Feeling at home in a ‘normal’ neighbourhood; investigations into the policy and practice of community care

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Abstract

More and more people who would have lived in an institution in the past are now housed in residential
neighbourhoods. The fundamental idea behind this change is that it is better for people with a physical or
mental handicap, psychiatric patients and the vulnerable elderly to live independently among ‘normal’ people
as far as possible. This is based on the assumption that people want or need to be as autonomous as possible,
and make their own choices. An important underlying notion is that neighbourhoods, meaning communities,
are ready to receive these groups.

Are these assumptions realistic? Are these residential neighbourhoods really such hospitable places?
Many working class neighbourhoods built immediately after the Second World War are now regarded as
deplorable, disadvantaged areas with monotonous, unimaginative housing and much antisocial behaviour
rather than social cohesion. Large-scale urban regeneration programmes are needed to turn this negative
situation into a more positive one.

We analyse the meaning politicians and professionals attach to ‘feeling at home’ for these vulnerable
groups living in ‘normal’ environments and we compare these meanings with data on the actual experiences
of the handicapped themselves. We want to know how the former conceptualise ‘feeling at home’ in their
policy ideologies, and how the latter experience their ‘social landing’ in these neighbourhoods: what types of
social contacts are presupposed and which do in fact materialize? Do people with a handicap feel at home
and if so, what kinds of contacts, bonds and environments make them feel at home?

Since the conceptualisations of policy makers turn out to be rather inadequate and fail to take
account of the diverse experiences of the people involved, we finally turn to theories on the concept of
‘feeling at home’ and look for broader, deeper definitions that cover all the various meanings people attribute
to their home, neighbourhood and community.
Introduction

Over the last twenty-five years, a policy of 'deinstitutionalisation' has been deployed in the Netherlands and many other countries. People with a handicap and the elderly would no longer be banished to institutions tucked away in the woods or the dunes: they should be allowed to live in ordinary neighbourhoods in towns and villages, just like other people. Of course, once they were out in the community they would be given some extra support, but they had to to live their own lives in the first place. They would live in their own homes as independently and autonomously as possible, instead of in an institution; this was the credo of the sector. In this way, the handicapped and the elderly would once again be part of society, which is why this policy is referred to broadly as care in the community or 'deinstitutionalisation'.

When this policy is discussed by patients and clients, parents, carers and policymakers, the notion of 'feeling at home' crops up. For example, people say that patients do not feel 'at home' in an institution, whereas they do in a normal neighbourhood; this is where they really 'belong'. Why shouldn't people with a handicap be allowed to live among other people? In this paper we shall analyse the various conceptions of 'feeling at home' that are employed implicitly or explicitly in the deinstitutionalisation debate. Who is supposed to feel 'at home' where and why? We then compare the results of this analysis with what happens in practice when people with a handicap live out in the community; we examine not only whether the data available indicate that these people really do feel at home in the community, but also what exactly 'feeling at home' means for them. At the end of the paper we make a brief survey of the literature in search of a better definition of 'feeling at home' than that which dominates policymaking at present; we are looking for a definition that does more justice to the diverse ways in which 'feeling at home' is experienced by those concerned.

I. 'At home' on paper

Not so very long ago, people with certain shortcomings were hidden away in institutions deep in the woods or the dunes. Chronic psychiatric patients, people with mental disabilities and the vulnerable elderly spent years of their lives in such places, cut off from the rest of the world. Today, the fact that these people act somewhat differently is not regarded as a valid reason to shut them away. Why shouldn't they have a right to a normal life in an ordinary house in an ordinary neighbourhood, where they can do their own shopping, cook their own meals, make friends, enjoy their hobbies and go out? Where what they can do is more relevant than what they can't? It is also good for the local residents to encounter psychiatric patients, the elderly and the handicapped on the street or in the shops, or to step in to help if something goes wrong now and then. It increases their awareness of the things that can happen in a person's life, and also makes them more understanding and more ready to accept their more vulnerable fellow men (or women).

In broad lines, this is what deinstitutionalisation aims to achieve. Today, there is hardly anyone who is not in favour of it. Deinstitutionalisation or community care has been the basis of government policy regarding the handicapped, psychiatric patients and the elderly for many years now. The essence of this policy
is that people with a serious disability should have the same opportunities as any other individual to live in the community at large, and that they should receive support where necessary.

In the Netherlands, the term 'deinstitutionalisation' emerged in the nineteen-eighties. It was first used in the field of mental health care. At the time, it meant offering extramural support and treatment outside the psychiatric hospitals for psychiatric patients who needed long-term care (Kwekkeboom, 2004). A similar evolution took place in the care sector for people with mental disabilities and later also in the care for the elderly. This was a period when institutional care was coming in for a lot of criticism. People felt that care in residential institutions, which were often in rural areas far from towns and villages, made patients isolated and cut them off from normal society. This amounted to discrimination, and certainly did not make patients any less ill or disturbed than they were before entering the institution. Herding people together in large day rooms and dormitories, making them wear special institutional clothing and subjecting them to a strict timetable left no room for individuality. Moreover, critics like Foucault, Illich and Foudraine argued that it was not so much the inmates of these institutions who were ill or mad, but society itself. Society made people ill. So society needed to be made healthy again, and this is where psychiatric patients and people with mental disabilities could help. Their presence in society would confront 'normal' people with the vulnerable aspects of their own existence. This would make society as a whole kinder and more humane (Tonkens, 1999).

In many other countries in Western Europe, criticism of residential institutional care for psychiatric patients and people with mental disabilities erupted earlier, and more violently. In Italy and later also in the United States, the UK and the Scandinavian countries, whole psychiatric hospitals and institutes for the mentally handicapped were closed. These were replaced by small facilities in the normal community and local extramural care. Norway and Sweden have passed laws giving everyone with a disability of any kind the right to live in a house in an ordinary neighbourhood (in fact they have no other options, since these countries no longer have any residential institutions). But in practice, community care has not materialised very successfully anywhere so far. The America and the UK, local care and social services are handicapped by a structural lack of funds, which means that care professionals are chronically overworked. Cooperation and coordination between the different branches of the social services is also problematic, and this is also the case in the Scandinavian countries (Kwekkeboom, 2001; Overkamp, 2000).

The Netherlands was not so quick to dismantle its institutions and there were no widespread closures. No laws were passed giving people with a mental (or other) disability the same rights as other citizens, and residential institutions were not abolished by law. Nevertheless, since the seventies, a great deal has changed in the way people in the Netherlands regard the handicapped and in the practical organisation of care and support for these members of society. Until the seventies, the medical model was dominant: people with mental disabilities and those with serious mental problems were seen as patients who needed nursing, and this could be done best in large mental institutions out in the country, far from the towns. There, patients could be given care and supervision 24 hours a day and they would find peace and quiet, ample space and a well-regulated life. In the course of the seventies, more and more doubts were voiced about this approach by the 'residents' of these institutions and their families, the doctors treating them, their carers and a growing number of critical researchers.
Initially, criticism focused mainly on how things were run inside the institutions and critics aimed to achieve more humane treatment of the inmates, their right to privacy, good complaint procedures and recognition of patients' councils. Later, the large scale and remote location of institutions were also called into question. As a result of this criticism and developments in other countries, people in the Netherlands also came to believe that people with mental disabilities and psychiatric patients had a right to lead as normal a life as possible. That implied that they should enjoy the same living conditions as other members of society, as far as possible (Overkamp, 2000; RMO, 2002; De Klerk, 2002). But this 'normalisation' principle did not lead to the widespread closure of institutions in the Netherlands, as we mentioned earlier. Initially, people attempted to introduce normalisation within the institutions. The institutions were completely transformed rather than abolished (Overkamp, 2000) and their large scale and impersonal nature disappeared. Gradually, small-scale sheltered living units were set up in the grounds of the institutions, and later they were also established outside the confines of the institutes, in residential neighbourhoods in towns and villages. Hostels designed to replace the family unit for the care of the handicapped followed, and supported living units for psychiatric patients. All these small-scale group homes in residential neighbourhoods are still officially included in the statistics of the intramural capacity of the institutions, but in practice, the care they offer is radically different from the institutional care of the past. This should be taken into account when considering the high number of places in institutes in the Netherlands as compared with other countries. In actual fact, the number of people with a handicap living in ordinary residential neighbourhoods has increased steeply in the Netherlands, as in other countries, since the seventies.

The normalisation principle has dominated government policy over the past decades. Since 1984, Dutch mental health service (GGZ) policy has veered away from the closed, large-scale nature of institutional mental health care. This 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' (TK, 1983/1984a; p.53). The number of beds in psychiatric institutions was therefore to be reduced and all or part of the funding this released was to be spent on extramural care for these patients in the form of more ambulatory care and sheltered living schemes where psychiatric patients would be provided with supervision and support in addition to a form of independent living. This policy responded to the criticism from clients and their families and mental health care professionals. At the same time, it was also prompted by the need to control expenditure on mental health care.

Other policy documents in the nineties expanded on the theme of deinstitutionalisation. The motto of the ministry of Welfare, Health and Culture memorandum ‘Onder anderen. Geestelijke gezondheid en geestelijke gezondheidszorg in maatschappelijk perspectief’ (‘In the community. Mental health and mental health care in a social perspective’) was ‘mental health care (back) in the community where possible’. This was to ‘prevent chronicity and/or rehabilitate chronic psychiatric patients on the basis of the means presently available’ ((TK, 1992/1993; p.76)). A 'community based concept of care' is central to this approach. (p.20). To achieve this, the mental health care service must seek to cooperate at local level with social services, centres for the homeless, the legal services, and employment and social regeneration projects. The notion of substitution is significant in this memorandum; beds in institutions must be phased out to make way for different instruments which will give psychiatric patients better prospects in society: for example, extra places
in sheltered living units, supported living projects, hostels for homeless (ex-)psychiatric patients, day centres, psychiatric care in the home and employment rehabilitation projects.

Policy documents from the second half of the nineties (TK, 1997/1997; TK, 1998/1999) indicate that the switch to care in the community was not proceeding as expected. 'Strengthening and normalising the position of the chronically sick' (which includes psychiatric patients – JWD/LV) remains very much the aim of the ministry of Health, Welfare and Sport, but for the first time there are indications that there are limits to how far this process of deinstitutionalisation can go. 'Extramuralisation should not detract from the quality of life' stated the minister of Health, Welfare and Sport. For some of the chronically ill, the quality of life will improve if they can live independently outside the confines of an institution. But it is not the intention that those who are not able to live independently should suffer by having a lower quality of life imposed on them. For this group, psychiatric hospitals must continue to function as a place of asylum. 'In my view, the move towards mental health care in the community should not lead to a further deterioration of the quality of life for these patients, many of whom already lead a marginal existence' (TK, 1997/1997; p.7). In addition, the extent to which extramuralisation is introduced must not exceed what the community is able to support, according to the minister. Placement of patients in the community can entail an extra burden for parents and families and also for the neighbourhood in which they live. We must therefore ensure that patients are well spread out over different neighbourhoods. 'Community care is not only the order of the day in the health care services but also in other sectors such as the care and treatment of drug addicts. To avoid putting too much strain on the local residents and prompting negative reactions, we must ensure that "special" groups are not concentrated in certain neighbourhoods. Extramuralisation will have a negative effect if it undermines the quality of life in certain neighbourhoods.' (TK, 1997/1997; p.8). The minister, Els Borst, also observed that mental health institutions were still not investing enough in extramural help and support. She intended to accelerate and intensify this process by setting up a special fund for the improvement of care services. In addition, she considered that there was too little cooperation with other local partners. Reducing institutional care can only be justified if social support functions are set up in the local community to replace it. Particularly support to help chronic patients reintegrate into society, for example through employment rehabilitation. 'Experience in other countries has demonstrated that without this support, the move to mental health care in the community can lead to the exclusion, decline and increasing isolation of patients.' (TK, 1997/1997; p.10). Two years later, this view is put even more strongly: 'As a result of extramuralisation and the changing wishes of patients, we see increasing involvement and interdependence between the mental health sector, other care sectors, social organisations and local government bodies, in matters connected with housing, employment and participation. The mental health care sector cannot and should not attempt to offer a complete range of services for all aspects of life. The patient is a citizen like any other and as such, he has a right to access to general amenities for the public. My point of departure for the coming years is normalisation: for everyone where possible, with specific provisions for certain categories where necessary (TK, 1998/1999; p.17).
In policy documents about psychiatric patients and political debates about the direction and the tempo of deinstitutionalisation, interpretations of 'feeling at home' are expressed, explicitly or implicitly. In the initial phase (1975-85), many participants in the debate focused mainly on presenting reasons why institutes located deep in the woods or out on the heath could not be a good home for people with a handicap. The large scale of these institutes made them an impersonal environment in which the patient did not count as an individual; the anonymity and lack of privacy were the reasons why patients could never feel 'at home' in these large institutes. The response to this problem was to reduce the size of the new institutions built; people were placed in ordinary houses.

In the second phase, roughly 1985 to 1995, another problem emerged: patients were now housed on a more homely scale but since these sheltered living units were built in the grounds of an institute, patients were still cut off from the community. If people with a handicap were to be really included in society, they needed to 'come home' to an ordinary residential neighbourhood. This desire to 'mix them in' with the other residents in the community was not only based on the idea that a normal neighbourhood would be a better place for them to live, but also on the view that it would also be better for society as a whole if these people were not excluded. The minister Els Borst expressed this as follows:

... people with psychiatric problems should also be able to remain among other people in the community and they should receive treatment in their own neighbourhood, wherever possible. [ ] Extramuralisation makes madness visible on the streets. That is a logical consequence of our policy and not an undesirable side effect. I think it is a good thing if the street image of Dutch society includes more than just attractive, socially successful types striding along with a mobile phone clamped to their ear. That would present a very false picture of our society, and in my opinion, an extremely boring one too. To me, the criterion should be whether or not the people on the streets actually want to be out in the community. (TK, 1998/1999; p.26)

According to the minister, patients wanted extramuralisation, which was always presented in policy documents as a form of 'demand-driven care', and it was thought to be a good thing for the other local residents as well. But did local residents really think this was a good idea? And what is more important, could they really make people with a handicap feel that they 'belonged' to the community, and did they actually want to do so? These are the questions which were raised in the third phase, from 1995 till now. People were somewhat disconcerted to realise that although what was wrong with the system had been formulated in the initial phases – the large scale of the institutions and the fact that the handicapped were cut off from the rest of society –, they had a much less clear perception of what living in an ordinary neighbourhood would mean for the handicapped themselves. At the beginning of the third phase, it struck people that the concept of an 'ordinary neighbourhood' had never been clearly defined in the many documents produced between 1975 and 1995. It was apparently taken as self-evident that living outside an institution was much better for the handicapped, even if this was only because people had a rosy picture of an ordinary home in an ordinary neighbourhood as the desirable opposite of the failing intramural care in the large institutions of the past.¹

¹ Those in favour of extramuralisation on the basis of radical criticism of social structures were the only ones who had a clear view of these neighbourhoods, but it was certainly not a positive view: under capitalism, they were by definition
It is striking that the dominant argument is that as far as possible, people with a handicap should have the same options as the other residents in the neighbourhood, i.e. use the same amenities etc. The more normal their life was, the happier they would be. People did recognise that groups with a specific disability would probably need special amenities to enable them to feel 'at home' there, but access to the amenities for the general public and participation in normal social life in the neighbourhood was the priority (see Borst). The 'normalisation' approach pays no attention to the fact that feeling 'at home' means different things to different people, according to their circumstances. It was assumed that in order to feel at home, everyone needs to live in their own home, run it themselves and lead their own lives independently, at least as far as possible. At the same time people did realise that a social network in the immediate neighbourhood was important for individuals with a narrow radius of action. In the third phase, discussion consequently focused more and more on the social quality of the neighbourhoods.

Many politicians were concerned about this. On 6 July 2000 (TK, 1999/2000), minister Borst announced that in view of this concern, she intended to set up a Taskforce Vermaatschappelijking (Deinstitutionalisation). She states that deinstitutionalisation 'stands for a different type of care whereby the capacities and the wishes of the client form the basis of the care provided.' This must be the central focus in the care sector and the concept of demand-based care must therefore be worked out in more detail. A 'support system' must also be set up on a local basis. 'More attention must be paid to the patient's family and environment' (TK, 1999/2000; p.2). The Taskforce should focus on
drawing up a procedure founded on the direct living environment of the patient, which in all cases should involve local residents and neighbours, all parties concerned and the relevant organisations.

[...] The challenge is to create tools and to ensure that this happens everywhere. (TK, 1999/2000; p.2)

Within the mental health care sector, an important question arises at the end of this third phase: when is it really better for clients to live in ordinary neighbourhoods? On what conditions and which neighbourhoods meet these conditions?

Policies on care for the disabled went through a similar evolution in the nineteen-nineties. This can be seen most explicitly in the Memorandum 'De perken te buiten. Meerjarenprogramma Intersectoraal Gehandicaptenbeleid 1995-1998'. ('Beyond limitations. Multi-year Programme Intersectorial Policy on Care for the Handicapped 1995-1998') (Ministerie van VWS, 1995) People with a handicap are citizens with equal rights and responsibilities, writes secretary of state Terpstra in this memorandum. They must be given the same opportunities as everyone else and should receive support where necessary (p.15). 'First and foremost, the handicapped must be given more freedom to make their own choices in how they lead their lives.' (p.16). Accordingly, the ministry of Health, Welfare and Sport will no longer finance traditional extensions of institutes, hostels designed to replace the family unit (GVT’s) and day centres from 1996 onwards. Taking the paradigm of 'citizenship' as point of departure – a model in which the equality of all citizens appears to be paramount – those with a mental handicap should also be allowed to live as independently as they themselves

'sick' and this is why it would be a good thing if they became more mixed. For these radical social critics, whether these patients would feel more at home there was not relevant; the presence of the mentally ill would prove to the world that society itself was sick.
wish. 'Living in an ordinary house in an ordinary neighbourhood' (p.43) was literally to be the criterion from now onwards. In the same Memorandum, the ministry announced the introduction of the 'personal budget' (PGB). This would make individuals who needed care and support services more 'self-aware' and 'critical consumers' (p.47).

In 1997, the ministry of Health, Welfare and Sport set up an advisory committee to examine the possibilities and risks inherent in a policy of community care for the handicapped. This advisory committee (Beraadsgroep Community Care) presented its report in 1998. Community care was defined as support for people with serious disabilities (including support for their social network) to help them live in the local community and be part of it. A striking aspect of this report was that it recommended that the community should actively share responsibility for the care and support of people with (serious) disabilities (Beraadsgroep Community Care, 1998). The ministry of Health, Welfare and Sport accepted this advice. In the Beleidskader gehandicaptenzorg 2001 (Policy Framework for care of the handicapped 2001), it was stated that support for the inclusion of people with a handicap in society must come from the community itself in the first place. This means for example housing associations, businesses, schools, community centres, sports facilities and public transport, in addition to the daily contact they need in their direct environment (Ministerie van VWS, 2001).

From 2002 onwards, the ministry of Health, Welfare and Sport began to link deinstitutionalisation in the mental health care sector more and more with the same process in care for the elderly and the handicapped. Many similarities can be seen in the evolution of care policy in these three sectors. For all three groups, the aim is normalisation and autonomy, reinforced by a strong aversion to institutions. And for all three sectors, the motto remained 'for everyone where possible, with specific provisions for certain categories where necessary'. For the welfare of these three groups, the ministry explicitly calls for greater involvement of society in general. The task of directing all this is assigned to the local authorities (Plemper and Van Vliet, 2002; TK, 2001/2002). From then onwards, the debate was about care in the community for 'vulnerable groups' or 'people with disabilities'.

Although these groups are still recognised as different from the general public, politicians nevertheless consider that they should be supported as little as possible by specific services and amenities for their category of disability, and should use the services and amenities for the general public wherever possible. In the course of debates on this policy strategy, it appeared to be motivated by the predominant idea that people with specific disabilities will feel most at home in their living environment, which is often new, if they do not stand out too much from the rest. Living in an ordinary residential neighbourhood requires people with a handicap to act as 'normally' as possible; this makes life more comfortable for the people around them, and for themselves. The fundamental assumption is that living as normal a life as possible is what makes every individual feel 'at home', including those with a disability. There is apparently a norm for 'feeling at home', and this appears to be the same for everyone.

However, being part of the normal community requires a considerable amount of special help and support (even though some people with a disability find they can do more than they had expected). 'Society',
which means neighbours and the local community, are expected to provide this support. But does it really happen in practice?

**Statistics**

In 2000 there were about 30,000 places for people over the age of 18 with mental disabilities in general institutions for the care of the handicapped. This type of institution provides living accommodation, care, nursing, supervision and day activities for people with all levels of disabilities. In 1999 there were 17,500 places in a 'family'-type unit (GVT). A GVT provides living accommodation, care and supervision but no nursing. Many GVTs are in ordinary residential neighbourhoods. Each has about 25 places. Today, GVTs often have annexes, which are even smaller in size. In addition there are many projects for intensively supported independent living, with support from a GVT. All together, there were some 47,500 places for adults with mental disabilities in 2000. An estimated 60% of this target group live in an intramural or semi-intramural environment. In 2000 90% of the residents in GVTs and 30% of the residents in an AIVG (general institution for care for the handicapped) lived in an ordinary street. There has been a striking increase in the construction of accommodation units in ordinary streets, especially between the nineteen-seventies and the nineteen-nineties. AIVGs are building sheltered living units and hostels in this type of location, as well as other types of accommodation (De Klerk, 2002; p.219). Among those who live with their families or independently (with support), the majority has a slight learning disability and only 5% a serious learning disability. 60% of residents in an AIVG have a serious or very serious learning disability, and 70% of them also have serious physical disabilities, which entails a heavy burden of care (De Klerk, 2002; p.214).

According to the Taskforce Vermaatschappelijking (Care in the Community) there are 48,000 people who are receiving some form of treatment from the mental health care service. 20,000 members of this group receive daily treatment in a department of a psychiatric hospital or in a sheltered living unit. The latter type of living unit has become much more widespread over the past decades. The remaining 28,000 patients receive some form of ambulatory support at home, such as intensive psychiatric home care, supervision for living at home, case management (at the end of 1997 there were only 12,000 patients in this category; since this type of care has been promoted strongly over the last few years, according to the Taskforce we can assume that this group has grown considerably), or clinical treatment (slow-release medication) (Taskforce Vermaatschappelijking, 2002).

The majority of the group with a physical handicap live independently. Only 9,000 of the non-elderly with a physical or sensory disability make use of residential facilities (De Klerk, 2002; p.201).

**II. ‘At home’ in practice**

In practice, deinstitutionalisation or community care has proved to be difficult to achieve. Community care means that care inside an institution has to be replaced by care in the community. But as yet, this has hardly been achieved anywhere. Even if the client lives independently outside the institution, the institution remains the care provider in most cases. The difference is that the care is now provided by the institution in the community. ‘You can take the resident out of the institution, but you can’t take the institution out of the resident’ is how this state of affairs is described in a report by the RMO on community care (Plemper and Van Vliet, 2002). Recent research by the SCP on the deinstitutionalisation of care has also indicated that the cooperation and harmonisation among care providers, social services and providers of living accommodation that was so strongly advocated in policy documents and reports has not yet materialised. There is some degree of cooperation between institutions and organisations with the same source of financing or who focus on the same target groups, but that is all. The role of the local authorities, who were assigned the task of managing all this according to the same policy documents and reports, is far from clear to all parties concerned, including the local authorities themselves. The fact that the municipal authorities have no control
over care providers and housing associations financed by the AWBZ (insurance fund for special medical expenses) makes this all the more difficult to achieve.

What do we know about the landing of vulnerable groups in urban neighbourhoods? Is it a hard or soft landing? Little research has been done into this as yet, but we do know something. For example, we know that the mental health care clients who have gone to live in an ordinary neighbourhood in an ordinary house remains at a below-average level for our country on a number of points. To start with, half of them have no paid or voluntary work. Furthermore, many of them have no permanent partner; loneliness is prevalent and they do not feel they have made much contact with the community (Michon e.a., 2003). Earlier reports also expressed some doubts about the prompt integration these people were supposed to achieve in an urban environment. According to the researchers, the patients became desperate and could hardly see how they could keep their head above water, let alone integrate into a complex society and find their own niche in an increasingly heterogeneous neighbourhood. And on top of this there was the problem of the ‘tempo of urban life’. ‘It is so busy in the town that it makes me feel completely chaotic’ (Duurkoop, 1995; p.272).

A survey of extramuralised people with mental disabilities indicated that they did make more use of facilities for the general public than before they moved into the community, but that their informal social contacts with people who did not belong to the institutional world or their own family hardly increased at all (Overkamp, 2000). Another survey of people with mental disabilities showed that they often find it difficult to make new social contacts in a new environment. Counsellors from the institution often play a part in making contacts: they take the initiative and teach their clients basic social rules such as offering something to drink when someone comes visiting, returning a telephone call or cancelling an appointment, thanking people, etc. However, some clients fail to learn from experience, and the result is that other people give up on them, since reciprocity is extremely important in social contact. Many volunteers also give up for the same reason (Schuurman, 2002). Recent research into the psychiatric department of a Regional Institution for Sheltered Living (RIBW) revealed that although many interviewees said they felt ‘at home’ in the neighbourhood, half of them said no one ever came to see them or that they received a visit less than once a month! (Olij, 2004).

Another point that emerged from various SCP surveys is that the social networks of the different groups with a disability are smaller than average. Sports clubs, community centres, associations and other clubs do not always welcome people with a mental handicap or learning disability. This means that they are often obliged to find their social contacts among fellow care clients (Taskforce Vermaatschappelijking, 2002; p.36). In recent SCP research on deinstitutionalisation in the care sector, various care providers express their doubts about whether people with a disability are accepted by the community. Residential facilities for chronic psychiatric patients regularly encounter opposition from the neighbourhood; people with mental disabilities hardly even have any contact with their neighbours. Users of voluntary services would rather not be helped by a volunteer who is also a psychiatric patient (Koops en Kwekkeboom, 2005; p.59).

A study on an integration project in two neighbourhoods in Den Helder (Samen in de Wijk, 2005) showed that mental health care clients and people with mental disabilities were teased and harassed by young people in their neighbourhood, mainly in the summer. Furthermore, people felt the lack of structural social centres in the neighbourhood where people of all kinds could just drop in.
People with a disability often see fellow clients and patients as their most important social contacts (Kwekkeboom, 2001; ‘Samen in de wijk’, 2005; Schuurman, 2002). The neighbourhood has not yet proved to be a viable support structure or a 'better home' for these groups of people. Contacts in the neighbourhood are negligible in comparison with contacts with close members of the family, fellow sufferers and acquaintances (Kwekkeboom, 2001). The care sector would appear to overestimate community care: the neighbourhood does not necessarily contain a host of buddies with whom residents have intensive social contact. The strong social networks dreamt of in the new Wet op de Maatschappelijke Ondersteuning (Law on Community Support) can only be found in a few small corners of these neighbourhoods, and then usually only within a family or an ethnic group. Without wishing to detract from all the admirable work done by volunteer helpers, their contribution is not adequate in the final count, certainly when the outside world gets harder and tougher.

Community involvement and the integration of the care client in the community, two crucial elements in the deinstitutionalisation theory, have certainly not materialised as expected so far. The fact that this was not foreseen is mainly because people had not given it enough thought beforehand. It is striking that in all the plans and discussions about community care, it was hardly ever explicitly explained why independent living and integration into the community was so desirable, and how exactly it should be achieved in practice. There were great expectations of the benefits of living in an ordinary house in an ordinary neighbourhood, but virtually nowhere in the literature was this ideal substantiated and worked out in detail. It gradually came to be accepted as an unquestioned principle: living independently in an ordinary neighbourhood was good for everyone, both 'normal' citizens and vulnerable groups. Living locally meant you had a better home, compared with the old institutional 'homes' of the past which were perceived as too big and impersonal, the opposite of a 'normal' home, belonging to no one – a sort of no-man's land. The argument was that living in an ordinary neighbourhood was better because clients were living in an ordinary, normal – even natural – home. This idea of 'home' was good for everyone and the same for everyone. All residents would appear to be the same in this respect.

In practice, extramuralisation leads to an influx of all kinds of residents with specific problems, particularly into the less popular neighbourhoods of the town. This is because reasonably priced rented accommodation is increasingly concentrated in post-war urban neighbourhoods which are often known to be disadvantaged areas. There are two different, contrasting views of this type of working-class area: the poorer neighbourhood is seen by some as a 'health resort' (kuuroord) and by others as a cold, hard place to live (guur oord).

In the first view, which is shared by the care sector, a positive evaluation of these neighbourhoods predominates. The neighbourhood is seen as an attractive, hospitable place, ideal for restoring the socially vulnerable to health (source: Cie. Brinkman). As Els Borst said in an interview as minister of Health, Welfare and Sport:

The community must take responsibility for society's problem cases. […] Large cities have their advantages. I am from Amsterdam myself and I know the Zeedijk and the Warmoesstraat well: there is something going on there all day long. There are wonderful cafés there full of colourful types on the dole. In fact, the whole neighbourhood is colourful. And the nice thing about these
neighbourhoods is that there is still a feeling of social cohesion there, the atmosphere immortalised in
the books of Carmiggelt. I would never advise patients to go and live alone in the country. In the
towns, and in the poorer areas in particular, people still have real social contact with each
other.’(Langelaan en Schoemaker, 2000)

In stark contrast to this, there is the image that public housing officials in particular have of this kind of
neighbourhood. They see disadvantaged neighbourhoods in post-war areas as hotbeds of social disintegration
where all kinds of problems are concentrated, a cesspit of iniquity, the jungle. Extensive demolition and grand
new construction projects must provide for an influx of the middle classes, who are expected to give the
neighbourhood a positive injection (Duyvendak 2002).

According to the first view, the neighbourhood is safe, cohesive and harmonious; according to the
second it is unsafe, full of conflict and literally makes people ill. The vision of the neighbourhood as a healthy
and healing environment seems to be based on a romantic image of close social networks. It would obviously
be much better for psychiatric patients, the elderly, people with learning disabilities and the physically
handicapped to live in a neighbourhood like this rather than a large institution. The neighbourhood is even
expected to 'heal' these new residents or at least save them from hospitalisation. This vision of the
neighbourhood attributes characteristics to it (support, attention, social interaction, contact with neighbours)
that are diametrically opposed to the second vision of the neighbourhood as the 'wild side' where danger rules
the streets and social bonds have been broken. The contrast between these two views of the neighbourhood
is really striking: one camp sees completely different qualities in it from what the other camp sees. It looks as
though no one really examined the characteristics of this type of neighbourhood during the first two phases
of the debate on community care. Are working-class neighbourhoods really warmer communities than the
suburbs? (Blokland, 2000). Are people there really more community-minded, do people really look out for
each other more, help each other more? And neighbourhoods like the Bijlmer, which people probably
thought would be a good alternative to a psychiatric hospital like Santpoort in 1975, surely they had changed
radically by 1995?

That is indeed the case. Socially harmonious neighbourhoods that could function as a support system
for people with a disability appeared to be few and far between, despite expectations. Sometimes, life in a
neighbourhood like this is difficult enough for 'normal' residents, in view of the many problems with safety
and the quality of life. Policy-makers do not even have the beginnings of an answer to how people who are in
an even weaker social position could possibly manage under these circumstances.

Recently, partly as a result of experience with the handicapped living in 'ordinary' neighbourhoods, a
question which had arisen earlier cropped up again more insistently: apart from the question of the
disappointing absence of social support, is living as 'normally' as possible really the best possible way for
everyone to feel 'at home' somewhere? Tentative voices suggested that perhaps certain aspects of the hated
institutions could be precisely what made some clients feel at home there: protection, safety, living with
others with a disability, the daily routine?

Since we shall be publishing other papers going more deeply into the nature and quality of the social
support local residents can offer to their neighbours with a disability, we will now move on to examine briefly
what is actually required. So far, the anti-institutionalisation debate has thrown up very diverse assumptions
about what feeling 'at home' means for a person with a mental handicap. The predominant view was that if clients were to feel at home somewhere, their living environment had to be as 'normal' as possible. So to put it in a nutshell, what is needed is normalisation. But there is empirical evidence that 'feeling at home' can mean very different things to different people. Perhaps a short theoretical exercise can help us arrive at a more differentiated concept of 'feeling at home'.

III. Feeling at home in theory

What is it that really makes people feel at home? What are the decisive factors? Can any patterns be discerned in this? Does the environment always have to be safe and predictable? Or anonymous? Caring and attentive or leaving people in peace? If we can build up a clear picture of what is required, we can establish which neighbourhoods or areas could be a good home basis for the elderly and infirm and those with mental disabilities or a mental handicap. How can we define the necessary quality of the social networks in the area? How much help and assistance from volunteers will be available there in the future?

The policy documents on care in the community give no answers to these questions. No detailed analysis of precisely what it means to feel at home somewhere were to be found in any of these papers, and there is no suggestion that it might mean different things to different people. We therefore decided to search in the literature for place attachment.

In their article: 'Place attachment. A conceptual inquiry', Low and Altman define 'place attachment' as 'the bonding of people'. How people bond with a certain place has to do with the combined action of affect and emotions, knowledge and beliefs, and behaviours and actions in reference to a place. The term 'place attachment' implies that the primary target of affective bonding of people is to environmental settings themselves. At the same time, attachment can also be based on other people – family, friends, the community or even culture. 'Thus the social relations that a place signifies may be equally or more important to the attachment process than the place qua place. Places are, therefore, repositories and contexts within which interpersonal, community, and cultural relationships occur, and it is to those social relationships, not just to place, to which people are attached.' Cuba also strongly emphasises the social aspect: ‘Local social involvements – particularly those with friends, but also those involving kin, organization memberships, and local shopping – prove to be the most consistent and significant sources of sentimental ties to local places.’

The 'social relations that a place signifies' is an aspect that appears at first sight to have been largely disregarded in the Dutch attempt to move towards care in the community. And it is precisely this aspect that focuses on the need for social support and the importance of the family, friends and the neighbourhood. It is remarkable that in the Netherlands, this was not explicitly linked to any extent with the qualities of the neighbourhood where all this was to take place. Whereas a little attention was paid to the question of whether the physical characteristics of the neighbourhood and the street might be a hindrance to the new residents with a disability, absolutely no thought was given to what kind of social bonding could develop in which areas and which neighbourhoods. Just let these people live in ordinary neighbourhoods – that always has to be better than living in an institution. But which neighbourhoods are so 'ordinary' that social networks appear
spontaneously? In the friendly hustle and bustle of poorer quarters like the Warmoesstraat in Amsterdam that Minister Borst referred to? Or would they be better off in more middleclass areas where people have more social and cultural capital? And could the way public spaces are designed out in these areas also play a part in promoting social contacts, so that people would not only bond with the place as such but also attribute a shared social meaning to it (Van der Graaf 2004)?

A striking aspect of the results of evaluation studies on care in the community to date is that regarding place attachment, many people with a handicap do in fact bond with a place as such, and much less than we would have expected from the work of Low and Altman with the place as a scene of social bonding. People mention ponds, amenities, decorations and the familiarity of the environment as things that make a place feel like home. If people are mentioned, it is certainly not always as people with whom they have any actual contact but more as 'extras' with a walk-on part in the environment: "I live opposite a shopping centre and it's nice to see the shoppers passing. (Olij 2004:…)."

One of the conclusions we could draw from this is that feeling at home means something different to people with a handicap and the elderly than to other people: they do not necessarily have to take part in social contacts but they like to be in or near the place where they occur. This possible interpretation is worth looking into: if it is correct, building accommodation in busy locations could be a way of getting these groups into the community without their necessarily having to take part in all the hustle and bustle. It could also be that since 'feeling at home' means different things for different people, those with a handicap have simply resigned themselves to the fact that they will always be spectators, since social bonding just is not an option for them.

Many of the respondents in the RIBW survey also mentioned shopping as an important activity that contributes to making them feel at home in a place. So the presence of shops is an important criterion. It is a pity that the statistics for this finding are not broken down into figures for men and women separately, since there could be a difference in the significance of shopping for men and women, especially among the older generations. This would be in line with Cuba's finding that although men and women become equally attached to a place, women tend to identify with the neighbourhood rather than with the whole community and also speak in more emotional terms about their dwelling. On the other hand, men tend to speak in grandiose terms about their attachment to the community, whereby the community can be interpreted both in a social and a territorial sense.

A study by Cuba & Hummon demonstrated that feeling at home need not refer to just one place but that it could involve overlapping territorial units: the dwelling, the community and the region. A research project examining 'at-homeness' among residents in Cape Cod, Massachusetts (a popular place to retire to) indicated that all three (dwelling, community and region) made a substantial contribution to the process of identifying with a place. On the other hand, four of the ten respondents identified primarily with one place, one level of scale, and that one place could be the dwelling, the community or the region.

Since most people with a disability have a relatively limited radius of action, policies for these groups of people should not assume that the territorial levels beyond the dwelling are necessarily equally important for them as for the 'healthy' residents in the neighbourhood. Here again, there will be differences between what makes various people feel at home in a place. The literature could well be misleading in this respect; the
literature we consulted did refer to the variation in how people experience feeling at home, but did not expand in any detail on the possibility of any specific interpretation of feeling at home by people with functional limitations.

It was reported in the literature that place attachment is also strongly dependent on the time dimension. Temporal issues are part of bonding to places. This may be in the form of an attachment because it is similar to places one knew in the past. But it is more often the case that the temporal attachment formed is so great because certain events occur in a ritual situation which is linked to a certain place: neighbourhood parties, events, markets, barbecues etc. Cuba also mentions this in an interview:

Research on people’s attachments to particular neighborhoods or communities also documents that emotional ties to these locales grow in strength over time, in part because long term residence imbues the landscape with the meanings of life experiences, and in part because such residence nourishes local ties to friends, kin, and community organizations.

This implies that familiarity and recognition play an important role in feeling at home in a place. Do people with a disability also land in a neighbourhood they feel is familiar, both in the social and a physical sense? That is very much the question: neighbourhoods which undergo radical demolition and new building in the framework of a restructuring plan, areas which experience a rapid influx of non-Europeans, 'transit neighbourhoods' where over 20% of the residents move on – these socially weaker neighbourhoods are not the ideal choice, given the need to identify with a place, and it is precisely these neighbourhoods that receive a large influx of people with a disability.

Research by Thomese and Van Tilburg (2000) among the elderly indicates that residential mobility does indeed have a negative effect on the relative size of the social network in the neighbourhood. Stability of the local resident population is the most significant factor favouring larger networks, independently of the degree of urbanisation.

The literature shows that people can attach themselves to a place for a wide variety of reasons. However, these reasons are not random: certain groups feel at home somewhere for specific reasons. Some groups value safety and a sense of security, social control and predictability. Others prefer a busy neighbourhood full of life and unexpected events, and its dynamism and anonymity. On the basis of the existing literature, a list can be drawn up of possible reasons why people feel at home somewhere; we have already sketched in the broad contours of this list above. It is high time that policymakers examined the different groups to be placed for care in the community to establish what makes them feel at home in a place – and surely that is what is all about?
Literature


Beraadsgroep Community Care, (1998). Leven in de lokale samenleving, Utrecht, NIZW.


