

unnamed in silence

People with intellectual
and multiple disabilities
are becoming an
"invisible population".
By **Sheridan Forster**.



People with profound intellectual and multiple disabilities (PIMD) sit unnamed and in silence. In Australia, they are not identified as a discrete group, as are other groups, such as those with autism, vision or hearing impairment. Consequently, their needs are poorly understood and remain largely unaddressed by policy makers and service providers. In the UK, in an effort to address these issues, a report was commissioned by the English Department of Health, *Raising Our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities*.

Raising our Sights author Professor Jim Mansell recently visited Australia and shared the insights from this report on growing number of initiatives to improve the lives of people with PIMD (or the UK equivalent, profound learning and multiple disabilities - PMLD) in the UK. Professor Mansell believes that given this group in England, estimated by Professor Eric Emerson to number 16,000 (and growing), represents a relatively small number of people in the population, the improvement of services and supports should be easier than for other larger groups.

Internationally, the term, PIMD, has been used to refer to people who, in addition to profound intellectual disability, have severe physical disabilities, which may result in an inability to walk. People with PIMD may also have vision and/or hearing impairments and health conditions, such as epilepsy and gastrointestinal problems (eg. reflux and constipation). People with PIMD may be able to use a very small number of words or gestures, but many rely solely on facial expressions and body language to communicate. They have a limited understanding of the speech of other people. Nevertheless, most people are able to react, showing likes and dislikes. Importantly, despite their limitations, people with PIMD are able to engage in relationships with other people and can be valued members of their family and the communities in which they live.

In Australia, the understandable fear of misdiagnosis and of the political imperative not to differentiate people with disability has contributed to an avoidance of using the label, PMID, subsequently creating a lack of recognition of this group's distinctive characteristics and needs. This has resulted in people with PIMD - arguably with the highest level of needs among all people with disability - being relatively invisible. Furthermore, this lack of recognition of this group's distinctive characteristics has contributed to generic disability policies and practices that are relatively incomprehensible when applied uncritically to this group.

For example, personalised supports that are predicated on a person clearly expressing what they want, their hopes, and aspirations for the future (commonly based on practices referred to as Person Centred Planning) are unworkable when the person is only able to show their reactions to current experiences. This is not to say that personalisation is not possible; it is necessary, but ascertaining what the persons needs and would like has to be based on things other than an explicit statement from the person and must take into consideration perspectives of families and support workers.

Identification of this group of people is necessary in Australia if we are to move forward. Demographic studies are needed to find out how many people have PIMD. Review of the specific applicability of policy, practice guides, and standards, is needed, in light of the complex cognitive, physical, sensory, and health needs experienced. These needs cannot be left off the public record, and remain unrepresented in policy and practice.

People with PIMD deserve the dignity of being named, counted and recognised for who they are, what they need, and how they might be unique part of our community.

It may be implied that the issues of identification and recognition of people with PMID has been addressed in Australia with the use of terms in research and public policy, such as complex or high support needs. However, in concordance with the UK PMLD Network's statement,

these terms are overly inclusive. Complex needs and high support are often inclusive of people with challenging behaviours, complex health needs and, at times, forensic populations, who don't necessarily have a profound intellectual disability. The term, PIMD, identifies that a profound intellectual disability is the primary issues. That is, a profound impairment in attention, problem-solving and memory, affecting choice-making and ability to interact with people around them.

In addition, using the term, PIMD, allows for the special needs of families, carers, and support services involved with these individuals to be highlighted.

We can raise our sights regarding how people with PIMD are living in Australia, but we cannot lobby for an invisible population. People with PIMD deserve the dignity of being named, counted and recognised for who they are, what they need, and how they might be unique part of our community.

Sheridan Forster is currently completing a PhD at Monash University, looking at interactions between adults with PIMD and their disability support workers. She authored HOP: Hanging Out Program, a booklet advocating the need to regularly spend 10 minutes of time with people, giving the person 100 per cent attention, to develop interactions and reduce isolation. 