

Chapter 25

**A Service Model For The Mental Health Needs Of Children And Adolescents
With Intellectual Disability**

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Introduction

In Australia and many other parts of the world, health services lack designated specialist mental health services for individuals with intellectual disability. This presents a challenge to provide such a service using the combined efforts of separate specialist intellectual disability services, health, and mental health services.

The decline of institutional provision of care for people with intellectual disability and mental health problems has depended on a change in community and political attitudes, backed up with significant additional funding for community support and accommodation. The focus therefore, has been on intervention for adults who had been institutionalised, with little planning for what was needed for the new generation of young people with intellectual disability and mental health problems, and their carers. There is growing evidence of the inadequacy of community based service provision for this population. A study of carers by Cummins and colleagues (2007) showed that the mental wellbeing of carers of people with an intellectual disability was significantly worse than other carer groups, with 50% suffering depression. Additionally, the Australian longitudinal study of people with an intellectual disability (Einfeld & Tonge, 1996b) demonstrated the level of persisting severe psychiatric morbidity (40%) and lack of adequate access to specialist mental health services (9%). If mental health services were to provide for this level of need, it has been estimated that this would require an investment equivalent to all services provided for Schizophrenia! Similarly, Beange and Lennox (1988) highlighted the lack of attention and identification of general health problems of this population in general practice.

In Australia, specialist service provision for people with an intellectual disability have been transferred from state health departments to welfare departments

over the years, and it was assumed that equity of access to generic state health services would meet their health/mental health needs. Unfortunately the generic mental health services have been seen to provide poorly for this special need group. Indeed the state specialist mental health services provide for severe mental illness, and the federal funded medicare is expected to provide the community based services for general practice and subsidise private mental health services. The economics and epidemiology of mental health need make clear the deficits. For example, in New South Wales (NSW), Child and Adolescent Mental Health Services are responsible for 30% of the mental health burden of health but only receive 6% of the funding. In the UK it has been shown that although children and adolescents with an intellectual disability constitute between 2-3% of the population, they constitute 14% of the mental health burden of care (Emerson & Hatton, 2007). In NSW this is not reflected in the service provision, and indeed it is a commonly reported experience that having an intellectual disability is grounds for exclusion from a mental health service. Furthermore, in the absence of a capacity to communicate information on mainstream abnormal mental phenomena, young people presenting with an intellectual disability are likely to be seen as mentally disordered or having challenging behaviour rather than having a mental illness, although to the lay person this might seem to be using semantics to limit access to overstretched services.

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Proposed Service Model

In order to alleviate some of the difficulties in the provision of mental health services to young people with intellectual disability within a limited system, a tiered service model is proposed. This model is based on the holistic model of bio-developmental-

psycho-socio-cultural mental health and wellbeing, along with problem solving and collaborative approaches across clinicians and organisations.

Assumptions

The proposed service structure is based on a number of assumptions. These are outlined below.

1. Mental health problems of young people are complex and persisting. Parents have always had complex explanations for the behaviour of their child.
2. There is limited funding for mental health services which means that other health and human services are essential to meeting the need.
3. There should be a spectrum of services ranging from prevention to early intervention, to specialist intervention, rehabilitation and community support, and accommodation. Accordingly common problems should be managed with preventative and universal approaches.
4. A tiered structure of specialist service provision provides a problem solving framework for more challenging cases, with increased involvement of different professionals for assessment and intervention as the complexity and severity of these cases increases. These then have to be couched in a humane and community based system of service provision and care.
5. The specialised skills of different disciplines for the mental health needs of young people with intellectual disability are not found in any one agency which therefore requires protocols for interagency collaboration.
6. This book provides an empirically based holistic bio-developmental-psycho-social-cultural model framework that can enable all disciplines to work together for the needs of the children and adolescents.

7. The recognition of the rights and special mental health needs of young people with an intellectual disability necessitates access to a subspecialty multidisciplinary psychiatry services. The critical role of pharmacology in community mental health care requires the inclusion of psychiatrists with special expertise in intellectual disability.
8. While it is evident that clinicians' explanations for mental health problems are often limited, complex, and uncertain, it is essential to support the development of expert clinicians with subspecialty skills who pursue clinical research to advance the evidence base.
9. These clinical academic subspecialty clinicians contribute to a 'learning institution' which shares new knowledge with less specialised and more generic services over time. Such a framework can accommodate the advance of knowledge in a way that not only improves the services for people with intellectual disability, but also enriches mainstream health and mental health services.

A Tiered Service Structure

The proposed tiered service structure is described below and in Figure 25.1. The tiers are explained using examples from the current service system in NSW.

[Insert Figure 25.1 here]

Tier 1 - Generic Health Provision

Tier 1 involves service integration of the mental health needs in general health, education and community services. This is in keeping with the community acceptance

of ‘mild and moderate’ mental health problems and recognised under the rubric that ‘*mental health is everyone’s business*’. This tier would include general practitioners (GPs), community nurses, community health teams and special education provision, including that provided in a mainstream setting.

Tier 2 - Community Disability Service: Case Management And Targeted Prevention Interventions (e.g., specialist parent training)

Tier 2 involves a first level of specialist disability or mental health clinician with responsibility for case management for the individual/family. Disability case managers are often in a better position to access other intellectual disability resources such as various forms of respite to tackle the inordinate burden of care. However, GPs and general paediatricians frequently take on the case coordination role, acting as gate keepers to more specialist services.

Case managers should have a defined range of generic holistic clinical skills. Given the evidence base, the case managers should be trained in specialist parent training programs that could be provided in conjunction with special education resources. This would build both the relationship between parents and schools, and strengthen community connectedness and access for families and schools. Other prevention, promotion and early intervention approaches for mental health would need to be developed and validated in specialist educational services.

Tier 3 - Multidisciplinary And Multi-Agency Collaboration

In NSW, collaborative services for a young person with an intellectual disability may include such agencies as Ageing, Disability and Home Care (ADHC, Department of Human Services NSW), Department of Education and Training (DET), Department of

Health, possibly Mental Health, Community Services (CS; that provide social and welfare services) and other non-government services. In other states of Australia and in other countries, Tier 3 of the proposed service structure would involve a multidisciplinary team that may/may not include a paediatrician and access to a psychiatrist from the public or private health system. The multidisciplinary team may include a combination of professionals including: behaviour clinician, speech pathologist, occupational therapist, social worker, family therapist, psychologist, GP, paediatrician, psychiatrist, neurologist etc.

The multidisciplinary team works on collaborative good intent, guided by the best interests of the young person with intellectual disability, as viewed by their parents or carers. Any of the above child orientated agencies could initiate the multi-agency process, but the individual's presentation may guide which agency has the primary role. For example, disability services may have the lead role for challenging behaviours or externalising disorders, paediatrics may have the lead role for developmental psychiatric disorders such as Autism Spectrum Disorders or Attention Deficit Hyperactive Disorders, and mental health services may have the lead role for severe mental health problems such as depression and psychosis.

Tier 4 - Complex Case Management Decision Making Model

Tier 4 must have a cross agency, multidisciplinary management decision making capacity, that involves both intellectual disability and mental health specialist expertise. This tier of service integrates the best available clinical opinion with the individual's environmental needs (whether this is within or outside of a family setting) to provide complex clinical insight. This process drives the business case for funding.

Tier 4 would provide a common language and mechanism for establishing priority of need, both for short term interventions but also long term placements. This level of decision making should ensure that all available expert clinical perspectives are taken into account. Such a 'complex case conference' should have a mechanism for each agency to make requests of other agencies for professional assessments of the individual or assistance as required/necessary. Provision of assistance across agencies/government departments should be afforded priority, consistent with 'best endeavours'. Monitoring the frequency and outcome of such 'best endeavours' requests, would provide a centralised measure of the success of inter-agency collaboration.

Tier 5 - Acute Short Term Psychiatry Model

Tier 5 is emergency mental health involvement, mental health in-patient assessment and treatment and the input of specialist mental health services of intellectual disability. In short, this tier tests out what neuropsychiatry and in-patient assessment can contribute. However, this service tier is necessarily short-term as is the case for all acute psychiatry services and longer term management would necessitate services from *Tier 4 Complex Case Management Decision Making Model* to be engaged to manage the multifaceted nature of community based care.

The Need For Specialist Mental Health In Intellectual Disability Services

It is a widely held view that it is chronic mental health co-morbidity that is the greatest reversible handicap in people with an intellectual disability. This leads to great costs to the individuals with intellectual disability, their families and wider community including the services that are provided in terms of the financial costs, the

impact on quality of life, and standards of humanity. The bio-developmental-psycho-socio-cultural model leads to the division of mental health problems into, i) challenging behaviour, ii) developmental problems, and iii) psychiatric problems, which places a primary responsibility on disability services, paediatric services and child and adolescent mental health services. There are a range of other services and professions involved in these problems as illustrated in Figure 25.2.

[Insert Figure 25.2 here]

The biggest failure of this system is for young people with dangerous or complex challenging behaviour who have a high of risk of unrecognised severe mental health problems or disorders. These young people often do not receive adequate early intervention in the education system, which results in threats of harm to self or public safety. Failure of treatment and reduced access to generic child and adolescent mental health services, due to lack of 'intent' or insufficient verbal skills, threaten the child/adolescent's placement in the family, predispose to abuse, and may lead to the need for long term out-of-home placement. The latter may result in major costs and service challenges (e.g., blocked beds in respite care placements).

It is this group of young people that need an empirically orientated specialist mental health and multidisciplinary intellectual disability subspecialty team. Equity of access to appropriate services and standards for relief of distress and chronic impairment demand the availability of such a service. Such a clinically expert team could also provide education and training to generic services and take account of the special needs of this group, for example enabling admissions to general hospitals for other health issues. A clinical expert group can keep pace with the knowledge

revolution for this population. This would enable a learning culture for the entire health system in this growing area of specialist knowledge.

Conclusion

The service development of the last generation has seen improvements in the capacity of professions and services to cure conditions, improve disabling problems, build compensatory skills, minimise handicap, improve the quality of care, and humanising support. Harnessing the advance of knowledge is the least costly intervention to continue the betterment of the quality of life of children and adolescents with intellectual disability, which is the basis of the proposed service model.

In the UK, the Royal College of Psychiatrists has set out service standards for a specialised comprehensive mental health service for children and adolescents with intellectual disability that describes four tiers of specialist psychiatric service (Dugmore & Hurcombe, 2007). This sets a gold standard for benchmarking such psychiatric services internationally and the UK has embarked on the road of providing separate specialist mental health services for this population. The literature indicates that subspecialty skills are required for an adequate service structure. The debate for professionals is how much should these skills be mainstreamed into generic child and adolescent mental health services versus developing and maintaining separate subspecialty mental health services.

Psychiatrists in the UK, where they have a significant subspecialty in intellectual disability and in children and adolescents, support an increase in mainstreaming of the specialty skills. On the other hand, psychiatrists in Australia, where there is no subspecialty, have identified a need for developing a workforce with subspecialty skills (Torr, Lennox, et al., 2008). In Australia, psychiatrists report that

people with a severe intellectual disability are poorly treated in mainstream psychiatric in-patient units, whereas those with mild intellectual disability are adequately managed. Supporting paediatricians to provide a key role in these services will require strengthening the service pathway with and consultation support from child psychiatrists.

Since the evidence shows that intellectual disability is a biological risk factor for mental health problems, those with an intellectual disability have a greater vulnerability for all types of mental health problems. In the context of the growing epidemic of mental health problems, specific and coordinated planning is essential for the full spectrum of mental health needs for this special need population. This will require collaboration between agencies and professional disciplines, with leadership from the professional bodies to recognise the special clinical knowledge, skills, and programs. Thus pro-active political will is required to provide equitable services to meet the mental health needs of young people with intellectual disability.

Figure 25.1

**Tiered Pyramid of Services For Children And Adolescents With Intellectual Disability
And Mental Health Problems**

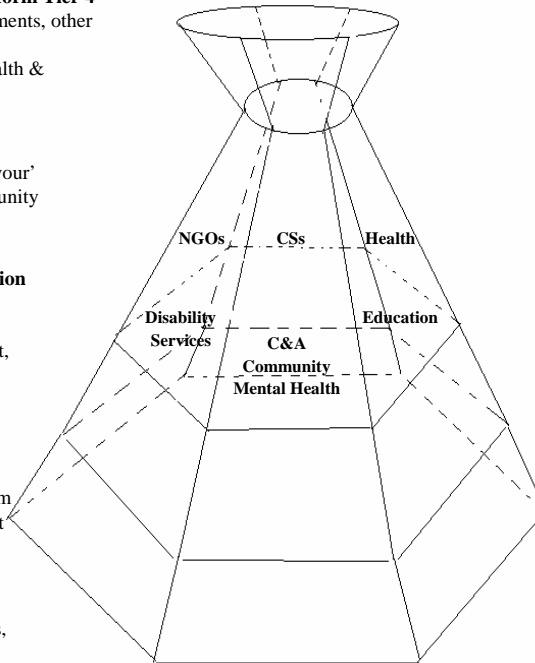
Tier 5: Acute short/medium term interventions that inform Tier 4
Includes: Emergency departments, MH in-patients assessments, other residential behaviour services; and **Specialist/Tertiary MH in ID clinicians** from mental health & disability services.

The Tier 4 Circle: The Final Common Pathway
Complex case management decision making; 'best endeavour' obligations including decisions about out of family community placements.

Tier 3: Multidisciplinary and Multi-agency Collaboration
Disability Service: ADHC behaviour clinician, speech pathologist, OT, other specialist psychology service;
Health: GP, paediatrician or neurologist; MH Psychologist, SW, family therapist, psychiatrist; and
Education: teacher, aide, school counsellor, principal, behaviour support specialist.

Tier 2: Community Disability Services providing case management and specialist parent training. Mainly from ADHC but can be MH or other agency or non-government organisations.

Tier 1: Generic Health Provision for families
Includes: GPs, community nurses, child community teams, Families NSW, Triple P



3D Model provides for all other human services to be part of the pyramid

Figure 25.2

Understanding The Pathways To Care

