A transformative framework for deinstitutionalisation

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Abstract

Closing the remaining institutions where some people with intellectual disability live is increasingly urgent following government commitment to the UN Convention on the Rights of Persons with Disabilities, the National Disability Strategy and the full National Disability Insurance Scheme. How can the transformative opportunities that this new policy context opens for people leaving institutional care be realised? This article analyses the rights of people leaving institutions by drawing on the data from an evaluation of the closure of three NSW institutions and the related development of four new facilities. The closures aimed to achieve a better quality of life, however the results were mixed. While participation, growing and learning, health and wellbeing, social relationships and autonomy improved for some people, results were not consistent between sites and worsened in some cases. Community inclusion was not the focus of the closures and social isolation negatively affected their quality of life. The implications are that meeting new legislative and rights obligations requires that rather than building new facilities, remaining closures must apply a rights based framework. This includes: taking a person-centred approach to housing support; using closure as a transformative opportunity for community living; identifying people's choices through informed supported decision making; applying sophisticated change management with families, staff and unions; and using the resources, expertise and successful closure experiences from the disability community to inform the process and opportunities for housing support. Applying the framework could draw on the evidence and experience from Australia and other countries.

A transformative framework for deinstitutionalisation

Closing the remaining institutions where some people with intellectual disability live is increasingly urgent following government commitment to the UN Convention on the Rights of Persons with Disabilities (CRPD 2006), the National Disability Strategy (NDS 2010-2020) and the National Disability Insurance Scheme (NDIS). The new policy context opens potentially transformative opportunities for people leaving institutional care. This article analyses the rights of people leaving institutions by drawing on an evaluation of the closure of three NSW institutions and related development of four new facilities, posing some critical questions. Do the outcomes from the closure process demonstrate that the rights of people moving from institutions to community based support were prioritised? If not, what are the implications processes to prioritise the rights of people with intellectual disability in remaining closures?

This article introduces national and international literature on housing support for people with intellectual disability in the current policy context. It explains the methods used to collect and analyse the empirical data through the evaluation, and draws implications for what a transformative framework might look like to maximise the rights of people moving from the remaining institutions. It speculates about how that framework might be applied in the context of preparing for the full NDIS and under the NDS.

Policy context

Closing institutions and supporting people to move into community settings (or deinstitutionalisation) has a long history that many people thought had been achieved in some uncomfortable distant past. However, nearly 8 per cent of all Australian disability accommodation support is institutional accommodation – 2210

people still live in 53 government and nongovernment large institutions, mainly in NSW; small nongovernment institutions (730 people), mainly in Queensland; and nongovernment hostels (519 people), mainly in Victoria (AIHW 2014). Institutions are mostly older style facilities that provide 24 hour residential support for people with disability in a congregate setting of 7-20 people (small institutions) or over 20 places (large), mainly resembling hospital care. The largest group in residential care is people with intellectual disability. This background describes the Australian policy context and institutions in NSW to highlight the reasons why research with implications for a transformative framework for closing the remaining institutions is so vital.

Comparative research on outcomes from living in the community rather than congregate settings consistently finds benefits in inclusion, participation, quality of live and lower risk of abuse and neglect (Kozma et al., 2009; Robinson & Chenoweth, 2011); which contribute to effectiveness and even cost efficiency (Johnson, 1998a, b). People who have lived in institutions and move to the community also experience these benefits, as long as sufficient quality and quantity of housing support, staff management and funding are provided (e.g. Walsh et al., 2010; Young & Ashman, 2004). However, the process of closing institutions also comes at a short term cost and challenges other interests during the transition, including loss of familiarity with the institutional arrangements by the people living there and their families; financial costs of managing the transition, alternative housing and new staff; and loss of jobs and commercial interests (Bigby & Fyffe, 2006; Johnson 1998a,b).

Closing institutions is consistent with the government obligations in Article 19 of the CRPD and the NDS, to support people to live independently in the community. The full implementation of the NDIS is expected to strengthen these possibilities, because the National Disability Insurance Agency has declared that it will not fund support that is contrary to CRPD obligations. In short, this means that in theory all disability institutions in Australia must close by 2018. The benefits of institutional closure are clear, but managing the change remains politically and logistically difficult.

NSW institution closures

Deinstitutionalisation has been a NSW policy commitment since the 1980s. Today, over 1300 people, mostly with intellectual disability, in NSW still live in 31 government and nongovernment institutions, constituting 13 per cent of NSW accommodation support (AIHW 2014: 13, 61). In 1998, the NSW government reannounced a commitment to the closure of all institutions, with no further admissions after 2012, unless in exceptional circumstances, which still occur (AIHW 2014). The policy may finally be implemented with the roll out of the NDIS. People living in the Stockton institution in the NSW NDIS trial site are currently being assisted to plan for their future housing, preparing for the institution closure.

Three institutions in and near Sydney, housing over 160 people, were closed between 2006 and 2010 (Table 2). The Grosvenor Centre had a history of intensive support services for people with intellectual disability in a hospital-style setting. The Centre included 17 respite places for children and adults with complex health care needs and 20 places for permanent housing. The Lachlan Centre was in the grounds of a psychiatric hospital. Eleven apartments were grouped into four units for people with challenging behaviours or high medical physical support needs. Peat Island Centre had 28 buildings, across a 23 hectare site, primarily housing people with intellectual disability.

The closure projects included building four new facilities (Table 3). Summer Hill is for people with intellectual disability and complex health needs (two units with ten bedrooms for adults and two units with five bedrooms for respite services for adults and children). Norton Road is for people with intellectual disability and complex behaviours (10 five bedroom units). Casuarina Grove caters to people with intellectual disability and complex ageing needs (10 units, connected with a shared corridor and amenities, each with 10 bedrooms). Wadalba is contracted to an NGO and comprises four co-located five bedroom group homes. A large part of this closure experience focused on the building of the new congregate care facilities. The focus of this article is to understand the outcomes from the closures, and the implications required for transformative opportunities in the new Australian policy context for people leaving institutional care to improve outcomes in future closures.

Methods

The NSW government commissioned the evaluation to review the process and outcomes of the three closures and transition to new facilities, in order to inform the closures of the remaining institutions (eg. NSW Ombudsman, 2014: p97). The specific research questions, methods, analysis and findings are detailed in the full evaluation report (Fisher et al., 2013). The data collection methods and sample sizes relevant to the specific question in this article are summarised in Table 1. The procedures and content for each method overlapped for triangulated data analysis. Limitations to the methodology included small sample sizes and a union ban on the data collection at one site. Possible implications for the sample representativeness from these limitations were addressed through a mixed methods inclusive research approach. Findings are presented about housing; outcomes for the people who moved; and other outcomes for families, community and staff.

Table 1: Sample sizes

	People with intellectual disability	Family, carers, community	NSW Government
Quality of life face to face interviews and observations	36	16	-
Case file reviews	12	-	-
Process interviews	11	16	16
Total samples	40	17	16
Total people who moved	147**		

Note: **plus 17 people who died before moving

Quality of life was measured in terms of how satisfied people were previously compared to their current situation. The quality of life data that were collected through interviews, case file reviews and case studies were quantified by the researchers in terms of subjective satisfaction from the perspective of the person who had moved from the institution (Heal & Chadsey-Rusch, 1986; Schwartz, 2003). Quality of life was defined as domains relevant to the policy intention of the closures and measurable with a sample mostly reliant on non-verbal communication

(Cummins and Lau 2005; Robertson, Frawley and Bigby 2008; CRPD 2006; NSW Ombudsman 2010). Comparative analysis was based on the data about the new accommodation compared to the Business Cases for closure, the Disability Standards and policy priorities at the time of planning for the closure (Disability Services Act NSW, 1993; Stronger Together, ADHC, 2011; CRPD (Article 19); NDS, 2011). The research team included a person with intellectual disability with personal experience of institutional living to inform the design and data analysis.

Housing after closure

The government intention of the closures was to develop new facilities that reflected the support needs of the people living at the institution (Table 2) and people who require these services in the future. Most people moved to the new facilities. Some people moved in with family, to group homes or to other institutions (Table 3).

Table 2: Characteristics of the people with intellectual disability living in the institutions

	Former institutions		
	Grosvenor	Lachlan	Peat Island
Age (years)			
Range	13-41	31-62	43-88
Mean	19	44	62
Sex		Per cent	
Women	63	24	11
Men	37	76	89
Primary other support needs	Health	Challenging behaviour	Health and ageing
Guardianship		Per cent	
OPG	11	23	22
Person responsible	89	76	65
None or unknown	0	0	13
Level of family involvement			
Frequent	47	45	31
Intermittent	11	36	21
Rare	32	8	22
Nil	5	2	26
Unknown or N/A	5	9	0
		Number	
Total people	19	53	90
Date of Business Case	April 2006	June 2007	November 2006
Date of closure	December 2008	November 2010	October 2010

Source: NSW Government

Note: At the time of the Business Cases

Table 3: Housing destination from former institutions

| Transitioned to	Former institutions		
	Grosvenor	Lachlan	Peat Island
New facilities			
Summer Hill	19	-	-
Casuarina Grove	-	-	54
Wadalba group homes	-	-	16
Norton Road		45	-
Other institution	-	-	5
Other group home	-	1	3
Family	-	1	1
Deceased	-	6	11
Total people	19	53	90

Source: NSW Government

Outcomes for people with intellectual disability moving from institutions

The redevelopment aimed to improve the quality of life of the people who moved. After the move, overall quality of life improved for most people included in the review, in particular their material standard of living. However, the extent of how satisfied individual people were varied by life domain and where they lived. A few people experienced greater autonomy in their own home (e.g. Wadalba), but others had to compromise on space and privacy (e.g. Casuarina Grove) (Figure 1).

Figure 1: Change in quality of life from institution to current housing at all other locations compared to Casuarina Grove (n=40)
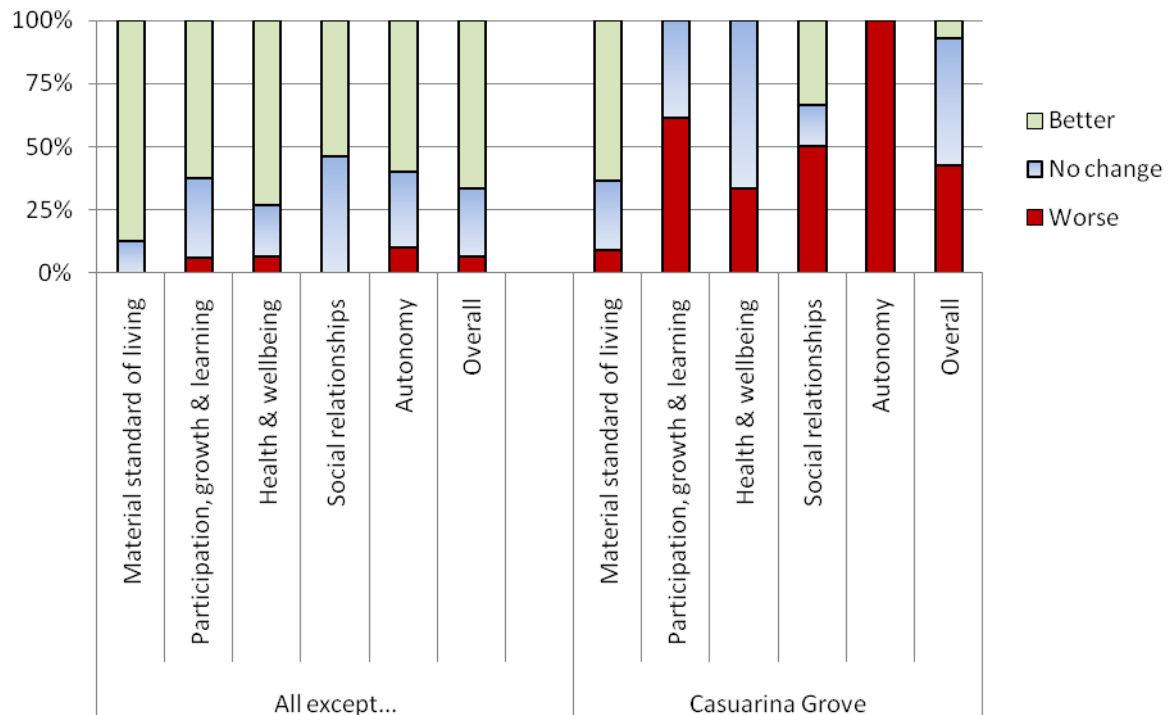
Note: Analysis for Casuarina Grove is presented separately because the sample size was larger and the results differed from the remainder of the sample.

The narrative case studies from the people who moved to new housing reinforce these findings. For example, some people stopped carrying their most precious possessions around because they no longer feared they would be stolen. Many people were proud to show off their new home and private bedroom. They enjoyed their newly gained privacy and ability to personalise their living space.

However, some people said they were worse off after the redevelopment. Some of these people had previously lived at Peat Island, where they had enjoyed relative freedom of movement. After the redevelopment, many were relocated to Casuarina Grove, a purpose built facility to accommodate needs related to ageing, not within walking distance of the nearest town and with poor public transport. Although their material standard of living had improved, their personal autonomy had reduced. The move also disrupted some previous relationships with partners, relatives and friends, leaving some people feeling distressed by separation. They felt unsupported to voice their choice to remain together or to maintain close contact.

The data showed little evidence of people forming new relationships and networks in the local community after the relocation, except for people living at Wadalba, where some community participation was achieved. Here, two people had developed friendships in the local community and participated more in community life. At Casuarina Grove, opportunities for incidental social encounters were constrained by the isolated location.

Participation, growth and learning improved for most people except at Casuarina Grove. In Summer Hill, families said that people accessed internal and external day program activities and one to one supported activities in the community. At Norton Road and Wadalba a mix of day program and community activities were available and some people now participated in domestic chores. In contrast, opportunities for participation, growth and learning reduced for people moving to Casuarina Grove. Some accessed the same external activities, but many people preferred activities which were no longer available in the isolated location.

People living at Summer Hill had complex health and support needs and families commented that medical and nursing care had improved after the move. At Norton Road, people felt more relaxed and less stressed and said they liked their new houses, which felt more like a home. At Wadalba, people reported feeling healthy, comfortable, relaxed and safe. Compared to Peat Island, many said they felt better in their new home. In summary, the evaluation found that the new facilities were traditional group home-style housing, rather than community housing that could have created more options for people with disability to exercise choice and control and to receive person-centred support.

Other outcomes

Families commented on their satisfaction with the modern facilities, better health care for their relatives and peace of mind that their relatives were well looked after. Other aspects family members appreciated included flexibility, increased morale and friendliness of staff, increase in staff training, more involvement in the person's care, and a family-like atmosphere in the new accommodation. While most family members supported the closure from the start, some stated that they were

concerned at first. One family member said, "At first I was petrified … [but now] I am gobsmacked at how beautiful it actually is."

Some families were not satisfied with the communication about the move or access to resources to make informed choices. Some families of people who moved from Peat Island were disappointed about having no involvement in the choice of the location. It appeared that the outcomes for families depended on their previous involvement with the institution, rather than good practice. For many families, their relative had been in care since childhood and therefore they felt inexperienced and overburdened with the expectations of the closure decision making.

There was little evidence about outcomes of the closure for the surrounding communities. The Business Cases intended to create greater community inclusion for people living in the new facilities; however, there was no evidence for most people included in the study except at Wadalba, mentioned above. Even though Norton Road and Summer Hill are close to places where people could interact with members of the community, e.g. shops and cafes, there was no evidence of people having contact with individual community members.

The research found that the workplace change management to prepare for the moves had not effectively built staff capacity to support changes in quality of life for people with disability. The outcomes were compromised as staff were not sufficiently trained for individualised person-centred assessment, planning and implementation. The outcomes for people were greatest at Wadalba, supported through a service delivery approach focused on person-centredness.

Discussion about the implications of the outcomes for closure processes

The findings about the quality of life outcomes demonstrated that the closure process did not meet the intended rights of the people who moved from the institutions. At worst, the quality of life reduced in some domains for some people in the move. From these results it can be presumed that adequate processes were not in place to prioritise the rights of current and future people receiving housing support over other conflicting interests. Conflicting interests in deinstitutionalisation include

workplace change, staff and management challenges and preference from some government officials for congregate care capital investment (e.g. Mansell, Beadle-Brown & Bigby, 2014: McConkey et al., 2004; McGlaughlin & Gorfin, 2004: Johnson,1998a) . Effective governance, change management and risk management processes could have anticipated and addressed these conflicts since they are common to other institution closures. An implication of these findings is that a more explicitly rights-based framework would be more suited to the current policy context to ensure that institution closures are transformative for people with disability. The remainder of this article focuses on what such a framework could include.

Person-centred approach to disability housing support

One way that closure projects are more likely to be compatible with current national and international standards for disability support (CRPD, Disability Standards, NDIS) is by implementing person-centred approaches to housing support arrangements. Person-centred support refers to approaches that emphasise the preferences and authority of the person in the way their assistance is organised (Mansell & Beadle-Brown, 2004). It considers the aspirations and capacities they express, or those speaking on their behalf (Mansell & Beadle-Brown, 2004), which often requires independent, expert support for people with intellectual disability (McConkey & Collins, 2010, Vickery 2007).

Decision making that is person-centred, informed and supported usually results in a wide diversity of choices about support preferences, including housing support (Robertson et al., 2007, Vickery, 2007. Relevant policy experience is available from other social housing policies and specialist support (such as individualised packages and local area coordinators); earlier closures (such as Hornsby Challenge and Kew Cottages); and input from members of the disability community who moved from institutions in the past.

If following a person-centred decision process, sufficient people choose to live with other people with intellectual disability, group housing possibilities include existing social housing, adding to social housing stock, adapting existing social or private housing or build new housing in the community. Only some of these options require particular facilities for people with disability, in which case government capital

investment in specialist disability housing, in addition to other social housing, is then relevant to closure of institutions.

Transformative opportunity for community inclusion

Institution closure has the potential to be a transformative opportunity for community inclusion. The evaluation found that for people in the sites other than Casuarina Grove, opportunities for participation, relationships, autonomy and wellbeing were increased after the move (e.g. the Wadalba group homes). Isolation, lack of autonomy and continued congregate living militated against community inclusion for many people at Casuarina Grove. While a wealth of successful experiences of people with a full range of support needs are well documented in the literature (Beadle-Brown, Mansell & Kozma, 2007; Craig & Bigby, 2014), the persistence of barriers such as these, particularly for people leaving institutions, need to be addressed (Mansell, Beadle-Brown & Bigby, 2014).

A greater focus on community inclusion could be founded on person-centred planning that builds on valued relationships and activities from before the transition and recognises frequent interaction with the local community as a priority for social participation (e.g. Craig & Bigby, 2014, Mansell, Beadle-Brown & Bigby, 2013). A further key for community inclusion is raising awareness about disability inclusion in the wider community, which may need targeted activities related to closures to change community attitudes (Thompson et al, 2011).

Informed supported decision making and communication

An initial step in a person-centred approach to closure is to understand the needs and preferences of people who live in an institution through active informed supported decision making and communication (ALRC, 2014). For each person this requires identifying or developing a meaningful and effective way to communicate their preferences, with commitment to the resources and time necessary for implementing this (McConkey et al., 2004). They may need active, supported involvement of family, a significant friend or carer, guardian or advocate who does not have a conflict of interest.

These processes take considerable time and resources because many people with intellectual disability living in an institution have had limited experience of the small and large decision making implicit in this approach, yet the decisions being made have significant implications for the next stage of their lives. These steps need to be managed by people with experience of informed supported decision making and communication, including peers, professionals and community members.

In these closures, local staff provided information about people with intellectual disability (e.g. communication, preferences etc.). It is particularly important that this information is framed from the perspective of the person's rights and preferences, rather than the resources required to support them. The involvement of an external third party, such as an independent mentor (e.g. Chng et al., 2013) for the person during closure not only opens prospects for people with intellectual disability, but also protects staff from being placed in a position of conflict of interest.

Change management for families, staff and unions

Adopting a change management approach to help families understand the transformative opportunities of community living for their family member is important to address their concerns, reassure them about future security and safety (personal, financial and emotional) and to address continuity of relationships in the short and long term. Families of people with intellectual disability living in institutions have an understandable concern about the wellbeing and safety of their family member (TØssebro & Lundeby, 2006; Walsh et al., 2001). Many families have previous institutional experience in which they were powerless in decisions about their family member. Although they may have been aware or unaware of wellbeing and safety breaches within the institution, they are likely to know even less about risks outside that environment. They are unlikely to know much about person-centred approaches to community living, because they have no prior experience of it. A change management approach should therefore rely on relevant experiential knowledge from people who formerly lived in an institution and their families (external mentors) who have gone through the experience of deinstitutionalisation or live independently.

Institution closure also requires sophisticated workplace change management at an organisational, individual and union level. To protect staff from conflicts of interest,

closure processes need to clearly delineate between roles that require staff to consider their professional self-interest and the roles where they must prioritise the needs of people with intellectual disability in the processes described above (Mansell, Beadle-Brown & Bigby, 2013). Individual plans for each staff member, including training, supervision and performance review are required to enhance workplace change management targeted at staff. Implementing person-centred approaches in an institution is a significant cultural change and requires practice change across a whole organisation from management to direct support staff.

Change management resources in the disability community

The framework derived from these findings requires considerable iterative expertise and resources drawn from within and outside government. A beginning point would be to draw existing resources together for use by people with the responsibility and commitment to implementing this approach, including people with intellectual disability, families, government managers, staff, disability community members and independent government and nongovernment advocates. A shared community of interest in transformational practice can document good practice so that future closures can learn from previous ones.

Existing resources and expertise include materials, stories and connections to people in the disability community who have experienced successful closure to inform the process and frame opportunities for future housing support. More innovative options for living in the community can include: drop-in specialist support in people's homes and single person homes in the community; person-centred approaches to increase access for people with intellectual disability to funding for home modifications, respite support, shared care and high level attendant care for people with intellectual disability to live independently or with family. These types of services offer specialist support suited to people's individual needs whilst creating opportunities for greater choice and control, flexibility and community inclusion; and transformative opportunities for community living and implications of person-centred approaches.

Community engagement is a specialist skill and support staff would benefit from training in this area in future. Some disability organisations employ community

engagement specialists, who provide expert support and advice in creating closer links with the community. Similarly, local self-advocacy groups offer training and aim to create awareness about disability issues and are therefore a beneficial resource for both people with intellectual disability and community members. Self-advocacy groups provide a range of valuable supports for people with intellectual disability, empowering people to make their own decisions, speak up for themselves and achieve maximum independence. To magnify the role of self-advocacy groups in future closure projects, proper funding separate from services needs to be ensured for their involvement.

Conclusion – how can the rights of people with intellectual disability be prioritised in remaining closures?

The empirical analysis in this article demonstrated that improving people's quality of life was not fully achieved in the closure of these institutions. Future closures of institutions will need to consider the implications of the opportunities envisaged in current national and international disability policy directions to address that shortcoming. In Australia, these include the implications of the CRPD, as articulated in the NDS and the support policy reorientation in the NDIS. Change processes require the commitment of resources to support people in new ways to make and act on decisions about moving to new housing arrangements of their choice. It requires radical culture change for most people involved, including those who support people in transition. Most importantly, to be transformative, deinstitutionalisation approaches need to invest in the development and sustenance of relationships with a range of people in order for people with intellectual disability to thrive.

In some places community resources are available to make that possible, particularly from peers who have already had positive experiences of alternatives. The inclusion of all stakeholders – people with intellectual disability, families, staff and advocacy bodies – during closure planning helps to gain understanding about the possibilities. Through sharing information about good practice, successful examples, and international standards, the involvement of community members during project implementation can open new possibilities at the levels of practice and political acceptability.

Grasping the opportunity for transformative deinstitutionalisation requires above all a focus on the rights of the people leaving the institution, and prioritising these rights over the sometimes competing voices of other stakeholders. There is a substantial body of evidence and experience to support a transformative approach, at national and international levels. Such a framework requires a capacity development approach to change involving all stakeholders (central and line managers, staff, families, people with intellectual disability and community members), including allowing adequate time and resources for developing understanding of and comfort with large and small scale decision making. Further, it includes taking a person-centred approach to housing support; approaching closure as a transformative opportunity for community living; identifying choices through informed supported decision making and communication; applying a sophisticated change management approach with families, staff and unions; using the resources, expertise and successful closure experiences of the disability community to inform the process and frame opportunities of future housing support.

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