

If anything can kick-start contemporary, resilient citizenship practices, it is a structure of institutional and cultural possibilities. When looking for ways to reconstruct community ('a new we') under these circumstances, think of local services providing small budgets and organizational advice to (potential) active citizens without asking larger administrative acts in return. Think of training 'new' active citizens instead of complaining about the vested active citizens and their well-known repertoire. Think of the administrative institutions and vested civil society organizations professionalizing in the art of dealing with citizens – not just 'listening' but also 'talking back', not just receiving a letter or organizing a hearing, but actually relating to its content and outcomes.

8 'Control over the Remote Control', or How to Handle the 'Normal' World?

The Policy and Practice of Community Care for People with Psychiatric or Intellectual Disabilities

Loes Verplanke and Jan Willem Duyvendak

Introduction

The past 25 years have witnessed a policy of deinstitutionalization for psychiatric patients and people with intellectual disabilities, both in the Netherlands and abroad. No longer banished to institutions in the countryside, the policy posits that it would be better for these people to once again be a part of society, to live in ordinary neighborhoods in towns and villages. While there would be additional support for these individuals, the idea was that they would live in their own houses (instead of institutions) as independently and autonomously as possible. Since the late 1990s, this policy has broadly been referred to as community care (Means & Smith 1998).

This chapter draws on the research project 'Living in the Community? Community Care for Psychiatric Patients and People with Intellectual disabilities'.¹ This project examines the effects of the policy of community care in urban renewal areas where many psychiatric patients and people with intellectual disabilities end up living (social housing, which these groups often depend on, is available in these neighborhoods). The focus lies in how psychiatric patients and people with intellectual disabilities living independently in these neighborhoods experience their new 'homes'. Next to archival and literature research, we conducted extended interviews with around 100 people with different psychiatric or intellectual disabilities.² The research took place in neighborhoods in three cities: Zwolle, Hilversum and Amsterdam – a mixture of smaller and larger towns in more metropolitan and rural surroundings.

After reviewing the criticisms of institutionalization, this chapter examines whether, and to what extent, the policy of deinstitutionalization has led to a sense of belonging in the neighborhood among psychiatric patients and people with intellectual disabilities. Why do we focus on

'belonging'? What does 'belonging' have to do with the quality of life of people with psychiatric problems or intellectual disabilities in poor, deteriorated neighborhoods? Quite a lot, as it turns out. In the Netherlands in the 1970s, the main criticism of housing these individuals in institutions focused on their alienation and exclusion from society. As a result, *living* outside institutions became the dominant aim. Deinstitutionalization in the Netherlands was seen primarily as an alternative means of housing these people – as a matter of accommodation. If housing conditions were improved, it was thought, other aspects of integration would follow automatically (Duyvendak 1999; Tonkens 1999). It was further assumed that having one's own house would mean being part of a local community. Whereas the institution had been criticized for separating and alienating people with handicaps from others, having one's own place in a regular neighborhood implied integration and 'feeling at home' while living together with others. If psychiatric patients or people with intellectual disabilities were to be included in society, they needed to 'come home' to an ordinary residential neighborhood.

But did this really happen? Our respondents' experiences show how difficult it is to feel at home in 'normal' neighborhoods.

Institutionalization criticized

Prior to the 1970s, psychiatric patients and people with intellectual disabilities were viewed as patients in need of continuous nursing and tucked away in countryside institutions. At the time, the therapeutic ideal prescribed that the best place to care for them was in large institutions far from their former daily environment. Patients could be cared for and supervised 24 hours a day; they would find peace and quiet, ample space and a well-regulated life.

In the 1970s, patient organizations as well as professionals and academics began to criticize this 'medical regime', asserting that remote institutions only served to isolate people from 'normal' communities. These institutions were not only deemed discriminatory; they failed to make people less ill or disturbed. *Asylums: Essays on the social situation of mental patients and other inmates* (1961), the iconic work by the American sociologist Erving Goffman, was a source of inspiration for the critics of institutionalization. Goffman compared psychiatric hospitals to other 'total institutions' such as prisons, barracks, convents and even concentration camps. Their 'total' nature was embodied in barriers such as locked doors, high walls, electric fences, water and woodland that precluded contact with the outside world. For Goffman, another feature of the total institution was that work, sleep and leisure were

group events – in the same location, regulated by a strict schedule, and under the same bureaucratic regime. The worst feature of the asylum was that the inmate's 'self is systematically, if often unintentionally, mortified' (Goffman 1961: 15). Goffman and other influential critics, including the psychiatrists Laing and Szasz, stated that it was not so much institutionalized inmates who were ill or mad, as society itself. Society made people ill. Society had to be made healthy again, and psychiatric patients and people with intellectual disabilities could play a role here. Their presence in society would confront 'normal' people with the vulnerable aspects of their own existence and make society more friendly and humane. Society could heal these mental and psychiatric patients if society itself was prepared to be healed by them (Tonkens 1999).

The work of the Swedish social scientist Nirjé was prominent in the field of caring for people with intellectual disabilities. Nirjé was one of the first to argue that people with intellectual disabilities should lead a 'normal life': 'The normalization principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society' (Nirjé 1982). Nirjé emphasized the importance of making living conditions for people with intellectual disabilities as normal as possible; he didn't mean that they had to behave as normally as possible. In his eyes, integration – participating in education, housing, work and having social contacts in society – was the road to normalization. In the Netherlands these concepts were expressed in the policy of Nieuw Dennendal, an institution for people with intellectual disabilities. In the 1970s this institution was famous for its progressive approach towards caring for its clients. The central concept in this approach was the spontaneous development of the self: everyone – including clients – was free to discover and unfold their own talents and possibilities. Society merely had the task of supporting this (Tonkens 1999). The late 1970s postulated a new ideal that not only tolerated deviant behavior, but even stated it was a healthy reaction to a sick society (Duyvendak 1999). It was therefore also in the interests of society that psychiatric patients or people with intellectual disabilities were part of it.

The era of deinstitutionalization

The reaction of policy-makers to this criticism was surprisingly responsive: they introduced a policy of deinstitutionalization, offering extra-mural support and treatment for patients who needed long-term care but who no longer lived in residential institutions (Kwekkeboom 2004). Several Western countries (the USA, the UK, Italy and the

Scandinavian countries) closed down many psychiatric hospitals and institutions for people with intellectual disabilities, replacing them with small facilities in ordinary communities providing local extramural care. Norway and Sweden introduced legislation that entitled anyone with any kind of disability to live in a house in an ordinary neighborhood; in fact patients had no choice as these countries no longer maintained residential institutions. In the Netherlands, policy-makers interpreted the criticism of institutions mainly as one of scale and type of housing: the size and impersonal nature of the institutions became a thing of the past as 'small' became the maxim of the 1980s and 1990s. Small-scale sheltered living units were established, first in the grounds of institutions, and later, beyond the institutions' confines in residential neighborhoods in towns and villages (Welshman 2006; Means & Smith 1998; Overkamp 2000).

The 1984 'New Memorandum on the Mental Health Service' explicitly stated that the closed, large-scale approach to institutional mental healthcare was to be replaced by a care system 'in which the client can be helped close to his home, maintaining his social contacts as far as possible' (Parliamentary Papers 1983/1984: 53). The number of beds in psychiatric institutions was to be reduced; some of the released funds were to be spent on extramural care for these patients in the form of ambulatory care and sheltered living schemes. While these policy changes were a response to criticism, they were also prompted by the need to restrain mental healthcare expenditure.

Other Dutch policy documents in the 1990s expanded on the theme of deinstitutionalization. The maxim of the memorandum 'In the Community: Mental Health and Mental Healthcare in a Social Perspective' was 'mental healthcare (back) in the community where possible' (Parliamentary Papers 1992/1993: 76). A 'community based concept of care' was central to this approach (p.20), to be achieved by mental healthcare services cooperating at the local level with social services, homeless centers, legal services, and employment and social rehabilitation projects.

In the Netherlands, care policies for people with intellectual disabilities evolved in a similar fashion. The new policy was captured in the memorandum 'Beyond Limitations: Multi-year Program Intersectoral Policy on Care for the Handicapped 1995-1998' (Ministerie van VWS 1995) which stated: 'First and foremost, the disabled must be given more freedom to make their own choices about how they lead their lives' (p.16). 'Living in an ordinary house in an ordinary neighborhood' (p.43) became the guiding principle. Once again – as was the case with the mental health service – the need to curb expenditure was an additional argument in favor of deinstitutionalization.

However, policy documents from the late 1990s (Parliamentary Papers 1996/1997, 1998/1999) indicate that the switch to community care did not develop according to plan. Although supporting and normalizing the position of psychiatric patients and people with intellectual disabilities remained the aim, there were, for the first time, indications that the process of deinstitutionalization was not fulfilling its goals. According to the Minister of Public Health, Welfare and Sport, there were signs that community care was negatively influencing the quality of life of those handicapped people who had begun living on their own. The minister also observed that care institutions were still not investing enough in extramural help and support, and that cooperation with local partners was unsatisfactory. Reducing levels of institutional care could only be justified if it was replaced by social support functions in the community. 'Experience in other countries has demonstrated that without this support, the move to mental healthcare in the community can lead to the exclusion, decline and increasing isolation of patients' (Parliamentary Papers 1996/1997: 10).

Although politicians maintained certain reservations about the effects of community care, they only strengthened their policy that people with handicaps should not rely on services and amenities for their specific disabilities, but should – where possible – use those available to the general public. In 2007 this policy was explicitly formulated in a new law on social support (*Wet op de maatschappelijke ondersteuning* or *Wmo*), the central concept of which was 'participation'. Everyone was supposed to participate in society; those who for whatever reason were unable to participate on their own were entitled to the support of their social networks, neighbors, volunteers, and in the last resort, professionals. The new law applied to psychiatric patients and people with intellectual disabilities as well. However, being a part of the 'normal' community for these groups entailed a great deal of special help and support. The question thus became even more poignant: are all neighbors and neighborhoods willing and able to provide this help?

Having your own place

As already mentioned, we interviewed about 100 people with psychiatric or intellectual disabilities living on their own in 'normal' neighborhoods. Most of the interviewed psychiatric patients had spent considerable periods of their lives in psychiatric hospitals. Of the respondents with intellectual disabilities, half had previously lived in institutions run by professionals; the others had lived with their parents. Respondents all stated that they had chosen to live on their own. None felt obliged or forced by relatives or professionals to choose this option. Most

received a house in the town where they had grown up. About half had a lease contract in their own name; others leased via the care organization that supported them. Respondents had no explicit expectations about how it would be to live in their own place, nor any definite expectations about the atmosphere of their new neighborhoods, e.g. whether they would feel welcome or if their neighbors would help them settle in.

The urban renewal neighborhoods in this research project were: Holtenbroek in Zwolle; Noord and Liebergen in Hilversum; and De Banne and Vogelbuurt/IJplein in Amsterdam Noord. These neighborhoods were all built in the decades after World War II. In those years, the need for housing was very urgent. Due to the war, there wasn't much money, which resulted in rather cheap uniform social housing. The first residents were native-born families. In the 1980s, little by little most of them moved to suburban housing because of the bad quality of their apartments. Less prosperous immigrant families took their places. In the 1990s, many of these post-war urban neighborhoods declined: vacancy, pollution, burglary and vandalism flourished. As a response, policy makers decided to demolish and reconstruct the blocks of flats. This nowadays happens in all post-war urban neighborhoods with social housing projects in the Netherlands (Duyvendak 2002).

What do we know about the 'landing' of these groups in urban renewal neighborhoods? First of all, and to our surprise, most respondents were unaware that they lived in an urban renewal area. It was clearly not an issue for them (later we will see why). Second, respondents unanimously appreciated having their own houses where they could do what they wanted. They mentioned advantages such as not being constantly disturbed by others, being in control of what and when they eat, their bedtimes, pets in the house, having more autonomy, etc.: 'Finally I am in control over the remote control'. No one wanted to return to their former living situation.

Once you are free in your own house, that's really terrific. It's just positive. Even when the weather is bad, it still seems as if the sun is shining. That's my feeling here (man with intellectual disabilities, 30, Hilversum Liebergen).

I decided that it was enough with all those non-stop intakes in hospital. I really wanted to have a life in a place of my own. And here I am now: I am really calmer now that I am not continuously in and out of the institution and don't have to live in a group anymore. I have the tendency to adjust myself always to other people around me and I'm happy now that it's not neces-

sary anymore (woman, 45, psychiatric patient, Zwolle Holtenbroek).

I'm happy with this place. Above all I appreciate it to have a toilet for myself. I have many troubles with diarrhea and here I can sit as long as I want on the toilet. There's no one knocking at the door that I have to hurry up (woman, 41, psychiatric patient, Amsterdam Noord).

For many years I lived in institutions with a lot of people constantly around me. But it is no good for me to be with so many people all the time, because my head becomes too busy then. Maybe I get mad one day. That's why I have asked for a home of my own. And finally that worked out fine, because now I live here on my own and I like that very much (man with intellectual disabilities, 33, Hilversum Noord).

I want to have a normal life, I don't want to be constantly in a group with non-stop supervision. Now I have a place of my own with a lease contract with my name on it. And I have two parrots here! (man, 48, psychiatric patient, Amsterdam Noord).

Other research (e.g. Kwekkeboom 2006 and 2008; Overkamp 2000) has also concluded that most individuals with psychiatric problems or intellectual disabilities prefer to have their own accommodation, due to the privacy and autonomy this allows. In this respect, the quality of their lives has substantially improved.

Social contact

In general, the interviewees have very little, if any, contact with neighbors or other locals in their new neighborhoods. Most did not introduce themselves to their neighbors after they moved in; nor did supporting professionals suggest they do so. Only one respondent, a 60-year-old man with psychiatric problems in Zwolle, explicitly told us about his attempt to make contact with his neighbors:

Shortly after I moved in I called on the neighbors around ten in the evening. I said I'd just wanted to pop in for a drink, but they said: 'Sorry, it's far too late, not now'. Next day those neighbors complained to the care institution that I was a nuisance. So my contact with the neighbors was not much of a success.

Contact with neighbors was usually limited to saying hello, and, at best, to brief chats on the street. There was very little contact, such as occasionally drinking a cup of coffee together or helping each other with small tasks. Some interviewees mentioned unpleasant experiences with neighbors. A 31-year-old woman with intellectual disabilities, living in Hilversum Noord, told us that not long after her move she found bits of food on her doormat that had been stuffed through the letterbox. This happened at least five times. She was quite sure that it was one of her surrounding, mostly elderly neighbors who did this.

Interviewees' indoor visitors are mainly relatives and personal caretakers, who are particularly crucial for people with few family contacts. Respondents looked forward to their daily or weekly visits when they could talk about what was going on in their lives and what was bothering them. In these cases the caretaker was often called 'the most important person in my life'.

Respondents' outdoor contact was generally limited to people in the same position as themselves. They met each other at work (most often for people with handicaps), in the activity center (most often for people with the same handicap) or at the meeting place of the care organization. For many interviewees the latter functioned as a living room, a place to easily chat with others.

Few respondents had friendly contacts with 'normal' people. It is our impression that most felt more comfortable in the company of their peers. Several interviewees mentioned feelings like shyness, uncertainty and even fear when asked about friendly contacts with 'normal' people:

I feel more secure when I am with people like myself. Everywhere else I don't feel at ease. People look at you as if they think: What is he doing here? (man with intellectual disabilities, 30, Hilversum Liebergen).

Most normal people think you're not right in the head, so they don't want to have anything to do with you. I suppose that is discrimination. Or maybe not discrimination, but prejudice. Or even fear, maybe they're just scared (woman, 48, psychiatric patient, Zwolle Holtenbroek).

Look here, I'm someone with slight intellectual disabilities. I can stand up for myself, but you're never sure if normal people make a fool of you (woman with intellectual disabilities, 39, Amsterdam Noord).

The same fears of not being able to keep up with 'normal' people, and of being nagged or stigmatized, means most interviewees don't visit the community center or make use of other public activities in their neighborhoods.

Two or three times I visited the community center here, but I didn't feel happy there. There's more distance and coolness than in the DAC (activity center for people with psychiatric problems). Everyone comes there, maybe even your neighbors, you never know. That's a real threshold for me. That's why I prefer to go to the DAC. There I feel at home and there I'm not the only one who is seen as mad, because there are others who have also experienced a psychosis (woman, 52, psychiatric patient, Hilversum Liebergen).

Although respondents' social networks were generally small, this did not necessarily mean that they were dissatisfied with them. About 65 percent of interviewees thought their networks were large enough. This applied mainly to those who still lived in the neighborhood or part of town where they grew up, with nearby relatives frequently dropping in to help with small tasks. Some respondents even mentioned incidental contacts with one or more former classmates. The subgroup of respondents satisfied with their social networks also included individuals who hardly see anyone, mainly people with psychiatric problems. This 44-year-old woman from Hilversum Noord was typical:

I live here quietly; the heath is nearby. I like it here, the trees too. Because of my psychiatric problems I'm not allowed to work. My days have a simple structure: in the morning I take out my dog, make some coffee and after that I watch TV with a cigarette. Well, at those moments I sit really princely in my chair. In the afternoon I take a nap and after that I take the dog out again. And in the evening I go with the dog for the third time. I don't cook anymore, I don't like it. I just eat bread every day.

My family is far away; only my mother lives nearby. She is already 90 years old. Every Saturday evening we visit each other; one week I go to her place, the other week she comes to me. Once in two weeks someone from the care organization comes along.

I barely go outdoors, only for the shopping and with the dog. When I take the dog out I often see a man with another dog. We have a short chat now and then. Apart from my mother, the caretaker and the man with the dog, I don't see other people.

I'm a bit like a hermit, but that's what I want. Sometimes I feel lonely, then I listen to a nice CD and that helps a bit.

I'm just not someone who gets really involved in things. A few years ago I tried fitness and I also had a buddy, but I can't commit myself. After a while I just want to be at home: in my chair, with my dog and a cigarette. Then I'm fine.

Most respondents belonging to the 35 percent who were dissatisfied with their social networks lived in environments that were relatively new to them, without family or former acquaintances in the neighborhood. They long for more contacts but are simply unable to make or maintain them. For these people, personal caretakers are crucial. The story of a 46-year-old man with intellectual disabilities living in Hilversum is illustrative; he told us he never had visitors apart from his caretaker and mother. This was why he was willing to be interviewed – he would have a visitor! He often felt lonely; each time he did he would count to ten and back several times, which helped him calm down. Though he is pleased with his own home and independence, he misses a 'friendly, sociable atmosphere' in his neighborhood. When asked if he had ever initiated a conversation with anyone, he replied that he would be unlikely to do so again because his immediate neighbors – mainly older people – gossip about him.

Next to these differences in personal experiences, differences in respondents' problems play a role. People with intellectual disabilities tend more often than people with psychiatric disorders to have structured daily routines they are happy with: four or five days a week they go to the sheltered employment service or to other day-care centers in the neighborhood, where they can meet with their peers. Psychiatric patients generally find it more difficult to stick to a structured daily or weekly routine. The very nature of their disorder means they tend to be more emotionally unstable; they may suffer mood swings or feel inactive due to medication, making it difficult to maintain social contacts. One respondent expressed the condition convincingly. When asked if she would like to get to know more people in the neighborhood, she replied:

No, not at the moment. It's my head – having to cope with lots of different people is very, very tiring. It's not that I don't like it, it's just that I find things really difficult. My head makes me feel like a stranger in my own body, so I don't really feel at ease anywhere. Not even in my own home. I can't get to the real me, can you understand that? Things wouldn't be okay for me even if I lived in heaven, simply because it's a feeling I have inside me (woman with psychiatric problems, 37, Amsterdam Noord).

Feeling at home

We asked all respondents where and to what extent they felt at home, and whether they felt a sense of belonging to their new neighborhoods. Many immediately began to point around them, indicating they felt at home within their own houses. An important reason for this strong feeling of homeliness in one's house has to do with the fact that most rediscovered a place for themselves, free of disturbances, after having lived in groups for many years in different types of institutions.

As for the neighborhood, most interviewees did not mention definite feelings of attachment. For the reasons outlined above, the neighborhood for most of them has no meaning whatsoever. They do not know their neighbors and do not participate in the life of the neighborhood. Only in cases where they were born and raised in this (part of) the city do respondents mention an attachment to their environment that resembles a sense of belonging. Especially in Amsterdam Noord, separated from the rest of the city by the river IJ, there exist rather strong feelings of being a 'Noorderling'. Several respondents from Noord said they didn't care very much in which neighborhood they lived, so long as it was in Noord:

For me Amsterdam Noord is anyhow the best place to be. Everything is nearby, I like that. And there's silence and the housing. I can do my shopping here, take a walk, sit on a bench somewhere. I hope that I can stay here the rest of my life. But you never know of course; suddenly they can say that you have to go elsewhere (woman with psychiatric problems, 48, Amsterdam Noord).

Sociological research has shown that people attach a wide range of meanings to what it is to feel at home somewhere (Cuba & Hummon 1993; Low & Altman 1992). Some people mainly associate the feeling with safety, security, comfort, domesticity and intimacy; others with autonomy, freedom, independence and the ability to be oneself. Some see it as being 'among the same kind of people', while yet others see it as familiarity with people and things, with routine and predictability (Easthope 2004; Mallett 2004; Manzo 2003; Morley 2001). Whereas policy-makers tend to privilege the second interpretation – freedom and autonomy – many psychiatric patients or people with intellectual disabilities mostly experience a feeling of belonging when they feel safe and secure, when they are with people like themselves, and when they are in familiar surroundings. It is this last aspect they have difficulty achieving, as they do not manage to establish meaningful contacts with neighbors and other locals.

Conclusion

The majority of the psychiatric patients and people with intellectual disabilities we interviewed tend to live as solitary individuals in their communities (or on little islands in the case of clustered accommodation). They are happy with their autonomy. They feel at home in their houses. However, where these houses are located has limited relevance because there is almost no contact with other locals. This, then, explains the riddle of people with disabilities not being aware of urban renewal projects: as they don't participate in the lives of their neighborhoods, they don't know what is happening in them. To put it bluntly, their neighbors don't care for them and they don't care for the neighborhood. The outside world penetrates their houses almost exclusively via television, for here they can control the remote control – the outside world at a distance. What these vulnerable individuals are lacking are the tools to handle their social proximity.

In retrospect it is rather surprising that in the planning of deinstitutionalization so little attention was given to the social context these people would end up living in. In the 1970s, the idealistic critics of total institutions naively assumed that society as a whole would benefit from the arrival in local communities of psychiatric patients and people with intellectual disabilities. Policy-makers in the 1980s and 1990s rated highly the benefits of living in a normal house in a normal area, but failed to develop concrete ideas about what this would actually mean in the everyday lives of those involved. They failed to question whether society as a whole, and more specifically local neighborhoods, would show sufficient tolerance and solidarity for vulnerable people. Living an independent life in the community had become an indisputable principle, in part because this ideal for people with psychiatric and learning problems was, and is, derived from an ideal applicable to all citizens: living as independently and autonomously as possible. It is only recently that professionals and policy-makers begin to realize that a social network in the immediate neighborhood is important for individuals with a limited radius of action, like psychiatric patients or people with intellectual disabilities.

In the past few years, researchers in the Netherlands have examined how local communities feel about psychiatric patients or people with intellectual disabilities coming to live amongst them (Kwekkeboom 1999, 2001; Overkamp 2000). These studies have shown that the initial reaction to the arrival of more vulnerable people is fairly positive. However, when questioned further, people tend to be less open-minded. They think that there should always be a caretaker on hand 'just in case', and are rather reluctant to allow these people into their private lives. This reluctance to truly include psychiatric patients or

people with intellectual disabilities in local communities was found among all social strata. All these rather gloomy notions don't imply there is no room for improvement in the current state of affairs. Local authorities could pay closer attention to the physical environment and amenities that would contribute to a sense of public familiarity (Blokland 2008); care institutions could do much more to prepare communities for the arrival of people with disorders. We often see that local residents and welfare organizations remain uninvolved in plans to house psychiatric patients and people with intellectual disabilities in their communities; fear of the dreaded NIMBY (not in my backyard) effect plays a role in this. Involving the community beforehand in plans for independent accommodation would improve the chances of support coming from well-intentioned locals as well as local care organizations and institutions. Alongside the predictable protestors, there are always community members willing to be more involved if asked. This would most certainly be the case if accompanied by better communication with care supervisors and institutions, should problems arise.

Professional caregivers need to focus more on their clients' social environments once they have settled in particular areas. Caregivers are currently too often focused on supporting the clients themselves ('how to handle the remote control?'), whereas it is the professionals who could really make a difference in building bridges to their clients' potential social networks in their immediate proximity ('how to handle your neighbors?').

Should all this happen, the question still remains whether some people with psychiatric problems or intellectual disabilities would not feel more at home in a pleasant room in a small-scale institution surrounded by people like themselves. It is important for policy-makers, caregivers and scholars to raise this question, precisely because well-intentioned people helped to develop the policy of deinstitutionalization without carefully researching the conditions in which it could succeed.

Notes

- 1 'Living in the Community? Community Care for Psychiatric Patients and People with Intellectual Disabilities' is a three-year research program led by Jan Willem Duyvendak and conducted by researchers at the University of Amsterdam and the research and consultancy organization DSP-groep.
- 2 This chapter focuses on the deinstitutionalization of psychiatric patients and people with intellectual disabilities. In addition to these two groups, we also interviewed the frail elderly (who were also formerly institutionalized but who today stay for as long as possible in their own homes) and people with physical handicaps.