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# Primary health care for people with intellectual disabilities

Over half a million Australians have an intellectual disability and 61% of those have a severe or profound limitation in 'core' activities of daily living.<sup>1</sup> The sparse research available concerning health care service use by people with significant intellectual (or physical disabilities) in Australia suggests there is a higher rate of health care service utilisation in this group than for people without disabilities for all health care provider types.<sup>2</sup> While overall utilisation rates appear to be higher in this group compared to the general population, primary health care access may still be insufficient to meet their needs.<sup>3</sup> This *RESEARCH ROUNDup* investigates the reasons for primary health care disadvantage in people with intellectual disabilities, and strategies to overcome this disadvantage.

Australian research suggests primary health care service use by people with intellectual disabilities is higher than for people without intellectual disabilities.<sup>2</sup> Despite this higher utilisation primary health care may still be insufficient to meet their needs.<sup>3</sup> A number of studies around Australia have found very high rates of hospitalisation for infections, respiratory problems, 'mental issues'<sup>4</sup>, dental conditions and skin disorders.<sup>2</sup> All these conditions are considered to be preventable given appropriate primary health care.<sup>4</sup>

## Why do people with intellectual disabilities not receive the primary health care they need?

### People with intellectual disabilities have a high rate of undiagnosed illness

Important indicators of disadvantage and poor utilisation of primary health care services in this group are the very low rate of identification, diagnosis and treatment of illnesses and disorders.<sup>5,6</sup> In metropolitan Australia, there are high rates of unidentified skin disease, hypertension, heart disease and mental health problems among people with disabilities.<sup>5,6</sup> The low rates of diagnosis and treatment are consistent with studies on self rated health status (see Figure).

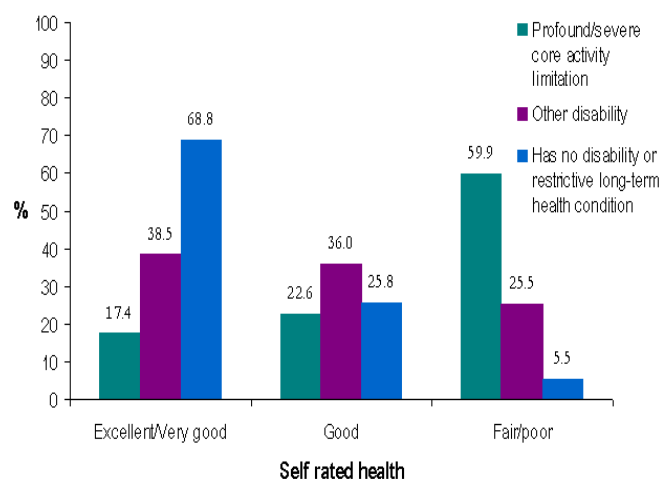
### People with intellectual disabilities have unique primary health care needs

People with disabilities have unique needs that require a tailored approach to primary health care service delivery.<sup>7-11</sup> A consistent theme that emerged from Australian primary health care research is practitioners' lack of knowledge about treating people with disabilities and their unique constellation of illness and disease.<sup>7-11</sup> While it might be preferable to develop specialist practitioners to assist individuals who have intellectual disabilities, this may not always be feasible.

### Deficiencies in areas of basic living present barriers to accessing care

Individuals with core limiting disabilities have unmet needs that extend beyond the health setting.<sup>12</sup> While geographical distance and transport to primary health care

Figure: Self rated health status of Australians with and without disabilities<sup>3</sup>



services is a common barrier for disadvantaged groups, this is exacerbated for people with an intellectual disability.<sup>12</sup> Similarly, unmet needs in terms of assistance with reading, writing, cognitive or other communication can be barriers to clear interaction between the health care provider and the client.<sup>7,10,13</sup>

### Establishing good communication is challenging

Poor communication is frequently a problem for the practitioner-patient relationship. These communication difficulties include:

- ⇒ obtaining a complete case history
- ⇒ conducting screening tests and assessments
- ⇒ ensuring patients understand instructions relevant to their health care.<sup>7</sup>

Communication difficulties become more pronounced with more severe intellectual disabilities.<sup>13</sup>

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## Diagnostic overshadowing can obscure undiagnosed illnesses

Diagnostic overshadowing refers to the tendency for health professionals to regard a diagnosis for an intellectual disability as the cause for unrelated illnesses.<sup>14,15</sup> For example, an individual with an intellectual disability may have undiagnosed mental or physical illnesses because the symptoms of the illnesses are thought to stem from the disability rather than a secondary, undiagnosed illness.

Whilst this bias was initially thought to affect psychologists and mental health clinicians<sup>14</sup>, more recent evidence suggests that GPs are also 'cognitively susceptible'.<sup>5</sup> The phenomenon of diagnostic overshadowing may partially explain the high number of undiagnosed conditions in people with intellectual disabilities.<sup>5</sup>

## Possible solutions

### Improving communication

The use of a communication aid that is independent of carers would overcome some of the difficulties incurred in the communication process.<sup>9</sup> The Advocacy Skills Kit (ASK) diary is one example of an effective strategy to facilitate communication for this disadvantaged group.<sup>16</sup> The ASK diary is a communication aid which is managed by the patient, and records information about their personal background, medical history, and communication or care needs that may assist practitioners during consultations.

### Providing on demand e-health support for health care practitioners

An easy reference for practitioners on appropriate service provision would be valuable.<sup>17</sup> An example of such a model is the 'Psych Support' program, which provides live treatment advice for GPs from specialist psychiatrists via the internet or telephone. Similar models have been evaluated and generally show positive results.<sup>18,19</sup>

### Undertaking comprehensive health assessments

The introduction of a regular, comprehensive health assessment program has been shown to increase the rates of identification of previously undiagnosed conditions in intellectually disabled people.<sup>20,21</sup> The Comprehensive Health Assessment Program, together with the ASK diary have been evaluated within the primary health care setting.<sup>20</sup> These interventions successfully detected previously undiagnosed illnesses or disorders and can be used within a health assessment consultation (MBS item numbers 703, 705, or 707).<sup>22</sup>

## Conclusions

Research on the use of primary health care services by those with intellectual disabilities is scarce. What is available suggests there is an under utilisation of primary health care for these people, which results in high rates of hospitalisation for conditions that could be avoided. A number of strategies have demonstrated improved service provision for people with intellectual disabilities. These are relatively low cost, simple interventions to implement and have the potential to improve quality of life for people with intellectual disabilities in Australia.

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