer <sup>19</sup>	67.0
<b>Anxiety disorder<sup>21</sup></b>	<b>66.0</b>
<b>Attention-deficit hyperactivity disorder<sup>21</sup></b>	<b>65.8</b>
<b>Mood disorders<sup>21</sup></b>	<b>65.7</b>
<b>Autism-spectrum disorder (all ages 0–18)<sup>19</sup></b>	<b>65.2</b>
<b>Autism-spectrum disorder (ages 13–18)<sup>19</sup></b>	<b>61.6</b>
<b>Pervasive developmental disorders<sup>21</sup> (i.e. autism-spectrum disorder)</b>	<b>61.5</b>
Cerebral palsy <sup>21</sup>	51.2

Mental health conditions are in bold.

a. The Pediatric Quality of Life Inventory (PedsQL) is a 23-item questionnaire for assessing children between 2 and 18 years old. It has a 5-point rating scale and asks participants to think only about the previous 1-month period. It evaluates four areas of health-related functioning: physical functioning, emotional functioning, social functioning and school functioning. The latter three scales are combined to determine a broad psychosocial summary score, while a physical health summary score is determined using the physical functioning scale. The items on the PedsQL surveys are converted into a 0–100 scale, with high scores indicating the best HRQoL.

b. Applicable to, and validated for, a wide range of health conditions and treatments, the EQ-5D collects data across five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). Answers are weighted to give a single figure between 1 and 0 (score of '1' represents the best health state imaginable and '0' represents a health state equivalent to being dead), thereby providing a single index value for health status that can be used in the clinical and economic evaluation of healthcare as well as in population health surveys. A visual analogue scale comprises a second part of the EQ-5D in which respondents are asked to rate their health on a scale between 0 (worst health state imaginable) and 100 (best health state imaginable).

**Table 2 Quality-of-life scores using EQ-5D scores of individual mental health conditions compared with physical health conditions**

Condition	EQ-5D index score	EQ-5D visual analogue score (where reported)
Normal (non-clinical population) <sup>22</sup>	0.85	87
Asthma <sup>23</sup>	0.79	
Hypertension <sup>23</sup>	0.78	
<b>Attention-deficit hyperactivity disorder<sup>24</sup></b>	<b>0.75</b>	<b>73.9</b>
<b>Attention-deficit hyperactivity disorder<sup>25</sup></b>	<b>0.74</b>	<b>72.4</b>
Diabetes <sup>23</sup>	0.74	
Schizophrenia <sup>26</sup>	0.73	
Neck/shoulder pain <sup>23</sup>	0.70	
Type II diabetes <sup>27</sup>	0.69	
Low back pain <sup>23</sup>	0.66	
Parkinson's disease <sup>28</sup>	0.58	
Intermittent claudication <sup>29</sup>	0.57	
Chronic fatigue syndrome <sup>30</sup>	0.56	54.3
<b>Personality problems/personality disorder<sup>31</sup></b>	<b>0.56</b>	
<b>Cluster C personality disorder (avoidant, dependent, obsessive-compulsive)<sup>32</sup></b>	<b>0.53</b>	
Rheumatic disease (including osteoarthritis, rheumatoid arthritis and fibromyalgia) <sup>33</sup>	0.53	63
<b>Cluster B personality disorder (histrionic, borderline, narcissistic, antisocial)<sup>34</sup></b>	<b>0.51</b>	
<b>Borderline personality disorder<sup>35</sup></b>	<b>0.50</b>	<b>50.5</b>
<b>Major depressive disorder<sup>36</sup></b>	<b>0.33</b>	

Mental health conditions are in bold.

## 4. Evidence-based treatments and interventions

Clinicians and commissioners may be more familiar with National Institute for Health and Clinical Excellence (NICE) guidelines detailing effective, evidence-based treatments for common mental health disorders (e.g. anxiety,<sup>37</sup> depression in adults,<sup>38</sup> depression in children and young people<sup>39</sup>) than with guidelines on effective, evidence-based treatments for neurodevelopmental disorders and personality disorder. Although the evidence-base for these latter conditions is undoubtedly not as robust, it does nevertheless exist.

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### PRACTICE EXAMPLE 1: HELPING YOUNG PEOPLE WITH COMMON EMOTIONAL OR MENTAL HEALTH PROBLEMS

Name of the service: Pathways

Location: Glasgow

Age group: 16–25 years

Referral system: Self-referral

Core activities: Pathways is an NHS primary care mental health team in south-west Glasgow which offers a range of short-term interventions to help people between 16 and 25 years of age who have common emotional or mental health problems. The service provides information about common mental health disorders and also has a website from which it is possible to download self-help booklets. Pathways also organises courses on topics such as 'Building self-confidence' and 'Getting the life you want'.

Funding: Greater Glasgow and Clyde NHS Trust

Website: [www.nhsggc.org.uk/content/default.asp?page=home\\_pathways16-25](http://www.nhsggc.org.uk/content/default.asp?page=home_pathways16-25)

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## NEURODEVELOPMENTAL DISORDERS

### *ATTENTION-DEFICIT HYPERACTIVITY DISORDER*

In 2009, NICE published a guideline to advise on the care, treatment and support that children, young people and adults with ADHD should be offered based on the best available evidence.<sup>40</sup> The guideline recommends (for adults) drug treatment as first-line treatment, unless the person would prefer a psychological approach (in which case cognitive-behavioural therapy may be considered). It also recommends that:

'Mental health trusts, and children's trusts that provide mental health/child development services, should form multidisciplinary specialist ADHD teams and/or clinics for children and young people and separate teams and/or clinics for adults. These teams and clinics should have expertise in the diagnosis and management of ADHD, and should... ensure age-appropriate psychological services are available for children, young people and adults with ADHD, and for parents or carers' (pp. 12-13).<sup>40</sup>

Also included in the guideline is the recommendation that:

'a multi-agency group, with representatives from multidisciplinary specialist ADHD teams, paediatrics, mental health and learning disability trusts, forensic services, child and adolescent mental health services, the Children and Young People's Directorate (including services for education and social services), parent support groups and others with a significant local involvement in ADHD services' (p.13)

be developed, which should 'consider compiling a comprehensive directory of information and services for ADHD including advice on how to contact relevant services'.<sup>40</sup>

The guideline also makes specific recommendations in relation to the transition from child to adult services, including:

- reassessment at school-leaving age to establish the need for continuing treatment into adulthood for all young people with ADHD receiving treatment and care from CAMHS or paediatric services;
- if treatment is deemed necessary, arrangements for a smooth transition to adult services should be made with details of the anticipated treatment and services that the young person will require (this process should usually be completed by the time the young person is 18);
- a formal meeting involving CAMHS and/or paediatric and adult psychiatric services should be considered during transition; the care programme approach should be used to aid the transfer between services, with the young person's involvement in the planning;
- post-transition to adult services, adult healthcare professionals should carry out a comprehensive assessment of the person with ADHD that includes personal, educational, occupational and social functioning, and assessment of any coexisting conditions.

Recommendations on the use of multisystemic therapy are also contained in Vizard *et al's* report commissioned by the Personality Disorder Programme of the Department of Health, a document which also points out that 'there is a lack of collaboration between agencies such as CAMHS and adult mental health services in the provision of transition services for children and young people showing antisocial behaviour'.<sup>16</sup>

## **AUTISM-SPECTRUM DISORDER**

A NICE guideline on autism-spectrum disorder in children and young people is due to be published in September 2011 (<http://guidance.nice.org.uk/CG/Wave15/78>), and a NICE guideline on autism-spectrum disorder in adults is in development (<http://guidance.nice.org.uk/CG/Wave23/1>), with a publication date of June 2012.

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## PRACTICE EXAMPLE 2: HELPING YOUNG PEOPLE WITH ADHD AND AUTISM-SPECTRUM DISORDER

Name of the service: Bridging the Gap

Location: Brighton and Hove

Age group: 14–25 years

Referral system: from AMHS, CAMHS, general practitioners and probation services

Core activities: The service is structured around five TAPAs (Teen to Adult Personal Advisors) who are qualified mental health workers based in Brighton and Hove's various youth hubs. They offer advice about mental health issues both to young people and to other professionals. The service was developed particularly to address the needs of young people in the area with behavioural and neurodevelopmental disorders (e.g. autism-spectrum disorder and ADHD), who were not accessing conventional services, although it currently caters to a wider client group.

Funding: Brighton and Hove CAMHS

Website: <http://youngpeopleinfocus.fastnet.co.uk/madetomeasure/casestudies/bridging-the-gap>

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## PERSONALITY DISORDER

Clinicians are naturally cautious about diagnosing personality disorder in young people, largely because of uncertainties about the reliability and validity of the diagnosis in adolescence and because of the possibility of stigma. Although research on personality disorder is limited in young people, the NICE guideline,<sup>41</sup> following a review of the literature, took the view that young people meeting criteria for borderline personality disorder should have access to all the services recommended in the guideline in the context of CAMHS. The guideline cautions against the use of polypharmacy and the use of brief psychotherapeutic interventions (less than 3 months duration) for this client group, especially in circumstances where presentations are more severe. In more severe presentations, NICE recommends that treatments should:

- use an explicit and integrated theoretical approach used by both the treatment team and the therapist, which is shared with the service user;
- provide structured care as outlined in the guideline (that describes management of crises, hospital admission and case management);
- provide therapist supervision.

In circumstances where reducing self-harming behaviour is a clinical priority, the guideline recommends dialectical behaviour therapy for female service users. Dialectical behaviour therapy is a comprehensive programme of treatment that incorporates individual psychological therapy, group skills training, telephone consultation between therapist and service user, and a consultation team for therapists.<sup>42</sup> Randomised controlled trial data on interventions for borderline personality disorder in adolescents is sparse. In Australia, a trial of cognitive analytic therapy by Chanen and colleagues showed no advantage over 'good' clinical care as usual, although both groups demonstrated a reduction in self-harm and internalising and externalising behaviours.<sup>43</sup> Results of two current trials are eagerly awaited: one of

dialectical behaviour therapy<sup>44</sup> and the other of mentalisation-based therapy (<http://clinicaltrials.gov/ct2/show/NCT01204346>).

The NICE guideline recommends the development of specialist multi-disciplinary teams/services for service users with a diagnosis of personality disorder.<sup>41</sup> Such teams may need to be available for adolescents at a regional level if not within Tier III services. Protocols to facilitate the transition between CAMHS and AMHS are necessary for this complex group of young people.

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### PRACTICE EXAMPLE 3: HELPING YOUNG PEOPLE WITH EMERGING PERSONALITY DISORDER

Name of the service: The Zone

Location: Plymouth

Referral system: Self-referral, professional referral

Age group: 13–35 years (depending on service)

Core activities: In addition to providing a counselling service and a range of mental, emotional and sexual health information (plus advice on other issues such as housing), The Zone runs an early intervention in personality disorder service for 16- to 25-year-olds called Icebreak. This service aims to help young people who have been 'experiencing emotional distress over a period of time, often reflected in problems of day-to-day living, e.g. self-harming or suicidal tendencies, difficulties forming/maintaining positive relationships' and who 'if left supported or excluded may be labelled with a personality disorder in later life'.

Funding: various, including NHS Plymouth, The Tudor Trust, BBC Children in Need & Plymouth Council

Website: [www.thezoneplymouth.co.uk/what-we-do/icebreak/home.html](http://www.thezoneplymouth.co.uk/what-we-do/icebreak/home.html)

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Although not having emerging personality disorder as a central focus, other NICE guidelines, however, do address this issue. For example, the NICE guideline on antisocial personality disorder<sup>45</sup> looks at the management of treatment of young people with conduct disorder (a precursor to antisocial personality disorder). It recommends parent-training programmes, brief strategic family therapy and functional family therapy for parents of young people aged between 12 and 17 years with conduct problems, and multisystemic therapy for young people with severe conduct problems and a history of offending, who are at risk of being placed in care or excluded from the family. The guideline also recommends that

'health and social care services should consider referring vulnerable young people with a history of conduct disorder or contact with youth offending teams, or those who have been receiving interventions for conduct and related disorders, to appropriate adult services for continuing assessment and/or treatment' (p.22).<sup>45</sup>

It also recommends group-based cognitive and behavioural interventions for adults with antisocial personality disorder.

Similarly, although the NICE guideline on borderline personality disorder relates to the management of people with borderline rather than emerging personality disorder, its acknowledgement that 'many young people who have been treated by CAMHS will not meet the referral criteria for adult mental health services, either because the services do not accept people with a personality disorder or because the service does not consider

their difficulties to be severe enough to warrant intervention' (p. 376)<sup>41</sup> is depressingly familiar.

However, the recommendation in this guideline that 'commissioners of CAMHS and adult mental health should collaborate to identify service gaps and explore service models, for example, jointly commissioned services across the age range, to address the needs of young people in transition from CAMHS to adult mental health services' (p. 376)<sup>41</sup> is one which, in our opinion, should be heeded in order that the range/type/modality of psychological interventions that NICE recommends for the treatment of borderline personality disorder can be accessed.

## 5. Commissioning guidance and good practice

The voluntary sector has produced commissioning guidance on transitions and young people's mental health in recent years (e.g. Young Minds<sup>5</sup>). As stated in the introduction, the National Mental Health Development Unit has recently published guidance on improving the transition from CAMHS to AMHS.<sup>1</sup> It provides a range of examples of good practice relating to effective transitional services in order 'to encourage commissioners to draw upon successful work from across the country and to make links to enable them to develop effective commissioning strategies and services for transition' (p. 24).<sup>1</sup>

Familiarisation with these documents will enable commissioners not only to better fulfil their statutory duties regarding transitions generally<sup>a</sup> and future planning of services<sup>b</sup> (developing a map of which services actually exist locally for the groups focused on in this paper will be an essential step), but also to take advantage of any opportunities afforded by the advent of 'any willing provider' (also called 'any qualified provider'),<sup>46</sup> in order to develop more effective and appropriate services for, and improve the quality of life of, the young people that this document focuses on.

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a. Information about specific legislative requirements concerning young people going through transition can be found in Parker *et al.*<sup>47</sup>

b. Recent statutory guidance from the Department of Health regarding young people with autism, for example, which states that: 'Where individuals do not fulfil referral criteria for adult mental health teams, it would be good practice for local authorities and NHS bodies to signpost on to other sources of support and information available locally and nationally. Commissioners should be informed of gaps identified in services in these instances to support future planning' (p.21).<sup>48</sup>

## 6. Conclusions

This Occasional Paper pulls together research data on the quality of life of young people with neurodevelopmental, mental health and physical health disorders. In doing so, it demonstrates that conditions with continuity into adult life – such as neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder – have an impact that is as great, or greater, than that of physical health conditions such as diabetes, hypertension, back problems, Parkinson’s disease or rheumatic disease. The paper also highlights the evidence-based interventions which exist for these disorders, along with presenting some evidence regarding the cost-effectiveness of such interventions.

It is the aim of this paper that commissioners, clinicians and providers will review and develop the range of services available for young people with these neurodevelopmental and mental health disorders in order that the quality of life they experience can be substantially improved.

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# Appendix

## A WORKED EXAMPLE IN RELATION TO THE COST-EFFECTIVENESS OF PSYCHOLOGICAL THERAPY FOR THE TREATMENT OF PERSONALITY DISORDER

Commissioners will naturally be keen to avail themselves of any cost-benefit analyses which pertain to any new service they are considering commissioning.

While further research on treatment for the three groups (neuro-developmental, emotional/neurotic and emerging personality disorders) focused on in this paper is undoubtedly required, detailed work has been done on one group (personality disorder) as shown in Table A1 overleaf. In summary, this large study of 1740 patients<sup>a</sup> (carried out in The Netherlands at the Viersprong Institute for Studies on Personality Disorders) into the costs and benefits of psychological treatment of personality disorder demonstrates that with long-term investment (i.e. a minimum of 5 years), every €22000 spent on treating people with personality disorder can lead to benefits of €33022 (therefore a saving of €11022 per patient per 5-year treatment period).

This is to say that an investment of €220000 for the psychological treatment of 100 patients with personality disorder can lead to benefits of €330220 and therefore savings of €110220 (i.e. the calculated benefits are at least 1.5 times the costs of treatment).

The figures for benefits and savings are conservative estimates because they do not take into account possible (and likely) savings such as a decrease in prison service costs or other societal costs.

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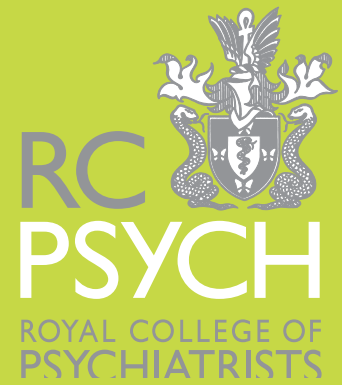
**Table A1 The cost-effectiveness of psychological therapy for the treatment of personality disorder: a worked example**

	Value per patient, €	What does this figure represent?
<i>Costs</i>		
Treatment costs per patient with personality disorder (lasting up to 1 year in this study)	22 000	The mean of out-patient, day hospital and in-patient treatment costs, i.e. €7445, €23 279 and €35 218 respectively
Total costs	22 000	
<i>Benefits</i>		
Improvement of quality of life (QALYs)	21 120	The mean EQ-5D value per year after treatment = 0.68 for Cluster B and Cluster C personality disorders (combined), an increase from a baseline EQ-5D value of 0.56 of 0.12 QALY <sup>a</sup> per year. Assuming the duration of this improvement will last over 5 years (the time period of this study), then the benefit is $5 \times 0.12 = 0.60$ QALY per patient. With a burden of disease of 0.44 (burden = $1 - QoL$ (i.e. 0.56)), the value of a QALY is €35 200 <sup>b</sup> (with a value of €80 000 with a maximal burden of disease of 1). The benefits of treatment can be estimated to be $0.6 \text{ QALY} \times €35 200 = €21 120$ per patient.
Reduction in costs due to healthcare consumption	4 100	The direct medical costs of patients with personality disorder before treatment in this research study amounted to €7 400 per year (of which €4 000 per year related to psychiatric care). 41% of patients had made a clinical recovery after 5 years; estimating, therefore, that for a reduction in psychiatric care treatment costs of a minimum of 50% (i.e. €2 000 per year), there is a reduction in costs due to healthcare consumption per patient of €4 100 (i.e. 41% of €10 000 (i.e. 5 years' worth of €2 000 per year savings in psychiatric care costs)).
Reduction in productivity losses	7 802	Costs due to productivity losses in the year prior to treatment were approximately €7 088. Given that the study found that of those 41% of patients who recovered 53.7% had a paid job, the savings due to people returning to work was €7 802 (i.e. $€7 088 \times 41\% \times 53.7\% \times 5$ (number of years of such savings)).
Total benefits	33 022	Sum of improvement of quality of life (QALYs), reduction in costs due to healthcare consumption and reduction in productivity losses
Savings from treatment	11 022	Total benefits minus total costs

QALY, quality adjusted life year.

a. QALY: a measure of the burden of disease, including both the quality and the quantity of life lived.

b. This is the value which society is willing to pay for a QALY (in the UK, this is estimated by NICE to be between £20 000 and £30 000).



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