



## **Council for Intellectual Disability: Briefing Paper for Members of Parliament**

### **The urgent need to address the high rates of preventable deaths and early deaths for people with intellectual disability.**

#### **The NSW government must act now to stop the deadly disability discrimination in our health services against people with intellectual disability.**

##### **What is wrong?**

- **38% of people with intellectual disability in NSW have preventable deaths**
- **People with intellectual disability are dying 27 years earlier than the general population.**

Recent University of New South Wales research (1) shows that 38% of people with intellectual disability die potentially preventable deaths. This is over double the rate for the general population. Research shows that people with intellectual disability have 2.5 times the number of health problems of the general population including 30% having mental disorders. There are low rates of accurate diagnosis and treatment-only 29% in a landmark study. There is poor management of risk factors for chronic health conditions. People with intellectual disability are also dying at an average age of 54 years which is 27 years earlier than the general population.

It is costing government a lot of money not to address this human problem. People with intellectual disability have twice the usual rate of emergency and hospital admissions with each admission costing twice as much.

##### **Why is this happening?**

- The attitudes of some health professionals in discriminating against people with intellectual disability have in some cases resulted in fatal misdiagnoses or in decisions not to offer vital survival and recovery treatment.
- There is also the communication challenge between doctor and patients with intellectual disability.
- Limited time allocation; complex diagnostic challenges and inadequate skills and training for health professionals to treat people with intellectual disability are other reasons for misdiagnosis and poor treatment outcomes.

##### **Why is this important?**

- This is a human rights issue. Everyone has a right to good health care and many people with intellectual disability are not getting it.
- This is about saving lives. Lives are being lost due to the deadly disability discrimination in our health services.
- **There are over 140,000 people with intellectual disability in NSW. With their immediate families, this is over 600,000 people with an immediate concern for this problem.**

##### **What are the solutions?**

1. The urgent and immediate concern is to ensure that all the intellectual disability health services currently funded by FACS (Family and Community Services) will continue to be funded after 30 June 2018. These include but are not limited to: a Statewide network of 16 specialist nurses with intellectual disability training; outreach psychiatric clinics in regional areas; and specialist swallowing clinics in Western Sydney. If these services close, many more people are likely to die.

2. Priority investment in a statewide network of **specialist intellectual disability health professionals** to back up the mainstream system in a similar way as applies to so many other groups who have complex and specific needs. For example, the health system has paediatric services and geriatric services. So it needs intellectual disability health services to provide clinical consultancy on referral and, very importantly, to be the catalyst for capacity building across the mainstream health system.

3. We want NSW Health to move from its current funding of three very small pilot intellectual disability health teams to **a statewide network of small specialist intellectual disability health teams** of the size recommended by KPMG in its economic analysis for NSW Health in 2009. (2). The economic analysis of KPMG confirmed a likely cost benefit from establishing intellectual disability health teams.

### **What is the cost?**

We have called on the Government to commit a new \$9.5 million in the 2018 budget. This would maintain the FACS funded health services, fund two new intellectual disability health teams and make fit for purpose the existing pilot teams

CID has called on the Government to move from the current three small pilot intellectual disability health teams to a statewide network of teams. We have asked the Government to commit to this happening over the next four years with staged increases and an annual cost in the fourth year moving forward of approximately \$17 million.

### **What does all this mean for your electorate?**

Currently, people with intellectual disability in your electorate are experiencing grave health inequalities and preventable deaths.

There are either none or inadequate intellectual disability health specialists available when GPs and hospitals need to consult on difficult cases. There are also a lack of specialists to drive the development of skills and capacity in the local health system.

If the government funds a statewide network of intellectual disability health specialists, there will be a major improvement in health for people with intellectual disability and far fewer preventable deaths.

### **References:**

(1) UNSW Professor Trollor's study into premature deaths of people with intellectual disability in NSW: <http://bmjopen.bmj.com/content/7/2/e013489> <https://3dn.unsw.edu.au/news/urgent-need-cause-death-reporting-system-australians-intellectual-disability>

(2) KPMG's economic analysis for NSW Health in 2009. [www.health.nsw.gov.au/disability/Documents/analysis-costs-benefits.pdf](http://www.health.nsw.gov.au/disability/Documents/analysis-costs-benefits.pdf)

Further information: [advocacy@nswcid.org.au](mailto:advocacy@nswcid.org.au)

### **Who is Council for Intellectual Disability (CID)?**

*Council for Intellectual Disability (CID) works for and with people with intellectual disability to actively promote inclusion, equity and rights. The majority of CID Board members and CID's Chairperson are people with intellectual disability.*

*CID has been playing a critical role in the lives of many people with intellectual disability and their families for over 60 years. Through its' systemic advocacy it enables and supports people with intellectual disability to be active and informed participants on decision-making bodies within their communities and within government.*

*Central to all the work that CID does is advocating for the rights of people with intellectual disability and empowering them to have their own voice on issues which impact on them.*