

Background paper for ASID position statement on intellectual disability and complex support needs*

Leanne Dowse¹, Angela Dew¹, and Alec Sewell¹

¹*Intellectual Disability Behaviour Support Program, University of New South Wales, Sydney, New South Wales, Australia*

Correspondence to: Professor Leanne Dowse, School of Social Sciences, University of New South Wales, Sydney, NSW 2052, Australia. Email: L.Dowse@unsw.edu.au

Introduction

When intellectual disability co-occurs with other issues such as mental illness, complex health conditions, complex communication needs, behaviours that may be a harm to self or others, substance misuse, homelessness, trauma, violence and victimisation, intergenerational or circumstantial disadvantage, or involvement with the child protection or criminal justice systems, individuals are said to have complex support needs. Complexity is also shaped by gender, ethnicity and being an Aboriginal Australian or a New Zealand Maori. Many individuals with complex support needs interact with a range of agencies that often do not adequately recognise the presence or impact of disability. Effective responses to complex support needs are also limited by the siloed nature of the policy and service context in Australia and New Zealand. This lack of appropriate recognition and response often in turn works to further exacerbate the complexity of an individual's support needs.

Defining complex support needs

While the terms 'complex needs' and 'complex support needs' are increasingly used in research, policy and practice across various disciplines and sectors, there is currently no consistent and agreed framework or definition. However key elements consistently identified as comprising complex support needs are:

- *Breadth* or range of issues that are interconnected, in conjunction with a *depth* or intensity in one or more domain including disability, health, social and economic issues (Rankin & Regan, 2004: 7);
- *Multiple* service use, with frontline agencies sharing clients but addressing different domains of need (Keene, 2001: 5);
- A *disjuncture* between the support needs of the individual and the support services available or the *absence* of appropriate simultaneous, integrated, multiple supports (Collings, Dew & Dowse, 2016);
- Not static or permanent but *change* throughout the individual's life course and are more likely to arise in certain situations, episodes or life stages and at key transition points or in times of crisis;

* This article was commissioned and funded by The Australasian Society for Intellectual Disability (ASID). Australasian Society for Intellectual Disability (2019). *ASID Position Statement on Intellectual Disability and Complex Support Needs*. Available at: <https://www.asid.asn.au/publications/position-statements>

- Arise in the *interaction* between the individual and their potential or actual support systems – reflecting the relationship between individuals, service agencies and systems.

Estimating the population

Identifying the prevalence of complex support needs in the population of people with intellectual disabilities in Australia presents a range of challenges primarily related to the absence of an accepted definition and the lack of an integrated framework for identification and quantification. Prevalence estimates are beyond the capability of current data collection approaches and estimates vary according to the epidemiological methods employed (Doran et al, 2012). The Australian Bureau of Statistics (2014) suggests an estimated 2.9% of the total population have an intellectual disability although these figures are also inclusive of those who have cognitive impairment caused by head injury, stroke, brain damage, and dementia. A better estimate provided by the Australian Institute of Health and Welfare (2008) identified the rate of 2.5% of the population under 65 years as having an intellectual disability and a further estimate derived via linked administrative data in Western Australia suggests a rate of 1.42% of children as having intellectual disabilities (Leonard, Petterson, Bower, & Sanders, 2003). In New Zealand, the New Zealand Disability Survey (2013) reported that 2.0% of the population have an intellectual disability, specifically noting that across both child and adult groupings males (3%) were more likely to be living with an intellectual disability than females (1%) (Statistics New Zealand, 2013).

International analysis undertaken by Whittaker (2004) similarly recognises the difficulty in arriving at a precise prevalence figure, confirming this to be between 1% and 3%, depending on the definition used. Significantly, Whittaker goes on to note that irrespective of the definition, the number of people who meet the criteria for having an intellectual disability will probably be greater than the number who have been labelled because before an individual can be labelled they must be identified (Whittaker, 2004:141).

With these caveats in mind the amalgamation of sources including population level data and smaller scale research studies that address possible markers of complex support needs (Dowse, Wiese & Smith, 2016) indicate a concerning picture of prevalence across a range of relevant domains including:

- Of those with intellectual disabilities, 10% to 17% experience challenging behaviour (Bouras & Holt, 2010);
- Mental health issues are likely to be present in between 14% and 75% people with intellectual disabilities (based on prevalence established by Buckles, Luckassaon & Keefe, 2013);
- UK studies suggest that 10 – 13% of individuals known to intellectual disability services had contact with the criminal justice system as offenders (McBrien, Hodgetts & Gregory, 2003, Vaughan, Pullen & Kelly, 2000).
- Children and young people with intellectual disabilities are over-represented within the child protection system with a small scale Victorian study finding 22% of care leavers had an intellectual disability (Raman, Inder & Forbes, 2005); as well, parents with intellectual disabilities have been found to be over-represented in child protection matters and have an elevated risk of child removal in the Australian court system (Llewellyn, McConnell, & Ferronato, 2003). Currently, there are no reliable New Zealand estimates available for either the number of children and young people with an intellectual disability in care, or how many parents with an intellectual disability have had children formally removed by the Family Court. However, anecdotal evidence suggests that New Zealand parents with an intellectual disability experience the same elevated risk for removal as do their peers in other developed countries.

- Homeless people are significantly more likely to have an intellectual disability than the general population (Oakes & Davies, 2008).

Evidence suggests significant numbers of people with intellectual disabilities experience complex support needs in aspects or at times in their lives. Measurement is hampered by definitional differences and the fact that intellectual disability remains poorly recognised, confused or hidden by other presenting issues in mainstream health, mental health, justice, drug and alcohol, child protection and homelessness services. This lack of data presents a significant barrier to effective policymaking and service response for people with intellectual disabilities who have complex support needs. Further attention to identifying the extent to which clients with intellectual disabilities are present in the range of frontline services is needed and may be at least partially addressed by adding a disability identifier to the data system of these services. This data would contribute significantly to capacity to understand how these systems respond to the support needs of people with intellectual disabilities.

Responding effectively to complex support needs

Ensuring that frontline agencies can effectively respond to people with intellectual disabilities who have complex support needs requires commitment from disability and mainstream sectors at the level of both policy and practice. Effective responses include attention to criteria for service eligibility, access, flexible support planning, and responsive and adaptable service provision grounded in a broad policy commitment to recognising and addressing complex support needs.

Eligibility

Individuals with intellectual disabilities and complex support needs are at risk of falling outside the multiple and varying eligibility criteria for the different types of support they may require. Having a number of low-intensity needs may mean that individuals will not meet the criteria for eligibility for any one service type because their support needs may not be judged significant enough to meet the threshold for a particular support type (Dowse, Cumming, Strnadová, Lee, & Trofimovs, 2014). Strict eligibility criteria may also exclude people with intellectual disabilities and complex support needs on the basis of the presence of issues that are outside the responsibility of any specific agency, for example people with particular behavioural issues, criminal offending or drug or alcohol issues. These eligibility issues significantly limit the pool of agencies designated, prepared, and capable of providing support to people who have complex support needs.

Access

Individuals with intellectual disabilities and complex support needs face particular challenges in accessing support across sectors, including disability, social services, justice, health, education, employment, and housing. Some agencies are insufficiently flexible to meet the individual's range of needs and lack capacity for collaborative and integrated responses to the complexity of these needs. Many people with complex support needs, due to past negative experiences with services, do not trust unfamiliar frontline workers and are reluctant to access services without significant efforts in outreach and trust building (Clift 2014). This combination of factors means that planning for access and provision is both more important and more challenging for this group (Dowse & Dew, 2016).

Planning

Support planning describes a range of approaches to facilitate service users' access to service agencies, to organise individualised funding and to assist users to assess the suitability of services to meet their individual goals (Collings, Dew & Dowse, 2016). It is an important means of giving

agency to people with intellectual disabilities. The impact of cognitive impairment on communication and decision making has been recognised as presenting particular challenges for people with intellectual disabilities (Mansell & Beadle-Brown, 2004) and when coupled with low expectations and previous infrequent opportunity to identify and express their wishes and aspirations, people with intellectual disabilities and complex support needs are likely to be unskilled to engage in support planning (Curryer, Stancliffe, & Dew, 2015). In the absence of planners who are skilled in working with diverse groups of people with disabilities, people with intellectual disabilities and complex support needs are at risk of poor planning experiences and outcomes (Dowse, Wiese, & Smith, 2016).

Service Provision

Several key features characterise effective provision of support for people with intellectual disabilities and complex support needs which span issues of workforce, models of timely support provision and advocacy, shaped by a coherent policy framework. A skilled and appropriately qualified workforce is pivotal. However, current evidence suggests that this most vulnerable of client groups is at risk of engagement with the least experienced workers. High levels of poor psychological wellbeing have been noted in the workers engaging with people with intellectual disabilities and complex support needs (Chung & Harding, 2009) leading to poor retention of experienced staff and younger and less experienced workers predominating. These workers tend to use more restrictive and less supportive techniques when working with such clients (Knotter, Wissink, Moonen, Stams, & Jansen, 2013). Systemic attention to the development and retention of a workforce that is appropriately skilled, stable and matched to the geographic distribution of people with intellectual disabilities with complex support needs is central to effective support provision (Dowse, Wiese, Dew, Smith, Collings & Didi, 2015).

Individualised case management is particularly beneficial for individuals who interact with multiple support agencies. This is especially relevant where individuals interact on an ad hoc basis with workers who may not recognise the presence of disability and respond instead to perceived noncompliance, aggression, or ‘challenging behaviours’ (Lowe, Allen, Jones, Brophy, Moore, & James, 2007). Case management can influence the nature of these interactions away from an emphasis on deviance to those emphasising support (Clift, 2014). Individualised advocacy in combination with case management is crucial to assist people in their interaction with frontline agencies (Dowse & Wiese, 2016). This is particularly so for those who have little family or informal support, are disengaged or suspicious of governments and service providers, or have little idea of what potential support options may exist (Collings, Dew & Dowse, 2016). For those whose complex support needs are associated with trauma, it is important that the case management relationship be sufficiently long-term for trust to be developed. Early intervention similarly has the potential to mitigate or prevent the exacerbation of complex support needs, although a subset of people may require ongoing intensive or episodic support to maintain an adequate level of social functioning throughout their lives (Keene, 2001). In New Zealand, a high and complex framework has been in place for some years to provide a range of supports and different responses for people with intellectual disabilities who come before the courts (New Zealand Ministry of Health, 2018).

Since people who experience complex support needs often require multiple supports typically involving multiple service sectors, a more carefully targeted approach from universal services is required (Rankin & Regan, 2004). As the national policy framework to meet Australia’s obligations under the UNCRPD, the National Disability Strategy requires the recognition and inclusion of people with disabilities in all aspects of Australian life. Current commitment to and capability for this in practice, particularly for people with intellectual disabilities is extremely limited, with reform

in a range of sectors such as health, disability, justice, and housing urgently needed to ensure accessibility, inclusion and inter-agency co-ordination, at the level of individuals, service agencies and systems (Collings, Dew & Dowse, 2016). In New Zealand, the strategic direction of disability support services has focused on ensuring that people with disabilities have greater choice and control over their lives, as well as improved outcomes (New Zealand Ministry of Health, 2015). In particular, there has been a trend towards more person-directed and flexible support options for early interventions.

The cost of complex support needs

The combined cost of intellectual disability to both families and governments is substantial. For example, in Australia, this is estimated to be \$14,720 billion per year (Doran et al, 2012). Add to this the costs to services including those in health, mental health, justice and welfare of unaddressed complex support needs in individuals with intellectual disabilities clearly results in significant human, social and economic costs. This group constitute a small but intensively serviced subset of the client population of frontline agencies. While relatively small in number, the frequency of their interactions and the intensity of their engagement with agencies suggests that they are likely to present a disproportional cost to government at both the state and federal level across a range of sectors. Without early intervention the costs to individuals, families, and communities can be extremely high. Baldry, Dowse, McCausland and Clarence (2012) found that the lifetime cost to government in responding to people with intellectual disabilities, mental health issues, and highly complex needs in contact with the criminal justice system, can be as high as \$1 million per annum per person. Of particular concern is that, on average, 63% of these costs stemmed from interactions with 'control' and 'crisis' agencies such as police, corrective services, juvenile justice and courts, with the remainder from support services such as housing, social security, health, and disability services. Cost benefit analysis shows that, robust, holistic, targeted disability support and intervention for this group would see that for every dollar spent on the early investment, between \$1.40 and \$2.40 in government cost is saved in the longer term (McCausland, Baldry, Johnson & Cohen, 2013).

This calls attention to the little acknowledged issue of responsibility shifting and associated cost shifting from support to control agencies and sectors which characterise current systemic responses to people with intellectual disabilities and complex support needs. Here the agencies best placed to intervene earlier and more effectively in a person's life in fact have the least involvement. Early intervention by disability, health, and human services will likely reduce intervention (and associated costs) by police and the justice system. Early intervention agencies generally do not have the direct incentive of the burden of consequences and in their absence, responses default to crisis and control agencies, which have little discretion and poor capacity to recognise and respond to the presence of intellectual disabilities. Addressing this systemic escalation of risk and regulation of those with complex support needs requires policy settings that incentivise support agencies to achieve outcomes that reduce social risks.

Conclusions

In summary, evidence suggests that, even on conservative estimates of 1% population prevalence, significant numbers of people with intellectual disabilities will experience complex support needs at some time in their lives, associated with challenging behaviour, co-occurring mental health issues, contact with the criminal justice system, and experience of child protection. Unaddressed complex support needs have been shown to incur significant costs to individuals and their families, and evidence suggests the costs to government in responding to people with intellectual disabilities, mental health issues, and highly complex needs in contact with the criminal justice system can be as

high as \$1 million per annum per person. Across the board research shows that effective systemic responses to this group are hampered by a range of issues which exclude them, including narrow eligibility criteria for services, difficulties accessing those services that may be available, inadequate planning for their complex support service needs, thin markets of providers willing to provide support services and an under-skilled workforce, particularly in rural and regional areas of New Zealand and Australia.

In Australia's newly emerging disability system, shaped by a greater focus on human rights under the influence of the United Nations Convention on the Rights of Persons with Disability, the concepts of personal and social support networks are transforming. Similar transformation of New Zealand's disability system is applying the same focus. Complex support needs are increasingly an important focus in this area. As well as the specific systemic issues already identified, attention to enabling better inclusion for people with intellectual disabilities via supported decision making and enhanced accessibility in communication and information will be essential components of this dialogue.

Individuals with intellectual disabilities and complex support needs are currently not adequately recognised in policy or supported across multiple service sectors. To address this situation we propose the need for:

- Development of a consistent definition of complex support needs and improved identification of those with intellectual disabilities who have complex support needs;
- Collection of data on the prevalence and diversity of complex support needs among people with intellectual disabilities;
- Cross sector, broad policy commitment to recognising and addressing complex support needs of individuals with intellectual disabilities;
- Development of effective cross sector service responses to supporting people with intellectual disabilities and complex support needs that address: eligibility criteria; access barriers; effective planning responses; and high quality service provision based on a skilled workforce.
- Applied research-based evaluation of intensive case management to establish its effectiveness as a model of support for people with intellectual disabilities and complex support needs.
- Commitment to appropriate and targeted early and ongoing intervention to increase quality outcomes for individuals with intellectual disabilities and complex support needs across their life course to reduce the current disproportionate high economic, social and human costs incurred in responding to crises and trauma.

References

- Australian Bureau of Statistics. (2014). *Intellectual Disability, Australia 2012*. Cat. No. 4433.0.55.003. Canberra: ABS
- Australian Institute of Health and Welfare. (2008). *Disability in Australia: Intellectual disability. Bulletin no. 67*. Cat. no. AUS 110. Canberra, ACT.
- Baldry, E., Dowse, L., McCausland, R., & Clarence, M. (2012). *Lifecourse institutional costs of homelessness for vulnerable groups*. National Homelessness Research Agenda. <http://www.mhdcd.unsw.edu.au/sites/www.mhdcd.unsw.edu.au/files/u18/Lifecourse-Institutional-Costs-of-Homelessness-final-report.pdf>

- Bouras, N., & Holt, G. (2010). *Mental health services for adults with intellectual disability*. New York: Psychology Press.
- Buckles, J., Luckasson, R., & Keefe, E. (2013). A systematic review of the prevalence of psychiatric disorders in Adults with Intellectual Disability, 2003-2010. *Journal of Mental Health Research in Intellectual Disabilities*, 6(3), 181-207.
- Chung, M. C., & Harding, C. (2009). Investigating burnout and psychological well-being of staff working with people with intellectual disabilities and challenging behaviour: The role of personality. *Journal of Applied Research in Intellectual Disabilities*, 22(6), 549-560.
- Clift, K. (2014). Access to the National Disability Insurance Scheme for people with intellectual disabilities who are involved in the criminal justice system. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 24–33. doi:10.1080/23297018.2014.910863.
- Collings, S., Dew, A. & Dowse, L. (2016). ‘Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme’. *Journal of Intellectual and Developmental Disability*, 41(3), 272–276.
- Curryer, B., Stancliffe, R., & Dew, A. (2015). Self-determination: adults with intellectual disability and their family. *Journal of Intellectual and Developmental Disability*, 40(4), 394-399. doi: 10.3109/13668250.2015.1029883.
- Doran, C. M., Einfeld, S. L., Madden, R. H., Otim, M., Horstead, S. K., Ellis, L. A. & Emerson, E. (2012) How much does intellectual disability really cost? First estimates for Australia, *Journal of Intellectual and Developmental Disability*, 37(1), 42-49.
- Dowse, L. & Wiese, M. (2016). Case management and complexity: Challenges in the National Disability Insurance Scheme. In E. Moore (Ed.), *Case management: Inclusive community practice*. Melbourne, Oxford University Press.
- Dowse, L., Cumming, T. M., Strnadová, I., Lee, J. S., & Trofimovs, J. (2014). Young people with complex needs in the criminal justice system. *Research and Practice in Intellectual and Developmental Disabilities*, 1(2), 174-185.
- Dowse, L., & Dew, A. (2016). Commentary on “Reducing the inequality of luck: Keynote address at the 2015 Australasian Society for Intellectual Disability National Conference” (Bonyhady AM, 2016). *Research and Practice in Intellectual and Developmental Disabilities*. doi: 10.1080/23297018.2016.1220262.
- Dowse, L., Wiese, M., Dew, A., Smith, L., Collings, S., & Didi, A., (2016) More, Better or Different? NDIS workforce planning for people with intellectual disability and complex support needs. *Journal of Intellectual and Developmental Disability*, 41(1), 81-84.
- Dowse, L., Wiese, M., & Smith, L. (2016). Workforce issues in the Australian National Disability Insurance Scheme: Complex support needs ready? *Research and Practice in Intellectual and Developmental Disabilities*, 54-64. doi: 10.1080/23297018.2016.1161542
- Keene, J. (2001). *Clients with complex needs: Interprofessional practice*. Blackwell, Oxford.
- Knotter, M. H., Wissink, I. B., Moonen, X. M., Stams, G.-J. J., & Jansen, G. J. (2013). Staff's attitudes and reactions towards aggressive behaviour of clients with intellectual disabilities: A multi-level study. *Research in Developmental Disabilities*, 34(5), 1397-1407.
- Leonard, H., Petterson, B., Bower, C., & Sanders, R. (2003). Prevalence of intellectual disability in Western Australia. *Paediatric and Perinatal Epidemiology*, 17, 58-67. doi:10.1046/j.1365-3016.2003.00469.x
- Llewellyn, G., McConnell, D., & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, 27 , 235 – 251. doi:10.1016/S0145-2134(03)00004-8

- Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: Prevalence and topographies. *Journal of Intellectual Disability Research*, 51(8), 625-636.
- Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, 17(1), 1-9. doi: 10.1111/j.1468-3148.2004.00175.x
- McBrien, J., Hodgetts, A. & Gregory, J. (2003). Offending and risky behaviour in community services for people with intellectual disabilities in one Local Authority. *Journal of Forensic Psychiatry*, 14, 280-297.
- McCausland, R., Baldry, E., Johnson, S. & Cohen, A. (2013). *People with mental health disorders and cognitive impairment in the criminal justice system: Cost-benefit analysis of early support and diversion*. Sydney, UNSW. Available online at <https://www.humanrights.gov.au/sites/default/files/document/publication/Cost%20benefit%20analysis.pdf>
- New Zealand Ministry of Health. (2015). Disability Support Services Strategic Plan 2014-2018. Available from: <https://www.health.govt.nz/publication/disability-support-services-strategic-plan-2014-2018> (accessed 5 February, 2019).
- New Zealand Ministry of Health. (2018). *Where I live; how I live: Disability support services community residential services strategy, 2018 to 2020*. Wellington, New Zealand: Ministry of Health.
- Oakes, P. M. & Davies, R.C. (2008). Intellectual disability in homeless adults: A prevalence study. *Journal of Intellectual Disabilities*, 12(4), 325-334.
- Raman, S., Inder, B., & Forbes, C. (2005). *Investing for success: The economics of support for young people leaving care*. Melbourne: Centre for Excellence in Child and Family Welfare.
- Rankin, J., & Regan, S. (2004). *Meeting complex needs: The future of social care*. London: United Kingdom: The Institute for Public Policy Research.
- Statistics New Zealand (2013). *The New Zealand Disability Survey 2013*. Available from: www.stats.govt.nz/disability (accessed 5 February, 2019)
- Vaughan, P.J., Pullen, N. & Kelly, M. (2000) Services for mentally disordered offenders in community psychiatry teams. *Journal of Forensic Psychiatry*, 11, 571-586.
- Whitaker, S. (2004), Hidden learning disability. *British Journal of Learning Disabilities*, 32: 139–143. doi:10.1111/j.1468-3156.2004.00264.x