

Social Inclusion and People with Intellectual Disability and Challenging Behaviour: A Systematic Review

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Abstract

Background: Social inclusion is central to disability policies internationally. The high risk of social exclusion for people with intellectual disability is compounded for those with challenging behaviour. **Method:** A systematic literature review examined how social inclusion of people with intellectual disability and challenging behaviour has been researched and operationalised in the empirical literature, and evidence about the extent of social inclusion by people with intellectual disability and challenging behaviour. **Results:** A thematic analysis of the fourteen papers identified that social inclusion has been poorly defined and measured, and that the little research that has occurred in respect of people with challenging behaviour has demonstrated their potential to be socially included. **Conclusions:** Clearer conceptualisation of inclusion, greater understanding of practices that support social inclusion and system level mechanisms, that ensure goals around inclusion gain prominence in funding and support plans, may address the neglect of this critical quality of life domain for people with challenging behaviour.

Social Inclusion and People with Intellectual Disability and Challenging Behavior: A Systematic Review

Social inclusion occupies a central place in Australian social policy. The Federal government asserts that social inclusion is about everyone and that ‘all people have the capabilities, opportunities, responsibilities and resources to learn, work, connect with others and have a say’ (Commonwealth of Australia, 2009a, p. 2). Similarly social inclusion is central to disability policy. As a signatory to the United Nations Convention on the Rights of People with Disabilities (2006), Australian governments are committed to take effective and appropriate measures to facilitate the full inclusion and participation of people with a disability in the community.

The terminology used in policy documents is notoriously loose and often social/community and inclusion/participation are used interchangeably. O’Brien and O’Brien’s (1987) distinction between ‘community presence’, as the sharing of ordinary places and ‘community participation’, the experience of being part of a growing network of personal relationships that includes people other than people with intellectual disability clients, paid staff and immediate family is commonly used in the disability literature. A later section of this paper discusses problems with the conceptualisation and measurement of the concepts embedded in social inclusion.

People with intellectual disability are among the most disadvantaged and socially excluded in society (Kozma, Mansell, & Beadle-Brown, 2009). The risks of exclusion are compounded for the estimated 10-15 percent of people with intellectual disability who also have challenging behaviour (Emerson, 2001; Myrbakk & Von Tetzcnner, 2008). This group are more likely than others with intellectual disability to live in ‘out-of-home’ care, be excluded from community services, placed in larger scale congregate and secure accommodation, be re-institutionalised, subjected to abuse and restrictive practices, and experience poor outcomes from community services (Beadle-Brown, Murphy, & DiTerlizzi, 2009; Beadle-Brown, 2006; Emerson et al., 2005; Felce, Lowe, Beecham, & Hallam, 2000; Kozma, Mansell, & Beadle-Brown, 2009; Myrbakk & Von Tetzcnner, 2008). Their potential for social exclusion is evident in the very definition of challenging behaviour as;

‘behavior of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or behavior which is likely

to seriously limit or deny access to and use of ordinary community facilities’ (Emerson et al., 1987 cited in Department of Health, 2007, p. 6).

Research suggests challenging behaviour can be long-term and persistent irrespective of changes to living situation (Murphy, 2009; Thompson & Reid, 2002). Despite this, there has been a long-standing emphasis on reduction of challenging behaviour as the primary aim of intervention (Carr, 1999a; Campbell, 2007). The implicit assumption being that social inclusion is dependent on the reduction of challenging behaviour (the sense that people have to be ‘made ready’ for social inclusion). For example, a review of behavioural intervention papers from 1985-1996 found improvement to lifestyle was only mentioned as a goal for 10% of all participants (Carr, et al., 1999b). This was also illustrated by research on deinstitutionalisation which has investigated changes to the nature and frequency of challenging behaviour. However these researchers have seldom separately reported outcomes such as quality of life in general or social inclusion in particular for people with challenging behaviour (Emerson & Hatton, 1996; Kozma, et al., 2009; Young et al., 1998).

The relative neglect by intervention studies of social inclusion and the conditions necessary to sustain positive outcomes for people with challenging behaviour in the messy real world are evident from the paucity of research in community settings. For example, Scotti et al. (1991) found less than 10% of intervention studies between 1976 -1987 had been conducted in a person’s home or the community. Similarly Carr and colleagues (1999a) reported that most intervention research took the form of tightly controlled experiments in laboratory type settings, designed to identify and assess the variables controlling the behaviour. Neither has the long-term effectiveness of interventions been empirically investigated. For example, only 18 of 96 intervention studies identified by Carr et al. (1999a) reported any follow up, and those that did only had a mean period of 5 months. Similarly a Cochrane review of behavioural and cognitive-behavioural interventions for people with intellectual disability and challenging behaviour pointed to a similar absence of research with long-term follow-up (Hassiotis & Hall, 2008).

Enhancing social inclusion per se may be a *means* of intervention for people with challenging behaviour, i.e. increasing social inclusion, whilst an important outcome in its own right, may also reduce their level of challenging behaviour. Some components of social inclusion, such as small scale ordinary community housing, employment, and engagement in meaningful community activities are also central to the implementation of Positive Behaviour Support (Department of Health, 2007; Magito-McLaughlin et al., 2002). However, evidence

about the association between increased social inclusion, such as a move from institutional to community living, and a reduction in challenging behaviour is equivocal and varies with research design (Emerson & Hatton, 1996; Kozma, et al., 2009). For example, Young (2006) identified the qualitative change in the nature of challenging behaviour following a move to the community which had been surmised by Emerson and Hatton (1996). They suggested that reductions in challenging behaviour were more likely to be reported when observational measures were used rather than those that relied on staff report. Observational measures they suggested may be more sensitive to change in some types of behaviours, such as stereotypes that occur for significant proportions of time, than behaviours that are relatively infrequent and brief.

Since the 1990s, proponents of Positive Behaviour Support have advocated for greater attention to social inclusion and other quality of life outcomes for people with challenging behaviour, proposing that effectiveness of intervention should be judged in terms of social validity; that is

..... by the effects of the support plan on the person's quality of life, on the person's increased independence and competence, social and community presence and participation, productivity, personal empowerment and choice, and relationships and support network' (O'Brien & O'Brien, 1991 cited by LaVigna & Thomas, 2005, p. 22)

Services should therefore attend to both the challenge the person presents and to supporting their achievement of a good quality of life in spite of their problems (Department of Health, 2007; Emerson et al., 1992). In 1993, Mansell (Department of Health, 1993) suggested the ability to support social inclusion for people with challenging behaviour should provide a benchmark of service quality for all people with intellectual disability. His conclusion, more than a decade later that, 'there has been a failure to deliver the benefits of previous policy to people who present a challenge to services' (Department of Health, 2007, p. 1) should be of significant concern to disability service system providers and policy makers.

Somewhat optimistically, Carr and his colleagues (2002) suggested that research on challenging behaviour had evolved to the point where external validity and intervention in natural environments had taken on a greater significance. They suggested research required: outcomes to be measured in terms of comprehensive lifestyle leading to meaningful participation in a variety of community settings; practical and relevant intervention strategies that could be implemented by frontline staff or family in everyday contexts and; demonstration of long-term implementation and change. Aims such as this suggest the

importance of the operationalising and measuring social inclusion for people with intellectual disability and challenging behaviour, both elements that are poorly developed in the social policy and disability literatures (Commonwealth of Australia, 2009c; Verdonschot et al., 2009).

This paper aims to systematically review the empirical literature on the social inclusion of people with intellectual disability and challenging behaviour. The review was guided by two broad questions: 1) how has social inclusion by people with intellectual disability and challenging behaviour been researched and operationalised in the empirical literature; and 2) what is the evidence about the extent of social inclusion by people with intellectual disability and challenging behaviour. The focus is on adults with more severe intellectual disability that use the disability service system rather than those with milder intellectual disabilities who are more likely to be involved with the criminal justice system (see for, example UK descriptions of the two service systems, Mansell, McGill, & Emerson, 2001 and Murphy, Holland, Fowler & Reep, 1991).

Method

A Boolean search of ten databases (APAIS Health, CINAHL, Cochrane Library, ERIC, Expanded Academic, Medline, Proquest Social Science and Humanities, PsychInfo, Social Services Abstracts and Sociological Abstracts) was undertaken. The search used the various terms that refer to intellectual disability; including learning disability, developmental disability, and mental retardation; challenging behaviour and the more recent term used in Victoria, behaviours of concern; inclusion; quality of life; and participation. The search was conducted in mid-2010 with no limit on the period covered. PsychInfo produced the most substantial number of articles (n=71), a number of which were repeated in other databases. A total of 135 articles or reviews were identified by abstract and title. A close reading of these reduced the overall pool of journal articles to 99. Dissertations and books were excluded. After examination of abstracts, 30 were discarded as either not relevant to the research questions or having a primary focus on children or adolescents. The remaining 69 papers were read to assess their relevance to the broad topic of social inclusion of people with challenging behaviour and effective interventions and support. For example, papers that used a quality of life framework but reported sub-domains relevant to social inclusion were included. At this stage an additional 29 papers were read, which had been identified from either the citations or a search of the indexes of the Journal of Positive Behaviour Interventions as no papers from this journal had been identified in the original searches.

Papers were then selected on the following criteria; reports of descriptive, qualitative or quantitative findings from empirical research specifically in respect of people with intellectual disability and challenging behaviour about commonly used components of social inclusion such as, community activities, community participation, social interaction with family and friends, employment, community presence or use of community facilities. Fourteen papers met these criteria, which are summarised in Table 1. The contents of the papers were analysed qualitatively to synthesise and interpret the findings from these fairly disparate sources and integrate them into broader conclusions. This type of analysis can be characterised as thematic (Bryman, 2008) whereby themes are extracted from the content of sources, rather than relying on those identified within articles by authors.

Insert Table 1 about here

Findings and discussion

Limited research on social inclusion of people with challenging behaviour

The relatively peripheral nature of social inclusion in most of the identified papers was illustrative of the paucity of research specifically concerned with social inclusion of people with challenging behaviour. Social inclusion was a minor element in findings rather than being central to research questions in most of the 14 papers described in Table 1. Typically it was one of the various domains investigated under the broader concept of quality of life, or included as part of a description about life experiences. These findings support the conclusions reached by Murphy in her 2009 keynote address, that little research has investigated the social inclusion of people with challenging behaviour. This was confirmed by Verdonchot et al. (2009), who, using the search term community participation, found research had primarily focused on people with mild intellectual disability.

Operationalising and measuring social inclusion

Most of the studies identified used single or small case study designs and reported descriptive data about social inclusion. None defined social inclusion and only a few articulated a theoretical framework that informed the way data were collected. As Table 1 illustrates there was little consistency in the way social inclusion was described or measured. Descriptive accounts included elements such as; paid or voluntary employment, living situation, friendships, acquaintances, use of community facilities and commercial premises, meaningful activities located in community settings, social interaction with community members and

simply the number of times the person went out of their front door into ‘the community’. Some of the descriptors loosely fit the quality of life domains of *interpersonal relations* (affiliations, affection, intimacy, friendships, interactions) and *social inclusion* (natural supports, integrated environments, participation) (Schalock et al., 2002). This accorded with the suggestion by Murphy (2009) that quality of life is often taken as a proxy for social inclusion.

Studies that used formal measures in addition to description (1, 4, 6, 8, 9, 10, 11, 12, 14) focused on two key elements: the nature of personal networks such as size, relationships and frequency of contact; and the frequency a person left their home and places visited. The most commonly used measure was the *Index of Community Involvement (ICI)* (Raynes et al., 1994), which, relies on staff reporting to collect data about the frequency and range of a person’s activities in the community in the previous month. Though producing quantifiable and comparable data, this tool does not provide data about the precursor to the activity (was it chosen or a routine event); the quality of social interactions (was it hostile or convivial); the nature of activities (were they participatory, engaging or passive); or with whom outings or activities were shared (was it as part of a large group or as an individual). Qualitatively quite different experiences of community presence are therefore scored similarly. Nor does the ICI provide any indication of the temporal and evolutionary nature of community presence for people with challenging behaviour who may, for instance, have spent long periods in institutional care.

Tracy and Whittaker’s (1990) *Social Network Assessment* tool has been used to collect data about people with whom an individual has active contact over a specified period of time. However, different approaches to analysis and reporting of the data collected makes comparability of findings difficult. Studies have differed in respect of who is included as a network member. For instance, some excluded paid staff, and different methods of data collection are used, with some studies relying on self-report and others using staff or family as informants (see, for example, Bigby, 2008; Forrester-Jones et al., 2006; Robertson et al., 2001).

The type of observational, valid and reliable measures that have been developed in respect of engagement of people with intellectual disability or staff assistance (see, for example, the Active Support Measure, Mansell & Elliot, 1996), were largely absent from these studies of social inclusion. Saxby et al. (1986) was the only study that used momentary time sampling and a standardised measure of aspects of social inclusion. The type of data collected were quantitative about the frequency of activity outside of the home and

qualitative about the nature of interactions when people with challenging behaviour were present in the community and used shops, cafés and other businesses.

Overall these studies suggested a very narrow interpretation of social inclusion has been adopted by researchers. In most, data collection focussed only on one of the four broad domains (engage/social participation), identified as headline indicators of social inclusion by the Social Inclusion Board (Commonwealth Australia, 2010). The other three domains, learn, work and have a voice, were largely absent.

The lack of clear definitions or theoretical frameworks and the relatively superficial or ad hoc methods of measurement or description in these 14 studies reflected the general literature on social inclusion and people with intellectual disability. For example, in their review of 46 deinstitutionalisation studies published from 1980-1994, Emerson and Hatton (1996) found that almost half (20) used the frequency that community facilities were used to measure what they termed community participation. Verdonschot et al. (2009) in a systematic review of community participation research found only 2 of 23 identified studies were based on theoretical frameworks and concluded that data about community participation were collected using ad hoc and un-validated instruments.

The qualitative data in these studies exemplified however, the value of case studies and qualitative research in providing insights into the processes of service delivery and the subtle changes that occur in people's social inclusion over time. As Felce and Toogood (1988, p 9) remark about a demonstration project for people with severe intellectual disability and challenging behaviour.

..research has tended, in the name of objectivity, to avoid detailed personal accounts... much of the *quality* of the change in the lives of the adults who have lived at 10 Summerton Road would go unrecorded if we had restricted ourselves just to reporting the information gathered by the objective research measures employed.

Few of the studies identified in this review however, would meet requirements imposed for a detailed account of analytical method or demonstrable trustworthiness criteria that are currently evolving in the world of peer reviewed publishing (Milton Keynes Primary Care Trust, 2002). This may mean a significant proportion of this type of research remains in the relatively inaccessible grey literature, without mechanisms such as peer review to act as a guide to quality or rigor. Good qualitative studies also have considerable potential to inform the development of new concepts and development of more formal measurement tools.

Recognising and measuring multiple manifestations of social inclusion

This review suggested research on social inclusion is weighted towards open ended description or very simple measures of community presence such as the ICI. The personalisation of support through, for example, the use of mechanisms such as person-centred planning and individualised funding, has generated debate about the multiple possible manifestations of social inclusion for people with challenging behaviour (Clegg, 2008; Hall, 2005). This work flags potential problems with high level measures of social inclusion. Community presence or activity in the community are not ends in themselves and are of little value unless referenced to an individual's preferences. Ideally individual planning processes should aim to ascertain preferences and shape judgements about personal inclusion goals. For people with more severe levels of impairment, such processes are lengthy, resource intensive and rely on multiple informants with a depth of relationships with others who know the person well (Bigby & Frawley, 2009). Nevertheless, articulation of individual goals can be informed by a theoretical framework that conceptualises the domains of social inclusion. The content of individual plans can then act as a guide to practice, and be used to structure data collection or as a means of greater accountability at a service level through monitoring and evaluation of outcomes (see, for example, McConkey & Collins, 2010). If expected individual outcomes and measures of social inclusion are not articulated it is left to frontline staff to devise their own.

It may therefore be necessary to develop multiple measures of social inclusion, at the individual level, the more general level of populations of people with challenging behaviour and people with intellectual disability, and the community level. There is a complete absence of research beyond the level of the individual that considers for example, the inclusive nature of localities or locally based clubs and organisations. If audits of physical access are feasible, so too might be measures designed to audit the socially inclusive nature of localities or clubs. Research must move beyond an approach that tends to equate social inclusion with simple counts of how many times a person goes out their front door to visit the community. In pursuing a more finely grained understanding, descriptive data can be more useful if researchers, funders and policymakers adopt clear theoretical or organising frameworks to guide its collection and analysis.

This review suggests that research on social inclusion of people with challenging behaviour has lagged behind research on other key aspects of people's lives such as engagement in meaningful activity. There has, for example, been no sustained focus on the development of practices and theoretical frameworks to support social inclusion similar to

thoes associated with person centred active support developed to support engagement in meaningful activity (Mansell & Beadle-Brown, 2012), which in turn has led to clearer definitions of outcomes and more refined measures. One strategy to foster the operationlisation of social inclusion may be to focus on the development of practice skills and frameworks that complement those derived from active support, as it is likely that different approaches or skill sets are required to facilitate community participation, social interaction and relationships with community members or organisations. Internationally, it has been through well-researched and evaluated demonstration programs that possibilities, processes and practices to support aspects of the lives of people with challenging behaviour have been developed. For example, a demonstration program and action research to more clearly define and evaluate strategies to build social inclusion for people with more severe intellectual disability was successfully used in a project undertaken in the UK by the Foundation for People with Learning Disabilities (Swift & Mattingly, 2009; Wightman, 2009).

Evidence about social inclusion of people with challenging behaviour

All the studies in Table 1 that considered outcomes for people with challenging behaviour after a move to individual or small group community living (1, 3, 5, 6, 7, 8, 10, 13, 14) reported positive improvements on various dimensions of social inclusion. This reflected the larger body of deinstitutionalisation and community living literature that demonstrates the beneficial outcomes for people with intellectual disability of moving from congregate to small group living (Felce, et al., 2008; Lakin & Stancliffe, 2007; Mansell et al., 2008). However, most of the studies identified by this review did not report on ‘standard’ deinstitutionalisation programs, as both participants and programs were of quite a different order. Research participants had often been selected as having the most severe challenging behaviour and the programs were often demonstration projects designed and resourced intensively by specialists.

As already discussed, most deinstitutionalisation studies have not reported outcomes, separately for people with challenging behaviour, other than behavioural. This means there is little evidence about the similarity of their outcomes compared to other people with intellectual disability. For example, the findings by Felce et al. (2000) suggested that people with higher levels of challenging behaviour experienced less frequent community activities compared to other residents who have moved to small group homes.

The study by Saxby and colleagues (1986) is one of the few with a specific focus on the nature of social inclusion of people with challenging behaviour. Their findings indicated

that the use of shops and facilities may involve only momentary social interactions. This reflected the conclusions reached by the larger body of research about people with intellectual disability that community presence does not equate with community participation in the form of increased relationships with others outside the distinct social space of family, staff and other residents (Bigby & Vitzel, 2011; Clement & Bigby, 2009; Hatton & Emerson, 1996; Kozma et al., 2009).

Eight studies demonstrated that intensive, carefully executed planning and support can improve outcomes for people with severe challenging behaviour on the various dimensions of social inclusion investigated (Table 1, 1-8). Lowe et al. (1996) showed however, the variable impact of specialist services on outcomes, suggesting that it is the quality rather than specialist services per se that is important. The findings of Robertson and her colleagues (2004) were similar to those of Mansell et al. (2003) and demonstrated the advantages for social inclusion for people with challenging behaviour of not being congregated with other residents with challenging behaviour. Young (2006) demonstrated the relative advantage, for social inclusion, of dispersed small group homes compared to similar housing in more clustered settings.

The conclusions reached by these studies about practice and service system components necessary to support inclusion are broadly similar to those identified as necessary to support other dimensions of quality of life for people with challenging behaviour, which have been articulated by the leading researchers in this field (Carr et al., 2002; Department of Health, 2007; LaVigna & Thomas, 2005). However, Robertson et al. (2004) referred to a number of studies by Emerson and colleagues, for example, that pointed to the low levels of implementation of these types of support in shared accommodation services in the UK (Emerson, 2001, Emerson et al., 2000 cited in Robertson, et al. 2004). The absence of any studies that considered broader environmental factors that support social inclusion echoes the findings of a systematic review on this topic by Verdonchot et al. (2009).

Conclusions

Key questions about the meaning and nature of social inclusion for people with challenging behaviour have not been empirically explored, though writers such as Clegg et al. (2008), Reinders (2002), O'Brien & O'Brien (2002), and Carr et al. (1994) discuss these questions on value based or philosophical planes. The paucity of empirical research suggests perhaps that the research community or those who commission and fund research may have accepted as an

insurmountable *fait accompli* that challenging behaviour is ‘likely to seriously limit or deny access to and use of ordinary community facilities’ and therefore warrants no further investigation. Alternatively it could mean that quality of life has been accepted as a proxy for social inclusion and reliance has been placed on extrapolating from the accepted negative association between quality of life and severity of intellectual disability (Beadle-Brown, Murphy, DiTerizzi, 2009; Felce & Perry, 1995; Thompson et al., 1996), and between propensity for challenging behaviour and more severe intellectual disability (Borthwick & Duffy, 1994, cited in Hassiotis & Hall, 2008).

The small body of research about the social inclusion of people with challenging behaviour means there is a dearth of evidence on which to base decisions about specific psycho-social, behavioural and clinical interventions or the organisation of programs to support social inclusion (Gustafsson et al., 2009; Hassiotis & Hall, 2008; Prangnell, 2009; Balogh et al., 2008). The likelihood that the type of evidence-based practice possible in medicine will ever be replicated in human services has been questioned however (Gray, Platt & Webb, 2009; Reinders, 2010; Pawson, 2006), and it may be that the field will not find the ‘set of algorithms that allows us to proceed systematically from the person centered planning process to ...real world contexts that best promote quality of life’ (Carr & Horner, 2007, p. 5). The field of intellectual disability will have to rely on more diverse types of evidence, and acknowledge the value of case reports, and the evaluation and systemic sharing of day-to-day practice.

The absence of research in this important area reinforces the importance of drawing on the broader substantive bodies of empirical and theoretical knowledge about social inclusion and people with intellectual disability in general, which includes: 1) the beneficial outcomes of moving from congregate to small group living, the variability in costs, quality and outcomes of small dispersed community residential services, and the complexity of practice and organisational factors that impact on resident outcomes (Felce et al., 2008; Lakin & Stancliffe, 2007; Mansell et al., 2008). 2) The Applied Behavioural Analysis, and more recently the Positive Behaviour Support literatures that demonstrate the application of principles from behavioural psychology and begun to theorise and investigate the application and validity of these principles to community settings and the efficacy of models for multi-component interventions (Allen, 2005; Carr et al., 1999a, 199b; 2002; LaVigna & Thomas, 2005). 3) The medical literature that has demonstrated the minimal effect of antipsychotic medication as a means of managing challenging behaviours in the absence of a diagnosed mental illness (Tyrrer et al., 2008). 4) The supported employment literature that has

demonstrated the potential for employment in community settings of people with severe intellectual disability (Brown, Shirga, & Kessler, 2006; Gold, 1978) and; 5) The quality of life literature that has conceptualised and validated eight domains, investigated the association between subjective and objective aspects and continues to investigate the most effective methods of measuring both (Schalock et al., 2002).

The lack of clear definitions and methods of measuring social inclusion present a challenge to the field to reach a consensus about its conceptualisation and the domains to act as common umbrellas or indicators. This would give direction to programs and services about expected outcomes and provide a framework to guide plans for individualised manifestations of inclusion. Existing potential frameworks include that of O'Brien and O'Brien (1987), quality of life (Schalock et al., 2002), and the comprehensive international classification of functioning (2001). Some alignment however, between the indicators of social inclusion adopted in disability policy and those used in broader social policy initiatives is important. This will allow the generation of comparable data through large-scale surveys of life circumstance, such has occurred in the UK through the national survey of people with intellectual disability (see Emerson et al., 2005). Such action may help to remove the relative invisibility of people with intellectual disability (and those with intellectual disability and challenging behaviour) in mainstream policy debate and strengthen the case to regard these subgroups as special populations that warrant additional attention and resources as part of the broader social inclusion agenda.

Comparison with other groups of the population will also draw attention to virtual exclusion of people with intellectual disability and challenging behaviour from many of the indicators of social inclusion being used for the general population (Commonwealth of Australia, 2010, 2009b). The Social Inclusion Board has already undertaken significant work on indicators of social inclusion (Commonwealth of Australia, 2010). An important challenge for the disability sector is to explicate these more specifically in relation to people with challenging behaviour. Indicators of social inclusion/exclusion, such as levels of literacy, access to the internet/technology, voting in elections, living in jobless households, and long-term unemployment, are largely inapplicable and fairly meaningless for people with challenging behaviour and/or more severe intellectual disability. Comparative research may also strengthen the case for more frequent inclusion of specific population subgroups in the large population surveys undertaken by government. For example, while data is available from the Australian Institute of Health and Welfare (2008) about workforce participation and unemployment rates for people with disabilities, there is no reporting for subgroups such as

people with challenging behaviour. Notably too, large scale population studies such as the Australian General Household Survey (Australian Bureau of Statistics, 2006), which include the domain of engagement and social participation for the general population do not report data for people with a disability in general or smaller subgroups.

Finally, ‘improving outcomes for people living with disability or mental illness and their carers’ is one of the priorities identified in the Federal Government’s *A strong, fairer Australia* (Commonwealth of Australia, 2009a, p. 4). If people with challenging behaviour are to benefit from this prioritisation and be included in the broader social inclusion agenda it is critical their particular issues are acknowledged and debated outside the world of disability services, and indicators relevant to their circumstances developed and included in disability and mainstream policy documents.

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