

Debating Deinstitutionalisation: The Fire at Kew Cottages in 1996 and the Idea of Community

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NINE MEN DIED LATE ON THE NIGHT OF 8 APRIL 1996 WHEN A FIRE RIPPED through Unit 31, a locked ward in the men's section of Kew Residential Services, Melbourne. Known popularly as Kew Cottages, and built in the grounds of Kew Hospital for the Insane in the 1880s, this was Victoria's largest institution accommodating people with intellectual disability. The men died where they had lived out most of their lives, in an institution established 110 years before, and still used to house more than 600 people. Kew Cottages was an anachronism, a relic of long-forgotten policies, retained by successive governments as a place of last resort for intellectually disabled men and women, as other institutions were closed and their residents moved out mostly into homes in the suburbs. As seems to have happened frequently in the history of Kew Cottages, the fire caused but a brief frenzy of interest and was soon forgotten.

The fire raised four immediate issues. What caused the fire? An inquest that handed down its report in 1997 concluded that a resident had lit it. What had happened to Kew's safety system? It quickly became known that the alarm system was inadequate and that there was no sprinkler system in the unit. Its installation had been delayed because there was asbestos in the roof. What were the effects of cuts to government funding on staffing at Kew? It was well known that successive governments had neglected the institution and reduced funds whenever they could. However, the election in 1992 of the fiercely neo-liberal Kennett government, and a savage cut to all areas of government, had resulted in a major cut to Kew's funding. While the government denied that this had affected direct care staff, on the night of the fire there were still only two night staff on duty in Units 30 and 31 to look after forty-six people. Had the government abrogated its duty of care to the residents? The government denied this, of course, but the inquest established beyond doubt that it had contributed to the deaths by neglecting to have a fire safety system installed.¹

In the debate about who exactly was to blame for the fire, the issue of deinstitutionalisation was a secondary consideration ignored by the

inquest. Yet in the immediate aftermath of the inquest the issue was raised, at times with considerable bitterness. Had the residents of Kew Cottages been sacrificed at the altar of deinstitutionalisation? At the end of the twentieth century should such institutions even exist? What might be better alternatives? If there were better alternatives 'in the community', how would the institutionalised residents of Kew Cottages survive?² This article addresses the question implicit in this debate: if residents were to be relocated in the community, what kind of community would it be? It argues that the opponents of deinstitutionalisation regarded the community 'out there' as all but dystopian, and that proponents of deinstitutionalisation regarded it as utopian. Neither group seems to have been able, or prepared, to give the question detailed consideration, yet their opinions about the future of the residents of Kew Cottages, and of deinstitutionalisation itself, depended on their constructions of community.

This article sets out the origins and meaning of deinstitutionalisation in the field of intellectual disability, examining first its associated doctrine of normalisation and, second, the way the proponents of normalisation conceptualised community. It will then examine the history of deinstitutionalisation of people with intellectual disability in Victoria, before moving on to explore how proponents and opponents of the process conceptualised community, how they appropriated the literature about community in their writing about normalisation, and to what extent they used other sociological and political writing about community to formulate their arguments. The article uses the fire as a focus to examine the issue but goes beyond it to explore the debates among parents and advocacy groups across the 1980s and 1990s, as the history of deinstitutionalisation in Victoria unfolded. It concentrates on STAR (originally the State Association for the Retarded, but by the 1990s known as the Victorian Action on Intellectual Disability), an advocacy group committed to deinstitutionalisation, and the Kew Cottages and St Nicholas Parents Association, and the Community and Institutional Parents Action on Intellectual Disability (hereafter CIPAID), fierce opponents of the community option.

As much of the debate about community has centred on Kew Cottages, this paper will briefly set out its history. Established in 1887 in a moment of optimism as a school for so-called 'idiot children', Kew Cottages' existence was premised on the belief that such children could be educated to good effect—if not to take their place in the community, then at least to contribute to their well-being.³ However, as occurred in similar institutions around the Western world, this optimism was soon replaced with the conviction that people with intellectual disability were a danger to the race ('the menace of the feeble minded') and should be permanently segregated. The chill wind of eugenics might have

passed by World War II, but permanent exclusion remained the lot of generations of residents who lived and died in the institution.⁴

Many scandals have marked the history of Kew Cottages. Its history is also a catalogue of abuse and neglect, of run-down, ramshackle and unhygienic buildings, of residents with nothing to do: in short, of wasted lives. However, over time changes did occur at Kew Cottages. Periodically, governments and the public, shamed by exposés of neglected children and idle adults, spent money on small alterations such as improving domestic architecture, building new facilities, employing new therapies, and providing new programs.⁵ In the 1980s and 1990s attempts were made to ‘normalise’ Kew by dividing some wards into ‘flats’, establishing gardens and increasing day programs in an attempt to improve the residents’ quality of life.⁶ The number of residents continued to rise, from 232 in 1900 (including eleven who were ‘boarded out’), to 431 in 1930, to 944 in 1971.⁷ By the time of the fire, Kew accommodated more than 600 residents. Just under half of these had high support needs, many with challenging behaviours that required supervision, while the rest needed only moderate or little support. According to the *Age* newspaper, 156 residents were confined daily.⁸ Immovable, intractable, Kew Cottages became the last frontier in the struggle for deinstitutionalisation in Victoria. Even the 1996 fire did not move the then State government to close Kew. Instead it spent large sums doing what previous governments had done: renovating existing structures and trying to make it a little more liveable.⁹ Yet Kew Cottages remained the institution it had always been.

Deinstitutionalisation

The deinstitutionalisation of people with intellectual disabilities has accompanied other deinstitutionalisations of people with psychiatric disorders from mental hospitals and the short-lived policy of decarcerating people from prisons and juvenile detention centres. The logic was similar in all these cases: that institutions did not work; that they caused more problems than they solved; and that the community, where these problems had their origins, might be the best place after all to look for solutions. In addition, civil rights concerns, new emancipatory politics, and a more prosaically political concern by governments with costs, all added weight to what, in the fields of intellectual disability and psychiatric illness, seemingly became unstoppable movements.

The deinstitutionalisation of people with intellectual disabilities seems a simple enough process. It has three elements: the expectation that parents would bring their children up at home; that governments would consequently stop admitting people to institutions; and that insti-

tutions themselves could be closed and residents relocated into houses in the community where they would be supported by trained staff. Deinstitutionalisation was to become associated with the belief that the community was a source of integration, inclusion and renewal.

The deinstitutionalisation of people with intellectual disabilities was also associated with, and indeed was based on, an idea particular to the field—normalisation. First implemented in Denmark in the late 1950s, then developed in Sweden in the 1960s particularly by Bengte Nirje, normalisation has dominated policy in Victoria since the 1970s. Normalisation means that people with intellectual disabilities should live, and indeed have a right to live, as normal a life as anybody else, rather than an abnormal life based on what other people think their condition requires. Normalisation came to be seen as the obverse of the artificial life in institutions; that is, living in ordinary housing, ideally dispersed throughout the community, with normal daily, weekly and annual rhythms, living through the normal life cycle, being educated, working, enjoying recreation, accessing benefits and services. All these ends, argued the normalisers, had become subordinated to institutions' needs for efficiency. Normality could best be returned to people when they were living in the same way as everybody else.¹⁰

This immensely powerful idea was reformulated in the 1970s and 1980s by the North American sociologist Wolf Wolfensberger, who had already written about the way that socially constructed images of people with an intellectual disability shaped the way in which they were treated. In a major text written in 1972, Wolfensberger shifted the emphasis from providing people with intellectual disabilities with a normal life to re-creating them in socially valued roles. He set out the terms in a new definition: 'The utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors or characteristics which are as culturally normative as possible.'¹¹ By the 1980s he wanted to establish some clarity in policies that, he said, were too often based on confusion between a desire to provide people with a normal life and a desire to make them normal. He coined the rather unwieldy phrase 'social role valorization', which as Brown and Smith put it 're-emphasises the centrality of supporting individuals in attaining socially valued roles, rather than a specious conformity'.¹² Thus, he surmised, if people with intellectual disability could acquire socially valued roles in the community then acceptance and inclusion would follow. As a policy—and, later, a program—it neatly turned on its head the devaluing of people and their consequent exclusion.¹³

There is a certain taken-for-grantedness about the concept of community in this writing on normalisation: nowhere is it explicitly defined or critiqued. In the writing emanating from Scandinavia the commu-

nity was where ‘normal’ things happened, where the ordinary, everyday life which normalisers wanted could be mined for programs for their intellectually disabled clients. In 1969 Gunnar Dybwad summarised the major tenets of normalisation:

Maximal integration is achieved by the retarded person who lives in an ordinary family setting, in ordinary community housing, who moves and communicates in ways typical for his [*sic*] age, limited though they may be, and who utilises, in typical ways, typical community resources such as schools, churches, hospitals and clinics, bowling alleys, swimming pools and job placements.¹⁴

Community was conceptualised through things that ‘normal’ people did in their life cycle—such as going to school, discovering sexuality, getting married—and accessing both the resources, like government services, that were to be found in a ‘normal’ world and the institutions—churches, families, hospitals—which ‘normal’ people inhabited. It can be seen in the key words and phrases that dot the literature—ordinary, everyday, typical. The community was, well, normal!

The community is always in the background of Wolfensberger’s work. Much more inclined to use the language of North American sociology than the Scandinavians, Wolfensberger’s concept of community is expressed by phrases such as ‘social integration’, the ‘culturally normative’, the ‘mainstream culture’, and ‘primary and intermediate social systems’. The culturally normative is his key concept and it can be found at three levels: firstly what he calls societal systems; secondly, primary and intermediate social systems; and, thirdly, the person.¹⁵ Like the Scandinavians he does not spell out the meaning of community, but it is clear that community is his middle category, where people with intellectual disabilities can access ‘generic government services’—schools, doctors, dentists, recreational facilities—and where they can interact with ‘normal’ people—in a workplace community, for example—on a day-to-day basis. Again, key words dot his writing—neighbourhood, family, ordinary, typical.

Hints about the nature of community can also be found in the other side of Wolfensberger’s work, specifically in the programs he developed—PASS and PASSING, the latter standing for Programme Analysis of Service Systems Implementation of Normalisation Goals—to implement the normalisation principle. Services are judged in comparison with ‘valued activities, settings and systems’, neighbourhood settings that ‘blend in’, the available ‘ordinary resources’, ‘proximity’ to ordinary resources, mixing in with ‘the public’.¹⁶ Although Wolfensberger clearly has an idea of community in mind, it seems to be as taken for granted as it was by his Scandinavian predecessors.

Victoria seems to have become aware of the principle of normalisation in the early 1970s. In a letter to the *Age* newspaper in 1973 a STAR spokesperson wrote: ‘All over the world, except in Victoria, there is a visible recognition of what is known as the normalisation programme.’¹⁷ At the same time the then head of the Health Department made it clear that he did not favour more expenditure on big institutions, and, in 1976, the Victorian Mental Health Authority formally adopted normalisation as its key objective.¹⁸ Another major step in the recognition of the principle arrived in 1977, when a committee of specialists set up to advise the Victorian Liberal government on issues relating to intellectual disability recommended the adoption of the principle of normalisation, as it was used elsewhere in the 1970s.¹⁹ The then Minister for Health wrote in a memorandum to other ministers:

There has during the last decade or so, been a complete re-orientation in thinking regarding the needs of the mentally retarded, and the way of coping with their needs. Throughout the world there has been a move away from hospital-type buildings and institutions towards hostels and group housing as similar as possible to those which exist normally in the community: away from the medical and nursing approach, except where it is appropriate, towards a psychological social and educational approach: away from the centralization of services for the retarded towards decentralization and the provision of services and care as much within the community as possible.²⁰

Accompanying the doctrine of normalisation was an implicit shift in the model of care for people with intellectual disabilities: from the ‘medical model’, where intellectual disability was defined as a medical problem, an incurable illness and dealt with by seclusion, to a developmental model, which implied that there were no necessary limits to the potential of such persons and that the proper people to provide for them were those who could enhance their development—teachers, psychologists, and therapists of various kinds. And because normalisation was, in part, a product of the growing belief in the civil rights of all people, a normal life in the community came to be seen as the inalienable right of people with intellectual disability as human beings. This has come to be seen as the ‘rights model’ of care.²¹

At the time that Victorians discovered the principle of normalisation there were approximately 3600 people with intellectual disability resident in eleven separate institutions: 925 at Kew, another 825 at Sunbury Training Centre (located in a town just north of Melbourne), and smaller numbers in the rest, accommodated in wards with an average of about thirty-five residents in each.²² In 1973, Kingsbury Training Centre in Melbourne’s north was opened to prepare residents

for day-training centres, sheltered workshops and hostel accommodation, and there is evidence of residents trickling out of training centres in the late 1970s.²³ Normalisation, however, won its biggest prize in 1981 when the State government took the decision to close St Nicholas Hospital, an institution for severely disabled ‘children’ in Melbourne’s inner city. St Nicholas was a good candidate for closure. It was gloomy and run down and had been the centre of considerable controversy in the 1970s when a worker there, Rosemary Crossley, alleged that some of its residents were of superior intelligence. The sale of the property promised to fund the purchase of enough group homes (by now called Community Residential Units or CRUs) to house all of its 120 or so residents. Ranging in age from six months to twenty-four years—it was a common fate of institutions ostensibly for children to become warehouses for the same children once they had grown up—the residents of St Nicholas were successfully relocated in a process that took just over a year.²⁴ One parent expressed views that would become common as other institutions were closed and, in so doing, ratified the normalisation process:

It’s unbelievable. I cried and cried the day she moved. I’d repressed all the feelings I had when I put her in St Nicholas ten years ago, and the night before she moved out it all came back. I hadn’t been able to face it for those ten years. Now it was ended. I felt released. I never dreamt [she] could live in such a beautiful place as this. Now I feel it is proper that she should live away from me. She’s nearly 18, when many, many girls move to their own place. And she looks so happy.²⁵

The then Labor government shifted its attention to mental hospitals for the rest of the 1980s, closing Willsmere (formerly Kew Mental Hospital) and Allambie, and reordering the administration of its services for people with intellectual disability. In 1986, the government shifted responsibility for disability services from the Health Department to the Community Services Department, putting the last administrative nail in the coffin of the medical model. It also passed through Parliament the *Intellectually Disabled Persons’ Services Act 1986*, which required service plans to be developed for each individual in the system to enable them to reach their full potential.²⁶ The process, however, was not always straightforward. Towards the end of the 1980s, the government declined to implement the recommendations of another report that recommended further closures.²⁷

The Victorian government continued to relocate residents away from its institutions. With an end to new admissions and with often high mortality rates, numbers in residence fell from 3200 in 1982 to 2700 seven years later. Eight training centres existed solely to accommodate

people with intellectual disability, while another three were run jointly by intellectual disability and psychiatric services. That there were only sixty children in training centres in 1989 shows how quickly normalisation was changing the face of care in Victoria.²⁸

Governments recommenced deinstitutionalising training centres in the early 1990s when Caloola, the former Sunbury Training Centre, was closed: 218 residents were relocated to group houses, forty-three were sent to nursing homes and the rest distributed to other institutions. By June 1992 there were 1963 residents in training centres. A year later, when Mayday Hills at Beechworth and Aradale at Ararat were closed, the number had fallen to 1126. St Gabriels was closed in 1994 followed by Janefield and Kingsbury, in the outer Melbourne suburb of Bundoora, with most residents moving to group homes, although, significantly, about 100 were re-housed in a new village complex on the existing site.²⁹ By the end of the century, after further movement out of Kew, fewer than 800 people remained.³⁰ Then, in 1999, the Kennett government announced that it would close Kew Cottages, a decision ratified in 2001 by the new Bracks Labor government. Kew was finally to close by 2010.³¹

Most proponents of deinstitutionalisation tend to depict this process as a fairly smooth one with, on the whole, happy results. There have, however, been counter-arguments that come from within their own camps. A follow-up survey of former residents of Caloola, five years after relocation, found mixed results. While most residents had been physically located in the community the survey found that there had been minimal social integration and few meaningful interpersonal relationships had blossomed. Similarly, family visits had not increased, nor had the residents' independent living skills.³² All three of these were basic pillars on which the logic of deinstitutionalisation rested. Furthermore, Kelley Johnson, whose superb study analyses the closure of 'Hilltop' (a euphemism probably for Caloola) and the relocation of female residents from a locked ward, found the process riven by argument, anguish and trauma. She also found that the discourses of intellectual disability which framed the residents changed little during the process, even though it was underpinned by the language of rights:

Far from challenging or reshaping the discourse in which the women were positioned, the de-institutionalisation process sustained and even amplified it. ... The women's resistance to their positioning within the discourse, was either unheard or reconstituted as part of it.³³

The survey of former Caloola residents still thought the process worthwhile and that the advantages to the residents outweighed the disadvantages. On the other hand, Johnson, an activist with STAR and

committed to deinstitutionalisation, came away from nearly two years of action research with the women at 'Hilltop' deeply ambivalent about the process.³⁴

Discourses of community and deinstitutionalisation

This article now turns to the discourse about community among the proponents of deinstitutionalisation in Victoria. STAR, the State Association for the Retarded as it was first known, was and is one of the foremost advocacy groups in Victoria for people with an intellectual disability. Established probably in 1970, it was one of a number of such organisations: others were the Villamanta Legal Service, People First, Janefield Speaks Up, Reinforce, Say It, Westernport Speaking Out, Westmove, VICRAID (Victorian Residential Association for Intellectual Disability), and VALID (the Victorian Advocacy League for Individuals with Disability), the umbrella group for advocacy groups. With few exceptions, all these groups developed and maintained strong support for the processes of deinstitutionalisation and normalisation.

When proponents of deinstitutionalisation spoke about community, they meant two separate things. At one level, community was just a place, a home in the suburbs, but the opposite, nevertheless, of the institution and all that the word implied. On the other hand, community meant neighbourhood, family, diversity, and participation. The community in this discourse was utopian, generous, welcoming, open-hearted and rich with diversity and opportunity. Proponents of deinstitutionalisation did not spend much time analysing the concept of community. They knew that it involved everyday things—such as freely engaging in work, education, recreation, shopping, having a home, privacy, and the right to determine daily lives. There was, however, much more. What Jim Brown reproduced in the STAR newsletter in 1991 typifies the utopianism that shaped the movement's language:

Living in the community means living in relationship with others and being accepted and valued for who one is and what one has to contribute, to exercise as much control as possible over one's life and to be able to participate in a valued way.³⁵

Wolfensberger himself could not have expressed the aspirations of normalisation any better.

The proponents of deinstitutionalisation based much of their sense of community on the belief that real communities could become something better if people from institutions were relocated within them. Jan Harper, reviewing the relocation of the residents of St Nicholas

Hospital in 1984, showed how relocating people in the community could enrich *everybody's* lives:

Although it may not be aware of it yet, the community too is gaining by the project. 'People next door' are turning into real neighbours, offering their services, giving support to staff, entertaining residents and attending their barbecues and house warming parties. Tram travelers, motel clientele, patrons of restaurants and entertainment events are realizing that the disabled people in the community can live normal lives and participate in normal activities. Their lives are being enriched.³⁶

Ethel Temby, from STAR, expanded on the idea in 1995:

To ensure people with intellectual disabilities are included in society is of the utmost importance. They have vital lessons to teach the rest of us. It is only by direct experiences and contacts with persons who have intellectual disability that attitudes of ignorance and prejudice will be broken down.³⁷

Teaching tolerance would:

enable the possibility of renewing family and neighbourly links and also retain the natural population properties of people with disabilities and others. It assists assimilation and integration and helps to complete the population diversity that makes a whole community.³⁸

Enriching communities and overcoming prejudice were common aims of the proponents of deinstitutionalisation. However, Temby's argument that society had, in the past, been diminished through the exclusion of categories of its members and could be renewed by re-integrating them took the ideology of deinstitutionalisation to a new level.

The proponents of deinstitutionalisation used a concept of community that was both descriptive and prescriptive. With few reservations they believed that all the requirements for a rewarding community life for people from the institutions were already there. Yet they also believed that the community could be educated to welcome people from the institutions and that the presence of those people would make for a better society. What is common to these depictions is that community is dynamic, fluid and constantly changing, but, more importantly, that community is capable of being changed for the better. In this sense, STAR was acting as other communitarian organisations do—building community, in this case, through building diversity.

Proponents of deinstitutionalisation always grounded their depiction of the community in doctrines of rights. One of STAR's key prin-

ciples stated that: ‘All people with intellectual disability have the same rights, same value and the same worth as any other member of the community.’³⁹ And as Tom Roper, then Minister for Health, put it in 1984 when opening the first CRU for former residents of St Nicholas Hospital:

It is a milestone in Government policy towards the disabled and an affirmation of the fact that the State Government and the Health Commission recognize that intellectually disabled people have the same rights and needs as all citizens.⁴⁰

The community, where residents of institutions would be relocated, was an egalitarian one, and ideas about rights, value and worth were appropriated to define this egalitarian discourse, as was a belief in the ‘richness’ of community. The community alone could provide a ‘rich choice of leisure and recreation’, and a ‘rich network of relationships’.⁴¹ Former residents of St Nicholas Hospital and Caloola now led ‘enriched lives’.⁴²

Another depiction of community that can be found in the writings of the proponents of deinstitutionalisation is that the community option works. On hearing about plans for the village settlement at Janefield, the STAR newsletter wrote:

It is astonishing that here in Victoria plans are afoot to establish just such a village in 1995... It is worth remembering that recent research published by academics at Latrobe University in regard to the closure of Caloola has again stated the finding of many similar research studies, ‘that a focus on the value of community placements for people with intellectual disabilities be maintained and promoted’, and that ‘overall the study lends substantial support to the delivery of community based residential services for people with intellectual disabilities’.⁴³

That the later report on the relocation of Caloola’s residents gave less than substantial support to the process would not have undermined, nor did it, STAR’s general commitment to the idea. Finally for STAR, the fire at Kew was overwhelming evidence that institutions were inherently dangerous. As Gary Steadman, STAR president, told the Australian, ‘The risk of something like this happening is so much greater in institutions. ... Had the people in Kew been living in the community, this wouldn’t have happened.’⁴⁴

In Victoria two organisations represent the views of those opposed to the process of deinstitutionalisation of people with an intellectual disability. The Kew Cottages Parents Association (KCPA) was formed in 1957 and expanded in 1964 to include the parents of children at

St Nicholas Hospital. It has always acted as a pressure group, prodding government to improve conditions at Kew Cottages and raising funds to provide services that governments would not. By the late 1970s it had to confront new ideas like normalisation, which were radically different from those it was used to. The KCPA opposed the deinstitutionalisation of St Nicholas Hospital, and appears to have been gratified by the slowing of deinstitutionalisation in the later 1980s. However, it found itself increasingly isolated as deinstitutionalisation again gathered pace in the 1990s.⁴⁵ It was probably in the 1990s that it became part of an umbrella group of parents' associations called the Community and Institutional Parents Action on Intellectual Disability (CIPAID). The 1996 fire, which exposed Kew Cottages and intellectual disability services to public scrutiny, gave both organisations a much higher profile than they had ever before experienced.

At the outset it must be said that the parents' organisations did not hold to a completely consistent line on the process of deinstitutionalisation. From time to time they would suggest that they did not oppose community options for those who could, with adequate support, cope well, or for those whose parents wanted them out of Kew Cottages.⁴⁶ However, as organisations they formally represented parents who had committed their children to institutions and who were also committed to their permanent institutional placement. Their perception of the community must, therefore, be seen in these contexts. One critic of the Kew Cottages Parents Association's opposition to the closure of St Nicholas Hospital pointedly suggested in 1985 that:

Parents in other institutions felt that if it was shown that it was possible for their children to live in the community, how were they justified in sending them to an institution in the first place?⁴⁷

And it may be, as was suggested in one newspaper, that places like Kew Cottages were 'held in place by parents who don't trust governments and fear their children will be turned out and eventually returned to them'.⁴⁸ Yet it should be remembered that at the time of institutionalisation, from the 1950s to the 1970s, the only advice ever given to parents was that they must institutionalise their children. Why they had done so was not an appropriate question for the 1980s and 1990s. Rather, the question should have been whether their children should remain institutionalised and if not what would the alternative be? Whatever the alternative was for the parents' groups, it was not out in the community.

These parents' organisations have always had a bleak and dystopian view of the community, of what it was 'really like out there', yet they routinely separated the community 'out there' from the more com-

fortable idea of community as something safe and all-embracing. This is made clear in the following passage from the KCPA's newsletter written in 1997 about the residents of Kew.

We make clear our strong objection to the push of residents into the 'community'. Would not an appropriate development at Kew Cottages constitute a community? What is it about [sic] this so called external 'community' which makes it preferable to all other forms of accommodation? The Cottages community—as indeed it is—is a safe and social environment for residents who are essentially very vulnerable people. Put them in the community and you instantly isolate them from all their accustomed contacts. Show us, we ask, the residents who, when moved to community houses, successfully become part of the community? Are friendships developed with neighbours and shopkeepers? Can they walk the streets and go shopping safely? Or is the reality for these relocated residents an isolated existence in an anonymous and sometimes threatening suburbia?⁴⁹

Another parent, of a Janefield resident, referred to the outside community as 'at best, uncaring and often antagonistic'.⁵⁰ Yet another described it as 'troubled' and 'frantic'.⁵¹ From time to time, to illustrate this argument, newsletters ran stories about people for whom deinstitutionalisation had not worked. One young woman, for example, was arrested in a city hotel after:

she had been talking to 3 or 4 groups of people in the bar and the manager decided enough was enough and told her to leave. When she refused he fetched three policemen. She still refused and resisted arrest. She was arrested and went to court on 9th August.⁵²

The dangerous, threatening and isolating community was constantly compared and contrasted to the safe, secure and familiar community of the institution.

However, despite their hostility to the community 'out there', the opponents of deinstitutionalisation were compelled to recognise the sheer power of the idea of community, its undeniable attraction, the power it held over the public, politicians and service providers. As we have already seen, one strategy adopted by opponents of deinstitutionalisation was to appropriate the word 'community'—insisting that institutions were communities in their own right, insisting that Kew Cottages was already part of the community, or describing their ideal of the village, cluster system of accommodation as a community. CIPAID, of course, had included the word in its title. In 1995, the organisation wrote a submission to the then government's Intellectual Disability Taskforce:

I hope this Task Force will abandon the misleading dichotomy between institutions and group homes and recommend instead a policy of diversification so that a range of accommodation facilities, to include institutions and cluster housing, is developed to meet the needs of intellectually disabled people and allow changes in residence as they and their needs change. The pejorative dichotomy between institution and group homes, so that one of them is described as community living whilst the former is linked to incarceration should be ended. Either or both maybe a form of community living, dependent on the way they are run and the quality of life of residents.⁵³

Two years earlier the Kew Cottages Parents Association had written in similar vein:

Clients are not locked away from society [in Kew Cottages]. No, they live in their own houses called units in the Kew society. Many of Kew's residents go out into the community to buy their clothes, have their hair cut, go for afternoon tea or meals, go to the pictures in the city. When you go to Doncaster Shopping Centre you can always see some of the clients shopping or having a cuppa.⁵⁴

In reality, though, retaining Kew Cottages was not the first preference of either CIPAID or the KCPA. The latter made it very clear after the fire that it disapproved of renovating the damaged units. Most of all they wanted village settlements or cluster housing on the grounds of the existing institutions, where their children could live in a 'real community', live 'normally' in real homes, separate but protected from the outside world. As the President of CIPAID, Bob Riddiford, wrote to the *Age* on the morning after the fire:

Surely [the residents of Kew Cottages] have been crucified long enough for being born disabled and now is the time for their resurrection through funding adequate enough to enable them to live in decency in group houses, clusters or hostels according to their choice, on the redeveloped Kew site.⁵⁵

Their ideal was described in the early 1980s by the secretary of the Janefield Auxiliary:

Janefield—the land divided into building blocks with roads, kerbs, small parks, a milk bar, post office, newsagent, hairdresser etc, and interspersed with cottages for the residents. The remaining land to be sold to the public for housing, ensuring that the people who did build there would know and accept the intellectually handicapped people living among them.⁵⁶

The Kew Cottages and St Nicholas Parents Association described a somewhat less bucolic scheme in 1998:

Villa housing at Kew will have the appearance of an attractive housing estate. Homes will be grouped around tree-lined streets and be surrounded by the established parkland of heritage significance. The proposal envisages a mix of four to six bedroom dwellings with communal lounges and kitchens equipped with purpose built furniture and appliances. The Department has already set the example at Janefield and Kingsbury redevelopment which was opened in October 1997.⁵⁷

Successive governments rejected cluster housing for Kew, and to the proponents of deinstitutionalisation it still smacked of an institution. Yet in the Kennett government's redevelopment of Janefield, it had allowed and built precisely that, a cluster complex it called Plenty Residential Services.⁵⁸ Kew Cottages Parents Association, however, was never able to get the government to build such a cluster at Kew.

It seemed self-evident to the parents' associations that the community would never welcome their children. As one parent put it in 2002, he feared that his son would become 'a visual object in the normal society'.⁵⁹ Yet a KCPA newsletter published that same year all but suggested deliberately making a spectacle of the residents of Kew Cottages. In response to a Disability Services brochure, handed out to neighbours on either side of a planned CRU, which had asked the question 'what do people with intellectual disability want from life?', and answered 'the same as everybody else', the newsletter had begged to differ:

Parents would be delighted if their sons and daughters could ever achieve [this]. Wouldn't it be more honest to say that many of them have disabilities that preclude them from participating in the above delights, ie, behavioural problems.

It went on, angrily ironic:

Perhaps a better way to enlighten prospective neighbours would be for the relocation teams to run some coffee mornings at Kew and give the neighbours a chance to meet the residents.⁶⁰

Apart from their stated objections to deinstitutionalisation, the parents' associations also worked with several unstated assumptions. The first was that the community 'out there' was unchanging, immutable and incapable of being built to the point where it would welcome people with intellectual disabilities. This assumption contrasts starkly with the more fluid sense of community held by their opponents, and sits

oddly with the principle on which their own fundraising was based: appeals to the community. They certainly did not believe, as their opponents did, that the community might be enriched by the presence of people with intellectual disabilities.

Their second assumption was that their children were not capable of developing living skills such that they could take their place in the larger community. However, the findings of most reports in Victoria and elsewhere have shown that people with an intellectual disability have made real advances in their adaptive abilities and living skills. Yet the parents knew their children best, knew their limits and behaviours and believed these made living 'out there' impossible.

The parents' associations were equally adamant that there was but one aim in community living,—to improve their children's interaction with the community. Independence and happiness were not factors that they spoke about often, except in the sense that deinstitutionalisation would disrupt already existing friendship circles. Undoubtedly they thought their children were happy in their segregated surroundings and would be better off there because they, the parents, were concerned with their children's safety above all else. The parents' organisations always cast their own experience against ideology. Deinstitutionalisation and normalisation were 'buzz words', 'ideologies' or 'dogma', the work of 'fanatical do-gooders'.⁶¹ As Bob Riddiford from CIPAID put it in 1990:

De-institutionalisation is supposed to be the magic password, guaranteed to open the gates of paradise on earth for the intellectually disabled. The closure of the institutions is to provide a pot of gold to buy a ticket to community living, to liberate them from confinement and oppression. There is a lot of noise about individual rights, but a deafening silence about individual needs. One basic right is ignored: the right to live in an institution.⁶²

This small claim on rights typifies CIPAID's view of rights. For those proponents of deinstitutionalisation, rights meant those set out by the United Nations in its 1971 and 1975 declarations and in the International Year of Disabled Persons in 1981, which translated into the right to a normal and fulfilling life. For parents at Kew, rights meant little more than their right to decide about their children's lives and their children's rights to safety and security.

Community, normalisation and sociology

When the discourses on community in the debates about deinstitutionalisation in Victoria are compared with the writing on normalisation two things become clear. The first is that community in the

former is as untheorised as it was in the latter, the taken-for-grantedness can be found in both supporters and opponents of deinstitutionalisation. The second is that both sides of the debate used the principles outlined by the Scandinavian normalisers more than they did those of Wolf Wolfensberger. Perhaps this was because of the common-sense way in which normalisation was first described, particularly when compared with the impenetrability of Wolfensberger's prose and because his ideas quickly became professionalised by service providers. Yet there are some contradictions and ironies in this.

Despite their hostility to the idea, opponents of deinstitutionalisation seemed to adopt some of the principles of normalisation in their vision of village settlements. As Nirje described normalisation, and as it was originally practised in both Denmark and Sweden, it was possible, in part, to normalise peoples' lives in a relatively segregated setting, for example, by organising routines around normal daily, weekly and annual rhythms. The opponents of deinstitutionalisation had convinced themselves that normalisation meant group homes in the community, that is to say that they had all but embraced the view of normalisation adopted by their political opponents. The segregated setting that the parents' groups had in mind, however, did not fit easily into the principles of normalisation. As the proponents of deinstitutionalisation never tired of pointing out, a settlement in the grounds of Kew Cottages was still a congregate and segregated setting.

The picture the parents' organisations drew of the community—as alienating, dangerous and uncaring—had no place in the early normalisers' vision. On the other hand, the utopianism inherent in the language of community spoken by proponents was based on the utopianism of the early normalisers. The community offered the same possibilities as it was made up of the same institutions, places, processes, and relationships. Yet in some important respects the Victorian proponents of normalisation had gone beyond the image held by the early normalisers.

One fundamental premise of the Victorian proponents of deinstitutionalisation was that communities could become better places by integrating people with intellectual disabilities. This was a new idea in the doctrine of normalisation. To the early normalisers community was static—to be mined or infiltrated. The later dynamic view of community as something to be built links the proponents of deinstitutionalisation to the new social movement, known as communitarianism, which began to find its feet in Australia in the 1980s.

The idea of community exerts such a powerful attraction today that it has become a political project and the key to the future. Communitarianism promises to return power to the people, to the local, to the grass-roots. The idea is now familiar in moderate left politics where,

in the context of the supposed failure both of old left projects such as the welfare state and the cruelties of new right individualism, community politics has become a 'third way' to social and political integration. For Peter Botsman and Mark Latham, two prominent figures in new Labor Party thinking, the 'old state' that provides and orders should be replaced with a 'new state' that enables 'communities to be serviced by the state not be servants of the state'.⁶³ And community activists and academics Sue Kenny and Jim Ife not only rigorously conceptualise community but also show how communities might be built.⁶⁴ As another community activist, H. Babacan, explains:

Community development helps people identify their needs, obtain resources and collectively empowers people to have more control over their own lives. The key ingredients are sharing of power, grass roots involvement, democratic participation and empowerment of people. The rationale of community development interventions is to alter the way things are done, to change structures of society which render people powerless along class, ethnicity, sexual preference, age and disability divisions.⁶⁵

What is important here is the argument that communities can be *built* by activists working with 'the people'. STAR was attuned to this thinking about the politics of community building. It became communitarian because its view of normalisation, when it was connected to deinstitutionalisation, was always about building communities that were inclusive.

The Victorian debate about community is redolent with symbolism and imagery about the meaning of both community and its apparent obverse, the institution. For the proponents of deinstitutionalisation Kew Cottages symbolised a century of the cruelty and neglect that was implicit in the word 'institution'. The village cluster settlement proposed by the opponents of deinstitutionalisation abounds with the imagery of rural, almost pre-industrial, life of small-town simplicity, harmony, mutuality, and shared interests. Their vision looks remarkably like the community described by Ferdinand Tönnies, the founder of the academic discipline known as community studies. His famous distinction between *Gemeinschaft* or community and *Gesellschaft* or society is explained here by North American academic and activist Suzanne Keller:

Gemeinschaft, or community, refers to a pattern of social life based on personal attachments, traditionalism and deep personal affinities', while '*Gesellschaft*, denotes a more abstract, impersonal, formalized system of social rules, roles and institutions.⁶⁶

The way Tonnies cast the affective character of community against society has been matched by much recent thinking on the subject. Now community is contrasted not only with society, but also with modernity and post-modernity, with the city and the process of urbanisation, with individualism and neo-liberalism, and with globalisation.⁶⁷ Indeed, community is sometimes cast against history itself, as history expresses the move from simplicity to complexity, from inclusiveness to alienation and powerlessness. As Ron Wild once wrote, community is seen as disappearing with the passage of time.⁶⁸

For the parents' associations, community was possible but only away from society, which was cast as dangerous, isolating, uncaring, 'frantic', and 'troubled'. The city and suburbia, 'out there', was shorthand for isolation and loneliness. The community they sometimes espoused was truly an antidote to the modern world. For the supporters of deinstitutionalisation, community as utopia, community as modernity was already there, 'out there', but was at the same time still capable of being built.

What is lacking from the debates in Victoria is a notion of community that can account for diversity, difference and conflict, a notion that takes up the characteristically critical analysis of societies from the 1960s and beyond. In left-wing views, community is an ideology that conceals the real conditions of existence—inequality, oppression and powerlessness. As Stanley Cohen asks: 'Is community a concept to be employed in the study of human societies or an ideology which diverts people's attention away from things which control their lives?'⁶⁹ Socialists criticise community for riding roughshod over social class, while feminists criticise it for ignoring gender.⁷⁰ Australian academic community studies, exemplified by sociologists from Ron Wild to Ken Dempsey, have shown that really existing communities do not rely on some putative consensus for their cohesion; they depend on social control to render inequalities normal or natural and on the stigmatisation and exclusion of outsiders.⁷¹ Stanley Cohen defines communities in large part by the way they produce and reproduce their boundaries.⁷²

Neither side of the Victorian argument about deinstitutionalisation described a community divided by differences of class, gender or ethnicity. Yet STAR was aware of diversity and difference. On the one hand it may be argued that its view of community privileged unity over difference by its reliance on a utopian version of community. On the other, in Ethel Temby's writing for STAR, there is a hint of the possibility of a post-modern world of difference and diversity once people with intellectual disability were restored to their communities.

STAR's position was the more explicitly theoretical and more theoretically sophisticated of the two sides of the argument. It knew that societies police boundaries partly by stigmatising and isolating partic-

ular groups they regard as dangerous or undesirable: because its own policy took up Wolfensberger's already explicitly worked-out social theory behind the idea of normalisation. STAR also used history in different ways to its opponents. It did not contrast community with modernity, rather it embraced the modern world, casting community against the history of institutions and the barbaric past of institutional solutions to supposed problems.

One of the most tragic stories to emerge from the fire at Kew Cottages was that of Ron Aldridge, a resident killed in the fire. Ron's family split up shortly after he was born. His father died, his mother disappeared and his siblings seem to have been distributed around various institutions. A so-called 'blue baby', Ron was sent to Kew Cottages, probably when he was a year old. In his thirty-odd years there he did not have one visitor, and it was only when a local newspaper got in touch with his surviving siblings that they knew the brother they had thought long dead had actually lived. The *Herald Sun* headlined his story 'The Man the World Forgot'.⁷³

Would Ron's story have given support to either side of the debate about deinstitutionalisation? It is easy to imagine that the parents' associations would have used it to suggest that in the absence of a real family or community to care for him, Ron had his own family and community in Kew Cottages. For the proponents of deinstitutionalisation Ron would have been a victim of the system, not so much lost in it but rendered invisible by it, and that his would have been another story in the compilation of a case against institutions for people with intellectual disabilities. More than one source has attributed the continued existence of Kew Cottages to the conflict between parents and advocacy groups.⁷⁴ The fire made little difference to this conflict. The respective discourses on community were just too different. Not even Ron Aldridge's story could have brought them together.

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1. See *Age*, 9 April 1996, p. 1. For issues raised by the fire, see *Age* from 9–18 April 1996, and *Herald Sun* from 9–18 April 1996. For the findings of the inquest see 'Inquest Findings', *Comments and Recommendations into Fire and Nine Deaths at Kew Residential Services on 8 April 1996*, State Coroner's Office, Melbourne, 1997, p. 12, Conclusion to Findings, Comments and Recommendations, numbers 5–8.

2. See for example *Age*, 13 April 1996, p. A6, in which parents of residents suggest that the money used to pay for deinstitutionalisation is spent at the expense of residents in Kew Cottages. See also p. A17 and *Australian*, 13–14 April 1996, p. 22.

3. See Charles Fox, "'Forehead Low, Aspect Idiotic': Intellectual disability in Victorian asylums, 1870–1887", in Catharine Coleborne & Dolly MacKinnon (eds), *'Madness' in Australia: Histories, Heritage and the Asylum*, Queensland University Press/API, St Lucia, Queensland, 2003, pp. 145–56.

4. There is now a substantial literature on eugenics in Australia. The best introductions are S. Garton, 'Sound Minds and Healthy Bodies: Reconsidering eugenics in Australia, 1914–1940', *Australian Historical Studies*, vol. 26, no. 103, 1994, pp. 163–81; and R. Watts,

'Beyond Nature and Nurture: Eugenics in twentieth century Australian history', *Australian Journal of Politics and History*, vol. 40, no. 3, 1994, pp. 318–34.

5. M. Lloyd, *Payments by Results: Kew Cottages' First 100 Years*, Kew Cottages and St Nicholas Parents Association, East Burwood, 1987, is the only published source for the history of Kew Cottages. For an account of one client's life see Cliff Judge & Fran van Brummelen, *Kew Cottages: The World of Dolly Stainer*, Spectrum Publications, Richmond, Victoria, 2002.

6. 'Inquest Findings', p. 16.

7. Lloyd, *Payments by Results*, pp. 113–4.

8. *Age*, 13 April, 1996, p. A6.

9. *Kew Cottages and St Nicholas Parents' Association Newsletter* (hereafter *KCPA Newsletter*), August 1997, LaTrobe Library, Melbourne.

10. E. Emerson, 'What is Normalisation?', in Hilary Brown & Helen Smith, *Normalisation: A Reader for the Nineties*, Tavistock, Routledge, London, 1992, pp. 10–11. For B. Nirje's account of the development of the concept of normalisation see B. Nirje, *The Normalisation Principle Papers*, Uppsala Centre for Handicap Research, Uppsala, 1992.

11. For his first major text see W. Wolfensberger, 'The Origins and Nature of our Institutional Models', in R. Kugel & W. Wolfensberger (eds), *Changing Patterns in Residential Services for the Mentally Retarded*, President's Committee on Mental Retardation, Washington, 1969. For his reformulation of the idea of normalisation see W. Wolfensberger, *et al.*, *The Principle of Normalization in Human Service*, National Institute on Mental Retardation, through Leonard Crainford, Toronto, 1972, p. 28.

12. H. Brown & H. Smith, 'Introduction', in Brown & Smith, *Normalisation*, p. xvi.

13. For Wolfensberger's explication of social-role valorisation see 'Social-Role Valorization: A proposed new term for the principle of normalization', *Mental Retardation*, vol. 21, no. 6, 1983, pp. 234–39.

14. Gunnar Dybwad, 'Action Implications, USA Today', in Kugel & Wolfensberger (eds), *Changing Patterns*, p. 387.

15. Wolfensberger, *et al.*, *The Principle of Normalization*, p. 32.

16. See the summary by E. Emerson, 'What is Normalisation?' in Brown & Smith, *Normalisation*, pp. 10–11.

17. STAR to *Age*, 9 June 1973, in Disability Folder, Riley Collection, LaTrobe Library, State Library of Victoria.

18. M. L. Jones, *Colony to Community: The Janefield and Kingsbury Training Centre*, Janefield and Kingsbury Re-Development Project, Melbourne, 1993, p. 89.

19. *Report on the Victorian Committee on Mental Retardation*, August 1977, bound and held in the Department of Human Services Library (hereafter DHSL) 555 Collins Street, Melbourne.

20. Quoted in J. Harper, *The St Nicholas Project: Service Dream and Administrative Nightmare*, Melbourne, June 1985, p. 5. This document is a government report.

21. For discussions of the medical and developmental models see K. Carman-Brown & C. Fox, 'Doctors, Psychologists and Educators: The professions and intellectual disability', in E. Cocks, C. Fox, M. Brogan & M. Lee (eds), *Under Blue Skies: The Social Construction of Intellectual Disability in Western Australia*, Centre for Disability Research & Development, Faculty of Health & Human Sciences, Edith Cowan University, Perth, WA, 1996, pp. 205–48. For the rights model see G. Fulcher, *Disabling Policies? A Comparative Approach to Education Policy and Disability*, The Falmer Press, London, 1989; and Kelley Johnson, *Deinstitutionalising Women: An Ethnographic Study of Institutional Closure*, Cambridge University Press, Cambridge, 1998, pp. 153–5.

22. *Report on the Victorian Committee on Mental Retardation*, p. 24.

23. L. Richards, *History of Janefield*, Swinburne College Press, Melbourne, 1984, p. 11. For Kingsbury see Jones, *Colony to Community*, p. 84.

24. The story of the closure can be followed in Harper, *The St Nicholas Project*. See also R. Crossley & A. McDonald, *Annie's Coming Out*, Penguin Books, Melbourne, 1980, and for a contrary view of Crossley's claims see the then Government's Committee of Inquiry to Investigate claims About Children at St Nicholas Hospital, *Report*, March 1984, held in DHSL.

25. Quoted in Harper, *The St Nicholas Project*, p. 248. Harper was project officer for the closure.

26. J. Wallace, *Pleasant Creek, Training Centre, Stawell*, Report for Director General of Community Services, Victoria, n.d. but c.1990 or 1991, held in DHSL.

27. *ibid.*

28. These figures come from *State Plan for the Development of Intellectual Disability Services 1989–1992*, Office of Intellectual Disability Services, Community Services, Victoria, 1989, pp. 3, 20, 72, held in DHSL.

29. Report to the Honorable Michael John, Minister for Community Services, from the Intellectual Disability Task Force, April, 1995, in DHSL, p. 39. For the closure of Caloola see Ministerial Advisory Committee for Intellectual Disability Services, *Closing Caloola, 1992*, in DHSL. See also two reports from Human Resources Centre, Graduate School of Social Work, LaTrobe University, *Relocation of People with Intellectual Disability in Victoria*, Final Report, 1994, (DHSL) and *Evaluation of the Relocation of Caloola Clients Project. A Three-Year Follow up of Former Caloola Training Centre Clients*, March, 1997. For the Janefield relocations see Jones, *Colony to Community*, and *Age*, 27 October 1997, p. A4.

30. Department of Human Services, Victoria, *Annual Report 2001–2002*, p. 74. The actual number was 794.

31. *KCPA Newsletter*, September 1999, October 2001. See also *Age*, 8 September 1999.

32. Human Resources Centre, *Evaluation of the Relocation of Caloola Clients Project*, 1997.

33. Johnson, *Deinstitutionalising Women*, p. 184.

34. *ibid.*, p. 186.

35. *STAR Newsletter*, September/October, 1990, quoting Judith Snow.

36. Harper, *The St Nicholas Project*, p. 249.

37. *STAR Newsletter*, April/May 1995.

38. *ibid.*, October/November 1991.

39. *ibid.*, October/November 1991.

40. Harper, *The St Nicholas Project*, p. 194.

41. *STAR Newsletter*, April/May 1995, November/December 1990.

42. *ibid.*, July/August 1995.

43. *ibid.*, April/May 1995.

44. *Weekend Australian*, 13–14 April 1996, p. 22 and ‘Inquest Findings’, p. 18.

45. Lloyd, *Payments by Results*, pp. 49 and 107. See also chapter 22.

46. *KCPA Newsletter*, July 1997.

47. Harper, *The St Nicholas Project*, p. 257.

48. *Australian*, April 13–14 1996, p. 22.

49. *KCPA Newsletter*, July 1997.

50. *STAR Newsletter*, July/August 1995.

51. *KCPA Newsletter*, December 2001.

52. *ibid.*, August 1993.

53. CIPAID submission in Report to the Hon. Michael John, 1995.

54. *KCPA Newsletter*, June 1993.

55. *Age*, 9 April 1996, p. A10.

56. S. H. Philpott, Honorary Secretary, Janefield Auxiliary, ‘Forward’, in Richards, *History of Janefield*, p. 2.

57. Kew Cottages and St Nicholas Parents Association submission to the Minister for Youth and Community Services, Dennis Napthine, 1998 in:

<http://kewcottages.alphalink.com.au/villa.htm>.

58. *Age*, 27 October 1997, p. A4.

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74. For instance, see *Weekend Australian*, 13–14 April 1996, p. 22.