Enabling Health

Appendix 3: Gaps in knowledge

VicHealth

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This section provides an overview of gaps in knowledge identified throughout the review and associated consultations. These findings should be considered when planning future research; however, other areas of potential research may also exist that were not identified.

Employment

A systematic review of people with a disability returning to work found studies with opposing results (Blank et al. 2008). Further research is required in this area.

There continues to be limited availability of 'meaningful data on the employment of people with intellectual disabilities, continuing high unemployment rates for this population, and the lack of an outcomes-focussed approach to evaluating whether employment services are meeting the needs of people with intellectual disabilities and their families' (Dempsey & Ford 2009, p. 233).

Education

Further research into the effectiveness of alternative schooling options such as Montessori programs, home schooling or community schools programs is required, as such information would enable parents to make informed choices.

Knowledge around the role of VET and how it can become more responsive to the needs of people with a disability is needed (Barnett 2004).

Research into the costs and benefits of VET for people with a disability is needed (see Griffin & Nechvoglod 2008).

Longitudinal studies regarding the impact of inclusive education are needed (Sharma, Forlin & Loreman 2008).

Housing

The effectiveness of supported accommodation, as compared to the provision of community supports, should be investigated through randomised trials (Chilvers, Macdonald & Hayes 2012).

Studies of housing in one state or territory do not necessarily hold across other jurisdictions (see Emerson 2004). Further studies need to be conducted in the context of geographical area and relevant policies, laws and regulations.

Transport

Focused studies on disability and transport disadvantage are required.

While it is well established that people with a disability in Australia experience a level of transport disadvantage, there is a lack of data around interventions and effective targeted approaches (Stanley, Currie & Stanley 2007).

Discrimination

The effectiveness of advocacy programs such as self-advocacy need to be more fully explored in the Australian context.

While there is much anecdotal evidence in Australia to suggest that discrimination (and neglect) occur in the area of hospital admissions and other areas of access to the healthcare system, more exploration of this topic is needed.

A UK study into access to health care revealed that the consequences of failing to make reasonable adjustments included untreated ill health and an increased likelihood of avoidable deaths occurring (Michael & Richardons 2008). Australia would benefit from a similar investigation into the current healthcare system.

Further exploration of issues of systemic discrimination (for example, within aged-care systems and dementia-care systems, which many people with a disability find hard to access) is required in Australia.

Violence

A recent systematic review and meta-analysis of international observational studies concluded that 'available studies have methodological weaknesses and gaps exist in the types of disability and violence they address. Robust studies are absent for most regions of the world' (Hughes et al. 2012, p. 2).

The experiences of disability hate crimes are currently poorly documented in Australia (VEOHRC 2010). Research to uncover and address this issue within the Australian context is needed.

An empirical evaluation of intervention and prevention programs is needed (Lund 2011).

Social connection and community participation

The absence of national outcome data gathered regularly means that it is not possible to be definitive about the degree of inclusion currently experienced by people with disability (Stancliffe 2012).

Intervention studies that trial or test strategies for community participation are required (Bigby 2008).

There is an over-reliance on data from the intellectual disability field, which may or may not be applicable to other forms of disability.

Health behaviours

Intervention studies are promising but are limited by small sample sizes, short-term intervention periods and a lack of follow-up. Good quality qualitative data is needed in mixed studies to ascertain the meaningfulness of the interventions for participants and their experience of the interventions (Heller et al. 2011).

A systematic review of trials using psychosocial interventions for people with substance-abuse problems and mental illness was inconclusive. More quality trials are needed in this area before conclusions can be drawn (Cleary et al. 2010).

A randomised controlled study of the impact of peer-support telephone calls to improve health and health behaviours is needed (Dale et al. 2008).

A systematic review of obesity interventions for people with intellectual disabilities found that there are large gaps in knowledge about effectiveness (Jinks, Cotton & Rylance 2011).

A systematic review of tobacco and alcohol-related health promotion interventions for people with intellectual disabilities found little evidence to contribute to this knowledge base (Kerr et al. 2012).

Health services

Further research is needed to determine the effects of different ways to organise [mainstream health] services for people with intellectual disabilities (Balogh et al. 2009).

Self-determination

One systematic review examined the involvement of people with mental illness in treatment decisions, but could draw no firm conclusions and recommended that further research is needed in this area (Duncan, Best & Hagen 2010).

While a link between self-determination and quality of life has been confirmed, more research is required in this area (Lachapelle et al. 2005).

Longitudinal studies that evaluate outcomes related to self-determination opportunities are required.