Lof der oppervlakkigheid: Contact tussen mensen met een verstandelijke of psychiatrische beperking en buurtbewoners

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Summary

Subject of research

At various places in The Netherlands, the settlement and residence of people with disabilities often tend to result in conflicts between people with disabilities and their neighbours. Neighbours complain about the inconvenience caused by grunting and screaming. They report being unable to hear their visitors speak, when sitting in their own backyard and at night, they are kept awake by the knocking and screaming (Dutch daily *Volkskrant*, July 29th 2013). The government, however, has high expectations for communities, with regards to people with disabilities.

Until the seventies, many people with intellectual disabilities or with mental disorders tended to live in large institutions, situated 'in the woods', far away from regular neighbourhoods. Since the seventies, there has been a change of course, with the introduction of new ambitions such as 'normalisation', 'deinstitutionalisation' and 'socialisation'.

Citizens with and those without disabilities ought to (learn to) accept one another. In addition, local residents are expected to contribute to the integration of people with disabilities. Citizens will have to share responsibility for care and reception of people with mental disorders and with intellectual disabilities (TK, 1998/1999d; Kwekkeboom, 2006:18; Overkamp, 2000:85-86). Citizens are summoned to shape their own well-being and show their solidarity with other, more vulnerable citizens in society.

What will come of these ideas? How do contacts proceed between neighbours, local residents, church members, club members and all other citizens in society who encounter people with disabilities? Will the woman next door help her neighbour with a mental disorder to maintain his garden? Will church members weekly visit a woman with an intellectual disability? Or do inconvenience and neighbourly disputes prevail? These questions have been translated in the following research question, which is addressed in this study:

*Which patterns of giving and receiving are encountered in contacts between people with disabilities and their fellow citizens?*

Key concepts

Fundamental to contact between people is the exchange of material goods or intellectual property (Mauss, 1990 [1923]; Komter, 2003). This exchange (giving-receiving-reciprocating) may manifest itself differently within different relationships and the balance of giving and receiving may differ as well. For example, neighbours tend to exchange services based on reciprocity (Linders, 2010). ‘You put out the dust bin when I am on holiday and I look after your plants when you are off.’ However, in the relationship between parents and
children, this balance is absent. Parents tend to serve their children hand and foot; they are at their children’s disposal. However, they do not expect their children to return this favour instantly (maybe parents might, once they have grown old).

Based on a literature study, an analysis framework has been designed, presenting various possible forms of giving and receiving that may occur in the contact between citizens with and those without disabilities (see diagramme 1). The balance of giving and receiving differs within each pattern of interaction. An example of a pattern of interaction is ‘charity’. Here, the citizen with a disability is the one who mostly receives and the citizen without a disability is the one who predominantly gives. In the pattern of ‘exploitation’, the citizen with a disability is mostly deprived. Another instance is that no exchange occurs at all. This pattern is referred to as ‘no contact’. A fourth pattern of interaction is ‘reciprocity’. In the case of reciprocity, not just one party either gives or receives, but both parties give and receive in the encounter. The expectations of the pattern of reciprocity in particular, are high. Reciprocity is supposed to ensure inclusion of vulnerable citizens, increase solidarity and people’s self-esteem, as well as promote the appreciation that groups of citizens will have for one another.

The various forms of contact (reciprocity, charity, exploitation and no contact) that emerge from the literature have been summarised in the following matrix. In it is shown which person gives and which one receives, as well as the sort of encounter this will lead to.

<table>
<thead>
<tr>
<th>Fellow citizen</th>
<th>Giving</th>
<th>Receiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving</td>
<td>Reciprocity</td>
<td>Exploitation</td>
</tr>
<tr>
<td>Receiving</td>
<td>Charity</td>
<td>No contact</td>
</tr>
</tbody>
</table>

Diagramme 1 Types of interactions between citizens

[In the design of the analysis framework of contact between people with and those without disabilities, the basic assumption is ‘giving’ or ‘not giving’. In case of the pattern of interaction referred to as ‘no contact’, both parties do not give, resulting in the occurrence of no contact.]

The research has investigated whether the above-mentioned forms of contact do occur in encounters between people with and those without disabilities and in what way these forms crystallise. The mechanisms underlying the various
patterns of interactions and the advantages and disadvantages of different patterns of interaction have been recorded for both groups. The hypothesis reads that specifically reciprocal contact may be beneficial for people with disabilities and may lead to sustainable contacts.

**Applied research methods**

In order to formulate an answer to the question posed, research has been conducted in two neighbourhoods in the Dutch city of Zwolle, i.e. Ittersummerlanden and Schellerlanden. Different types of research have been applied. Questionnaires have been distributed among citizens (both with and without disabilities) residing in the neighbourhoods involved, and interviews have been conducted with a number of the citizens in question (75 interviews). In addition, interviews have been conducted with social professionals, operating within these neighbourhoods (25 interviews). Furthermore, the researcher has participated in a number of projects in the neighbourhoods investigated, that ought to result in encounters between people with and those without disabilities, i.e.:

- A cafe meant for local residents, run by people with intellectual disabilities and/or with mental disorders (De keuken van Zuid – The South Kitchen);
- A handyman project, in which people with disabilities do odd jobs for local people (Het schuurtje van Zuid – The South Shed);
- Various projects and activities at the community farm ‘De Schellerhoeve’, involving local residents with and those without disabilities to collaborate (including the Pluktuin – The Picking garden).

**Do citizens with and those without disabilities encounter one another?**

The first empirical chapter reflects on the questions whether there is contact between people with disabilities and people without them, why is it that a large group of citizens without disabilities have no contact at all with people with disabilities and what is the nature of this contact in the group that does maintains such contacts.

There is evidence that citizens without disabilities do not look after citizens with disabilities naturally. The main category of the citizens (65 - 69%) that completed the written questionnaire does not have any contact with people with mental disorders or intellectual disabilities. There are various reasons why these contacts will not be established between people with and those without disabilities.

The disabilities prove to have an inhibiting effect. Due to their intellectual disability and their limited socio-emotional development, citizens with disabilities often do not understand others. People with mental disorders may suffer from disorders such as autism or borderline personality (BPD), because of which establishing and maintaining contacts are very complex.
In addition, disabilities often have considerable implications on social participation. Since they generally do not participate in the labour market, people with disabilities have limited budgets and hence little resources to go out for leisure activities or to pay for transport. They do not have a room of their own, or a mobile telephone.

An important reason for difficulties in the initiation and continuation of contacts is the lack of social skills needed to undertake initiatives, whether or not related to the disorder. Diffidence and a lack of self-esteem due to the disorder and the accompanying feelings of shame result in a reluctance to go out by citizens with disabilities and in isolation from others within society.

Additionally, both groups hold stigmas and prejudices with respect to one another. Images about the other hinder people to encounter one another. Other obstacles to encounter people with disabilities are a deviant appearance or a poor personal hygiene. As result, there are two worlds, a world of people with disabilities and a world of people without disabilities.

To step outside one’s own world seems to be very difficult. Especially since assistance is still mainly internally focussed and since network-oriented operation has not yet been given substance, citizens with disabilities are still left outside the regular world. For the group of citizens with disabilities who needs this kind of protection, it ensures a safe, defined environment of which they benefit greatly. Citizens with disabilities, who are situated in the fringe area between these two worlds, consider the step towards a world outside psychiatry or outside the care for the intellectually disabled to be big, and sometimes even too big to take.

Another important observation according to this study is that policymakers should take into account the supportive power of citizens without disabilities. Currently, the housing policy results in the placement of citizens with disabilities in weaker neighbourhoods, forcing vulnerable citizens to take care of citizens with disabilities. There is a risk of overcharging these citizens, who often struggle with their own problems. Resilient citizens are not called upon, in this situation. Hence, the principle of ‘the resilient supports the vulnerable’ becomes an illusion.

Which people, then, do have contact with people with disabilities after all? These are mostly people who are already familiar with people with disabilities, as they are employed in healthcare, or as they are vulnerable themselves, or because they are related to someone with disabilities. Furthermore, more women than men appear to be involved with people with disabilities. When contacts occur, these generally do not have the nature of the warm helping and caring relations that policymakers strive for. The largest part of the contacts is light (undemanding) and superficial by character. People will greet each other and make small talk within the public domain. There, most citizens meet each
other. People mostly become acquainted with each other within their
neighbourhood and there they maintain light contacts.

**Reciprocity**

Chapter 5 deals with the reciprocal contacts between people with and those
without disabilities in society. Many people without disabilities (the group of 30 -
35% of the respondents in this study that do have contact indeed) will have
superficial contact in the street, during which they greet *each other* and chat
with *each other*. For both people with and those without disabilities who
completed the questionnaire, this proved to be the prevailing type of contact.

These light and superficial contacts, as is evidenced by this study, often will
emerge spontaneously within the public domain: in dog walking areas, in the
streets or in a store. This is where people with and those without disabilities talk
to each other and maintain light contact. In the case of contact in the street,
people do not need to receive each other within their private domain, which is
in line with the ‘rules’ that are applied at the neighbourhood level: i.e. keeping
proper distance and refraining from interference in each other’s private domain
(see: Blokland, 2005; Jager-Vreugdenhil, 2012). Furthermore, contact within the
public domain may be interrupted easily. When one of the conversation
partners runs out of things to talk about, he continues his walk.

These restricted contacts provide a level of security for people without
disabilities. They have the situation under control, because they can decide for
themselves whether to continue or to interrupt the contact. These well-defined
situations are comfortable for people with disabilities as well, since they can
assess the situation and the roles in the conversation are mostly clear-cut. ‘You
are the shopkeeper and I am the customer, and we can have a short chat, and
this is all that is expected from me’. The easiness of the contact ensures people
will not get in trouble with complex social codes.

Apparently, these light and restricted contacts are important for both citizens
with and those without disabilities. These contacts represent bridges between
the two mostly separate worlds of people with disabilities and people without
disabilities. People may become acquainted with the world of ‘the other person’,
without this becoming threatening. Concerning people with disabilities, they get
to leave the world of psychiatry or of the intellectually disabled, and they may
dismiss the role of ‘patient’ or ‘client’. They may explore other forms of their
hybrid identities (Wiesel et al., 2013). Additionally, a mere greeting, a wave or a
chat at the baker’s have proven to contribute to the sense of recognition and
‘feeling at home’ in a neighbourhood. This is of utmost importance, since
people with disabilities stay within their neighbourhoods most of their time.

Although most citizens limit the intensity of contact to greeting and having small
talk, people without disabilities tend to give advice and support as well, to
people with psychiatric disorders, and spend leisure time with them. The
situation is different for people with intellectual disabilities. The majority of the citizens in the study limit the contact to greeting and chatting in the street. Contact with people with psychiatric disorders is hence closer than contact with people with intellectual disabilities.

When contacts intensify and people, for example, will spend leisure time together or render a service for the other, the reciprocity often becomes unbalanced. Within forms of reciprocal contact that are more intensive, the balance of reciprocity, as it takes shape in ‘regular’ relationships, will be converted into the social norm of ‘charity’. Citizens without disabilities bear the disability in mind and therefore, they expect a smaller gift or act in return. When this ‘norm of reciprocity’ is converted into the ‘norm of charity’ (Gouldner, 1960), something changes in the relationship between citizens with and those without disabilities. The equivalence in the contact diminishes and this will evoke resistance on both sides. Why is it impossible for the contact to be ‘normal’? Only a limited group of people with disabilities have access to reciprocal relationships involving empathy and love.

The resistance that arises when people are no longer expected to return a favour shows the importance of reciprocity. People with disabilities like it when they are able to give something in contact. This makes them feel needed and like they have something to offer. They are able to detach themselves from their role as ‘patient’. Their competencies are being addressed and they may fulfil a ‘role’ in society. Therefore, mobilising reciprocal relations is of great significance. It is a way of empowering people with disabilities.

Charity

Another form of contact found in this study is the pattern of interaction referred to as ‘charity’. Chapter 6 discusses this pattern of interaction. Charity relations are characterised by asymmetry in giving and receiving. The citizen with a disability is not asked to return a favour and often not expected to do so. Charity comes first and reciprocity is not involved.

For a particular group of citizens, for whom dependency is unnecessary, this causes feelings of guilt and shame. They start to feel that the debt in the relationship accumulates constantly and that this debt may not nor cannot be redeemed. When people with disabilities are not able to redeem this debt in other relationships either, because they are in receiving and dependent positions more often, this may destroy their sense of self-esteem. At some point, they will start believing they do not have anything to give nor to offer. This may lead to another extreme situation, when citizens with disabilities become passive and submissive and expect others to take all initiatives. In that case, acceptance trepidation and resistance against dependency seem to have vanished.
For people without disabilities such contacts are unpleasant as well. Especially when people carry their dependency too far and accept help without appreciation and when they may even be capable of manipulating other people into helping them. People feel exploited and used when gratefulness is not expressed after the help they have given. Here, limitation seems to be appropriate. Too much asymmetry within contacts in which emotional commitment is weak, may otherwise result in a conclusion of such relationships.

Exploitation

It becomes apparent from this study that, in situations where limitation of contact is not being observed, contacts between citizens with and those without disabilities may take a negative turn. In chapter 7, the situation is discussed that it is common for benevolent citizens, who are willing to commit themselves to people with disabilities, to reach a deadlock in this contact. Especially when boundaries are missing, becoming blurred and are exceeded, problematical situations may easily arise.

Such conflicts originate from violation of tacit expectations regarding privacy in the neighbourhood. When appropriate distance is not kept, problems arise. Noise pollution, the thought of being watched, people who ask for your help at untimely hours, are not being tolerated nor accepted. Additionally, unacceptable and demanding behaviour appear to be an important cause for conflicts. Because citizens with disabilities (in particular people with intellectual disabilities) have difficulty taking perspectives (i.e. empathy) (Teeuwen, 2012) and are not socially reflective (Lichterman, 2005), they have difficulty estimating the appropriateness of their visit or call for help. People without disabilities tolerate people with disabilities in their vicinity, but they should not come too close. People without disabilities appear to be less receptive to people with disabilities and to have less appreciation for them, than policymakers hoped for. By misunderstanding on both sides, irritations arise that may build up and often end in harassment and vexation on both sides.

Moreover, citizens with disabilities are easy victims for malevolent people. Various forms of exploitation happen to occur (financial, mental as well as sexual) to half of the 25 interviewed people with intellectual disabilities and to approximately one third of the 22 people with mental disorders. People without disabilities (such as neighbours, distant friends, acquaintances and salespersons) palm products that are too expensive and subscriptions off on people with disabilities, sell them stuff for too little money (i.e. ‘receiving’), deploy them as delivery service for parcels with questionable content, use their house as a place to hang out, steal their money and things, or issue registration certificates for cars and mopeds in their name, so they will be saddled with the fines in turn. This is a very alarming observation. Particularly citizens with intellectual disabilities, who live on their own in society, frequently appear to become victims of malevolent fellow citizens. Still too little attention is being paid to this
in the political debate. Socialisation seems to be an ambition policymakers easily side with, but it does not seem to be self-evident, taking in consideration the above-mentioned observations.

Conclusions and recommendations

Chapter 8 answers the main question this research focuses on, i.e. whether contact is established between people with and those without disabilities in society, and how this contact may be characterised. This research shows that it is not realistic to expect that sustainable, warm relationships, where people on both sides will pay attention to each other, help and care for each other, will be established naturally between citizens with and those without disabilities. Helping each other, taking care of one another and visit each other regularly does not occur quite often and when this kind of contact does occur, the manifestation of problems is probable. Positive contacts do emerge, but these are mainly contacts among vulnerable people themselves or contacts between resilient and vulnerable people, while the resilient citizens are already oriented towards people with disabilities, as they are experienced in this type of contacts. These contacts usually remain light and superficial. Occasionally, contacts will develop which bridge the social gap. This happens more often in the case of people with mental disorders. Although their contacts generally remain light, closer contacts are frequently established that are increasingly reciprocal. Contacts with people with intellectual disabilities remain mostly superficial and are found to be more problematic. This occurs particularly, when neighbourly contacts between people with intellectual disabilities and people without disabilities are involved.

Under favourable circumstances (for instance, in case the citizen with a disability is balanced and is capable of empathising with others), in compliance with certain conditions (i.e. the acceptance of imbalance, the observation of rules within the contact) and with an active application of matching and support by a professional, it seems possible to stimulate and develop contacts between citizens with and those without disabilities. Under condition of an appropriate limitation of contacts, they may remain positive of nature. Especially when circumstances limit contacts in length, frequency or intensity, or when those involved will limit the contacts, contacts may retain a pleasant character. However, when contact is unrestricted and those involved are not able to set boundaries themselves or do not have the opportunity to do so, it is very likely that inconvenience, conflicts, incomprehension, anger, exploitation and/or exhaustion will arise.

It is considered important to aim for light and superficial contacts and to delight in those few contacts based on charity that occur naturally. Light, superficial and restricted contacts seem to be more fitting with the skills of citizens with disabilities (including limited social reflectiveness and difficulty in taking perspectives), and more fitting with how neighbours and local residents like to
maintain relationships with one another (appropriate distance) and with this, the danger of mutual overcharging is confined within these contacts. Moreover, superficial contacts are more profound than people may think, as is evidenced by this research. The profit of such light, restricted, superficial contacts is substantial for both parties.

The recommendations stated in the final chapter aspire to bring about positive contacts between people with and those without disabilities, in compliance with the abovementioned condition. That is, aiming for light and restricted contact, based on reciprocity, when possible. One of the recommendations is launching projects within the neighbourhood, where people with disabilities will have a distinct role, for example such as a children’s farm, bicycle repair station, public parks and gardens maintenance service, a store or a restaurant. These are places where well-defined situations may be created. Here, people with disabilities or mental disorders may find a meaningful daytime activity that will contribute to their sense of self-esteem. Furthermore, situations are created in which residents may be introduced to people with disabilities in a natural, uncomplicated way. Prejudices may be corrected on both sides; this contributes to the mutual appreciation of groups of citizens. Moreover, these kinds of projects contribute to a liveable neighbourhood or area.

The theoretical value of this research is the observation that scientists easily assume that relationships are equal with regards to reciprocity, while in society many relationships occur in which those involved occupy dissimilar points of departure. This applies, for instance, to contacts between parents and children, local residents who are foreign or native, and between people with and those without disabilities. In addition, this research shows that those concepts that ought to verbalise forms of reciprocity fail. Regarding contact between people in an unequal relationship, another form of reciprocity is required, that is: adapted reciprocity.