

# Transition from child to adult mental health services: needs, barriers, experiences and new models of care

SWARAN P. SINGH, HELENA TUOMAINEN

Division of Mental Health and Wellbeing, Warwick Medical School, University of Warwick, Warwick, UK

Transition from child to adult health care is a common experience for young people with enduring health problems who reach the age boundary between services. Transition is distinct from transfer (1), since it is more than a discrete administrative event. Good transition should be a co-ordinated, purposeful, planned and patient-centred process that ensures continuity of care, optimizes health, minimizes adverse events, and ensures that the young person attains his/her maximum potential. It starts with preparing a service user to leave a child-centred health care setting and ends when that person is received in, and properly engaged with, the adult provider (2).

In physical disorders, transition became a clinical and research priority as an increasing number of young people with previously life-threatening conditions survived into adulthood and needed ongoing care. Systematic and narrative reviews in cystic fibrosis (3), haemophilia (4), diabetes (5), congenital heart disease (6), cancer (7), cerebral palsy and spina bifida (8) and palliative care (9) have all identified transition as a risk period for disengagement and deterioration, but also a therapeutic opportunity for ensuring good outcomes into adult life.

Three broad categories of interventions have been tried: those aimed at the patient (educational programmes, skills training); those aimed at the staff (named transition coordinators, joint clinics run by paediatric and adult physicians); and changes in service delivery (separate young adult clinics, out of hours phone support, enhanced follow-up) (10). Yet the clinical and cost evaluation of such transition programmes is inconsistent and there are no robust and validated transition-related outcome measures (11).

## TRANSITION IN MENTAL HEALTH

Transition in mental health appears to be equally, if not more, problematic than in physical care settings. Seamless transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) is not the norm; instead young people with mental health problems frequently find themselves without professional support or a referral to an adult service (1,12). Alternatively, they may be referred, but the adult services are ill equipped to meet their needs (13).

Studies from the U.K. and U.S. show that mental health service use declines drastically when young people reach 16 years of age (by 24% and 45%, respectively), and even more

so at the age of 18 (over 60% in the U.K.) (14,15). While young people with severe mental disorders such as psychosis are more likely to transition to adult services, those with neurodevelopmental, emotional/neurotic and personality disorders are far less likely to cross the boundary, and have more pronounced transition difficulties (15).

In the U.K., only about 15% of young people with attention deficit hyperactivity disorder (ADHD) make a transition (16); the figure for Ireland is 7% (17). In the U.S., there is the additional problem of lack of, or inconsistent, health insurance coverage for ADHD (18). Adult ADHD services are sparse or non-existent and many professionals are sceptical about the existence of ADHD in adulthood (19).

A particularly vulnerable group is represented by looked-after young people in the public care system, who are less likely to have family support but have significant mental health and social problems, including higher risk of self-harm and suicide, poorer educational achievement, and greater risk of unemployment, homelessness and incarceration (20). The labyrinthine service structures and interface means that the complex mental health needs of care-leavers remain unmet as they fall through the care gap (21) or disengage from services (22), increasing their use of crisis care (23) and ultimately leading to poor outcomes.

## MENTAL HEALTH NEEDS AND PREFERENCES OF YOUNG PEOPLE

Some key findings in recent years have changed our understanding of developmental psychopathology and age of onset of adult mental disorders. Large longitudinal epidemiological studies have confirmed continuity of childhood psychopathology into adult life, including both homotypic continuity (a disorder manifesting in the same manner across time) and sequential comorbidity (24). Our understanding of different developmental trajectories of the same disorder has improved; we know that juvenile onset disorders have poorer prognosis in adult life (25) and that sequential comorbidity may be due to a shared underlying diathesis (26).

The National Comorbidity Survey Replication from the U.S. has radically altered our understanding of the age of onset of different mental disorders (27). This large dataset allowed the authors to explore the prevalence of mental health problems, and also determine the age of onset for each recognized (DSM-IV) disorder. Overall, half of all

lifetime cases started by the age of 14, three quarters by the age of 24, with later onsets usually being comorbid conditions. The weight of evidence is such that adult mental health disorders are now being reframed as “extension of juvenile disorders” (28).

Studies across the developed world show that young people do not engage well with adult services (29). Young people may not be aware of what is available or refrain from seeking help because of stigma and unhelpful beliefs about autonomy (30). Their fluctuating clinical presentation with multiple comorbidities may not meet stringent criteria for stretched and struggling services. They may face a bewildering array of developmental and situational transitions that accompany health care transitions, such as changes in housing and relationships, gaining greater independence and moving on to adult roles (15,31).

Parents and young people find services particularly unhelpful during the transition period (30,32). Young people do not feel adequately prepared or supported during transition, lack understanding of adult services, feel insecure at the loss of the familiar and dread of the unfamiliar, and both young people and their families feel that their voices are not heard during the transition process (15,31,33). Abrupt and unplanned transition has been likened to “having to move house due to a flood” rather than a planned process determined by choice, appropriate advice and informed decision making (34). The current child-adult split in mental health services, therefore, creates weakness in the care pathway where it should be most robust (35) and is a major “design flaw” in current configuration (29).

## **BARRIERS AT THE CAMHS-AMHS INTERFACE**

Historically, child and adult psychiatric services have developed under very different societal needs and demands (36). In the U.S., child psychiatry dates its beginning to 1899, with the establishment of the first Juvenile Court in Chicago, when a group of influential and socially concerned women started campaigning for better understanding and management of juvenile delinquency (37). The influence of child psychoanalysts such as A. Freud, H. Hug-Hellmuth and M. Klein ensured that child psychiatry had its ideological and conceptual roots firmly in family, community and society rather than in a biological or diagnostic paradigm.

Over the subsequent decades, behavioural and educational psychologists, psychiatrists, criminologists, paediatricians, neurologists and social workers, often with starkly differing concepts about the causes and treatment of childhood mental disorders, contributed to the development of child psychiatry. Unlike adult psychiatry with its focus on individual psychopathology and diagnosis-led treatment, child psychiatry recognized early the wider influences of family and interpersonal processes in both the genesis and management of childhood mental disorders.

Over time, child and adolescent services have developed a culture, an organization and models of functioning very different from adult care, and these pre-existing differences get accentuated at the transition boundary (15). A range of obstacles hampers communication and collaboration at the CAMHS and AMHS interface (38,39). Separate funding and governance structures result in distinct systems with rigid boundaries and lack of understanding of services across the divide (40). Legal, logistic and clinical differences, combined with time and resources constraints, prevent services working together to provide parallel care, with particular concerns about where the responsibility of clinical care lies (31,36).

This lack of experience of working together contributes to limited understanding of what is needed, what is expected and the purpose of good transitional care (38). Some barriers relate to users and carers. Many young people and their families decline referral to adult services due to stigma and misperception. All these barriers contribute to a lack of referrals despite ongoing need for care, young people dropping through the care gap, and poor experience of care for those who make it to the other side (15,31).

## **NEW MODELS OF CARE**

Although barriers to good transition have been mapped, little has been tested to make transition better (41). Systematic reviews have identified a small number of interventions that facilitate transition, but the evidence is based on small, non-random, retrospective studies often with no comparison group (39).

A recent international Delphi study identified six essential elements of a successful transition programme: a) assuring a good coordination (such as timing of transfer, communication, follow-up, remaining available as a consultant, etc.) between child and adult professionals; b) starting planning transition at an early age (at least one year before the transfer boundary); c) discussing with patient and family about self-management; d) including young person’s views and preferences in transition planning; e) if developmentally appropriate, seeing the adolescent alone at least for part of the consultation; and f) identifying an adult provider willing to take on the young patient before transfer (42).

In the looked-after population, transition support services that provide training and promote independence and self-sufficiency have been tried, but the evidence remains equivocal and the studies suffer from the same methodological limitations as identified in other reviews (43).

Identifying what is needed appears much easier than actually providing it. In current clinical practice, there is no consensus on who can be discharged on reaching the transitional boundary, who should receive transitional care, how this care should be delivered, what outcomes should be measured, what are the outcomes of those who fall through the care

gap, and what are the individual, organizational and societal costs of poor, inadequate or inappropriate transition.

Recent evidence confirming that treatment in the early stages of a disorder is likely to be both a clinically and a cost-effective strategy to reduce long-term disease burden has led to very strong arguments that the early intervention paradigm should be applied to all disorders of youth onset (44). And instead of fixing “the broken bridge” between two models of care, neither of which serves young people well, there should be a radical redesign with a seamless new pathway within a stigma free, youth friendly specialist model.

Several such models have sprung up in Australia, U.K., Ireland, Singapore and Denmark, with new ones proposed in Canada, U.S. and Israel (29). While some might argue that having a 0-25 service, as planned in Birmingham, U.K. (<http://forwardthinkingbirmingham.org.uk>) simply shifts the transition boundary to 25, the new pathway will be robust at the period of maximum risk both of discontinuity of care in early onset disorders and of the peak incidence of emerging mental disorders.

Meanwhile, the search for good transition models continues. MILESTONE is a European Union (EU)-funded transition project ([www.milestone-transitionstudy.eu](http://www.milestone-transitionstudy.eu)) that aims to delineate the child-adult interface, including policies, service structure and organization, and transition-related training in mental health care across Europe; identify a large (N=1000) prospective cohort of transition age youth in eight EU countries and track their journey across the transition boundary; robustly test the clinical and cost-effectiveness of a model of managed transition in improving health and social outcomes using a cluster-randomized design; and create training, commissioning and policy guidelines for improving transitional care across the EU.

## CONCLUSIONS

Young people receiving care from child mental health services are at high risk of falling through the child-adult service gap as they cross the transition boundary between services; or experience poor care, leading to high risk of disengagement from services and discontinuity of care. The transition boundary spans the maximum risk period for the emergence of serious mental disorders, hence focussing on transitional care has the potential for transforming outcomes in youth mental health.

We need to urgently develop and implement reformed service models that are specifically geared to meeting the unique needs of adolescents and young adults, are based on needs and preferences rather than strictly aligned to chronology and rigid diagnostic boundaries, and provide high quality evidence-based interventions that promote well-being, self-sufficiency, autonomy and fulfilment. Our young people deserve nothing less.

## References

1. Paul M, Ford T, Kramer T et al. Transfers and transitions between child and adult mental health services. *Br J Psychiatry* 2013; 202(Suppl. 54):s36-40.
2. Coleman EA, Berenson RA. Lost in transition: challenges and opportunities for improving the quality of transition of care. *Ann Intern Med* 2004;141:533-6.
3. Tuchman LK, Schwartz LA, Sawicki GS et al. Cystic fibrosis and transition to adult medical care. *Pediatrics* 2010;125:566-73.
4. Breakey VR, Blanchette VS, Bolton-Maggs PHB. Towards comprehensive care in transition for young people with haemophilia. *Haemophilia* 2010;16:848-57.
5. Nakhla M, Daneman D, Frank M et al. Translating transition: a critical review of the diabetes literature. *J Pediatr Endocrinol Metab* 2008;21:507-16.
6. Dearani JA, Connolly HM, Martinez R et al. Caring for adults with congenital cardiac disease: successes and challenges for 2007 and beyond. *Cardiol Young* 2007;17:87-96.
7. Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. *J Clin Oncol* 2010;28:4810-8.
8. Binks JA, Barden WS, Burke TA et al. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabil* 2007;88: 1064-73.
9. Doug M, Adi Y, Williams J et al. Transition to adult services for children and young people with palliative care needs: a systematic review. *Arch Dis Child* 2011;96:78-84.
10. Crowley R, Wolfe I, Lock K et al. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child* 2011;96:548-53.
11. Prior M, McManus M, White P et al. Measuring the “triple aim” in transition care: a systematic review. *Pediatrics* 2014;134:E1648-61.
12. Singh SP. Transition of care from child to adult mental health services: the great divide. *Curr Opin Psychiatry* 2009;22:386-90.
13. Dimitropoulos G, Tran AF, Agarwal P et al. Challenges in making the transition between pediatric and adult eating disorder programs: a qualitative study from the perspective of service providers. *Eating Disorders* 2013;21:1-15.
14. Pottick KJ, Bilder S, Vander Stoep A et al. US patterns of mental health service utilization for transition-age youth and young adults. *J Behav Health Serv Res* 2008;35:373-89.
15. Singh SP, Paul M, Ford T et al. Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. *Br J Psychiatry* 2010;197:305-12.
16. Ogundele M, Omenaka I. An audit of transitional care for adolescents with ADHD in a North West England district. *Arch Dis Child* 2012;97(Suppl. 1):A129.
17. McNicholas F, Adamson M, McNamara N et al. Who is in the transition gap? Transition from CAMHS to AMHS in the Republic of Ireland. *Irish J Psychol Med* 2015;32:61-9.
18. Montano CB, Young J. Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. *Postgrad Med* 2012;124:23-32.
19. Swift KD, Sayal K, Hollis C. ADHD and transitions to adult mental health services: a scoping review. *Child: Care, Health and Development* 2014;40:775-86.
20. Department for Children, Schools and Families/Office of National Statistics. Children looked after in England (including adoption and care) year ending 31 March 2009. London: Department for Children, Schools and Families, 2009.
21. Campbell F, O'Neill PM, While A et al. Interventions to improve transition of care for adolescents from paediatric services to adult services. *Cochrane Database Syst Rev* 2012;4:1-11.

22. Tripp J, Amiel S, Balen A et al. Bridging the Gaps: health care for adolescents. London: Royal College of Paediatrics and Child Health, 2005.
23. Meltzer H, Gatward R, Corbin T et al. The mental health of young people looked after by local authorities in England. London: Her Majesty's Stationery Office, 2003.
24. Hofstra MB, Van Der Ende J, Verhulst FC. Continuity and change of psychopathology from childhood into adulthood: a 14-year follow-up study. *J Am Acad Child Adolesc Psychiatry* 2000;39: 850-8.
25. Wickramaratne PJ, Greenwald S, Weissman MM. Psychiatric disorders in the relatives of probands with prepubertal-onset or adolescent-onset major depression. *J Am Acad Child Adolesc Psychiatry* 2000;39:1396-405.
26. Krueger RF. The structure of common mental disorders. *Arch Gen Psychiatry* 1999;56:921-6.
27. Kessler RC, Chiu WT, Demler O et al. Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry* 2005;62: 617-27.
28. Kim-Cohen J, Caspi A, Moffitt TE et al. Prior juvenile diagnoses in adults with mental disorder: developmental follow-back of a prospective-longitudinal cohort. *Arch Gen Psychiatry* 2003;60: 709-17.
29. McGorry PD, Goldstone SD, Parker AG et al. Cultures for mental health care of young people: an Australian blueprint for reform. *Lancet Psychiatry* 2014;1:559-68.
30. Davis M, Butler M. Service system supports during the transition from adolescence to adulthood: parent perspectives. Alexandria: National Technical Assistance Center, 2002.
31. Hovish K, Weaver T, Islam Z et al. Transition experiences of mental health service users, parents, and professionals in the United Kingdom: a qualitative study. *Psychiatr Rehabil J* 2012;35: 251-7.
32. Jivanjee P, Kruzich J. Supports for young people with mental health conditions and their families in the transition years. *Best Pract Ment Health* 2011;7:115-33.
33. Fegran L, Hall EOC, Uhrenfeldt L et al. Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. *Int J Nurs Studies* 2014; 51:123-35.
34. Wilson A, Tuffrey A, McKenzie C et al. After the flood: young people's perspectives on transition. *Lancet Psychiatry* 2015;2:376-8.
35. McGorry P, Bates T, Birchwood M. Designing youth mental health services for the 21st century: examples from Australia, Ireland and the UK. *Br J Psychiatry* 2013;202(Suppl. 54):s30-5.
36. Singh SP, Evans N, Sireling L et al. Mind the gap: the interface between child and adult mental health services. *Psychiatr Bull* 2005;29:292-4.
37. Schowalter JE. The history of child and adolescent psychiatry. *Psychiatry* 1994;2:1-13.
38. McLaren S, Belling R, Paul M et al. 'Talking a different language': an exploration of the influence of organizational cultures and working practices on transition from child to adult mental health services. *BMC Health Serv Res* 2013;13:254.
39. Embrett MG, Randall GE, Longo CJ et al. Effectiveness of health system services and programs for youth to adult transitions in mental health care: a systematic review of academic literature. *J Ment Health Pol Econom* 2015;18:S12-S5.
40. Davis M, Sondheimer DL. State child mental health efforts to support youth in transition to adulthood. *J Behav Health Serv Res* 2005;32:27-42.
41. Swift KD, Hall CL, Marimuttu V et al. Transition to adult mental health services for young people with Attention Deficit/Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences. *BMC Psychiatry* 2013;13:74.
42. Suris JC, Rutishauser C, Akre C. Does talking about it make a difference? Opinions of chronically ill young adults after being transferred to adult care. *Arch Pediatr* 2015;22:267-71.
43. Everson-Hock ES, Jones R, Guillaume L et al. Supporting the transition of looked-after young people to independent living: a systematic review of interventions and adult outcomes. *Child Care Health Develop* 2011;37:767-79.
44. Birchwood M, Singh SP. Mental health services for young people: matching the service to the need. *Br J Psychiatry* 2013;202(Suppl. 54):s1-2.

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