

FROM EARLY INTERVENTION IN PSYCHOSIS TO YOUTH MENTAL HEALTH REFORM: A REVIEW OF THE EVOLUTION AND TRANSFORMATION OF MENTAL HEALTH SERVICES FOR YOUNG PEOPLE

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Key word: Youth mental health; Service delivery, Early Intervention

Abstract:

Purpose: The objective of this review is to report on recent developments in youth mental health incorporating all levels of severity of mental disorders encouraged by progress in the field of early intervention in psychotic disorders, research in deficiencies in the current system and social advocacy. .

Methods: The authors have briefly reviewed the relevant current state of knowledge, challenges and the service and research response across four countries (Australia, Ireland, the U.K. and Canada) currently active in the youth mental health field.

Results: Here we present information on response to principal challenges associated with improving youth mental services in each country. Australia has developed a model comprised of a distinct front line youth mental health service (Headspace) to be implemented across the country and initially stimulated by success in early intervention in psychosis; in Ireland, Headstrong has been driven primarily through advocacy and philanthropy resulting in front line services (Jigsaw) which are being implemented across different jurisdictions; in the UK a limited regional response has addressed mostly problems with transition from child-adolescent to adult mental health services; and in Canada a national multi-site research initiative involving transformation of youth mental health services has been launched with public and philanthropic funding, with the expectation that results of this study will inform implementation of a transformed model of service across the country including indigenous peoples.

Conclusions: There is evidence that several countries are now engaged in transformation of youth mental health services and in evaluation of these initiatives.

There is a burgeoning interest in youth mental health services and the need for reform [1], accompanied by an equally strong interest in research and evaluation. Over recent years, several whole issues of or supplements to journals have been dedicated to this subject [1, 2]. In this report we review how interest in and development of youth mental health services and research started; what are the emerging issues that need to be addressed, and what strategies for improvement in youth mental health outcomes are being developed and applied in Australia, Canada, Ireland and the UK.

Early Intervention in Psychosis and Youth Mental Health Service Reform:

The research, development and implementation of early intervention (EI) services in psychotic disorders over the past nearly two decades are now well established and the benefits well documented [3-7]. This has been achieved through a major philosophical shift in the conceptual framework of the disorder and changes in the form and content of services modified to meet the needs of younger and treatment naïve patients. Psychotic disorders have been re-conceptualized from having an inherently poor outcome to presenting in relatively milder forms, including sub-threshold symptoms, early on during onset to a more severe disorder if left untreated for long or treated inadequately [8, 9]. Psychosis is now regarded as potentially amenable to profound positive change and personal recovery. The success of EI services in psychosis has influenced policy decisions in several jurisdictions and this may indeed be one of the rare reforms in mental health services which has resulted from a combination of innovation in service delivery, research, programme evaluation and advocacy.

Buoyed by the success of Early Intervention (EI) in Psychosis service development and research, greater attention to achieving better outcomes in all mental disorders affecting youth across all levels of severity is being observed. There are several lessons that have emerged from the psychosis EI field to facilitate this. Recent evidence suggests that mental disorders likely emerge in stages of varying severity and that over time individuals move across these stages, from mild to more severe ones and, possibly, vice versa [8-10]. The staging model also posits that interventions, if applied appropriately in form and intensity to each stage, may prevent progression to a more severe level of psychopathology.

In addition, campaigns directed at the community or even primary care for improving mental health literacy for *individual* disorders, usually with the objective of reducing delay in help seeking and treatment, have generally exposed the inadequacies of such diagnosis specific strategies [11, 12]. It appears that such literacy and knowledge transfer may be better applied for recognition and early intervention of a broader spectrum of mental health problems.

Background and Rationale for youth mental health service reform:

Over 75% of mental disorders first appear between early adolescence and young adulthood [13], initially presenting in milder, sub-threshold or polymorphous forms, with increasing severity over time [8]. Their outcome trajectories are defined relatively early. Given that the onset of many mental disorders coincides with junctures of life that entail significant transitions and dynamic social and vocational development, mental disorders result in serious short- and long-term negative consequences especially when untreated, treated late or treated poorly. Mental illnesses are also associated with significant suffering among affected individuals and their families as well as great societal cost [14]. Yet, access to care for (20-25% get help) [15] and outcomes of mental disorders remain deficient. For example, in Australia prior to 2008, young people had the worst access to mental health care at any time across the lifespan, with only 13% of young men and 30% of young women accessed help for mental health problems [16]. Similarly, only 20-25% of Canadian youth in need of help currently access any mental health services [15, 17].

Current practices:

The current service configuration of Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) is increasingly regarded as an impediment to holistic and comprehensive care for young people, especially those who make a transition from one model to another [18-21]. Disruption of care during transition adversely affects the health, wellbeing and potential of this vulnerable group. Ideally, such a transition should be a planned, orderly and purposeful process involving a shift from child-oriented to adult models of care [22-24] or appropriate discharge from mental health care if there is no further clinical need. Alternatively services should be organized

in a way that does not require transition based on age alone.

Traditional primary health care services have catered largely for physical illness, and consequently have been designed for young children or older adults, who bear most of the physical health burden. Furthermore, the culture of care has been largely insensitive to young people, who consequently fail to engage [10]. Young people's complex and evolving symptom profiles often do not meet the narrow criteria required for acceptance, particularly into an adult service, despite the significant distress and impairment already manifest. For groups of young people already at a disadvantage in the system such as those in Aboriginal communities or urban homeless, even basic services remain unavailable.

Apart from poor resourcing and fundamental faults of design, these limitations stem from how stakeholder groups (youth, families/carers, communities, researchers, service providers, policy/decision makers) and service sectors (health, criminal justice, youth protection, education and employment) operate in silos that impede access and communication. Help-seeking pathways are complicated by the disconnectedness of the settings where youth may initially present (schools, clinics, ERs, the justice system, etc.). This set-up has failed to deliver timely, sustained, high-quality care. Thus, "the challenge we face is... a matter of scale, scope, culture and expertise. Redesign and transformational change are needed [1]."

Four key issues emerge from an examination of the literature and the prevailing status of mental health services for youth in most economically developed countries. These include: (1) poor penetration rate of services for the youth in need and a high rate of untreated prevalence; (2) delay in first contact and eventual treatment if and when indicated; (3) treatment when available may not be suitable for the particular stage of illness; and (4) serious problems with transitions in services based on age (usually 18). In the following sections we have summarized how four countries (the UK, Ireland, Australia and Canada) have started to address these key issues.

The Australian response:

In response to these problems, in 2006, the Australian Government established headspace, the National Youth Mental Health Foundation, which was tasked with devising and building a national youth mental health service stream designed to provide highly accessible, youth-friendly centres that promote and support early intervention for mental and substance use disorders in young people. Each centre is operated by an independent local consortium, overseen by the headspace national office. Four core service streams are provided: mental health, drug and alcohol services, primary care (general health, sexual health) and vocational/educational assistance. This combination of frequently accessed services is designed to minimize the stigma often associated with a mental health service [25]. The therapeutic approach centres on brief psychosocial interventions, which are used as first-line therapy with the aim of preventing the development of sustained illness. Medication is used as an additive therapy only if the young person does not respond to initial psychosocial interventions, or presents at the outset with more severe symptoms or risk. This stepped care model ensures that care is linked to the stage of illness, and offers a proactive and preventive approach to therapeutic intervention. In addition to the 74 walk-in centres (100 by 2017) available around the country, headspace also runs a nationwide online support service (ehespace; www.eheadspace.org.au) where young people can chat with a mental health professional either online or by telephone and access assessment and therapeutic care, and headspace school support, a suicide postvention programme for schools affected by the suicide of a student.

The bulk of the young people using headspace services, even when highly distressed are in the early stages of illness; however, at most headspace sites there is also a substantial subset of young people with more complex, severe and enduring problems who currently are unable to gain access to the traditional CAMHS/adult system [26]. To begin to address this need, the Australian Government has funded the creation of up to nine ‘enhanced headspace’ services (hYEPPs: headspace Youth Early Psychosis Programs), which are resourced to deliver evidence-based early psychosis services, offering early detection, acute care during an initial psychotic episode, and recovery-focused continuing care featuring multimodal interventions to support the young person (and their family) to maintain or regain their social, academic and/or career trajectory during the

critical first 2–5 years following the onset of a psychotic illness [27]. The first of these enhanced services commenced operation in 2013, and it is hoped that ultimately they will be expanded to cover not only all headspace communities, but also the full diagnostic spectrum in young people with all the severe forms of mental illness.

At this stage, it is clear from a sample of 22,000 young people assessed by headspace nationally that this service is seriously addressing the issues of access and engagement [26], a conclusion further evidenced by the heavy demand for eheadspace services from across the nation. However, headspace is still a work in progress. Important gaps remain, notably the fact that more than half of Australia is not yet covered, as the current level of funding, together with Australia's geographic constraints, does not yet allow full national coverage. Furthermore, access rates for young men, some ethnic populations and young adults, while improved, are still too low, and the program does not yet adequately cover those with more complex and serious stages of mental illness. Clearly, the success of these reforms will ultimately only be able to be assessed after careful evaluation, and evidently more health services research is necessary to develop, refine, adapt and evaluate new service models, both within their individual contexts and cross-sectorally.

The long-term aim of these reforms is to develop a nationwide youth mental health stream that fully integrates care for young people with other service systems, notably education, employment, housing and justice, in order to provide a seamless coverage of mental health care from puberty to mature adulthood at around 25 years of age, with soft transitions with child and adult mental health care. This system acknowledges biopsychosocial development and recognizes the complexity and challenges faced by young people as they become independent adults, as well the burden of disease imposed on this age group by poor mental health. It has deliberately blurred the distinctions between the tiers of primary and specialist care, including some aspects of acute care, in recognition of the complexity of the presentation of much of the mental ill-health apparent in young people, allowing a flexible and appropriate response for each individual, depending on their own unique needs.

The UK response:

Findings from TRACK study (above) [18] have sharply focused the attention of policy makers and service providers on the need for improving transition and several policy documents have been launched such as *New Horizons* [28], *No Health without Mental Health* [29], Royal College of Psychiatrists Briefing paper (2011) [30], the charity Youngminds' report on transitions [31] and Social Care Institute for Excellence report on transitions [32]. In the UK, all major political parties have included youth mental health as a major strategic priority in their health plans. In Sept 2014 the UK Department of Health set up a Children's and Young People's Mental Health and Wellbeing Taskforce (www.gov.uk/government/groups/children-and-young-peoples-mental-health-and-well-being-taskforce) to improve children and young people's access to mental health care and to redesign the organization and commissioning of such services. Key themes were identified for creating a modern fit-for-purpose mental health service based on a set of principles: promoting resilience, prevention and early intervention; improving access to effective support; targeting care for the most vulnerable; accountability and transparency within the system; and developing a workforce capable of delivering such a service. A local initiative in Birmingham to develop a dedicated youth mental health service has shown significant promise in engaging young people through rapid response, high quality initial assessments and significantly lower drop out rates from service contact as compared to community mental health teams [33]. Based on the success of such initiatives health care Commissioners in Birmingham have commissioned a new 0-25 service, which will become operational from October 2015. The new provider Forward Thinking Birmingham is a consortium between NHS partners from child and adult services, voluntary sector and a private healthcare organisation and will offer a range of new services and facilities, based on the principles of prevention, choice and personalized care (<http://forwardthinkingbirmingham.org.uk>). This will be the first major service reform for young people's mental health care in the UK for over 30 years and is likely to be the template for further service reform in the UK.

Response from the Republic of Ireland:

The Republic of Ireland (Ireland) is an interesting example of how the convergence of a range of factors at a particular point in time became a catalyst for change, for innovation and for the development of youth mental health services. Ireland, an island nation on the western boundaries of Europe, has a population of just over 4.5 million people, 19% of whom are between the ages of 10 and 24 years (Central Statistics Office, 2011: www.cso.ie). Unlike other jurisdictions such as, Australia, the UK and Canada the origins of Ireland's youth mental health movement can be traced back to high levels of public concern about seemingly endemic rates of youth suicide (4th highest in Europe for 15-25 years old) (National Office for Suicide Prevention 2014) [34] and mental distress among Irish youth. Other factors propelling the movement were availability of philanthropic funding to develop mental health services in Ireland and 3 key Irish leaders from the fields of health and allied health began to drive a youth mental health agenda in both the public and political arenas.

The advocacy for youth mental health initially facilitated research, which has, in turn, strengthened the argument for the development of youth mental health services in Ireland. Latest epidemiological evidence suggests that 15.4% of 11-13 years olds [34, 35] and 19.5% of 19-24 year olds [35, 36] in Ireland are experiencing diagnosable mental disorders at any given time with lifetime rates of disorder as high as 56% among 19-24 year olds [37]. These findings and those from other key studies in Ireland provide sufficient evidence to leverage for a real change in youth mental health services as envisaged and advocated for by leaders in the field over many years.

Central to the emergence of the youth mental health movement in Ireland was a new funding stream from the One Foundation (www.onefoundation.ie), an Irish-based philanthropic foundation, which in 2006 provided significant funding towards the establishment of Headstrong, Ireland's first dedicated youth mental health organisation (www.headstrong.ie) and an on-line youth mental health organization, ReachOut.com. Along with research and advocacy, key to the work of Headstrong was the development of Jigsaw, a service delivery program that aimed to establish youth-friendly, communi-

ty-based mental health support structures for young people across Ireland. At present, there are ten Jigsaw sites now in operation across Ireland with each site containing a youth-friendly hub that provides primary mental health care and support to young people between the ages of 12 and 25 years. Since the first Jigsaw site opened in 2008, over 10,500 Irish youth have availed of the services offered by the Jigsaw program [38].

With involvement of key leaders in the field (McGorry and late O'Callaghan) a national Special Interest Group in Youth Mental Health was established in 2008 that quickly became a forum for professionals across sectors and disciplines and from both Ireland and beyond, to share knowledge and to promote the need for developments in the field of youth mental health in Ireland. The group established an annual Youth Mental Health Research Conference and hosted the Killarney Summit in 2010, at which a consensus was reached among leaders from across the globe to create a Declaration on Youth Mental Health. The latter written by Irish Special Interest Group [35] was formally launched at the International Association for Youth Mental Health Conference in Brighton in 2013 (www.iaymh2013.org). In 2013, this group was also successful in promoting youth mental health through the College of Psychiatrists in Ireland to the practising psychiatrists in efforts to develop new approaches to service delivery for young people within mainstream healthcare structures in Ireland. Most recently, the publication of a Special Youth Mental Health Edition of the Irish Journal of Psychological Medicine in 2015 has further advanced the importance of youth mental health.

Ireland remains at the forefront of advocacy for youth mental health, however, in spite of all of the progress that has been made to date, Ireland has a long way to go to reach its aim of ensuring that every young person can access the level of support and intervention they need across the spectrum of mental ill-health. While the impact of Ireland's devastating economic recession has clearly played a role in the lack of investment and commitment to youth mental health services in Ireland, many other factors have inhibited the level of progress that has the potential to be made in Ireland. Looking to the future, additional investment, a commitment among all service providers and a willingness to coordinate all efforts to support young people will be needed if Ireland is to ever real-

ise the ambition of leading advocates to develop comprehensive, coordinated, effective and youth-friendly mental health services that will truly meet the needs of all young people across Ireland.

Canadian response:

In Canada, addressing the larger problem of youth mental health at a national level has taken longer despite earlier attempts at improving aspects of youth mental health services in some jurisdictions [39]. The transformation of youth mental health services has taken a large leap recently through development of a strategic initiative of Transformational Research in Adolescent (youth 11-25 years) Mental (TRAM) health as part of the new Strategies for Patient Oriented Research (SPOR) program of the Canadian Institutes of Health Research (CIHR). This is funded (\$25M total) jointly by CIHR and a family foundation, the Graham Boekch Foundation, the latter being dedicated to improvement of care and outcome in mental health. Launched in Oct 2012, as a competitive process, the explicit purpose was to establish a national network project that would demonstrate transformation of youth (11-25 years) mental health services and provide evidence of its effectiveness over a period of five years. Limiting its scope to youth with established or emerging mental health problems and precluding primary prevention activities, the intention was to bridge the science-practice divide by applying existing evidence to transform the delivery of mental health care and to produce better outcomes. The ultimate goal is to scale up a transformed model of service delivery across the country.

The competitive process eventually resulted in establishing the Adolescent/young adult Connections to Community-driven Early Strengths-based and Stigma-free services (**ACCESS**) network. The ACCESS network includes youth, family/carer, community organization, service provider, researcher, and policy and decision maker stakeholder groups from six of the 10 Canadian provinces and one of 3 territories. ACCESS is in the process of implementing, evaluating and elaborating a transformation of youth mental health at 12 sites across the country. The purpose of this approach is to generate evidence, based on the model that will be deployed, in the form of processes involved in such transfor-

mation (e.g. stakeholder engagement, resource analysis, community and site capacity) as well as outcome for youth and families accessing the newly transformed services.

The sites have been chosen to represent variations in geography, culture and service availability. These include two urban population-based catchment area enhanced primary care sites (including one with very high immigrant and low socio-economic population); one urban site requiring creation of an amalgamated service from child-adolescent and young adult services; an urban site dedicated to providing services to homeless youth; one site situated within a university campus targeting all new entrants to the university; one small urban-rural site; several sites within a largely rural province; five remote sites comprised of three first nation (Cree, Mi'kmaq and Métis) sites and two Inuit sites, one each, in northern Québec and North West Territories. The objective at each site is to address the four major deficits identified in youth mental health through creating a system of care that takes into consideration contextually driven circumstances. These objectives are: (a) early case identification; (b) quick access (within 72 hours) for a first assessment; (c) continuous service across the age spectrum of 11-25, if required; (d) connection to specialized services depending on availability. The first two components will be strongly supported with development of new and utilization of existing electronic media technology to ensure multiple portals of entry. Access to specialist services will vary from embedding specialists within the enhanced primary care to direct links with specialized programs (e.g. early psychosis service, eating disorder program) to provision of specialized services through remote technology. Throughout the transformation of services strengthening individual and community resilience will be a major focus and for this ACCESS will rely on culturally appropriate practices.

An important aspect of ACCESS network project is that the transformation is based on political and systemic realities of service delivery within the Canadian federation in order to make the model scalable to all jurisdictions. Therefore, informed by site-specific resources and guided by local needs and contexts, ACCESS, through its additional resources, will reinforce strengths; enhance capacities through inter-sector, inter-service and inter-stakeholder collaboration; add trained staff; and deploy e-technologies. ACCESS will also create and use youth-friendly physical spaces as portals for help-

seeking and venues for youth peer support activities. New staff at these spaces will include ACCESS-trained clinicians and, where possible, a peer support worker.

The essence of service organization and delivery at each site is a site team that will include multiple stakeholders with youth, family and service providers as essential elements of this team but preferably including policy and decision makers. This structure is replicated centrally in its governance structure. Our organizational framework is the Theory of Change (<http://www.theoryofchange.org/>), a formalized framework for identifying steps required to proceed from a starting point to a long-term goal. Intensive training and knowledge transfer and their sustainability over time are a major focus and a source of building capacity at each site.

Given the overall objectives of ACCESS is to test the effectiveness of a transformed model of youth mental health services and make it scalable, the research and evaluation strategy has been defined by all stakeholder groups in the spirit of participatory action [40] and integrated knowledge translation [41-43]. Our research will assess structures, contexts, processes and performance to answer the question, “*How well does ACCESS work to identify youths in need and improve their access to high-quality mental healthcare?*” “*Among which youth and family/carer groups is the transformation most and least beneficial?*” and “*In which contexts is ACCESS most and least effective?*” Using a mixed methods framework we are conducting a step-wedged cluster randomized controlled trial at six sites and use the other six, with unique characteristics (remote, not centred around a population base etc) as demonstration sites. In addition, an economic analysis will be conducted at 4 of the RCT sites to inform the feasibility of scaling up the model to all jurisdictions through influencing mental health policy at the level of decision makers. It is envisaged that a transformed system of youth mental health care that utilizes evidence gathered world wide, is based on real needs and values of youth and families, has engaged multiple stakeholders in its creation and is applied within disparate contextual frameworks of varying level of resources, cultural and geographic realities will more likely succeed in influencing policy than an ideologically driven monolithic system

of care.

Conclusions:

Knowing the emerging epidemiology of youth mental health problems, were we to start again, we would simply not have a child and adolescent/ adult mental health service split at point of maximum risk of emerging mental illness [8]. The long shadow cast by childhood physical and mental health problems on adult life [14] and the impact of untreated or poorly treated disorders of children and young people extend far beyond just service use. We now have well-evidenced interventions for treating our vulnerable children and young people (www.nice.org.uk/guidance/lifestyle-and-wellbeing/mental-health-and-wellbeing). The long neglected area of youth mental health can and should no longer be ignored.

Conflict of Interest statement:

None of the authors have any conflict of interest in relation to the material being submitted for publication.

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