RESEARCH

‘I Want to Participate!’ Young Adults with Mild to Moderate Intellectual Disabilities: How to Increase Participation and Improve Attitudes

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People with intellectual disabilities are often regarded as subjects of care and support, rather than citizens with the same rights as others. This article aims to describe how young adults experience and perceive attitudes, treatment and participation in terms of the application process for daily activity/sheltered employment, as well as their transition into this activity and their first years’ experience of it. The study was carried out in a middle-sized municipality in Sweden. Data were collected from 14 people with mild to moderate intellectual disabilities, aged between 21 and 23 years. The interviews were supported by the use of pictograms. Qualitative content analysis was used to analyse the data. The participants stated that they wished to be listened to as adults, and to participate in decisions about daily activity/sheltered employment. They wished to be treated and accepted as individuals, not according to their disabilities. They wanted to participate, and the opportunity to do so would require an accepting environment.

Keywords: independence; self-perception; transition; supportive environment; opportunity

Introduction

According to Ellenkamp et al. (2015), people with intellectual disabilities value work as a significant part of their life in the same way as others do, but only 9–40% of them have regular paid employment, regardless of the country they live in. They have the same rights as other citizens in society (UN 1993, 2008) but most young people with an intellectual disability who leave school are offered daily activity/sheltered employment instead of regular paid employment. Their opportunities for becoming involved in decisions about their work and daily activity differ (Kjellberg 2010, 2002). They are seldom asked what they think or want, and have little opportunity to influence or exercise control over key parts of their lives (Arvidsson, Granlund & Thyberg 2008; Mineur, Bergh & Tideman 2009; Kjellberg 2002).

It is essential that society listens to and respects people’s rights (Kjellberg 2002). According to Lindqvist (Government of Sweden 1999), there are major shortcomings in the treatment of people with disabilities. The approach in society is often that the individual should adapt to society’s demands, while society’s responsibility to adapt to the requirements of the individual is rarely mentioned (Mineur, Bergh & Tideman 2009). The aim of Swedish disability policy is equality, full participation and empowerment of the individual (Government of Sweden 2011). Swedish law, SFS 1993: 387 gives people with intellectual disabilities the right to daily activity/sheltered employment, which is considered a form of assistance (Government of Sweden 1993). Daily activity takes place in the form of sheltered employment, either in a group with other people with disabilities or on the open labour market, similar to what is often described as supported employment. Today people with mild intellectual disabilities often tend to reject daily activity, because they have discovered that it is based on a disqualification, unlike ordinary work which generally involves qualifications (Olin & Ringsby Jansson 2009; Molin 2008). Young people with intellectual disabilities do not want to be discriminated against. They wish to be independent, and to live and be treated like everyone else (Kittelsaa 2014). The treatment of people with disabilities is affected by attitudes and values in society (Government of Sweden 1999). In Sweden the concept of participation is an important factor. According to Molin (2004), participation takes place when there is harmony between the individual and the environment. The interaction is marked by acceptance and reciprocity, provides a sense of belonging and can be active or passive. To experience participation, the right conditions must exist. These can be classified according to internal conditions, such as willingness and ability to participate, and external conditions, such as the availability of and opportunity for participation (Molin 2004). Arvidsson, Granberg and Thyberg (2008) have described how people with intellectual disabilities and their family members and relatives perceive participation. When people with intellectual disabilities describe how participation takes place they notice a sense of belonging, commitment and ability to make their...
own choices. When family members and relatives are asked, they tend to describe the ability to participate more
often than performance or their own wishes. New research in the field of work involving people with intellectual
disabilities shows that only a few studies focus on the employee’s perspective (Ellenkamp et al. 2016). People with
intellectual disabilities are rarely asked about what they think or want (Arvidsson, Granlund & Thyberg 2008; Mineur,
Bergh & Tideman 2009; Kjellberg 2002). This study therefore fills a gap in the research literature by approaching
people with intellectual disabilities themselves about these issues. The aim of this study was to describe how young
adults with mild to moderate intellectual disabilities experience and perceive attitudes, treatment and participation
in terms of the application process for daily activity/sheltered employment, as well as their transition into this
activity and their first years’ experience of it.

Methods
The people invited to take part in the study had finished school within the past three years. They had been granted
daily activity/sheltered employment in the spring of 2013 and were young adults with mild to moderate intellectual
disability, aged between 21 and 23 years. Sixteen participants were invited (n = 16) to participate and 14 agreed
(n = 14), ten women and four men (Table 1). The participants worked in sheltered employment, either in groups or
individual placements, for example as janitors, in retirement homes for the elderly, in service jobs or at a day-care
centre for dogs (Table 2). The participants could express themselves verbally. Some of them found it easier to describe
and explain, while some had more difficulty in speaking freely and required more follow-up questions.

Table 1: Description of participants regarding disability.

| Participant (n = 14) | Mild intellectual disability | Mild to moderate intellectual disability | Autism | ADHD | Mental impairments | Physical impairments |
|---------------------|------------------------------|------------------------------------------|--------|------|-------------------|---------------------|
| 1                   | x                             | x                                        |        |      |                   |                     |
| 2                   |                               | x                                        |        |      |                   |                     |
| 3                   |                               | x                                        |        |      |                   |                     |
| 4                   |                               |                                          |        | x    |                   |                     |
| 5                   |                               |                                          |        |      |                   |                     |
| 6                   |                               |                                          |        |      |                   |                     |
| 7                   |                               |                                          |        |      |                   |                     |
| 8                   |                               |                                          | x      | x    |                   |                     |
| 9                   |                               |                                          |        |      |                   |                     |
| 10                  | x                             |                                          |        |      |                   |                     |
| 11                  |                               |                                          |        |      |                   |                     |
| 12                  |                               |                                          |        |      |                   |                     |
| 13                  |                               |                                          |        |      |                   |                     |
| 14                  |                               |                                          |        |      |                   |                     |

Table 2: Description of participants regarding daily activities.

| Daily activity/Sheltered employment individual placement | female (n = 10) | male (n = 4) |
|--------------------------------------------------------|----------------|--------------|
| – transport company                                     | 3              | 1            |
| – kindergarten                                          |                |              |
| – retirement home for elderly                           |                |              |
| – janitor                                               |                |              |

| Daily activity/Sheltered employment in group            | female (n = 10) | male (n = 4) |
|--------------------------------------------------------|----------------|--------------|
| – janitor                                               | 3              | 1            |
| – daycare center for dogs                               |                |              |
| – service team                                          |                |              |

Education 4
An information letter was addressed to participants containing detailed information about the study and a question asking if they wished to participate or not. The letter contained a definition of the words ‘attitude’, ‘treatment’ and ‘participation’, and participants were encouraged to reflect on the concepts before the interview, as a form of preparation. A semi-structured interview was developed. Most of the questions were designed to ask participants to describe their experiences and perceptions of various phenomena and events. They consisted of two themes: an attitude and treatment theme and a participation theme. Two pages of pictograms (Figures 1 and 2) were developed to provide support for the participants, and involved the concepts of attitude, treatment and participation. The purpose was to make it easier for the participant during the interview.

Two pilot interviews were carried out to test the interview guide, and some changes were made. The two figures with image support initially had written text, which was taken away because the informants were influenced by it. These interviews were not included in the study. The interviews were conducted at the participants’ workplace or home. Before the interview, the participants were informed verbally about the aim, their anonymity and the interview process. In addition to the main questions, follow-up questions were asked to provide participants with opportunities to give examples of situations and to describe what they had experienced. They were also given time to reflect on their answers. During the interview, themes were clarified by the author, who began by saying that the interview would start with the attitude and treatment page (Figure 1). After this, the author gave oral information and the theme was changed to the participation page (Figure 2). The interviews lasted between 13 and 25 minutes. All interviews were conducted by one of the authors. Only the author and the participant were present during the interview. The aim was to investigate whether the questions had led to any further thoughts. Finally, each participant was informed that she/he could contact the author after the interview if she/he had any further questions. All interviews but one were recorded. A record of the latter interview was taken in writing, as literally as possible.

**Ethical aspects**

The research process was guided by ethical guidelines from the Council for Research in the Humanities and Social Sciences and the principles in the Declaration of Helsinki (WMA 2017). Participation was voluntary and the principle of informed consent was applied. Participants received written information about the study in simple language. It was submitted to the participants by a member of staff they knew well, and the participants had the opportunity to refuse to participate. All participants received both verbal and written information about the study, including notification that participation was voluntary. Participants could end their participation at any time. Richards and Schwartz (2002) highlighted ethical aspects from a participant’s perspective. Among other things, they pointed
out that the issues covered in an interview can cause anxiety and stress in participants, who may feel, for example, that they are being encouraged to answer more than they originally intended. They may find that their answers are taken out of context in the analysis, and that their words have been misinterpreted. Finally, there is always a risk that the participants can be identified. A short conversation was held with each participant after the tape recorder was turned off. The author met some of the participants a while after the interview to discuss the subjects, aims and interviews themselves. In this article, data were handled with confidentiality and in such a way as to guarantee anonymity.

**Data analysis**
Readers of qualitative studies should be able to determine whether the results can be transferred to another context through a detailed description of the study (Graneheim & Lundman 2004; Curtin & Fossey 2007). Whether or not a study is valid and reliable can be determined by the choice of participants, the number of participants and the author’s choice of citations (ibid). According to Curtin and Fossey (2007), a study has greater validity when a precise description is provided of the entire study, the approach and the analysis. Validity can also be improved when a co-researcher is included in the data analysis. For this study, a detailed description is given of the selection process, participants, data collection, analysis and circumstances in context. However, the participants in this study were not involved in the analysis. Through their current and former professional experience, the authors of the study had a good prior understanding of the issue in question, and of people with intellectual disabilities. This experience influenced the research process in terms of both the framing of the questions and the analysis. The greatest respect for everyone formed the basis for analysing the responses. The researchers’ own involvement and experience were highlighted and reflected on. Qualitative content analysis was conducted using an inductive approach, with a focus on how to describe variations such as differences and similarities (Graneheim & Lundman 2004). One of the authors conducted all the interviews, and transcribed them verbatim. The co-author read the transcribed interviews and participated in the process of analysis. The first step was to gain an overall picture of the data. All interviews were then read independently by each author a number of times. Graneheim and Lundman’s (2004) description of the model was given step by step and in detail. Meanwhile, the author was given the space to make her or his own interpretation of the text’s underlying message. The focus of content analysis is on describing and identifying variations (ibid). During the first part of the analysis process, participants seem to respond in similar ways, but a more careful reading of the transcribed texts reveals variants in the data. The process in the present research began by allocating codes. Each interview was scrutinised line by line and coded separately by the first and second author. Statements which were relevant to the aim of the study were identified and grouped into categories. The codes were categorised on the basis of underlying meaning, and the categories were labelled: attitude and treatment, participation, transition from school to employment and future.

**Findings**
The analysis identified five themes and 12 categories, which are presented in Table 3. The findings of the study reflect the participants’ own experiences and their perceptions of treatment and participation in their daily activity/sheltered employment.

**Attitude and treatment**
Perceptions of good attitudes and treatment
The participants in this study defined a good attitude and good treatment as greeting someone in a welcoming way, shaking hands, making eye contact and listening to the other person. They considered it important to be kind, nice, polite and friendly. Several participants felt it was important to be acknowledged and to be seen as an adult person. The participants considered it important for a person to be honest, and some considered it very positive when someone they encountered made an effort to be good: *That you really try /…/ if you are tired /…/ or if you wake up on the wrong side and still try* (P7).

Perceptions of bad treatment and attitude
A bad attitude was described as someone speaking ill of a person, being irritated, not greeting people, being unpleasant or showing a lack of interest. It was considered to involve *people not listening to each other and being rude* (P7). A bad attitude towards the participants was considered to involve not being respected or accepted, or not being taken seriously: *A bad attitude is when you are not taken seriously /…/ and not shown respect* (P13). A bad attitude can emerge in different situations: *I came into a room and staff barely said anything* (P14).

**Attitudes and approach**
Most participants asserted that individuals with disabilities should be treated with respect, and that this was not the case because they sometimes felt as if they were treated like children. If the person is an adult, they should be treated as an adult: *People should treat everyone equally, not keep on patronising /…/ you should be yourself* (P14). *Some people talk as if we were toddlers /…/ we are adults* (P10). One participant described how she/he felt angry
when she/he was treated in a disrespectful manner. Several participants emphasised the importance of seeing the person first and not their disability. Everybody should have a chance to show what they can do before they are judged. One participant said, I'm like any worker anywhere, it's just that I have an intellectual disability (P2). Several participants noted that they were discriminated against because of their difficulties: I want to be treated in a normal way (P1).

In Sweden, individuals with intellectual disabilities who receive assistance from the municipality are referred to as 'users'. Several participants disliked the use of this word. One participant suggested that a single word categorised everyone into a group and gave the group a label: That branding, people's reactions about what they think. You shouldn't discriminate […] just having a diagnosis doesn't mean you're inferior to everything (P13). Many see the concept of 'users' as synonymous with drug users, alcoholics and drug addicts: At first I thought it meant addicts, but of course I'm not … (P8). One participant said: I never understood what the word 'user' meant (P10).

**Participation**

Their own impact on participation

Several participants described participation in terms of their own will and their own contribution. To enable participation, it is important to be tolerant towards others, to listen, to be active and to contribute: It's when you take part in something and give your opinion and listen to others, and so on (P7). Not all the participants indicated that they could participate. They said that sometimes they would like to participate but did not have the energy: At big events and if there are many people around […] then it can be difficult for me and I get worried and confused […] then I can say I want to participate but I can't because it's too much (P8).

Opportunities for participation

Most participants said it was not enough to have the will to participate, and that supervisors and co-workers had to authorise it. They considered it important to be given a chance and to be informed, heard and allowed to engage. They wished to be given the opportunity to participate and to make decisions. Some participants said that to participate you must have the opportunity to take part in activities (P4). I find it hard to understand instructions and therefore often forget […] then it is difficult for me to participate (P8). It is important to be involved. If you are not informed, you cannot participate. Some participants found it difficult to see how they could participate unless they were invited to do so.

**Transition from school to employment**

Applications for daily activity

Most participants described the application process for daily activity/sheltered employment as someone else's decision, mostly their parents': It's my parents who took care of it, so I don't know (P6). They all said that their parents, teachers or other school staff helped them with the application. Many participants did not remember how the application process had been undertaken. None of the participants said it had been their own wish to engage in daily activity/sheltered employment or that they had applied for the assistance themselves. Most of the participants said they wished they had had the opportunity to be more involved, while some were pleased not to have been involved.

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**Table 3: Themes and categories.**

| Theme                          | Categories                              |
|-------------------------------|-----------------------------------------|
| Attitude and treatment        | Perceptions of a good attitude and treatment | Perceptions of a bad attitude and treatment | Attitudes and approach |
| Participation                 | Participation own impact                 | Opportunities for participation             |
| Transition from school to employment | Application for daily activities          | Initiation employment                         |
| Psychosocial work environment | Supportive factors                       | Hindrance factors                             | Opportunities           |
| Future                        | Development opportunities                 | Fears and concerns                            |
Starting employment

The start of daily activity/sheltered employment emerged as both a positive and a negative experience. It involved the participant feeling welcome, having good social support, being understood and receiving help: *I was very well received from the very first day* (P3). They thought it was fun that *I was there* (P4). Having a good introduction is important. Several participants noted that they had the opportunity to experience different daily activities/sheltered employment. Negative experiences involved the work not being as they had anticipated, or being persuaded to do it by someone else: *From the beginning, no, it was /.../ who decided /.../ I didn’t, and then it was a teacher at school who kept insisting* (P10). One participant described how difficult it was for people with a disability to get a job. He had previously been told that he asked too many questions and worked too slowly. After this he did not dare talk about his difficulties: *I never mentioned that I have difficulty* (P13). A bad start was considered to involve not feeling secure at the beginning, or supervisors and co-workers not being nice. Several participants talked about the transition from school to daily activity/sheltered employment: *I did not feel safe at the beginning. It was such a change to switch from school to daily activity/sheltered employment, and then suddenly, it was like, there is another way, what should I do now, where’s my schedule?* (P8).

Psychosocial work environment

Supportive factors

The participants considered themselves to have had a positive experience when they felt welcome, had good social support, felt understood and received help from the first day. A good introduction was perceived as important. A good working environment affected their mood positively. Someone asking how they felt was perceived as important by most of the participants: *They are nice and always ask how I’m doing /.../ they always show that they care* (P6). They always *greet me when I come in the morning and ask how things are going* (P14). It also emerged as important that people accepted their disability, had understanding and gave positive feedback: *They can explain if I don’t understand. They don’t get grouchy /.../ you needn’t be afraid to ask either, and I can work at my own pace. It’s nice* (P13). An accepting environment is therefore important, where it is acceptable to express views: *When you get to say what, you think /.../ and make suggestions* (P6).

Hindering factors

Limitations of psychosocial work included the participants not having the opportunity to participate or to influence their daily activity/sheltered employment: *Sometimes we just sit here for hours and don’t do anything* (P10). Several participants described obstacles in their working environment, such as not being listened to, and one participant described her experience of not being taken seriously: *They don’t take me seriously /.../ they can be grumpy and so /.../ they have difficulty believing in me* (P1). Some participants described not being accepted by supervisors because of their disabilities, such as the supervisor not taking their comments seriously. Some also felt that it was the work supervisors who made the decisions, so there was no point in expressing their own wishes: *It’s the work supervisors who decide* (P10).

Opportunities

It appears to be important for people to know their rights and have options. Some of the participants thought that they could and would influence their duties or working hours: *Maybe, maybe not. I have no idea* (P3). Some participants believed that they could influence a little but they had never tried: *It depends on what you do, I think. Sometimes maybe I can affect some of it. It depends on what you do* (P9). Some participants were confident that they were not allowed to influence their duties or working hours: *It’s the others who decide* (P11). Only three participants reported that they could participate in staff meetings. Eleven participants said they were not invited to any meetings, or that there were no meetings: *I want to participate /.../ so that I know what’s being said. I’m not allowed to join them* (P12). Most said that they wanted to have influence. Some wanted to reduce stress, some wanted to be able to influence their duties, some wanted to know more about what was happening. One participant said she/he wanted to have some influence *so that it becomes better, so that it becomes good* (P1). The participants who had the opportunity to participate in staff meetings experienced this as very positive: *We talk about how it feels, how the situation is… and a little about what’s going on* (P7). Some participants said they were not interested in participating in meetings.

Future

Development opportunities

All participants noted that they had no opportunities for development in their daily activity/sheltered employment. None had been offered any education to develop themselves in their field or to deepen their knowledge. Half of the participants were positive about future opportunities for education. One participant said she/he wished to avail of these options if the education made a difference in the job and if it gets better (P8). Another participant said it depended on what kind of education: *Perhaps I wouldn’t go at all but it would be interesting to go to something* (P5). In response to questions about whether the participants had the opportunity to take part in any fire training or medical-training such as cardiopulmonary resuscitation, CPR, everybody said they did not. None of the participants had practised procedures in the event of a fire. Most said they would like to attend courses like this if they had the chance.
Fears and concerns

Several of the participants experienced anxiety about the future. One concern involved not being good enough and not being able to live up to expectations. Another concern which emerged involved fears about changing their daily activity/sheltered employment: *I can’t cope when it gets too much* (P9). Being approved for a trial period in a daily activity/sheltered employment was perceived in different ways. Some considered it a nuisance: *they need to see if I can do it /.../ I have to do better* (P13). *I have my trial period now and if it works well, I get to be here* (P2). Some participants experienced anxiety when their performance was assessed, while some saw it as an opportunity.

Discussion

The aim of this study was to describe how young adults with mild to moderate intellectual disabilities experience and perceive treatment and participation in terms of the application process for daily activity/sheltered employment, as well as their transition into this activity and their first years’ experience of it. All participants in the study were generous in sharing their opinions. People with intellectual disabilities are seldom asked what they think or what they want (Arvidsson, Granlund & Thyberg 2008). Kjellberg (2002) states that they are not given the opportunity to be involved. The participants in this study noted that they were adults and wanted to be seen and treated as adults. It was important to be seen as a person and not just as a person with a disability. Being seen and judged in terms of their difficulties often led to anxiety and performance anxiety, according to the participants in this study. Several of the participants considered that they were treated and spoken to as if children. This is also one of the findings in Cramm, Finkenflügel, Kuijsten et al. (2009). In this study, the participants were given sweets by their employer on their birthday, which was not the case with their co-workers. Individuals with intellectual disability wish to be treated equally. They wanted to be treated like ordinary citizens and did not wish to be identified as people with disabilities (Olin & Ringsby Jansson 2009; Molin 2008; Kittelsaa 2014). Like most people, they did not wish to be placed in categories which had a negative connotation (Kittelsaa 2014).

The result shows that the participants wished to express their opinions and to influence their working day. Some participants were very satisfied with their work environment, especially those who reported that they worked in an open and permissive atmosphere where they were expected to express their wishes and participate in planning. Butterworth et al. (2000) noted that social conditions are one of the most important factors in a good working environment. Arvidsson (2013) suggested that greater participation provides greater wellbeing. Several participants believed that they had some slight influence on their working hours. Three out of 14 participants could attend staff meetings. Eleven participants had no platform through which they could receive information, and had few opportunities to express views which could influence their work. According to the National Board of Health (2008), anyone who takes part in a daily activity/sheltered employment should be able to influence its content and form. None of the participants in the study had the opportunity to receive any form of education such as fire or CPR training. Eria Ping-Ying (2004) has suggested that people with intellectual disabilities need training where they can learn about their rights and opportunities, and understand the meaning of discrimination. Cramm et al. (2009) have shown that people with intellectual disability wish to influence their own work. They wish to learn new things and have a clear working agreement with a non-threatening atmosphere. According to the participants in this study, a good attitude and positive treatment involve being nice and listening, appearing interested and accepting them as they are. A bad attitude and negative treatment were described as the opposite, in other words not being respected or accepted, and not being taken seriously. According to Cramm et al. (2009), a friendly co-worker is important.

For the participants in this study, the meaning of participation in daily activity/sheltered employment can be divided into two categories: impact and opportunities. The results appear to show that participation is only possible with a permissive environment and opportunities. Many participants indicated that they needed help in terms of becoming involved, and it was difficult for them to know how to unless they were invited. Craig and Bigby (2015) noted that some people with an intellectual disability need a personal invitation. Sthen (2005) indicated the same pattern, noting that the social environment determines the opportunities for participation. Community participation for people with mild or moderate intellectual disability has been defined as carrying out daily activities (Dusseljee et al. 2011). Dusseljee et al. have shown that most people with an intellectual disability who have work and other daily activities have social contacts and are engaged in leisure activities with others. On the other hand, people with intellectual disabilities hardly interact with people who are not disabled in this way. In this respect, it is important that young people with mild to moderate intellectual disabilities are offered sheltered employment on the open labour market outside day centres. A review study by Verdonschot et al. (2009) shows that people with intellectual disabilities are 3–4 times less likely to be employed than people without disabilities. They are more likely to work in daily activity/sheltered employment.

The result also shows that none of the participants indicated that they had been the ones who had opted for daily activity/sheltered employment or who had applied for it. Olin and Ringsby Jansson (2009) and Molin (2008) revealed that some people with mild intellectual disabilities did not take up opportunities to engage in daily activity/sheltered employment because they thought the assessment of their disabilities disqualified them. Young people with intellectual disabilities want to be independent and live like others do. They do not want others to define who they are (Kittelsaa 2014). Expectations from teachers are important for young adults in the transition
from school to work. A teacher’s expectations are the only meaningful way in which regular work/supported employment can be encouraged rather than sheltered employment or day centres (Holwerda et al. 2014). People with intellectual disabilities want to live an independent life, but there is also a risk that they will become socially excluded (Bates & Davis 2004). Some participants in this study stated that they had not been prepared for the difference in expectations and demands when they moved from school to daily activity/sheltered employment. Olin and Ringsby Jansson (2009) point out that many young people do not have sufficient knowledge of what daily activity/sheltered employment can offer. The information is not presented in a way which attracts them. It appears that people with intellectual disabilities have limited opportunities to influence and take decisions in key areas of their lives (Mineur, Bergh & Tideman 2009).

Several participants in this study expressed a concern about the future, about not being good enough and about not being able to retain their work. Several participants were concerned about their performance being judged all the time. Jahoda et al. (2009) obtained similar results in a follow-up study about people with intellectual disabilities who received support at work in terms of supported employment. Participants were worried about not having the skills required, and had concerns about the social context. Sthen (2005) notes that people with disabilities are often subject to special measures, and that this creates a feeling of not being good enough.

People with disabilities are often called ‘users’ in Sweden (National Board of Health 2008). The participants in this study indicated that they associated the word ‘user’ with drugs and alcohol, and responded that they were not ‘users’, nor did they know what the word meant. Most of them considered being categorised as and called something they did not accept or understand a form of negative attitude and treatment. Being labelled, and not being seen as a person can be compared to the concept ‘handicapped’. Michailakis (2003) discussed what the use of the word ‘handicapped’ means for a person with a disability. Labelling someone as handicapped elicits specific behaviour from the people around them. Being categorised makes it difficult to be an individual (Sthen 2005). By definition, the person is placed in a subordinate position, and the name given to a phenomenon is important.

In terms of the method, the following reflections emerged. Sixteen people were asked to participate and only two refused. The fact that a familiar person asked the participant may have contributed to the few dropouts. The open nature of the questions posed difficulties for some of the participants, and some of the follow-up questions had to be made more concrete. The participants who were familiar with the concepts could describe their perceptions and experiences of the concepts more easily, but those who had not previously heard the concepts all understood the meaning of them. During the interview, pictograms were used to help the participants maintain their focus on the interview and the theme they were discussing. Both the author and the majority of participants perceived this positively. Previous studies show that the use of pictograms in health care can promote understanding (Barros et al. 2014; Berthenet, Vaillancourt & Pouliot, 2016). The authors had a good prior understanding of the target group, which could have had a positive impact. The authors also believed that it may have contributed to the participants feeling comfortable and accepted. According to Richards and Schwartz (2002), an interview can produce anxiety and stress, and several participants in this study reported that they were a little nervous before the interview. The author felt, however, that the participants’ nervousness disappeared during the interview. Most participants expressed a positive feeling and were proud of the opportunity to be listened to and express their opinion. The majority of participants considered the questions important, which reassured the author of the study’s relevance.

Conclusion
The participants in the study needed help in terms of understanding their opportunities. They needed to be in a permissive environment where opportunities for participation were given. Most of the participants were not allowed to take part in staff meetings, and therefore had no forum for exchanging information. Most also lacked development opportunities within their area of knowledge. The participants in this study had difficulties in asserting themselves and did not think they could influence their daily activity/sheltered employment. Many of them did not question why others decided for them, and many of them needed someone to invite them to participate. The results of this study add knowledge about how people with mild to moderate intellectual disability perceive the transition from school into daily activity/sheltered employment. It also adds knowledge about their first years’ experience of their daily activity/sheltered employment regarding attitudes, treatment and participation. The conclusion is the importance in supporting people with mild to moderate intellectual disability to be active citizens in their own lives.

Competing Interests
The authors have no competing interests to declare.

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