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The ‘implementation gap’ in supported accommodation for people with intellectual disabilities

Foreword for Clement and Bigby (2009) Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation. London: Jessica Kingsley.
(pre-publication copy)

Almost since the beginning, there has been concern that the opportunities inherent in community living for people with intellectual disabilities were not being realised in practice. The strong, consistent policy narrative in many Western countries, that community living arrangements were better than care in long-stay institutions, has been accompanied by a counterpointed theme, that these services are not as good as they should be. Just as results showing exemplary outcomes from demonstration projects were being published, others were publishing results showing that ‘second-generation’ housing projects were not doing as well. Reviews of research have highlighted variation in results and pointed to programmatic and organisational variables as a key source of this variation, along with the characteristics of the people served (Emerson and Hatton, 1994; Kozma, Mansell and Beadle-Brown, 2009; Mansell, 2006).

One response to understanding the reasons for this gap between what has been shown to be possible and what is routinely achieved in supported accommodation has been to argue that group homes – the most widespread form of community living – are themselves necessarily institutional. The argument is that because group homes are organised by service agencies they inevitably come to recreate the institutional care practices of larger congregate-care settings. The key intervention to overcome this is to support people to have their own homes in their own right as citizens and to require services to provide support on terms dictated by the disabled person. Thus the problem is identified as one of the *categories* that the person and their home are placed in. If the person is a resident in supported accommodation run by a service agency, it is argued that it will be a constant battle to overcome the pressures of economy, management and regulation to adopt institutional practices and that eventually the setting will be just a smaller-scale version of the large residential institutions of the past. The solution is to re-classify the person as a private citizen, living in their own home, so that service agencies have to treat people as they would treat other members of the public (Ericsson, 1996; Kinsella, 1993). This has been a popular policy initiative and there is some evidence that people supported in their own apartments or houses, living with people they choose to live with and controlling the kinds of services they receive, experience a better quality of life, at least in some respects (Emerson *et al.*, 2001; Howe, Horner and Newton, 1998; Stancliffe and Keane, 2000). The implication is that a second wave of deinstitutionalisation from group homes to supported living is now required.

The first important contribution this book makes is to examine this position in some detail. The authors point out that a great many people now live in group homes and that it may be difficult to resource and organise a second wave of service development to move people into their own homes. They also make a more fundamental and telling point. For people with the most severe intellectual disabilities, Clement and Bigby point out that they are never in the position of making informed choices themselves about where they live, or with whom, or how they are supported to live their life. The nature of their impairments means that other people – family members, advocates, staff of service agencies, have to make decisions about these things on behalf of the person with intellectual disabilities. Using the language of the person as a private citizen, sovereign in their own home, may be helpful in cueing services

and society to respond to people with intellectual disabilities in certain ways but it is not an accurate account of what really happens.

Thus, in practice, many people with severe and profound intellectual disabilities will continue to live in circumstances largely dictated by other people. For these people, 'supported living' is not likely to be a guarantee of a better life. The task therefore remains, to understand why the quality of life people experience in community settings is often not as good as it could be.

There have been several attempts to suggest answers to this question. Landesman (1988) and Mansell *et al* (1987) suggested that sustaining quality over time was difficult given, for example, staff turnover and shifting management interest and pointed to self-evaluation against resident quality of life as a key intervention. Commenting at a broader, service-system level, Mansell (1996) cited unclear goals and lack of direction, insufficient help and preparation for staff and the absence of monitoring and accountability as causes of poor performance. At an even broader level, Felce *et al* (1998) and Castellani (2005) identify the impact of competing and conflicting policy requirements on the development of community-based services and illustrate how these cut across laudable aims in intellectual disability.

What this book does, for the first time, is to show how these factors play out in the lives of people with intellectual disabilities and the staff who support them. Starting with detailed descriptions of daily life, Clement and Bigby show how staff struggle to find a way through the lofty goals of community living, the substantial impairments of the individuals they support and the context provided by the organisation that employs them. They show how apparently trivial decisions by officials a long-way removed from the lives of the people served cut right across the aims and philosophy of the service staff are trying to provide. The picture that emerges is not only of a difficult task made harder, but of an organisation demonstrating over and over again that it does not understand, nor seemingly care very much, what it is doing to people with intellectual disabilities and the staff it employs to support them. It is an important contribution to the literature to trace the relationship between decisions made elsewhere and the reality of daily life. The rise of general management in human services has been accompanied by an assumed separation between management decisions and care practice, so that senior managers claim that their actions do not interfere with the delivery of good support by staff to the people they serve. This book shows that this is not true - the actions of senior managers directly affect the quality of life of people with intellectual disabilities in many practical ways.

In a sense, then, this book is about a failure of management and leadership. The development of community living to replace institutional care at Kew in Melbourne could be said to be a case study of the wrong buildings, in the wrong places, with the wrong furnishings, staffed by people with the wrong training, managed according to the wrong rules, with the wrong policies, the wrong leadership and the wrong purposes. The good that is being achieved is too often in spite of, rather than because of, the organisation that set up and runs the services.

But it is not as simple as this. The description given by Clement and Bigby could apply to many services in many countries. So this is not just a case study of poor implementation of the ideal of community living but an example of a common problem. Nor is the problem simply that these services were set up by Government rather than by non-profit providers. Some of the best exemplars of community living were set up by Government agencies (Felce and Toogood, 1988; Lowe and de Paiva, 1991; Mansell *et al.*, 1987; Mansell, McGill and

Emerson, 2001) and the efforts of the Victorian Department of Human Services to introduce active support show that they are trying to improve service quality.

Rather, this example illustrates how difficult it is to retain a focus on what really matters in providing services for people with severe and profound intellectual disabilities – the quality of life of the individuals concerned. Thus the fundamental issue is about the strength or importance of the criterion of the quality of life of people with severe and profound intellectual disabilities when judged against other criteria, such as the regulations for worker health and safety, or public building standards, or operating procedures for financial or personnel matters; or at a broader level when judged against organisational principles such as uniformity, reputation and dependence. At present, these demands seem more potent than the quality of life of the individual and whenever they are in conflict with that quality of life they win through.

Switching the balance of power so that the individual's quality of life trumps other considerations requires action on more than one front. First, legislative action to enshrine individual rights is important. If health and safety regulations are used to reduce the risk of staff being injured due to challenging behaviour by preventing the person with intellectual disability from taking part in everyday activities at home and in the community, then human rights and disability discrimination legislation can provide an important counter-balance. Second, evidence of the gap between policy and practice and evidence about what helps and what hinders achieving a better quality of life for disabled people provides a narrative about how things could be different. As Clement and Bigby point out, the rhetoric of evidence-based policymaking provides an important opportunity to debate the impact of decision-making on the quality of life of individual people. Third, political processes have to be used to give priority to the issue. Ultimately, what gets noticed and dealt with is what has a lobby putting its case. People using services (in so far as they can), families, advocates and staff have to work together to build and sustain that lobby as a collective force protecting the vision of community living for everyone, and the practical steps needed to make it a reality.

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