Submission to Independent Hospital Pricing Authority by the Australian Association of Developmental Disability Medicine

Pricing Framework for Australian Public Hospital Services 2015-2016

25 July 2014

Introduction

The Australian Association of Developmental Disability Medicine (AADDM) is an organisation of medical practitioners who specialise or have an interest in the health of the over 300,000 Australian children, adolescents and adults with intellectual disability (ID). The key aim of the AADDM is to improve the health of children, adolescents and adults with intellectual and developmental disability.

We commend the Independent Hospital Pricing Authority (IPHA) for examining the evidence for adjustments to mental health care patients with concomitant ID. We argue below that this analysis be extended beyond mental health care services into all hospital based health care services provided to patients with ID.

We argue there are significant cost implications for health services in the provision of health care for people with ID. Consultations and other health care interventions typically take substantially longer and require the involvement of more than one health and other professional than standard models of care. There are often many complex comorbidities that require a team of highly skilled clinicians to work in a collaborative approach to both diagnosis and treatment. Participation of the person with ID in their health care may also involve carers or other support people, and adjustments to the nature of communication between health professional, person with ID and their carer.

This submission is addressing 2 key areas of enquiry by IPHA: 9.2- adjustments to ABF and 5.4- Multidisciplinary Case Conferences (MDCC).

Recommendations:

AADDM recommends that the Independent Hospital Pricing Authority (IPHA):

1. Evaluates the benefit to the health care system and, ultimately to the health of people with ID, of adjustment to the National Efficient Price for intellectual disability.
2. Examines the cost implications of the highly complex, often multidisciplinary and time consuming nature of mental and physical health service provision to this population and accommodates them within any funding model.

3. Considers the needs of people with ID as the IHPA explores the implications of multidisciplinary case conferences in the absence of the client.
4. Acknowledges and addresses the sensitivities of people with ID and their experiences of discrimination to reduce the potential barriers to identification within the health system.

Why should adjustments be made for People with Intellectual Disability?

Poorer health status of people with ID

People with intellectual disability have poor health status. Overall they have very high rates of physical and mental health problems which are often not diagnosed or appropriately treated. Furthermore, their life expectancy is reduced by up to 20 years.[1,2] They often have the added burden of socio-economic disadvantage and experience many barriers to receiving health services which directly impact there health and health care.

Morbidity

Children, adolescents and adults with ID experience higher rates of many treatable health conditions compared to the mainstream population. Three Australian randomised controlled trials found high levels of unmet health needs in Australian adolescents and adults with intellectual disability.[3-5] These finding confirmed the community based population surveys of children and adolescents and adults with ID which demonstrates high levels of unrecognised and/or poorly managed physical and mental health conditions.[6] The most comprehensive study of this type finding 5.4 conditions per person; half of which were unrecognised or poorly treated.[7]

However, these finding underestimate the level of unmet health need in those with syndrome specific conditions. School age children with Down syndrome have high rates of ear (more than half) and of eye (more than three quarters) problems.[8] These conditions contribute to a significant burden on the families to meet increased need for health care services and management. Mental health conditions occur in as many as 40-60% of adolescents with ID[9] and 32% of adults with ID.[10] Young adults with Down syndrome continue to have high rates of health problems. Problems such as eye and vision (affecting 73%), ear and hearing (affecting 45%), cardiac (affecting 25%), respiratory (affecting 36%), musculoskeletal (affecting 61%), body weight (affecting 57%), skin (affecting 56%), mental health (affecting 32%) and menstrual conditions in young women (affecting 58%) significantly impact participation in employment and community leisure activities and contribute to safety concerns.[11]

Mortality

Life expectancy for people with ID is substantially reduced compared to the general population. A population based study showed that median life expectancies were 74.0, 67.6 and 58.6 years for people with mild, moderate and severe ID respectively.[1]

Significant gain in life expectancy can be achieved with good medical care. People with Down syndrome now have a life expectancy of 50 years, whereas in the 1950s it was barely 30 years, and much of these gains can be attributed to better health care.[12]

Socioeconomic disadvantage compounds poorer health outcomes

People with ID often have additional adverse determinants of health and wellbeing. Socioeconomic disadvantage has been demonstrated to affect not only the person with ID,[13-16] but also their family.[17] Further, children of mothers who are most disadvantaged are much more likely to experience ID.[16] There is clear evidence that socioeconomic adversity has a substantial impact on overall health and wellbeing.

Barriers to healthcare

There are many causes of this situation; communication barriers between patients and health professionals, complexity of diagnosis, lack of general and specialised skills in the health workforce, passive or active discrimination with in the health systems and absences of tailored health promotion campaigns and research not focusing on people with intellectual disability.[18,19]

People with ID encounter special challenges that are different to those of people with other types of disabilities in a number of important aspects; for example, they have difficulties in learning and applying knowledge and in decision making. They may also have difficulty in identifying and choosing options at key life transition points and difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change.[20]

People with intellectual disability are more likely to receive inappropriate and inadequate treatment, or be denied healthcare altogether. As identified in international reports and by the WHO people with intellectual disability and their families, face enormous obstacles in seeking the kind of basic healthcare many of us take for granted.[21-23]

Impact on health care services

There is increased use of the health system by people with ID across the lifespan and is relevant for those with both physical and mental health conditions. For example children with an ID, Down syndrome or Autism Spectrum Disorder experience an increased risk of hospitalisation after the first year of life that varied from 2-10 times that of the rest of the population.[24,25] Adults with Down syndrome continue to experience increased rates and longer periods of hospitalisation than the general community [26]

The Royal Australian College of Physicians recommends that multidisciplinary models of care should be established at the time of diagnosis of intellectual disability. These should be characterised by effective and sustained collaboration across sectors, health, disability, education and family and community services, and professionals.[27] Furthermore the RACP suggests adults with ID need access to multidisciplinary teams of specialists who are funded to give them the time and expertise needed for diagnosis and treatment of complex problems.[28]

Multidisciplinary Case Conferences – Recommendation 3

Health care of people with ID is very likely to involve multiple health professionals and multiple points of contact.[29] Ensuring this care is delivered in a coordinated and integrated manner requires close contact between the health professionals. People with ID have every right to be included in discussions about their own health care, however there may be valid practical reasons why this may not be appropriate. AADDM would recommend that the needs of people with ID be included as IHPA considers the implications of funding clinical services such as MDCC in the absence of the client.

People with ID incur increased health care costs.

People with ID and their families often experience increased costs compared to people without ID. A population based study of children and young people with Down syndrome found that mean annual direct health care costs were $4209 and that these decreased with age. Respite costs tended to increase with age.[30] Data on all children, adolescents or adults with ID and hospital admission is not available because we do not identify if the patient has and ID during the admission process, unlike other at risk groups.

Health problems in people with ID contribute to the overall health care burden of people with disability

Although people with ID differ in important aspects of their health care needs to those with disability due to other causes, they do form a significant but varying component of the overall population with disability across the lifespan.

There is a substantial gap in the health status of people with disability compared to those who do not. In 2007-8, almost half (46%) of Australian people aged 15-64 years with severe or profound ID reported poor or fair health compared to 5% of those without disability.[31] People aged under 65 years with severe or profound disability had a higher aged standardised prevalence rate of for all types of reported conditions than people without disability. The most commonly reported conditions were mental health problems, followed by back problems, arthritis, cardiovascular problems and asthma.

The 2007 National Survey of Mental Health and Wellbeing reveals that people with disability aged 16-64 years consult both mental health and non-mental health professionals 2-3 times those without disability.[29] The high use of health services among people with severe or profound disability was associated with a high prevalence of multiple conditions, and comorbidity of mental and physical conditions.

Comparison with a population acknowledged to be at high risk of adverse health outcomes

Persons who identify as being of Aboriginal or Torres Strait Islander origin are able to receive evidence based price adjustments in NEP14 (IHPA, 2014).[32]

In comparison to Indigenous Australians, a population justifiably and widely recognised for its poorer health outcomes and lower life expectancy, people with ID may have even poorer health and lower life expectancy. While we acknowledge difficulties arise with direct comparison due to different methods of determining prevalence of health conditions and the health outcomes chosen for measurement. Nonetheless, the available data does lend strong support to affording people with ID a similar level of targeted health service support and adjustments within health care funding in order to address inequities of health outcomes.

Responding to the special needs of people with ID in the health system

Provision of health services for people with ID typically take substantially longer and require the involvement of more than one health professional than standard models of care. The presence of comorbid health conditions only partially explains the difference in health service usage, suggesting that other characteristics of this group of people influence the nature and frequency of health services access. Potentially, health system characteristics may also contribute to this difference.

Person characteristics that may impact health service usage include;

- difficulties with verbal communication
- reliance on formal and informal carers for meeting health care needs
- need for others to support decision making and provision of consent
- needs for assistance to participate in community access and leisure activities that might restrict healthy lifestyles, e.g. adequate activity
- limited literacy skills
- inability to recall personal health information such as past major disease, operations or health interventions

Health system characteristics that may impact health service usage include;

- attitudes towards people with ID
- limited skills with adapting communication styles or use of augmented communication strategies
- short consultation times that don’t allow for adequate time for explanation
- fragmentation of within health services and with other services
- minimal availability of easy to read health literature

Case Studies highlighting clinical complexity

Specialist health services for children, adolescents and adults with ID tend to take more time and involve more clinicians than the general population.[33]

A young child referred for diagnostic assessment

A 4 year old boy was referred for diagnostic assessment by his general paediatrician. The paediatrician had identified significant language delay and referred to a speech pathologist for therapy.

The boy's development was much slower than his siblings, with his parents concerned about his limited interest in playing with toys, that he was only able to say a few single words to get what he wanted and had a lot of tantrums. He was attending child care and speech therapy. His mother had severe depression and was often bed bound for weeks at a time and his father worked evenings to support his family. Both parents had traumatic experiences in their country. The family was being supported by family and community services.

The diagnostic assessment involved the boy and both parents, the speech pathologist and the diagnostic team staff that included clinical psychologist, developmental paediatrician, advanced paediatric trainee and social worker. The paediatrician and psychologist conducted the developmental assessment that involved extensive history of the child's development, assessment of his health, early life experiences and intervention, formal cognitive testing and physical examination. The social worker did a family assessment given the known risk factors.

He was diagnosed with moderate global developmental delay. The emotional neglect was identified with further assessment undertaken of the parents' mental health.

The initial assessment was of 3 hours duration and involved 3 expert clinicians. Subsequent case planning and discussion involving the diagnostic team required at least 2 hours. This type of service enables a comprehensive diagnostic framework to be developed.

A school age girl with severe disability

A 7 year old girl with autism and severe ID was referred to the school clinic- an interagency, multidisciplinary clinic for students with moderate to severe disabilities at a special school. Her mother has an intellectual disability and receives assistance from her parents to care for the children. She no longer has a case worker.

There were major concerns about the girl's behaviour. Sometimes she can have a tantrum by throwing herself to the floor, kicking her feet, and crying. It is not always clear why she gets upset and they can last up to 60 minutes. She sometimes bruises herself. The possible relationship with transitions, difficulties with communication (she can only say about 6 single words) and physical health problems were explored. It was discovered that she had poor sleep, often not going to bed until 11pm, and that this would be making her behaviour worse.

During the interview, it became clear that she was having turns that might be seizures and these had emerged at the same time her behaviour deteriorated. She had been found to have a genetic disorder causing the disability, but hadn't been known to have seizures.

The mother and staff present discussed the problems occurring across environments, risk to other children, strategies being used and how effective they were and how to investigate and treat the likely epilepsy. A management plan was developed, and ideas shared between home and school about how to help this girl. The mother cried because she is still sad that her daughter won't catch up to other children. The social worker made plans to meet with the mother to discuss how she is managing at home and her ongoing grief.

In addition to her mother, the following professionals participated; school staff- principal, school counsellor and teacher, disability staff- psychologist, and health staff- social worker and developmental paediatrician. All staff were present for the entire consultation that lasted for over an hour, with the paediatrician spending additional time (2 hours) after the consultation making referrals and coordinating care. This model of care, involving 3 different agencies and 6 professionals relevant to the child's needs, is gaining acceptance as being a valuable way to effectively integrate care for children with disability and complex health care needs.

An adult with ID and complex healthcare

Andrew was born with cerebral palsy of unknown cause. He has a good quality of life as his family have supported him to be as independent as possible. The health challenges he faces means he is wheelchair bound, unable to communicate verbally and has frequent seizures which are proving difficult to control. He receives feeding through a tube into his stomach. In addition, he experiences recurrent constipation, pressure areas/ulcers and dependant oedemia and recurrent migraines. It is difficult for him to indicate where he has pain. Recently, Andrew become very agitated, irritable and anorexic. It was only after multiple consultations requiring Andrew to be transported to various locations that included assessments by his GP and the local Emergency Department, then a gastroenterologist, neurologist and a dietician, and extensive investigation, that a diagnosis of a relapse of his reflux oesophagitis was made and adequately treated. Patients with such complexity require extra time with multiple clinicians as assessment can be very difficult and time consuming.

The need to identify people with ID when they access health services

Provision of appropriate funding for the complex health care requirements of people with ID would require health systems to routinely identify ID. This is done either inconsistently or not at all across Australia. The benefits that have ensued from identification of people with disability within national surveys, eg ABS, have enormous implications for both improved understanding of their health care needs and capacity to plan a system around those needs.

An ABF system of funding health care is appealing for its simplicity and ease of cross jurisdictional comparison. However, implementation without adjustments, risks distortion of health care services towards more straight forward clinical care and those with fewer comorbidities providing a further barrier to healthcare for children, adolescents and adult with an intellectual disability.

In conclusion

AADDM would encourage the Independent Hospital Pricing Authority (IPHA) to investigate adjustment to the National Efficient Price for children, adolescents and adults with Intellectual Disability, a vulnerable population with complex mental and physical health care problems. We commend the IPHA for examining the evidence for adjustments to mental health care patients with concomitant ID, but propose this be extended beyond mental health care services into all mainstream health care services across the lifespan. This population not only has complex health care needs, but aspects of their disability have significant impact on the way health care services are provided. Unless action is taken, people with ID will continue to experience substantial and preventable health inequality and poorer health outcomes.

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