

All of this is much along the lines that Koenig urged in his editorial,<sup>16</sup> which leaves the simple question that King & Leavey pose, 'Why all the fuss?'

Andrew Sims, in his address to the College in 1993,<sup>12</sup> suggested that psychiatrists ignore the spiritual because they consider it unimportant or irrelevant, because they know little about it, or are embarrassed by it, or else because they consider it too personally challenging. The growing literature gives increasingly little excuse for ignorance and belies imputations of unimportance or irrelevance. Interestingly, this leaves us with a matter of importance and relevance that patients wish to discuss but which psychiatrists apparently find too embarrassing or too challenging. Perhaps this is the kind of thing that might be expected when the unacknowledged closed world structures of a secular age are challenged. What would seem clear is that it is not a good basis for clinical practice in such an age.

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### References

- 1 King M, Leavey G. Spirituality and religion in psychiatric practice: why all the fuss? *Psychiatrist* 2010; **34**: 190–4.
- 2 Taylor C. *A Secular Age*. Belknap, 2007.
- 3 Cook CCH. Addiction and spirituality. *Addiction* 2004; **99**: 539–51.
- 4 Mackey JP. *The Critique of Theological Reason*. Cambridge University Press, 2000.
- 5 Leavey G, Loewenthal K, King M. Challenges to sanctuary: the clergy as a resource for mental health care in the community. *Soc Sci Med* 2007; **65**: 548–59.
- 6 Lewis CA, Breslin MJ, Dein S. Prayer and mental health: an introduction to this special issue of Mental Health, Religion and Culture. *Ment Health Relig Cult* 2008; **11**: 1–7.
- 7 Sloan RP, Bagiella E, Powell T. Religion, spirituality, and medicine. *Lancet* 1999; **353**: 664–7.
- 8 Shuman JJ, Meador KG. *Heal Thyself: Spirituality, medicine, and the Distortion of Christianity*. Oxford University Press, 2003.
- 9 Huguelet P, Koenig HG (eds). *Religion and Spirituality in Psychiatry*. Cambridge University Press, 2009.
- 10 Cook C, Powell A, Sims A (eds). *Spirituality and Psychiatry*. RCPsych Publications, 2009.
- 11 Casey P. *The Psycho-Social Benefits of Religious Practice*. Iona Institute, 2009.
- 12 Cox JL. Psychiatry and religion: a general psychiatrist's perspective. *Psychiatr Bull* 1994; **18**: 673–6.
- 13 Sims A. 'Psyche' – spirit as well as mind? *Br J Psychiatry* 1994; **165**: 441–6.
- 14 Culliford L, Eagger S. Assessing spiritual needs. In *Spirituality and Psychiatry* (eds C Cook, A Powell, A Sims): 16–38. RCPsych Publications, 2009.
- 15 Committee on Religion and Psychiatry. Guidelines regarding possible conflict between psychiatrists' religious commitments and psychiatric practice. *Am J Psychiatry* 1990; **147**: 542.
- 16 Koenig HG. Religion and mental health: what should psychiatrists do? *Psychiatr Bull* 2008; **32**: 201–3.

## A child and adolescent mental health service for children with intellectual disabilities – 8 years on

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**Summary** This paper reports on the last 8 years in the development of a child mental health learning disability service. The growth, challenges and pitfalls faced by the service are charted here. The paper also shows how a service can cope with rising demand without the development of waiting lists and how a specialist service can be embedded within a generic child and adolescent mental health service (CAMHS) as a tier 3 team, thus creating synergies and commonalities of purpose, while avoiding service gaps that inevitably arise from separate services with specific referral criteria. This is a healthy service model that meets the needs of local children with moderate to severe intellectual disabilities and concomitant child mental health problems.

**Declaration of interest** None.

### Existing mental health services for children with intellectual disabilities

For 18 years the government has highlighted the need to improve health services for people with intellectual disabilities<sup>1</sup> and this has been clearly stated in the National

Service Framework for children.<sup>2,3</sup> Specific advice about commissioning these services goes back 12 years.<sup>4,5</sup>

Children with intellectual disabilities are more likely to have mental health problems than children without intellectual disabilities.<sup>6–12</sup> The impact on families is

considerable<sup>13</sup> and general practitioners (GPs) believe that they are not equipped to deal with the problems that present to them.<sup>11</sup> Prevention is not well prioritised.<sup>14</sup> Specialist mental health in-patient provision<sup>15</sup> is patchy across the country and often relies on private units<sup>16</sup> and Social Services accommodation<sup>17</sup> to fill the gaps. Many children are sent out of area a long way from their families, either for in-patient mental healthcare, or more commonly for residential education.

One review estimated that in a health district such as ours (Selby and York) with a population of 300 000 one would expect about 120 young people with intellectual disabilities who have 'substantial' mental health problems and considerably more if a wider group, with less serious problems, are included.<sup>18</sup> This fits well with our experiences setting up a new service, where after 1 year we had 119 new referrals into the service and were able to discharge only 19 of them in that same period, because of the high levels of need.<sup>19</sup>

### Selby and York service

Within this context, we, like many other children and adolescent mental health services (CAMHS) have striven to develop a comprehensive service for children with intellectual disabilities. York CAMHS developed the tier 3 intellectual disabilities team within its structure in January 1999. Funding did not come in any planned commissioned way but was opportunistic. A community nurse and 1-day-a-week clinical psychology time was initially transferred from an all-age service for people with intellectual disabilities when it wished to stop providing for 0- to 18-year-olds. This service quickly ran up a waiting list because of high levels of need. A bid for waiting list reduction money added 5 days of psychology time, 2.5 days 'other' therapist and 1-day-a-week psychiatry time. Since then, 2.8 whole time equivalents (WTE) have been moved within the wider CAMHS because local clinicians and managers recognised that this group of children and young people have an equal right to services. We understand that many localities have not shared out resources in this way when CAMHS and modernisation grant monies were made available, leaving large gaps in some services throughout the country for this group.

Standard 8 of the National Service Framework for children states that local authorities, primary care trusts and CAMHS must work together to 'ensure that disabled children have equal access to CAMHS'.<sup>20</sup> The Public Service Agreement targets introduced three proxy indicators for improvement in CAMHS, one of which was that a full range of CAMHS be available or accessible for children and young people with intellectual disabilities. An update in April 2007 reported that only 41% of CAMHS had met this target by March 2005, but 88% had met it by December 2006.<sup>21</sup> Given that no new targeted money has been available and no new staff or training has been commissioned across the country, this apparent increase is puzzling. It seems that the managerial imperative to improve government statistics has triumphed over any new resourcing of services.

This paper describes how one service has grappled with a desire to improve services for children and adolescents

with mental health problems and how it has grown as a result. It describes what the service now provides. The process of setting up our team is described by Green and colleagues;<sup>19</sup> we focus on its growth, challenges and developments.

### Staffing changes since the intellectual disabilities team was established

We now have 4.6 WTE staff: 0.8 WTE consultant child clinical psychologist, 1.0 WTE child clinical psychologists, 2.0 WTE community nurses, 0.6 WTE therapist (speech and language therapist and teaching experience) and 0.2 WTE consultant child psychiatrist. Department of Health guidelines<sup>5</sup> suggest 'staffing levels for tier 2/3 intellectual disability specialist CAMHS will need to be in the order of 5–6 specialist staff per 100 000 population provided by staff with necessary competencies to address mental health difficulties in children and adolescents with intellectual disabilities.' This would be four times the numbers of staff we have.

### Referrals

After the initial influx of referrals in the first year, the number of new referrals has settled at around 75 per year. In 2007, the majority of new referrals (71%) came through primary mental health workers, who act as a crucial link with tier 1 professionals and also offer short-term interventions. They signpost appropriate referrals to education services, Social Services, voluntary agencies and the CAMHS intellectual disability team. These referrals in turn came from a variety of sources including GPs, a regular paediatric liaison meeting,<sup>22</sup> health visitors, social workers, school nurses and special school teachers, educational psychologists, specialist teaching advisors and special educational needs coordinators. About 15% came from paediatricians for the more complex autism assessments and parent intervention groups.

Around 57% of referrals are for assessments and interventions for children and young people with autism-spectrum conditions and 43% for children with intellectual disabilities. Approximately five cases a year are for young people with serious mental illness such as bipolar disorder. The team rapidly found that unlike CAMHS for people without intellectual disabilities many children had ongoing problems. In the wider CAMHS much work was short-term, but the intellectual disability team was finding that most work was long-term. As a consequence of the growing numbers of children on our case-loads, the team has had to find creative ways of managing the service without holding a waiting list.

### What does the team now offer?

The team now offers a range of services to children, young people and families.

### Support and consultation to tier 1

The amount of time spent in consultation has grown but has been extremely fruitful and cost-effective. The number of

new referrals for individual work has dropped as a consequence, with tier 1 workers feeling better able to support families as a result of consultation meetings. The meetings include the following:

- a. Multi-agency information sharing days: twice yearly, organised with the local authority; presentations are given by the wide variety of agencies offering services for young people with disabilities and provide the opportunity for professions, parents and carers to share information with each other.
- b. Paediatric liaison meetings: weekly for an hour, act as a forum for discussion about the interface between the physical and psychological components of children's difficulties, joint intervention plans and general sharing of expertise.
- c. Multi-agency forum about sexuality issues: developed out of a growing number of referrals for young people struggling with understanding about appropriate sexual behaviour, touch, social engagement and hygiene; the team works alongside teachers and school nurses in special schools to develop teaching sessions and discuss complex issues as they arise.
- d. Social Services and respite consultation: one per term meeting with respite services provides consultation, with additional contacts on request; this has resulted in joint work at times within the respite premises.
- e. Consultation to special school: twice a term consultation meetings with individual special schools, with a named team link person for each school.

In addition, the team provides weekly consultation with primary mental health workers who assess all children referred to CAMHS. Teaching and training to schools and special educational needs coordinators is provided on request, as well as co-working with social workers and other professionals and regular multi-agency meetings around specific children or issues. There is a large gap in provision of CAMHS into the child development centre, which still awaits commissioning.

## Tier 2

The main function of the team is the provision of assessment and treatment of mental health problems in children with intellectual disabilities. This includes behaviour management advice to families, weekly consultation and liaison with tier 2 CAMHS where there is concern about possible intellectual disability or ASC, co-working with other professionals on particular cases and training at all tiers in CAMHS.

## Tier 3

Within the team we have a range of more specialist functions.

### *Autism-spectrum conditions*

The prevalence of autism-spectrum conditions in the team's current case-load is around 50%. The team works closely with a local multi-agency, multidisciplinary autism forum for diagnosis and intervention planning. The forum is structured to include a rigorous procedure using ICD-10 criteria in

which clinicians present cases in great detail. Various clinicians are trained in specialist assessment schedules: the Autism Diagnostic Interview-Revised (ADI-R),<sup>23</sup> the Autism Diagnostic Observation Schedule (ADOS)<sup>24</sup> and the Developmental, Dimensional and Diagnostic Interview (3Di).<sup>25</sup> The CAMHS intellectual disability team is well integrated into this forum. This has improved the skills of a range of other professionals and led to better understanding of the assessment process. Referrals to our service for assessment have decreased as a result – the team now tends to assess only the more complex cases of possible autism. However, the number of referrals for interventions for autism-spectrum conditions has risen. The team has found one of the most successful ways of supporting parents of children with autism is through group intervention programmes. It offers input into the EarlyBird programme<sup>26</sup> for parents with children under 5 and runs two programmes a year for parents of children and young people between 5 and 19 years old (the ASCEND programme, see below).

### *Group work for children*

The team runs groups for siblings of children with intellectual disabilities and groups for siblings with autism, therapeutic groups for young people with Asperger syndrome, and more recently a one-off animation group exploring Asperger syndrome through the eyes of the young person, working with clinicians and professional animators. This was sponsored by the Wellcome Foundation and won an award at the 2008 International Mental Health and Arts festival in Edinburgh.

### *Group work for parents and carers*

Parent support is an important team role and includes a support and intervention group for parents of children with intellectual disabilities, a Social Stories<sup>27</sup> drop-in group for parents and carers. We also co-run the EarlyBird programme,<sup>26</sup> licensed by the National Autistic Society, and the locally developed Autism Spectrum Conditions: Enhancing Nurture and Development (ASCEND) programme.<sup>28,29</sup> The latter, an 11-week course, is an intervention and support programme for parents of children with autism-spectrum conditions. For 2 h per session parents gain a better understanding of autism, how to analyse and better understand specific problems and how to develop strategies for improving both the situation and the child's development. The course has been very positively evaluated with good parent/carer satisfaction ratings and positive outcomes in terms of both the acquisition of new skills by parents and statistically significant improvements in child behaviour.<sup>28</sup>

The team also provides informal family therapy and transition planning alongside parents and professionals from other agencies. This includes regular meetings with adult intellectual disabilities team, meetings with a multi-agency transitions team and a multi-agency planning forum for process issues in transitional care. Medication is used in rare situations for symptoms of severe obsessive-compulsive disorder, extreme anxiety or aggression in autism, severe sleep disorders not amenable to behaviour

strategies, depression, bipolar disorder, catatonic symptoms and psychosis.

#### Tier 4

There is no commissioned in-patient provision in our locality. Young people attend a unit 80 miles away. The funding for our service did not include in-patient provision. Where families decline offer of admission to a distant unit, we have supported *ad hoc* arrangements including community mental health nursing intellectual disability support to either our local generic in-patient unit or the local Social Service respite facility. Although labour-intensive and not formally commissioned, families have always been very positive about these alternatives.

## Discussion

### Waiting lists

In order to minimise waiting list development, the team works in a goal-directed manner with families rather than attempting to provide ongoing support in the long term. High-quality consultation and liaison services also help in this regard. Additionally, improved staffing levels have allowed us to develop a number of early intervention initiatives to support parents before difficulties become entrenched, such as siblings groups, parent training programmes and parent support groups. The majority of newly referred users are now seen within 1 month. The current active case-load is 157. This is growing steadily by approximately 10 cases per year which reflect the numbers of more complex cases. A small number of children with very complex cases remain on our case-loads for longer periods of time due to their high level of need. A recent audit showed that the majority of these were related to various combinations of factors: dual diagnosis (e.g. attention-deficit hyperactivity disorder and autism), the need for medication, severe autism, severe aggression, and ongoing child protection or parenting issues.

### Equal access

One of the elements of a comprehensive CAMHS is that young people with intellectual disabilities and mental health problems should access a full CAMHS.<sup>30</sup> We offer the same service to all children and young people entering CAMHS.

By working alongside the primary mental health workers and the generic CAMHS team there has been an increase in the confidence and skills of the whole team in working with this group of children.

There remains an issue about in-patient services for young people with intellectual disabilities and mental health needs. This is an area where this group's needs are not adequately met, and commissioners are currently exploring the best way to deal with this issue.

### Out-of-area placements

There have been three out-of-county residential placements for children with intellectual disabilities over the past 7

years. These were for children with difficulties at the severe end of the autism spectrum. As in many areas, respite care continues to be under-resourced. We continue to liaise with our local Social Services departments co-working on several cases. We are currently exploring the possibility of developing a more robust outreach service to support families in more practical ways in their own homes.

## Planning for future services

There are local guidelines and ongoing multi-agency discussions about best practice in transition. These discussions have resulted in the formation of a multi-agency co-located transitions team which began in October 2009. We would like increased resourcing for CAMHS work into the child development centre and paediatric neuro-developmental and epilepsy clinics. More clinical time to enable a dedicated family therapy team would also be of benefit.

## Research

Various team members are involved in research projects, including evaluation of innovative services, work exploring deficits in facial emotion recognition in autism-spectrum conditions, urine metabolites in autism and brain activation using magnetoencephalography.

## Training

The CAMHS intellectual disability team are involved in a range of professional training courses at local universities (e.g. paediatrics, clinical psychology, psychiatry, CAMHS intellectual disability professionals).

## Summary

In summary, the CAMHS intellectual disability team has come a long way in 8 years. A number of new strands to the team have developed and new staff have been trained. We remain integrated within the wider CAMHS and are within the same building, but have a distinct identity, with our own away-days for future planning and training events.

Models of intellectual disability CAMHS proposed in the literature vary.<sup>31,32</sup> They include stand-alone intellectual disability specialist CAMHS, which may be useful as supra-regional services (tier 4). The intellectual disability CAMHS described here exists within a generic CAMHS team.<sup>19,32</sup> This has the advantage of allowing easy networking, joint training, joint working and secondments. It also avoids unnecessary service access issues where different services may not have complimentary referral criteria, leading to service gaps; it therefore provides equity of access within local services, and integrates the team within discussions about new developments and commissioning.

We believe strongly that this model, with cross-fertilisation of ideas between different parts of CAMHS is effective. It also allows for more flexible use of staff with secondments and trainees spending time in the team. We have had to be strategic in managing small resources. One of the strengths of the group is its close links to community



groups and other agencies. In particular, joint working with other agencies allows sharing of good practice, but also allows a range of activities to take place that would otherwise be too difficult to resource by any one agency. This includes group work, a thriving autism forum that coordinates diagnosis and intervention planning, and a range of other services.

We hope that in a further 8 years the team will be stronger still, with more resources. And what of the country as a whole? There has been a long wait for improved services and improved commissioning. Hopes of an accessible service from publications such as *Signposts for Success*<sup>4</sup> have had little impact. Another government report, *Aiming High for Disabled Children*,<sup>33</sup> rightly declared that 'disabled children should be considered both a local and a national priority'. We would welcome this, particularly if it came with active commissioning of new resources into services.

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### References

- 1 Department of Health. *Health Services for People with Learning Disabilities (Mental Handicap) HSB (92) 42*. Department of Health, 1992.
- 2 Department for Education and Skills. *Every Child Matters*. TSO (The Stationery Office), 2003.
- 3 Department of Health. *National Service Framework for Children, Young People and Maternity Services*. Department of Health, 2004.
- 4 Department of Health. *Signposts for Success in Commissioning and Providing Services for People with Learning Disabilities*. Department of Health, 1998.
- 5 Department of Health. *Child and Adolescent Mental Health Services Grant Guidance 2003/4*. Department of Health, 2003.
- 6 Tonge B, Einfield S. The trajectory of psychiatric disorders in young people with intellectual disabilities. *Aust N Z J Psychiatry* 2000; **34**: 80–4.
- 7 Stromme P, Diseth TH. Prevalence of psychiatric diagnoses in children with mental retardation: data from a population based study. *Dev Med Child Neurol* 2000; **42**: 266–70.
- 8 Dykens EM. Psychopathology in children with intellectual disability. *J Child Psychol Psychiatry* 2000; **41**: 407–17.
- 9 Emerson E. Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *J Intellect Disabil Res* 2003; **47**: 51–9.
- 10 Emerson E, Hatton C. *The Mental Health of Children and Adolescents with Learning Disabilities in Britain*. Institute for Health Research Lancaster University and Foundation for People with Learning Disabilities, 2007.
- 11 Mencap. *Treat Me Right! Better Healthcare for People with a Learning Disability*. Mencap, 2004.
- 12 Whitaker S, Read S. The prevalence of psychiatric disorders among people with intellectual disabilities: an analysis of the literature. *J Appl Res Intellect Disabil* 2006; **19**: 330–45.
- 13 McIntyre LL, Blacher J, Baker BL. Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *J Intellect Disabil Res* 2002; **46**: 239–49.
- 14 Foundation for People with Learning Disabilities. *Count Us In: The Report of the Committee of Inquiry into Meeting the Mental Health Needs of Young People with Learning Disabilities*. Mental Health Foundation, 2002.
- 15 Hepper F, Rose G. Use of an in-patient psychiatric service by learning disabled children. *Br J Learning Disabil* 2004; **32**: 119–22.
- 16 O'Herlihy A, Worrall A, Banerjee S, Jaffa T, Hill P, Mears A, et al. *National In-Patient Child and Adolescent Psychiatry Study (NICAPS)*. Royal College of Psychiatrists Research Unit, 2001.
- 17 Allington-Smith P. Mental health of children with learning disabilities. *Adv Psychiatr Treat* 2006; **12**: 130–8.
- 18 Royal College of Psychiatrists. *Psychiatric Services for Children and Adolescents with Learning Disabilities (College Report CR123)*. Royal College of Psychiatrists, 2004.
- 19 Green K, Williams C, Wright B, Partridge I. Developing a child and adolescent mental health service for children with learning disabilities. *Psychiatr Bull* 2001; **25**: 264–7.
- 20 Department for Education and Skills, Department of Health. *National Service Framework for Children, Young People and Maternity Services. Standard 8: Disabled Children and Young People and Those with Complex Health Needs*. Department of Health, 2004.
- 21 Department of Health. *Child and adolescent mental health update. Children, Families and Maternity E-Bulletin 2007*; April, Gateway 8075.
- 22 Black J, Wright B, Williams C, Smith R. Paediatric liaison service. *Psychiatr Bull* 1999; **23**: 528–30.
- 23 Lord C, Rutter M, Le Couteur A. Autism diagnostic interview-revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *J Autism Dev Disord* 1994; **24**: 659–85.
- 24 Lord C, Risi S, Lambrecht L, Cook EH, Leventhal BL, DiLavore PC, et al. The Autism Diagnostic Observation Schedule-Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *J Autism Dev Disord* 2000; **30**: 205–23.
- 25 Skuse D, Warrington R, Bishop D, Chowdhury U, Lau J, Mandy W, et al. The developmental, dimensional and diagnostic interview (3DI): a novel computerised assessment for autism spectrum disorders. *J Am Acad Child Adolesc Psychiatry* 2004; **43**: 548–58.
- 26 Shields J. National Autistic Society EarlyBird programme: partnership with parents. *Autism* 2001; **5**: 49–56.
- 27 Gray C. *Social Stories*. The Gray Center for Social Learning and Understanding ([http://www.thegraycenter.org/store/index.cfm?fuseaction=page.display&page\\_id=30](http://www.thegraycenter.org/store/index.cfm?fuseaction=page.display&page_id=30)).
- 28 Wright B, Williams C. *An Intervention and Support Programme for Parents of Children with Autism Spectrum Conditions: A Facilitator's Manual*. Jessica Kingsley Publishers, 2007.
- 29 Pillay M, Alderson Day B, Wright B, Williams C, Urwin B. Autism Spectrum Conditions Enhancing Nurture and Development (ASCEND). An evaluation of Intervention Support Groups *J Child Psychol Psychiatry* 2010; in press.
- 30 National CAMHS Support Service, Health and Social Care Advisory Service. *CAMHS Partnership Self Assessment Matrix 2005–6. Guidance Booklet*. Health and Social Care Advisory Service, 2005–6 ([http://www.hascas.org.uk/pdf\\_files/CAMHS%20self%20assessment%20matrix%202005-6.pdf](http://www.hascas.org.uk/pdf_files/CAMHS%20self%20assessment%20matrix%202005-6.pdf)).
- 31 Berney T. Psychiatric services. In *Developmental Disability and Behaviour* (eds C Gillberg, G O'Brien): 159–70. MacKeith Press, 2000.
- 32 Williams C, Wright B. Learning disability services. In *Child and Adolescent Mental Health Services: An Operational Handbook* (eds G Richardson, I Partridge). Gaskell, 2003.
- 33 HM Treasury, Department for Education and Skills. *Aiming High for Disabled Children: Better Support for Families*. Office of Public Service Information, 2007.