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Social integration in a reversed integration neighbourhood?

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Chapter 6

The role of volunteers in the social integration of people with intellectual disabilities

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Abstract

Background: Direct support professionals (DSPs) play an important role in the social integration process of people with intellectual disabilities. However, due to limited time and/or client-DSP ratio, even enhancing mere physical integration seems hardly possible. Volunteers may step in, but their role in enhancing social integration has not yet been investigated. This study focuses on physical integration, the first step to social integration. **Method:** In study I, an explorative inventory was executed on the current tasks of volunteers. In study II, using a questionnaire, 235 DSPs rated which tasks they considered being suitable for volunteers to perform. **Results:** Most volunteers are performing activities that enable physical integration. DSPs, however, mostly believe that activities in the community are not suitable for volunteers. **Conclusions:** Volunteers already play a role in the social integration of people with intellectual disabilities. However, the DSPs do not see these current and future possibilities.

6.1 Introduction

Social integration is subject of much research about people with intellectual disabilities (e.g. Carnaby, 1998; Cramm, Finkenflügel, Kuijsten & van Exel, 2009; Makharadze, Kitiashvili & Bricout, 2010). However, in the literature different definitions of social integration are used. For instance, Russell (2009) defines social integration as “the degree and content of our relationships with others”. Van Alphen (2011) defines it more specifically as having “valuable relationships with others in a community, in which the person with intellectual disabilities is fully accepted and valued as an interaction partner, without denying their differences or limitations”. Despite the differences in the definitions, social integration seems to be an umbrella term for a process, which in all studies contains two preconditions: physical integration and social contacts (van Alphen, Dijker, Borne & Curfs, 2010; Bos, 2015; Carnaby, 1998; Cummins & Lau, 2003; den Daas, Nakken, Smrkovsky, & van der Struik, 2007; van Genep & Ruigrok, 2002; Thorn, Pittman, Myers & Slaughter, 2009).

Physical integration, i.e., being present in the community, is a first and crucial step to social integration. Only when people with and without intellectual disabilities are in the same community and are able to see (and hear) each other, interaction between them can be initiated. When people with and without intellectual disabilities frequently meet, they will become familiar with each other, and actual social contacts between them can be established. This way, a next step in the social integration process can be made. Social contacts in neighbourhoods are day-to-day interactions that predominantly consist of greetings and small talk (van Alphen et al., 2010; Bos, 2015; Bredewold, 2014; Johnson, Douglas, Bigby & Iacono, 2012). These brief contacts typically contain verbal communication (van Alphen et al., 2010; Bos, 2015). However, it is important to note that even though physical integration is a precondition for social contacts, it does not guarantee that these contacts will actually take place.

Several studies have shown that both physical integration and – even more so – social contacts are difficult to realise for people with high support needs, like people with severe or profound intellectual disabilities and people with intellectual disabilities and behaviour and/or psychiatric problems (e.g. van Alphen et al., 2010; Bigby, Clement, Mansell & Beadle-Brown, 2009). First of all, these groups of clients do not

often come outside (van Alphen et al., 2010; Bos, 2015); due to the severity of the disabilities and/or the degree of problem behaviour they are depending on others to get into the community (den Daas et al., 2007; Mansell, 2006). Second, people with profound or severe intellectual disabilities mostly communicate non-verbally rather than verbally (Bigby et al., 2009). For these people it is important to get to know each other before some kind of mutual contact can be developed.

Direct support professionals (DSPs) who support people with intellectual disabilities in their daily activities, play a crucial role in the social integration of people with intellectual disabilities (van Alphen, 2011; Chowdhury & Benson, 2011; Mansell, 2006; Mansell et al., 2002; Overmars-Marx, 2011; Venema, Otten & Vlaskamp, 2015). However, there is potentially another group who could play an important role in the social integration of people with intellectual disabilities: volunteers. First of all, the presence of volunteers and their contact with people with intellectual disabilities in itself already promotes the social integration of people with intellectual disabilities. But it seems plausible to assume that volunteers could contribute more to the social integration process. Surprisingly, though, the role of volunteers in social integration of people with intellectual disabilities has not been investigated yet.

To investigate the role of volunteers in enhancing the social integration of people with intellectual disabilities, our first study aimed at understanding the current role of the volunteers in the physical integration of people with intellectual disabilities and in enhancing such integration. In this matter the opinion of DSPs about the content of the volunteer work is important. The second study is building on the evidence from the first study by asking the DSPs which tasks are suitable for volunteers to perform. Together, the two studies may provide valuable knowledge that could help organisations to make better use of volunteers as facilitators in social integration of people with intellectual disabilities.

6.2 Study I

6.2.1 Methods

Participants and setting

The research took place at several locations that belong to a large organisation supporting approximately 1500 people with intellectual disabilities in the Northern part of the Netherlands. The organisation provides support for living in both community houses and residential facilities. The support varies from support on demand to

intensive support. To get a representative overview, three different types of locations participated in the research: a residential facility, a reversed integration facility and a neighbourhood with community houses. In reversed integration, the residential facility is transformed into a neighbourhood wherein people without intellectual disabilities choose to live next to people with intellectual disabilities (Venema, Vlaskamp & Otten, 2016a). There were about 500 clients living in the participating locations, with a total of 238 volunteers. On every location one DSP was responsible for the volunteer work. Of these DSPs, a total of 86 DSPs, participated in this study.

Instrument

In the inventory, DSPs were asked about the number of volunteers, the tasks of the volunteers, the severity of the intellectual disabilities, and the degree of behaviour and/or psychiatric problems of people with intellectual disabilities who had a volunteer.

Procedure

The researcher went to all the participating locations and asked the DSPs who were responsible for the volunteer work, about the volunteer work on the location.

Analysis

To categorise the tasks of volunteers, we used a categorisation developed in a previous study (Venema, Vlaskamp and Otten, 2016b). In this categorisation, we distinguish between type and location of the activities and tasks. First a distinction was made between recreational activities and other tasks (e.g. care tasks and transport). Next, the recreational activities were divided in activities in the residence of people with intellectual disabilities, activities in the direct area of the residences and activities which are performed outside the neighbourhood. For the present study, two adjustments were made. To distinguish between activities where people with and without intellectual disabilities can meet, and activities where people with intellectual disabilities mainly meet other people with intellectual disabilities, the category 'group activities organised by the organisation for people with intellectual disabilities' is added. Moreover, 'other tasks', originally divided in 'other tasks, committed to a specific client' and 'other tasks, not committed to a specific client' was changed into 'other tasks that are performed outside the facility' and 'other tasks that are

performed inside the residence'. For every category the percentage of volunteers who were performing these tasks was measured. This was also calculated per target group (people with mild intellectual disabilities, moderate intellectual disabilities, severe intellectual disabilities, profound intellectual and multiple disabilities (PIMD) and intellectual disabilities and behaviour and/or psychiatric problems) separately. Differences between the target groups were measured using Chi square.

6.2.2 Results

Actual tasks of volunteers

Group activities that are organised by the organisation for people with intellectual disabilities are activities that are performed the most by volunteers (see table 6.1). In addition, almost a third of the volunteers assist in sporting activities.

Table 6.1. Percentage of volunteers who execute the tasks or activities

| | Total | Mild intellectual disabilities (ID) | Moderate ID | Severe ID | PIMD | ID and behaviour and/or psychiatric problems |
|--|-------|-------------------------------------|---------------------|-------------------|--------------------|--|
| Sporting activities | 33.0 | 22.2 ^a | 36.5 ^{abd} | 49.5 ^b | 16.9 ^c | 35.4 ^d |
| Group activities organised by the organisation | 46.9 | 54.4 ^a | 60.3 ^a | 34.7 ^b | 62.0 ^a | 35.4 ^b |
| Trips | 19.0 | 24.4 ^a | 19.0 ^{ab} | 23.7 ^a | 8.5 ^b | 17.3 ^{ab} |
| Activities inside | 19.9 | 25.6 ^a | 27.0 ^a | 23.7 ^a | 18.3 ^{ab} | 10.2 ^b |
| Other tasks, inside | 22.1 | 12.2 ^a | 15.9 ^a | 11.3 ^a | 12.7 ^a | 45.7 ^b |
| Other tasks, outside | 5.8 | 6.7 | 6.3 | 3.1 | 2.8 | 8.7 |

Note: all variables were measured on five-point scales with 5 indicating the most positive score. Means with different superscripts are significantly different: $p < .05$

Differences in tasks and activities were found between the target groups. Compared to the other groups, volunteers of people with severe intellectual disabilities are primarily assisting with sporting activities and volunteers of people with intellectual disabilities and behaviour and/or psychiatric problems are performing mostly other tasks inside, such as cleaning and doing odd jobs.

6.2.3 Conclusion

The results of this exploratory study show that volunteers already play a relevant role in the physical integration of people with intellectual disabilities. The majority of the volunteers are supporting activities in the community. Nevertheless, overall, helping with group activities organised by the organisation for people with intellectual disabilities is most frequently mentioned. During these activities people with intellectual disabilities typically do not meet many neighbours without intellectual disabilities, but predominantly have the opportunity to make contact with other people with intellectual disabilities.

6.3 Study II

6.3.1 Methods

Participants and setting

All DSPs at the participating locations were invited to participate in this study. From a total of 894 DSPs who received the questionnaire, 235 completed it, resulting in a response rate of 26.3 percent. We can only speculate about the reasons for this quite low response rate. Possibly, filling in a questionnaire on volunteer work did not have priority because of the typically high work pressure. Most of the participating DSPs were women with an average age of 45 years (see table 6.2). The DSPs worked with people who were covering the whole range of intellectual disabilities. The majority of DSPs (75%) had been working with people with intellectual disabilities for more than ten years.

Table 6.2. Characteristics of the participating DSPs

| Characteristics DSPs | N | Percentage |
|---|-----|------------|
| Gender | | |
| Men | 41 | 17.4 |
| Women | 194 | 82.6 |
| DSPs' work location target group | | |
| Mild intellectual disabilities (ID) | 68 | 28.9 |
| Moderate ID | 107 | 45.5 |
| Severe ID | 85 | 36.2 |
| PIMD | 86 | 36.6 |
| ID and behaviour and/or psychiatric problems | 203 | 86.4 |
| Type of work location | | |
| Residence | 176 | 74.9 |
| Day service setting | 59 | 25.1 |
| Distribution in the questionnaire of DSPs for every target group | | |
| Mild ID | 40 | 17.0 |
| Moderate ID | 43 | 18.3 |
| Severe ID | 36 | 15.3 |
| PIMD | 52 | 22.1 |
| ID and behaviour and/or psychiatric problems | 64 | 27.2 |

Instrument

The results of the inventory on the participating locations were the starting point for the development of a questionnaire. Subsequently, 15 DSPs were interviewed about the tasks volunteers perform and were invited to add activities of which they believed to be suitable for volunteers. After developing the questionnaire, a draft version was pilot-tested with a small group of DSPs (N=10). These DSPs were positive about the content of the questionnaire and the time it took to fill in. They did not suggest any modifications.

The questionnaire started with questions about characteristics of the DSP (gender, age, work location, work location target groups and years of working experience). After finishing these questions, the DSPs were randomly assigned to one of the target groups he or she was working with. For this specific target group the

DSP answered the questions about which tasks volunteers could do. The tasks were divided into sporting tasks, tasks on the work location, trips, and other tasks. There were six sporting tasks, such as walking or cycling. Tasks on the work location consisted of fourteen tasks, e.g. drinking coffee, or cooking and baking. In the list ten different kind of trips were mentioned, such as going to church, or visiting the cinema. Eight tasks in the 'other' category were given. Examples were cleaning and buying clothes. The task list was the same for every target group. DSPs were asked to rate every task on a 5-point scale for how suitable the task was for a volunteer. The scale ranged from 1= totally not suitable to 5= totally suitable.

Procedure

DSPs received the questionnaire by email, which was created in Qualtrics software package. They could open the questionnaire by clicking on a link in the email and they had to finish it online. Four weeks were given to complete the questionnaire. After two weeks all the DSPs received a reminder and after three weeks they received an email from the director of the care organisation with the request to fill out the questionnaire.

Analysis

To analyse the tasks, the mean of every task was calculated. Next, for every target group all tasks were listed from the most suitable task to the least suitable task based on the mean. This created a list of the top 10 most suitable tasks and a top 10 least suitable tasks for each target group.

6.3.2 Results

Suitable tasks of volunteers

Looking at the top 10 most suitable tasks for volunteers according to DSPs, there are many similarities between the target groups. Five tasks are mentioned in (almost) every target group (table 6.3). However, DSPs who work with people with intellectual disabilities and behaviour and/or psychiatric problems gave lower scores on the tasks, indicating only nine tasks to be suitable for volunteers to perform concerning this target group.

Table 6.3 Top 10 most suitable tasks for tasks for every target group

| Target group | | | | | | | | | |
|--------------|---|------|-------------|------------------------------------|------|-----------|-------------------------------|------|------|
| Mild ID | | | Moderate ID | | | Severe ID | | | |
| | Task | Mean | SD | Task | Mean | SD | | Mean | SD |
| 1 | Listening to music | 4.28 | 1.00 | Read | 4.20 | .91 | Making music | 4.29 | .87 |
| 2 | Doing odd jobs or gardening | 4.22 | 1.34 | Listening to music | 4.18 | .84 | Listening to music | 4.24 | .89 |
| 3 | Doing handicrafts or painting | 4.19 | .98 | Making music | 4.18 | .90 | Read | 4.18 | .97 |
| 4 | Playing bingo or pool | 4.17 | .97 | Drinking coffee | 4.10 | .96 | Cooking or baking | 4.03 | .80 |
| 5 | Working in the garden with the person with ID | 4.14 | .96 | Doing handicrafts or painting | 4.05 | 1.01 | Walking | 3.97 | .85 |
| 6 | Drinking coffee | 4.14 | 1.31 | Cooking or baking | 4.05 | 1.04 | Doing handicrafts or painting | 3.94 | .81 |
| 7 | Helping with the computer | 4.08 | 1.03 | Pampering (e.g. make-up, dress up) | 4.05 | 1.10 | Household tasks | 3.88 | 1.21 |
| 8 | Cooking or baking | 4.03 | 1.25 | Doing groceries | 4.03 | 1.17 | Doing odd jobs or gardening | 3.88 | 1.07 |
| 9 | Going to the library or garden centre | 3.94 | 1.18 | Household tasks | 4.03 | 1.10 | Playing with water | 3.85 | .93 |
| 10 | Church | 3.94 | 1.18 | Going to the church | 4.03 | 1.11 | Drinking coffee | 3.85 | .78 |
| | Making music | 3.94 | 1.37 | Playing bingo or pool | 4.03 | 1.10 | | | |

| Target group | | | | | | |
|--------------|------------------------------------|------|------|--|------|------|
| PIMD | | | | ID and behaviour and/or psychiatric problems | | |
| | Task | Mean | SD | Task | Mean | SD |
| 1 | Making music | 4.41 | .79 | Doing odd jobs or gardening | 3.39 | 1.43 |
| 2 | Read | 4.41 | .82 | Household tasks | 3.28 | 1.45 |
| 3 | Listening to music | 4.39 | .84 | Making music | 3.27 | 1.27 |
| 4 | Walking | 4.24 | .94 | Listening to music | 3.25 | 1.35 |
| 5 | Pampering (e.g. make-up, dress up) | 4.19 | .93 | Read | 3.20 | 1.35 |
| 6 | Tasks that stimulate the senses | 4.18 | 1.04 | Playing with water | 3.16 | 1.32 |
| 7 | Playing with water | 4.14 | .98 | Playing bingo or pool | 3.05 | 1.35 |
| 8 | Cooking or baking | 4.14 | 1.09 | Doing handicrafts or painting | 3.02 | 1.31 |
| 9 | Household tasks | 4.10 | 1.22 | Cooking or baking | 3.00 | 1.36 |
| 10 | Snoezelen | 4.05 | 1.12 | Tasks that stimulate the senses | 2.98 | 1.41 |
| | Going to the church | 4.05 | 1.15 | | | |

Table. 6.4 Top 10 less suitable tasks for volunteers for every target group

| Target group | | | | | | | | | |
|--------------|---|------|-------------|---|------|-----------|---|------|------|
| Mild ID | | | Moderate ID | | | Severe ID | | | |
| | Task | Mean | SD | Task | Mean | SD | Task | Mean | SD |
| 1 | Giving a massage | 2.50 | 1.58 | Care tasks | 2.29 | 1.37 | Accompanying to the dentist, doctor or hospital | 2.03 | 1.03 |
| 2 | Care tasks | 2.50 | 1.48 | Accompanying to the dentist, doctor or hospital | 2.53 | 1.27 | Care tasks | 2.44 | 1.11 |
| 3 | Snoezelen | 2.83 | 1.56 | Giving a massage | 3.00 | 1.43 | Fishing | 2.91 | 1.26 |
| 4 | Accompanying to the dentist, doctor or hospital | 2.97 | 1.41 | Swimming | 3.00 | 1.26 | Football game, cinema or theatre | 2.97 | 1.36 |
| 5 | Horse riding | 3.08 | 1.31 | Football | 3.07 | 1.36 | Giving a massage | 3.00 | 1.13 |
| 6 | Examining the cleaning | 3.09 | 1.63 | Horse riding | 3.11 | 1.35 | Buying clothes | 3.03 | 1.23 |
| 7 | Tasks that stimulate the senses | 3.22 | 1.66 | Snoezelen | 3.30 | 1.27 | Swimming | 3.06 | 1.04 |
| 8 | Football | 3.38 | 1.35 | Buying clothes | 3.39 | 1.22 | Football | 3.11 | 1.14 |
| 9 | Playing with water | 3.39 | 1.66 | Tasks that stimulate the senses | 3.45 | 1.15 | Horse riding | 3.14 | 1.20 |
| 10 | Swimming | 3.43 | 1.24 | Examining the cleaning | 3.47 | 1.33 | Helping with the computer | 3.21 | 1.49 |

| Target group | | | | | | |
|--------------|---|------|--|---|------|------|
| PIMD | | | ID and behaviour and/or psychiatric problems | | | |
| | | Mean | SD | | Mean | SD |
| 1 | Care tasks | 2.46 | 1.31 | Accompanying to the dentist, doctor or hospital | 1.81 | 1.15 |
| 2 | Accompanying to the dentist, doctor or hospital | 2.49 | 1.52 | Care tasks | 2.30 | 1.28 |
| 3 | Football | 3.02 | 1.65 | Swimming | 2.42 | 1.27 |
| 4 | Buying clothes | 3.07 | 1.41 | Giving a massage | 2.46 | 1.33 |
| 5 | Fishing | 3.14 | 1.72 | Person with ID visiting the volunteer | 2.48 | 1.30 |
| 6 | Person with ID visiting the volunteer | 3.21 | 1.52 | Shopping | 2.50 | 1.31 |
| 7 | Transport | 3.27 | 1.30 | Football game, cinema or theatre | 2.50 | 1.23 |
| 8 | Swimming | 3.30 | 1.45 | Fishing | 2.54 | 1.35 |
| 9 | Horse riding | 3.39 | 1.42 | Football | 2.55 | 1.31 |
| 10 | Helping with the computer | 3.39 | 1.65 | Horse riding | 2.59 | 1.35 |

There are also similarities in the top 10 least suitable tasks for volunteers. Six tasks are mentioned in (almost) every target group (table 6.4). Of all the tasks in the task list, two to four tasks are not suitable for the target groups, besides the group of people with intellectual disabilities and behaviour and/or psychiatric problems.

Physical integration of people with intellectual disabilities

In the questionnaire half of the tasks in the list were tasks or activities that occur outside. In the top 10 most suitable tasks five different tasks were mentioned that enhance the physical integration, i.e. they occur outside. Two of these tasks were present in the mild intellectual disabilities group, two in the moderate intellectual disabilities group, one in the severe intellectual disabilities group and two in the PIMD group. The group of persons with intellectual disabilities and behaviour and/or psychiatric problems had no tasks in their top 10 that take place in the community. In the top 10 least suitable tasks for volunteers ten different tasks were mentioned that enhance the physical integration, such as swimming, shopping, or accompanying the client to the dentist, doctor or hospital. For the group of persons with mild intellectual disabilities there were four tasks, for persons with moderate intellectual disabilities five tasks, for persons with severe intellectual disabilities and PIMD seven tasks, and for persons with intellectual disabilities and behaviour and/or psychiatric problems eight tasks. Taking all the tasks in every target group together this will give a distribution of nine tasks in the top 10 most suitable tasks and 31 tasks in the top 10 least suitable tasks that may enhance the physical integration.

6.3.3 Conclusion

DSPs believe that volunteers should support activities inside the residence of people with intellectual disabilities or perform general supportive tasks in which persons with intellectual disabilities are not involved, like cleaning and doing odd jobs. Therefore, enhancing physical integration is not a role which DSPs find feasible for volunteers. There is no relation found between the level of intellectual disabilities and the possible tasks of the volunteers. However, DSPs believe that volunteer work with people with intellectual disabilities and behaviour and/or psychiatric problems is not possible.

6.4 Discussion

The aim of this study was to investigate the role of volunteers in enhancing physical integration of people with intellectual disabilities. Overall it can be concluded that volunteers already play a role in this first step to social integration. However, DSPs believe that volunteers should *not* play a role in the physical integration of people with intellectual disabilities. This discrepancy between the actual and perceived appropriate tasks of volunteers can have several possible explanations. First, DSPs might have negative experiences with volunteers who took people with intellectual disabilities outside. Moreover, they may merely anticipate such negative experiences, because they feel strongly responsible for their clients' safety (Venema, Vlaskamp & Otten, 2016a). Second it may be that DSPs believe that volunteers should primarily play an *assisting* role in activities for people with intellectual disabilities, rather than taking the lead in initiating new ones. This seems to be confirmed by the fact that assisting DSPs when performing group activities, is mostly performed by the volunteers.

Another finding is that different levels of intellectual disabilities did not affect which tasks were considered suitable for volunteers to support the clients' physical integration. The complexity of the problems and the absence of verbal communication does not seem to be a barrier for volunteers to perform tasks in the community. Only people with intellectual disabilities and behaviour and/or psychiatric problems appear to benefit less from the presence of volunteers for their physical integration. These results could be explained by the opinion of DSPs, who believe that the current situation (without support of volunteers) is the best. This opinion, however, is an obstacle for the physical and social integration of people with intellectual disabilities and behaviour and/or psychiatric problems (Venema, Vlaskamp & Otten, 2016b).

Our study is not without limitations. There is a possible selection bias in the questionnaire, as only those DSPs might have filled out the questionnaire who were either very positive or very negative about the volunteer work. Second, the study was executed in one part of the Netherlands. To enhance the generalisability of our findings it would be good to replicate this study in other parts of the Netherlands. At the same time, we want to stress that our sample comprised of a substantial number of participants who worked with people with very different levels of intellectual disabilities. Hence, for various levels of intellectual disabilities we can already give

good insight in the actual and possible role of volunteers in facilitating social integration of people with intellectual disabilities.

Finally, we want to stress that in our current research we only investigated whether volunteers played a role in creating physical integration by helping their clients to be present in social environments where also – or rather predominantly - people without intellectual disabilities were present. Whether or not such co-presence of people with and without intellectual disabilities actually initiated further social interaction between these two groups was not investigated. Future research should therefore try to provide more information on how much direct contact does indeed result from the physical integration of people with intellectual disabilities in regular social environments. In our view, a number of practical implications can be derived from our studies. First, organisations for people with intellectual disabilities should make clear what they expect from volunteers, especially about the role of volunteers in the physical integration of people with intellectual disabilities. Second, organisations need to be aware of the sceptical or even negative attitude of DSPs towards volunteer work. This implies that organisations should listen to the DSPs to get a clearer picture of the experienced obstacles in the volunteer work and could allow the jointly development of proper solutions to such potential problems. More generally stated, organisations for people with intellectual disabilities should invest more in the recruitment and support of volunteers in their organisation. An essential step herein is making DSPs aware of their role in facilitating volunteer work, and especially in making optimal use of volunteers for the social integration of people with intellectual disabilities. As long as DSPs only ask volunteers to do activities with people with intellectual disabilities inside the residence of people with intellectual disabilities, their role in the social integration process remains minimal.

