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Social integration in a reversed integration neighbourhood?

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Chapter 1

Introduction

Since the 1960s, a paradigm shift in the support of people with intellectual disabilities has taken place (Mansell, 2006; Tøssebro & Lundebj, 2012). This shift aimed at bringing together the related practices of person-centred planning, development opportunities and personal growth, inclusion, self-determination, and empowerment (Schalock et al., 2010). Moreover, “the pattern and intensity of a person’s support needs is being used as a basis for agency and systems planning and resource allocation (Schalock et al., 2010)”. The residential facilities at that time were characterised by depersonalisation, rigidity of routine, treatment in the group without respect for the privacy and individuality of people with intellectual disabilities, and social distance (King, Raynes & Tizard, 1971). This did not fit the ideals of the new paradigm; therefore, in many countries these facilities were replaced by small-scale services in the community: the so-called deinstitutionalisation (Mansell & Beadle-Brown, 2010). The aim of these community living arrangements was to improve the quality of life, to give people with intellectual disabilities more control over their own lives, and to make the facilities in the community more accessible for people with intellectual disabilities (Chowdhury & Benson, 2011; Mansell & Beadle-Brown, 2010). Some countries like the Scandinavian countries, United Kingdom and United States of America even closed all, or most, of their residential facilities (Chowdhury & Benson, 2011; Mansell, 2006). However, in some countries, such as the Netherlands, community living is promoted, while residential facilities continue to exist (European Intellectual Disability Research Network, 2003).

Deinstitutionalisation is a first step towards the integration of people with intellectual disabilities (van Genneep & Ruigrok, 2002). Integration contains three aspects: physical integration, functional integration, and social integration (van Alphen, 2011; Nieboer et al., 2011). Physical integration is being physically present in the community. Functional integration means that people with intellectual disabilities use the facilities in the community. Social integration, finally, is defined as being part of a broader community in which the person with intellectual disabilities is appreciated and respected (van Alphen, 2011; van Genneep & Ruigrok, 2002). Especially physical, and sometimes also functional integration is, compared to a segregated facility, better facilitated when people with intellectual disabilities live in the same neighbourhood as people without intellectual disabilities.

A lot of research has been conducted about the outcomes of community living (e.g. Chowdhury & Benson, 2011; Kilroy, Egan, Walsh, McManus & Sarma, 2015;

Mansell, 2006; Mansell & Beadle-Brown, 2010). Recently, Chowdhury and Benson (2011) conducted a literature review and overall found that the outcomes of quality of life were better after people with intellectual disabilities moved to the community. However, when looking at the integration aspect, people with intellectual disabilities were often merely physically, but not functionally and socially integrated (Chowdhury & Benson, 2011; den Daas, Nakken, Smrkovsky & van der Struik, 2007; van Genneep & Ruigrok, 2002).

The outcomes of the integration process are poorest for people with high support needs, like people with profound or severe intellectual disabilities or people with intellectual disabilities and behaviour and/or psychiatric problems (European Intellectual Disability Research Network, 2003; Felce & Emerson 2001; Mansell 2006; Mansell & Beadle-Brown, 2010). They are generally the last persons to leave the residential facilities and the first persons to move back if the integration attempts failed. Therefore, in the Netherlands specific projects have been developed in order to facilitate their integration of these categories of people: the so-called 'reversed integration' projects. *Reversed integration* means that the grounds of the residential facility converted into a neighbourhood (European Intellectual Disability Research Network, 2003). People with intellectual disabilities stay at the same house with the same direct support professionals (DSPs), while people without intellectual disabilities move to the formal grounds of the residential facility and by doing so, choose to live next to people with intellectual disabilities. In reversed integration, the neighbourhood is more adapted to people with intellectual disabilities compared to regular neighbourhoods. For example, there are stricter speed limits. The expectation is that in such a neighbourhood people with intellectual disabilities, and especially people with high support needs, have better opportunities to become integrated compared to regular integration.

So far, hardly any research has been done about the effect of a reversed integration setting on integration process of people with high support needs. Therefore, it is unknown, for example, whether, and if so, what kind of advantages this type of location may have compared to other locations such as community houses and residential facilities. This present research focussed on the stakeholders in the support of people with intellectual disabilities who live in a reversed integration neighbourhood.

Perspectives

In reversed integration three stakeholders are involved in the integration process of people with intellectual disabilities: neighbours, family members, and DSPs. All these groups can be expected to have a specific perspective on the integration of people with intellectual disabilities; however, to the best of our knowledge, these perspectives have not yet been investigated in the context of reversed integration. Nevertheless, based on the literature about integrated settings, several assumptions can be made concerning these three stakeholders.

Neighbours without intellectual disabilities have chosen to move to a neighbourhood where the majority of people have intellectual disabilities. Therefore, the expectation is that they will have a positive, or at least a neutral attitude towards the integration of people with intellectual disabilities when they started living in the reversed integration neighbourhood. However, there is a possibility that their actual experiences will negatively affect their attitude over time. For example, their experiences with the severe level of intellectual disabilities and the high degree of behaviour and/or psychiatric problems of people with intellectual disabilities who live in the reversed integration neighbourhood or their experiences with the large number of people with intellectual disabilities who live in this setting (van Alphen, Dijker, Bos, Borne & Curfs, 2012).

Regarding the family members of people with intellectual disabilities, little research has been done about their perspective on integration. An exception is a study by Tøssebro and Lundebj (2006), who found that family members, whose relative with intellectual disabilities moved to community houses, were initially opposed to the deinstitutionalisation. However, after it was carried out, their attitude positively changed. Based on these results, the assumption is that family members of people with intellectual disabilities who live in the reversed integration neighbourhood will also be positive about integration after the reversed integration is realised.

Finally, the DSPs have to deal with a new and unpredictable environment with potential danger and safety issues once reversed integration is introduced. For example, there is more traffic in the integrated neighbourhood than on the grounds of residential facilities. In their work, DSPs are more occupied with controlling the risks and keeping everybody safe than facilitating the social integration of people with intellectual disabilities (McConkey & Collins, 2010). Moreover, a study by Bigby and collaborators (2009) found that DSPs, who work with people with intellectual

disabilities and high support needs, believed that integration was not feasible for these groups of people. People with intellectual disabilities and high support needs, however, are exactly people who typically live in a reversed integration neighbourhood. Nevertheless, in reversed integration the neighbourhood is more adapted to people with intellectual disabilities than in regular neighbourhoods. Therefore, the expectation is that people in these neighbourhoods are less concerned about topics such as safety. These advantages may also positively influence the attitude of DSPs.

Role of formal support

People with intellectual disabilities are depending – to a certain extent – on DSPs for support in their daily home activities, but also in community activities. The more severe their level of intellectual disabilities, the more dependent they are. Therefore, DSPs play a key role in the integration process of people with intellectual disabilities (van Alphen, 2011; Chowdhury & Benson, 2011; Mansell, Elliott, Beadle-Brown, Ashman & Macdonald, 2002; Mansell, 2006; Overmars-Marx, 2011). They have to initiate and facilitate the contact between people with and those without intellectual disabilities (Abbott & McConkey, 2006; Van Alphen, 2011). Such contact can vary in intensity and frequency, from mere greeting to being friends. *Nota bene*, already brief, superficial contact situations, such as greeting, have been found to be valuable for persons with intellectual disabilities (Bredewold, 2014). Because people with and without intellectual disabilities meet in a restricted and therefore safe way, they can get familiar with each other's world. This can stimulate the social integration of people with intellectual disabilities.

There are several studies that focused on the role of DSPs in the integration of people with intellectual disabilities, thereby focusing especially on the type of support the DSPs should give (Mansell et al., 2002) or on the tasks of DSPs (e.g. Chowdhury & Benson, 2011). Common denominator in these studies is that they signal the crucial and irreplaceable role of the DSPs for enhancing the integration of people with intellectual disabilities (van Alphen, 2011; Chowdhury & Benson, 2011; Mansell et al., 2002; Mansell, 2006; Overmars-Marx, 2011). However, even if DSPs know about their relevance in this process, and if their organisation actually expects them to invest effort in it, they may still be unwilling or unable to behave accordingly. It is therefore important to get a clear understanding of the psychological variables that

influence whether the DSPs are willing to invest effort in order to facilitate the integration of people with intellectual disabilities.

So far, there is little if any research done about this subject. The present research attempts to fill this gap by trying to predict the DSPs' effort for realising integration as a function of several psychological variables. To this end, it builds on psychological theories on the link between attitudes and the corresponding behaviour and behavioural intentions (Ajzen, 1985; Artis & Smith, 2013; Fishbein & Ajzen, 1975; Rise, Sheeran & Hukkelberg, 2010; Vorauer, 2013; Zolait, 2004).

Role of informal support

Currently, DSPs are facing high work pressure and shortage of time to accomplish their tasks for the sake of cost reduction in their work (Hatton et al., 1999; Hermsen, Embregts, Hendriks & Frielink, 2011; Kowalski et al., 2010). This obviously will have an impact on their possibilities to enhance the integration of people with intellectual disabilities. Besides relying on the DSPs, informal support could play an important role in the integration. However, family members are already heavily burdened with the care of their relative (Oudijk, de Boer, Woittiez, Timmermans & de Klerk, 2010), and in addition, they often either work or are already older (Brouns, Tap & Stam, 2013). Therefore it is uncertain how realistic it can be to further enlarge the role of family members. This makes the help of volunteers even more necessary, especially in enhancing the integration. First of all, any contact between volunteers and people with intellectual disabilities is already an instance of integration of people with intellectual disabilities. Second, they can also facilitate integration by taking the person with intellectual disabilities into the community and by creating contact between people with and without intellectual disabilities.

In line with this reasoning, the governments of different countries, such as the Netherlands and Ireland, also ask for a larger role for the volunteers in the support of people with intellectual disabilities (National Federation of Voluntary Bodies, 2008; van Rijn, 2013). In the Netherlands, the law regarding the support of people with intellectual disabilities has changed and gives people with intellectual disabilities more opportunities to choose the care they want and need. However, the new legislation also implies that for their support, they have to appeal more to their social network, which further enlarges the role of family members and especially volunteers

(de Boer & de Klerk, 2013). Unfortunately, the government does not give any concrete guidelines about how the role of volunteers should actually look like.

Nationally and internationally, there is little if any research done about volunteer work in the support of people with intellectual disabilities. Therefore, before research can be executed about the possibilities of *future* volunteer work, there should be a clear view of the current volunteer work. The present research attempts to fill at least some of these gaps in the knowledge about volunteer work in the support of people with intellectual disabilities. Furthermore, it investigates the possibilities of the volunteers in enhancing the integration of people with intellectual disabilities.

In sum, the present research sets to fill in the mentioned gaps in knowledge about reversed integration. More specifically, this research aims to get a better understanding of (1) the perspectives of people playing a relevant role in the integration process of people with intellectual disabilities in the reversed integration neighbourhood (i.e. DSPs, neighbours and family members), and of (2) the role of the formal and informal support in enhancing the social integration of people with intellectual disabilities.

1.1 Outline of the thesis

After this introductory chapter, chapter 2 and 3 focus on the perspectives and experiences of people involved in a reversed integration neighbourhood. *Chapter 2* presents an explorative study about safety and safety concerns, one of the most mentioned barriers of social integration, in a reversed integration setting. It presents data on perceived safety from the perspective of neighbours, DSPs, and family members of people with intellectual disabilities.

Chapter 3 describes a qualitative study about the attitudes of DSPs, family members and neighbours in a reversed integration setting about integration. Moreover, the DSPs' thoughts about the attitude of family members and neighbours regarding integration and regarding the DSPs and their work were investigated. A comparison is made between these meta-cognitions regarding the attitudes of family members and neighbours, and the actual attitudes of these groups.

Chapter 4 focusses on the role of DSPs in facilitating the inclusion of people with intellectual disabilities. This chapter describes a theoretical model in which five psychological variables are introduced that may influence the (intended) efforts of

DSPs to facilitate the inclusion of people with intellectual disabilities. More specifically, attitude, social norms, experiences competencies, identity and meta-evaluation were investigated as predictors of the effort that DSPs put into the inclusion of their clients. DSPs were asked to fill out a questionnaire with statements about these psychological variables and about facilitating the social integration. The theoretical model was tested with a regression analysis. Moreover, differences between locations (residential facility, reversed integration facility, community houses) were analysed.

Chapter 5 and 6 focus on the role of volunteers. *Chapter 5* gives insight in the typical characteristics of volunteers and their current volunteer work in the support of people with intellectual disabilities. Furthermore, the vision of the management, professionals, volunteers and family members on volunteer work and its possibilities, most of all concerning the social integration, is investigated. Results were obtained by means of a questionnaire that was filled in by volunteers, and by means of an organised expert meeting.

Chapter 6 reports data regarding the role of volunteers in enhancing the physical integration of people with intellectual disabilities. Physical integration is a precondition for social contacts and the first step to social integration. In order to completely understand the actual tasks of the volunteers, an inventory was done in the 86 participating locations of a large Dutch organisation. Together with 15 interviews of DSPs about the tasks of volunteers, a list was generated comprising possible tasks of volunteers in the support of people with intellectual disabilities. In a second step, a questionnaire was distributed amongst DSPs, which asked the DSPs to indicate how suitable the listed tasks were for being realized by volunteers. From these results, the top 10 most suitable tasks and the top 10 least suitable tasks for volunteers were created.

Chapter 7 is the last and concluding chapter. It summarises and reflects on the main findings of the five empirical chapters. In addition to addressing its practical implications, limitations of the research and its implications for further research are discussed.

