**“It’s our everyday life” – the perspectives of persons with intellectual disabilities in Norway**

**Abstract**

This study illuminates how adults with intellectual disabilities understand and describe their everyday life and its shortcomings when it comes to equal rights in the context of Norwegian community living. An inclusive research design, including nine persons with mild intellectual disability, two university researchers and two intellectual disability nurses from the municipality was undertaken. An inductive thematic analysis of data identified three key themes; Everyday life – context, rhythm and structure, social participation and staff – an ambiguous part of everyday life. Results show that service provision had institutional qualities; participants experienced lack of information and reduced possibilities for social inclusion and community participation like everyone else.

More attention on the role of policy development, support staff and leadership, in relation to facilitating an everyday life with more user involvement, social inclusion and community participation in people needing support is essential. Participatory, appreciative, action and reflection (PAAR) in workshops for persons with intellectual disabilities and support staff, represents a promising approach to promote the voices and interests of persons with intellectual disabilities.

**Accessible abstract**

This paper tells you about the everyday life of people with intellectual disabilities living in Norway. Nine people with intellectual disabilities worked together with two university researchers and two intellectual disability nurses in the community, in workshops. The people with intellectual disabilities liked to have their own apartment and going to work every day. They told that they wanted more social participation with friends and more participation in activities in the community, just like everyone else. They wanted to be treated with more respect by their staff. All participants in the project saw great value in working together and some of them are working together in a new project about involvement in improvement of support services for people with intellectual disabilities.

*Keywords*: everyday life, participation, collaborative group approach, people with intellectual disabilities, workshops, inclusive research, PAAR

**Introduction**

The Convention on the Rights of Persons with Disabilities (CRPD) (2006) recognises the equal rights of all persons with disabilities to live independently, to have full and effective participation and inclusion, equal opportunities and accessibility in society. However, discrimination against people with intellectual disabilities is a global issue and human rights are frequently violated internationally (Joint Committee on Human Rights 2008; Fyson and Kitson, 2010; McConkey and Keogh, 2016). The Joint Committee on Human Rights (2008) even suggests that violation of human rights is among many adult people with intellectual disabilities, seen as a normal part of their everyday lives.

Everyday life is what we all live in and through. It is both “close” and trivial, and at the same time possible to articulate. As a perspective everyday life roams two dimensions. Firstly, it represents actual conditions, phenomena that are possible to study. Secondly, it gives access to concrete descriptions of how people organise and live their lives. It gives researchers and participants access to insights in how central societal and policy areas affect and give meaning for people in their lives (Scott, 2009). Everyday life takes place and is lived in relation with housing and housing situations, and it affects and regulates activities, participation and relations in people’s lives (Gullestad, 1989). As such, the everyday life perspective is not disconnected from policy and regulations of welfare services (Scott, 2009). In this article everyday life is used as an umbrella term that refers to different dimensions of people’s lives.

Several studies have demonstrated that housing can both be a key and a barrier to achieving a social everyday life and participation, depending on i.e. location of house (Abbott & McConkey, 2006; Iriarte et al., 2016) size and segregation (Tøssebro and Kittelsaa, 2011). McConkey et al., (2007) and Tøssebro and Kittelsaa (2011) have identified marked variations in residents’ social networks and community participation across supported living arrangements, group homes and campus-style settings. A review of studies of community participation in persons with intellectual disabilities found that people with intellectual disabilities living in community settings participate more than people living in segregated settings (Verdenschot et al., 2009). The same study found that domestic life participation seemed to be ignored as a study domain and that the level of participation is much lower than among other disability groups. A number of studies have found that regarding interpersonal interactions and relationships, the social networks of people with intellectual disabilities are relatively small and mostly consist of other persons with intellectual disabilities or staff (Verdensschot et al., 2009; Dusseljee et al., 2011; McConkey et al., 2017). Staff represent an important environmental factor and are expected to fulfil a wide range of tasks in services that aspire to provide an ordinary everyday life for people with an intellectual disability (WHO 2001).

A growing number of studies show that people with intellectual disabilities experience that staff treat them as a group, when they want to be treated as individuals with different needs and interests (Bond and Hurst, 2010; Deguara et al., 2012). They desire to participate more in the community (Scott et al., 2014; Haigh et al., 2013) and want to make their own choices and decisions for themselves in their everyday life (Bjørnsdottir et al., 2014; Scott et al., 2014; Williams and Porter, 2017). Studies also show that people with intellectual disabilities experience lack of transport, information and finances as boundaries to live a happy everyday life (Haigh et al., 2013; Bjørnsdottir et al., 2014).

Although inclusive research projects with people with intellectual disabilities are growing

internationally (O’Brien, McConkey and Iriarte, 2014), studies point to a need to

increase the involvement of persons with intellectual disabilities in research, generally (Cleaver, Ouellette-Kuntz and Sakar 2010; Lai et al., 2006). People with intellectual disabilities do seldom come to express themselves in matters concerning their life situation, and they are often dependent on others to make strategic choices (Williams et al., 2010). WHO recommends more qualitative research on the lived experiences in people with disabilities (2011) in order to understand the present quality of everyday life and the shortcomings. The user voice is essential in getting new perspectives on everyday living, services as well as developing more appropriate provision (Abbott and McConkey, 2006).

In Norway, health and care services for persons with intellectual disabilities are mostly provided by municipal health and care service organisations (Official Norwegian Report 2016:17) and with basis in the Health and Care Act (2011). Among services that municipalities must provide are i.e.; social, psychosocial and medical (re)habilitation, homebased healthcare, personal and individualised services, including practical support, training and support person (see explanation in the discussion, second paragraph). Service delivery is mostly organized and provided by a group of staff in or in relation with the accommodation, characterizing a cluster of houses with separate apartments, or shared housings (individual apartments but within the same building) (Statistics Norway, 2016). National health care covers planned and acute primary care and rehabilitation, while home-based care and institutional care for people with functional reductions require means-tested, high cost-sharing of up to 85 percent of personal income (Lindahl, 2017). The main income for most people with intellectual disabilities in Norway is disability insurance (Tøssebro and Søderstrøm, 2011). Norwegian policy has for a long time been founded on the same values and goals as the CRPD, but the Norwegian Report to the Storting no. 45 “Freedom and Equality” (2012-2013) states that the political ambitions are not achieved, and that the development within several areas is going in a wrong direction. Human rights breaches not only include access to services but also everyday life dimensions like relationships and participation in the community (Official Norwegian Report 2016:17).

**Aim of study**

The purpose of the project was to facilitate and encourage persons with intellectual disabilities to express their opinions about their everyday life and services by working together in workshops. The aim of this study is to explore the perspectives and experiences of their everyday life and its shortcomings. In addition, methodological aspects of conducting workshops will be discussed.

**Methods**

Participants and study context

The study was carried out in a collaboration between one of the largest municipalities in Norway and a disability nurse programme in Central Norway. The project team included two university researchers (both women) and two intellectual disability nurses (one man and one woman) from the municipality.

A public service unit for people with intellectual disabilities aimed to establish a new skills program in order to develop and better coordinate the skills of the professionals working close to the service receivers with intellectual disabilities. Both intellectual disability nurses had a professional role in planning this skills program, and were therefore recruited. As there is little tradition of self-advocacy groups for people with intellectual disabilities in Norway (Report to the Storting nr. 45 (2012-2013)), working collaboratively in workshops could be one way to provide user-based knowledge to the program, as well as provide mutual information, ideas, competence and confidence in the group.

Participants with mild intellectual disability were recruited by municipal employees and came from different geographical areas in the municipality. Being able to give informed consent and to participate actively in workshops made the rationale for recruiting the participants. The workshops comprised 9 participants, 3 men and 6 women, aged from 22–58. All participants lived in their own apartments in 6 separate shared housings with access to staff. All housings had 24 hour staff cover, but beyond assigned individual support (i.e. guidance in everyday life situations, personal support to shower or practical support to make dinner), in practice all participants primarily had on call access to support staff.

Insert Table no. 1 about here

Four workshops were held from February–December 2015. The workshops took place on the university campus during daytime from 09.00–14.00. The study followed ethical research guidelines and was approved by the Norwegian Centre for Research Data. Written consent was obtained to participate and for workshops to be audio-recorded, and participants were reminded of their control to withdraw and leaving the group without explanation at any time.

The research design was inspired by a collaborative group approach as described by Bigby, Frawley & Ramcharan (2014). This approach combines the skills of people with intellectual disability and academic researchers to generate knowledge that neither group could do alone. Characterizations of the group work is reciprocal relationships based on trust, and genuine belief in learning from being involved in processes together (Bigby et al., 2010; Nind, 2011). Moreover, members may not be involved in every aspect of the project, but they should have a sense of the project as a whole (Nind, 2011).

The project had a participatory action research design inspired by the PAAR model – *participatory appreciative action research*, developed by Tony Ghaye et al. (2008). PAAR aims to add a third dimension to the best practices of participatory action research, namely, “appreciative interactions”, bringing together action and reflection. PAAR is not simply about change. It is more about improvement and sustaining success by building on aspects of the positive present. Thus, PAAR deliberately asks questions about what is working well and includes activities with “an appreciative gaze” – meaning that it begins with an appreciation of strengths and successes, not weaknesses and faults. Central to PAAR is the focus on “we” and on the idea of knowing through relationships, which requires users of PAAR to draw upon their social skills and interactions – connecting aspects of the present with a desirable end goal (Ghaye 2010). In line with the PAAR design, project activities and methodologies in the current project were planned, accomplished and evaluated in an appreciative collaboration, but were led by the researchers.

Data collection and material

Researchers planned the content of the workshops – but each workshop was based on experiences from the previous workshop, and included and depended on participants’ work/preparation ahead of each workshop and evaluation of activities each time. Before the first workshop, participants prepared a presentation of themselves together with one of the two intellectual disability nurses from the municipality or their staff. The first workshop included talking about an ordinary week for them. Participants chose as many pictures as they wanted from a variety of pictures of everyday life situations in order to present themselves and talk about their everyday life in groups. In all workshops, small film clips/video clips or reading aloud poems or pieces from books relevant for the day’s topic were chosen to illustrate and trigger conversations about the workshop’s theme. The second workshop included talking about friendship, including boyfriends and girlfriends. During this workshop, one activity included writing down three positive and three challenging things about friendship. The comments were put in a hat and the participants picked comments from the box and then introduced the specific comments to discuss in the group. Before the third workshop, participants brought photos and stories about their family, leisure activities, holidays and the high feasts. The fourth workshop included talking about daytime activities and work. Across the workshops and the themes, participants talked about their experiences with and wishes for services.

In line with the PAAR design, activities were chosen to build a friendly, energizing and collaborative atmosphere. During each workshop, the group chose energizing activities like listening to music, stretching, quoits or balloon competitions and enjoyed a good lunch. During each workshop, barometers with smileys in order for participants to evaluate the activities were made use of. Adjustments were made from workshop to workshop based on the participants’ evaluations and researchers’ and co-workers’ observations. All participants had their own loose-leaf binder to put materials from and between each workshop, and to keep system and identification to the project. In the last two workshops, the group discussed ways to round off the project, and participants’ wishes to follow up on central results and discussions. Participants received diplomas for their participation and contribution to the project, and the group went out for dinner together.

In order to promote variety, each workshop varied between conversations in the group as a whole or in smaller groups. Large poster size pieces of paper and colourful pens were used to summarize and visualise themes from the discussions. The smaller groups were strategically composed in order to try out different permutations across factors such as gender, age, living in the same housing or not.

The data included approximately 100 pages of transcribed text and field notes.

**Analysis**

An inductive thematic analysis was applied in order to interpret data. The inductive thematic analysis approach has as primary goal to describe and understand how people think, feel and behave within particular contexts relative to a specific research question. Thus, keeping analysis close to data is emphasized. The analysis approach implies an iterative, systematic and inductive process where key themes in text are identified and coded (Guest et al., 2011).

The two authors read all data and performed initial coding separately. The authors compared and discussed their preliminary themes and codings, and performed further analysis together.

Examples of initial coding are: using Facebook, watching you-tube and TV, doing housework, making dinner, being alone or with others, going to the cinema, studying good-looking women, talking to or being with mum or dad, receiving visitors, going to bed at nine o’clock, going to work every morning, waiting for staff, feeling anger and frustration, receiving necessary staff support.

Focused coding examples are: having a rhythm in everyday life, doing domestic life activities, striving with feelings, managing on your own or with a little support, talking about staff, social participation with family, friends and neighbours, using social media, desiring a support contact for social and leisure activities, and interacting with other people with intellectual disability.

Finally, the analysis showed that everyday life embraced the following main themes; Everyday life – context, rhythm and structure, social participation and staff – an ambiguous part of everyday life. The themes include sub-categories and dimensions. In line with the inclusive research design, and in order to increase validity and credibility, the findings were presented and discussed with participants at two different occasions. Thus, keeping findings close to data was necessary.

**Results**

**Everyday life – context, rhythm and structure**

Participants expressed pride and contentedness with regard to having and living in their own home. Home represented an important context for meaningful participation and well-being.

Paul: *“My home is important to me, it’s a place where I can be myself and relax”.*

Anna; “*Yes, and I have a balcony where we can sit when the weather is nice*”

Everyday life at home included managing practical tasks, making home a comfortable place and keeping it tidy. Tasks such as shopping, cooking, cleaning and getting yourself straight – were managed with or without support from staff. However, it seemed important for the participants to express their independence, and a frequent expression was “[--] *I do that myself*”.

A contrast to the homeliness of living in a place of your own, was an institutionalized language that participants applied when talking about where they lived, such as “*the shared accommodation*”, “*the base*” (staffs’ place), and “*users*” in their descriptions of themselves and other persons with developmental difficulties.

The participants’ everyday life followed a common rhythm and structure including getting up at the same time in the morning, taking a shower, eating breakfast and getting themselves ready for different activities outside the home. Working hours were spent in sheltered workshops or in a sheltered manufacturing company, offering activities like; woodcutting, working in the cafeteria, post-delivery in the health and welfare organization in the municipality, exercising to keep fit, visiting a farm, or doing other hobby activities. Work or activities ended by 15.00. Daily transport, such as going to and from work by disabled taxi, in a vehicle adapted for wheelchair users, or taking the bus, was a part of the daily life structure.

Performing the same repetitive tasks after work at home, such as making and eating dinner, watching the same TV series, looking in on neighbors, having a regular phone call from mum or dad, and going to bed at the same time each night contributed to the rhythm and structure of everyday life at home.

The regularity of service delivery and staff coming and going was a part of and influenced the participants’ rhythm in their everyday life. They stated i.e. that when staff had regular “overlaps” between shifts, they stayed away.

Rachel said: *“When they sit there and talk they must not be disturbed” (…) I have to wait then, even if I need help. It’s their decision”.*

**Social participation**

The findings showed that the home, community housing/neighborhood and leisure activities were important arenas for the participants' social life. Families and friends turned out to be particularly central to participants’ social lives, and contact with family and friends had many qualities beyond the merely day-to-day routine.

Belonging to a family

It transpired that there were many positive feelings associated with belonging to and being a family member, like security, continuity, happiness and trust.

*Peter: I am in touch with my mum every day.*

*Karen: Every day?*

*Anna: I am in touch every day too, my mum helps me with things and she loves me, too*

*Peter: mum rings once a day, sometimes more, too.*

*Ralf: Me too.*

*Lisa: I send a good night message every night before I go to sleep. We talk often, mum and dad often visit me, and I will visit them*

*Ralf: They are kind. I would like to meet my dad more often – once a week is not that much. We play boccia and have a laugh*

Those participants, whose parents or other family members did not live close by, explained how they visited them at weekends. Several participants also stated that they traveled on short or longer holiday trips with their family. The family was also presented as a key social arena on public holidays. One dimension of being part of a family was a perception of being useful. Examples of this were looking after a nephew or niece, or family dog, knitting mittens for a sibling or visiting parents who were ill. Contrasts to this dimension were parents who "control too much", longing for more contact with individual family members, or concerns about parents who were ill.

Friendship: important and challenging

Having friends were associated with feelings like happiness and a sense of belonging, but also uncertainty, vulnerability, arguing and anger. Participants reflected upon how they should behave towards friends: do not bully them, have a nice time together, talk to each other and be kind, etc. June expressed herself thus: “*to care about each other and get along – this is very important!”*

However, establishing new friendships, finding friends to trust, keeping friends and resolving the conflicts that arise were associated with difficulties. Lisa said; *“Karen doesn’t want to talk to me now. We were friends. I want to be friends. I don’t know what to do”.*

Friendships included primarily neighbors, people with intellectual disabilities who participants shared community housing with or people they engaged in daytime activities with. Only a few of the participants talked about old friendships and about friends who lived somewhere else in the country.

The workshops turned out to represent an arena for consolidating friendships. Paul and Ralf said:

*"We are best friends, we will stay friends".* While others used the opportunity to solicit new friendships:

Anna; *"Someone has left my club, I want to make friends with someone new in that club – and I'm going to do this now!"*

Being part of a collective community was associated with benefits like visiting each other and enjoying each other's company. Sharing meals with friends, especially at weekends, was something participants perceived as positive. Some of them had shared meals, while others wished they could have shared meals or have more of them.

Common to the youngest participants was a preoccupation with boyfriends/girlfriends. However, only a minority had a boy- or girlfriend, but the topic was associated with enthusiasm and giggling. The others had experienced that being someone's boy- or girlfriend is difficult to handle and did no longer consider having one a priority.

Leisure activities

At home, the participants were up to date on TV programs, especially series, competitions and reality shows. All the younger participants were interested in music, using their mobile phones, Facebook, Instagram, other social media and gaming.

Overall, the participants wanted to participate in normal activities like most people do: going to the cinema, going on trips into town and visiting café's, working in the garden, going to football matches, going skiing or swimming. However, the majority of participants mainly took part in organized activities for persons with developmental disabilities: theatre, choir, sports activities, such as indoor bandy and football.

Activities such as going to the cinema, café or restaurants were referred to as something they had previously done with a support person (see explanation in the discussion, second paragraph). The support person scheme appeared to be vulnerable – as many participants had experienced that their support person had quit, and it was difficult to get a new one. It transpires that the problems related to getting a new support person were linked to both difficulties in recruiting and the fact that when a person initially lives in shared housing with a staff group, it is less likely they will be allocated a support person.

Peter put it like this:

*“It's like, they have told me that this will go through the community housing. We can't do anything about it, it's just how it is. We won't get a support person when we live in community housing. There's no point”.*

When talking about pipe dreams, having more friends and good friendships frequently came up. A support person was mentioned as a common pipe dream – with regard to having more to do during leisure time and to participate in activities like everyone else on their own without being part of a group of persons with intellectual disabilities. For a couple of the youngest participants, having a boyfriend/girlfriend and a sexual life was a pipe dream.

**Staff – an ambiguous part of everyday life**

The participants were used to interacting with staff in their everyday life. Paul stated: *“staff are a part of life”.* When they talked about staff in general, they described them as being generally understanding and kind. Overall, they were mainly content with them. Interestingly, potential challenges related to many staff, temporary staff, bustle or short visits were not initially presented as a problem. However, when talking about their relationships and interactions with the staff, several ambiguities became evident. One dimension of ambiguity concerned mutuality/reciprocity. Participants were concerned about kindness and respect, thinking that everyone should be kind to each other, including themselves. However, there were several contrasts in the picture of mutual kindness and respect. Maria said:

“*They (staff) vary, some of them act like angels, and others behave badly, break their promises or boss me around. We try as hard as we can to be kind to them, and then I think they should be kind in return”.*

When participants were asked about how they reacted to bad behaviour in staff, they stated: *“It pisses us off”.* Although kindness was strongly emphasised, it could also represent something ambiguous. For example, staff were often experienced as empathetic and good listeners, but sometimes these skills did not necessarily result in desired actions or change. Peter said:

*“Sometimes there is chaos in my head and I want to sort it out together with a member of staff. They are good listeners, but nothing happens, anyway. It can take a long time before anything happens, it’s frustrating and tiresome”.*

Lisa replied*: Yes, and I can talk with a member of staff about my problems but we don’t talk about how they can be resolved. For example, my mother is overprotective and she will remain so for the rest of my life. I think the staff and mum disagree with each other about a lot of stuff – it’s stupid. They are not good at talking calmly with each other; the chemistry between them is not as good as it should be.*

In addition, a desire for the staff to take more initiatives to stop by and talk became apparent. Participants perceived services as often being given as practical help or support and they had to fetch a member of staff if they needed to talk about difficult emotions. Ralf stated:

 *“I wish they could take better care of me and sometimes stay a little longer at night when I feel alone or afraid”.*

Another dimension of including staff as a part of everyday life touched upon opportunities to practice self-determination. Participants stated that they were grown-ups and wanted to make their own decisions and be independent in everyday life. However, they also stated that it is difficult to decide everything on your own and be independent. An aspect of everyday life that the staff particularly made decisions about was hygiene. June said;

*“The staff decide a whole lot of things” and “they are not always good at listening to our opinions”.*

The analysis showed that complying with staffs' needs instead of speaking one’s own mind or taking a decisive tone themselves was common. Despite wanting staff to listen more to their opinions, participants also wanted to believe the best about staff and were very understanding towards them. Peter expressed himself thus: *“They are just doing their job, right!”*

Having a key person among the staff

Participants emphasized and were generally content with having a key person of their own among the staff. The key person performed several functions including providing and coordinating personalized help, support, information and being a connecting link between the person, relatives and staff. Karen expressed:

*“My contact person helps me to make sensible choices”.*

It transpired that aspects like hours of employment and gender among staff, influenced on the possibility of choosing a key person and the relationship with him/her. It appeared that staff employed less than half time could not hold a key person role. The participants preferred to have a key person of the same gender. However, a predominance of women in the service could be challenging in several ways. Paul stated:

*“There are not many men around here. I don’t want to complain, but there are mainly women in this shared housing facility. I’m fine, but they are pushy and everything is supposed to happen right away, I have to hurry and wash my clothes and do the laundry. They are always getting on your case, and I think it’s a little too much, and then I get frustrated”*

Talking about their key persons also revealed several ambiguities. Anna described a tense relationship between her key person and her relatives. She had a good relationship with her key person and this put her in a difficult position. *"Yes and it was stupid and very hurtful.* *And I told her she had to make it right".* Moreover, when being asked whose responsibility it is to ensure that communication between parents and staff is good, the answer was: *"It is the responsibility of my key person".*

All participants believed that the key person was important to them in terms of help, guidance and information.

Information

An important finding was that participants felt they did not receive a sufficient amount of relevant information. Several stated that they wanted more information, and some stated that staff forgot to pass on messages. Emphasis was placed on the importance of staff communicating messages and information in a friendly way. One dimension of information was changes in the group of staff. Participants wanted information if any of the permanent staff were to stop working where they lived. This did not just apply to the key person. Some participants wanted to know this on the same day, others a good bit beforehand, so that they could prepare themselves for this. Who they received this information from was also of importance. They were of the opinion that the person who was quitting their job should be responsible for telling them, but that the key person had a particular responsibility for relaying all information. Maria sighed deeply after the group had seen a film in which the key person had quit without any message being given: *"Do you know what I identified with? I felt the same loneliness, the same sadness, the same sorrow".* Thus, a lack of information about changes in the staff group evoked strong feelings.

**Discussion**

Overall, the results from this study revealed that combining a collaborative group approach (Bigby et al., 2014) and PAAR (Ghaye et al., 2008) was suitable in order to identify multiple content and barriers of a meaningful everyday life in persons with intellectual disabilities. Thus, this study gives valuable contributions to a growing number of studies highlighting the voices of people with intellectual disabilities when it comes to everyday life and participation (Bond et al., 2010; Deguara et al., 2012; Haigh et al., 2013; Iriarte et al., 2016). Knowledge gained through this study suggests that working together in workshops with a PAAR approach on themes related to everyday life and equal rights, may be an empowering way to promote the voices and interests in persons with intellectual disabilities. The findings have shown that this approach can be fruitful to promote dialogues and processes based on trust, mutual information, reflection and discussions.

Norway has been to the fore in promoting community living for people with intellectual disabilities. However, findings in this study show a mismatch between policy (including legislation) and practice on several areas. Although a main finding was that participants were generally content with having a place of their own, and the rhythm and structure of their daily life, it turned out they experienced a variety of barriers for living the everyday life they strongly wanted. The CRPD article nr. 19 Living independently and being included in the community, recognizes the equal right of all persons with disabilities to live in the community, with choices equal to others. Further, article nr. 30 recognizes the right of persons with disabilities to take part on an equal basis with others in cultural life, including leisure activities and amusements (UN, 2006). Participants in the present study experienced that social and community participation like everyone else, outside the shared housing, was restricted. Consequently, they had a strong request for a support person. In Norway, a support person is both a right and a means to increase social inclusion, cultural life, community participation (Health and Care Act, 2011) and personalised active support (Beadle-Brown, Hutchinson and Whelton, 2012). The municipalities are free to organise this service as an individual or group organised service provision, and large varieties in this service provision exist among municipalities. There was a pronounced decrease in allocation of support person from 43% in 2001 to 27% in 2010, and from average 3,7 to 3,3 hours in the same period. The allocation of support person has the past six years been considered stable at the 2001level (Statistics Norway, 2016). However, a considerable problem is the recruitment and training of support persons, and the relational matching of support persons and persons with intellectual disabilities (Official Norwegian Report 2016:17).

Common arguments for building and offering shared housings for people with ID are exploitation of resources, less turnover among staff and prevention of loneliness among residents (Verdenschot et al., 2009; Tøssebro and Kittelsaa, 2011). In line with this, participants understood that their needs for social participation were supposed to be fulfilled in the shared housing. As it seems, participants experienced, in addition to lack of support person, that their staff did not prioritise social inclusion or ordinary community participation as a part of their services. These findings add to studies arguing that shared housings may not be the best means to promote social inclusion and community participation (Mansell and Beadle-Brown 2009), and that staff in congregated service settings tend to give greater priority to other tasks than to social inclusion tasks (McConkey and Collins 2010).

The CRPD article nr. 21 Freedom of expression and opinion, and access to information recognises the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice (UN, 2006). Participants in the present study were generally understanding and sympathetic with the staff. One explanation for the overall contentment in the participants may be an environmental failure to provide sufficient information and encourage them to speak up in their everyday life, as described by Abbott and McConkey (2006).

Important to note, is that appreciative activities in workshops over time, seemed to facilitate information, shared information and experiences, discussions and reflections. Thus, the PAAR approach facilitated more nuanced and ambiguous views and perceptions to come up.

Participants emphasised friendliness as an important interactional skill in their staff. However, the friendliness in staff could be experienced as a way of ignoring their message, a barrier for action and hence could render their messages harmless. Not surprisingly, this kind of interaction created feelings of frustration. As it may seem, many people with intellectual disability show signs of being socialised into careful ways of living, being satisfied, polite and careful not to criticise (Ellingsen and Kittelsaa, 2008). Their possibilities to make choices and to have control in their lives depend largely on their surroundings, like family and staff. Several studies have shown that self-determination and autonomy in many people with intellectual disabilities should be understood as interdependent processes depending heavily on interactions, information skills and behaviours of others in the environment (Finlay et al., 2008; Williams, 2011).

The significant role of family in the everyday life of people with intellectual disabilities has been documented in other studies (Haigh et al., 2013; Deguara et al., 2012). The findings in the present study underline the importance of having staff to recognize and being sensitive to the participants’ needs in relation to the family contact. Thus, staff need good communication skills and should recognize environmental factors like time and spaces for facilitating good conversations and for building trust between the parties (Weimand et al., 2010). Facilitators and barriers to mutual trust building and collaboration between people with intellectual disabilities, their family members and staff in the context of shared housing should be further explored.

**Methodological considerations**

PAAR is essentially an improvement process (Ghaye et al. 2008). It is therefore necessary to ask questions about what happened after the workshops. By working with PAAR approaches researchers are allowed to stimulate a process of reflection so that the participants can learn from each other and build upon the positive aspects of their lives (Cooperrider and Whitney, 2005). Thus, in the prolonging of this project, the two intellectual disability nurses had, and still have a central role in bringing findings into the skills program for support staff, relating them to CRPD breaches and provide reflection materials to broaden support staffs’ knowledge and understanding. PAAR includes building practical wisdom that is about improving working practices through local and regional ownership of issues. These processes take time (Ghaye et al. 2008) and may often include working with different stakeholders. During the workshop processes in the present project, participants became more conscious about their right to speak out about injustice in everyday life. In addition, they became conscious that they did not have the same possibility as other users of home based services to have a say about satisfaction or non-satisfaction with services. Some of the participants have engaged or are still engaged in projects that focus on involvement and improvement of services. Consequently, participants have together with the researchers prepared and presented results and needs for change from the projects to a local policy board. This can be seen as an empowering action in itself, and in line with the CRPD article 29 Participation in political and public life (UN, 2006). However, changing practice is complex and needs continuous ethical attention. We therefore emphasize the value of conducting workshops with a PAAR approach as one which professionals could emulate as part of service reviews and evaluations. Thus, we suggest training intellectual disability nurses and social workers to facilitate workshops together with persons with intellectual disabilities, to promote and facilitate the involvement and empowerment of persons with intellectual disabilities to a greater degree in matters that are important to them. It is important to remind that continuous reflections on how different power issues affect collaborative work among support staff and persons with intellectual disabilities is a necessary part of PAAR processes.

Retrospectively, one may question why we did not make individual action plans to bring about changes which the participants wanted to make, as this may often be part of a PAAR process. In that connection, one may also question if including key support workers as participants in the workshops would have been fruitful to promote commitment to necessary change. However, it is also necessary to consider that including key support workers in the workshops sometimes may hinder persons with intellectual disabilities to speak freely about their concerns. The workshops were conducted over a period of 8 months. It is important to note that greater continuity might have been achieved by holding them weekly or monthly.

**Conclusion**

Not surprisingly, the findings of this study suggest that how people with intellectual disabilities experience their everyday lives is dependent upon their relationship with staff, family members and the quality of the support they receive. From a CRPD perspective, there is a need to place more attention on the role of policy development, staff and leadership to facilitate an everyday life with more social inclusion and community participation in the everyday lives of people they support.

The data of everyday life derived from this project should not be taken as representative of all persons with intellectual disabilities living in Norwegian communities. However, the experiences from this study indicate that workshops are suitable for collaborative group work and to facilitate expression of meanings, different points of views and fruitful dialogues about important topics for the group. PAAR activities contribute to give time and space to come past power imbalance and possible automatic, “correct” or learned answers. Working together with everyday themes through engaging in a variety of activities may reveal and illuminate nuances and experiences that would not generally come up.

**Declaration of Conflicting Interests**

The authors declared no potential conflicts of interest with respect to the authorship, research and/or publication of this article.

**Ethics**

The main study was approved by the Norwegian Centre for Research Data, who confirmed that no further ethical review was required.

**References**

Abbott S and McConkey R (2006) The barriers to social inclusion as perceived by people with intellectual disability. *Journal of Intellectual Disability Research*, 10 (3), 275-287.

Beadle-Brown J, Hutchinson A and Whelton B (2012) Person-centered Active Support – Increasing Choice, Promoting Independence and Reducing Challenging Behaviour. *Journal of Applied Research in Intellectual Disabilities*, 25, 291-307.

Bigby C, Frawley P and Ramcharan P (2014) Conceptualizing Inclusive Research with People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 27, 3-12.

Björnsdóttir K, Stefánsdóttir GV and Stefánsdóttir A (2014) It’s my life Autonomy and people with intellectual disabilities. *Journal of Intellectual Disabilities*. No. 19 (1), 5-2. DOI: 1744629514564691.

Bond RJ and Hurst J (2010) "How adults with learning disabilities view living

independently." *British Journal of Learning Disabilities* no. 38 (4):286-292.

Charmaz K (2014) Constructing Gounded Theory. London. SAGE Publications.

Cleaver S, Ouellette-Kuntz H and Sakar A (2010) Participation in intellectual disability

research: a review of 20 years of studies. *Journal of Intellectual Disability Research*, 54 (3),

187-193.

Cooperrider DL and Whitney DK (2005) Appreciative inquiry: a positive revolution in change. San Francisco, CA: Berrett-Koehler.

Deguara M, Jelassi O, Micallef B et al. (2012) "How we like to live when we have the chance." *British Journal of Learning Disabilities* (2):123-127.

Dusseljee JCE, Rijken PM, Cardol M, et al. (2011) Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research*, 55 (1), 4-18.

Ellingsen KE and Kittelsaa A (2008) Å velge det trygge. «Choosing the safe. Intellectual disability and self-determination». *Fontene Forskning*, 2 (10), 4-16.

Fyson R and Kitson D (2010) Human Rights and Social Wrongs: Issues in Safeguarding Adults with Learning Disabilities. *Practice: Social Work In Action*, 22 (5), 309-320.

Health and Care Act (2011) <https://lovdata.no/dokument/NL/lov/2011-06-24-30> Ministry of Health and Care Services.

Ghaye T, Melander-Wikmann A, Kisare M, et al. (2008) Participatory and appreciative action and reflection (PAAR) – democratizing reflective practices. *Reflective Practice*, 9 (4).

Ghaye T (2010) *Teaching and Learning through Reflective Practice. A Practical Guide for Positive Actions.* Routledge.

Guest, G. MacQueen, K. and Namey, E. (2011) *Applied Thematic analysis.* Thousand Oaks: SAGE.

Gullestad M (1989) *Culture and everyday life*. Oslo: Universitetsforlaget.

Haigh A, Lee D, Shaw C, et al. (2013) What Things Make People with a Learning Disability Happy and Satisfied with Their Lives: An Inclusive Research Project. *Journal of Applied Research in Intellectual Disabilities*, 26, 26-33.

Iriarte EG, Stockdale J, McConkey R and Keogh F. (2016) The role of support staff as people move from congregated settings to group homes and personalized arrangements in Ireland. *Journal of Intellectual Disabilities*, 20 (2), 152-164.

Joint Committee on Human Rights. (2008) *A life like any other? Human rights of adults with learning disabilities* (Seventh report from the Joint Committee on Human Rights: Session 2007-08:HL 40-1, HC 73-1). London: Home Office.

Lai R, Elliott D and Ouellette-Kuntz H (2006) Attitudes of research ethics committee members toward individuals with intellectual disabilities: the need for more research. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 114-18.

Lindahl A K (2017) The Norwegian Health Care System. <http://international.commonwealthfund.org/countries/norway/>

Mansell J and Beadle-Brown J (2009) Dispersed or clustered housing for adults with intellectual disability; a systematic review. *Journal of Intellectual and Developmental Disability*, 34(4), 313-323.

McConkey R, Abbott S, Walsh PN, et al. (2007) Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research*, 51, 207-17.

McConkey R and Collins S (2010) The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, 54, (8), 691-700.

McConkey R and Keogh F (2016) Personalization of services and supports. Evolution or revolution? *Journal of Intellectual Disabilities*, 20 (2), 97-99.

McConkey R, Bunting B,Keogh F, and Iriarte EG (2017) The impact on social relationships of moving from congregated settings to personalized accommodation. *Journal of Intellectual Disabilities*, 1-11.

Nind M (2009) *Conducting Qualitative Research with People with Learning, Communication and other Disabilities: Methodological Challenges*. National Centre for Research Methods NCRM/02.

O’Brien P, McConkey R and Iriarte GE (2014) Co-researching with People who Have Intellectual Disabilities: Insights From a National Survey. *Journal of Applied Research in Intellectual Disabilities*, 27 (1), 65-75.

Official Norwegian Report (2016:17) *Being equal. Eight efforts to realize fundamental rights for people with intellectual disabilities*. Ministry of Children and Equality.

Pohl P, Sandlund M, Ahlgren C, Bergvall-Kåreborn B, Lundin-Olsson L, and Melander-Wikman A. (2015) Fall Risk Awareness and Safety Precautions Taken by Older Community-Dwelling Women and Men—A Qualitative Study Using Focus Group Discussions. *PLOS*. <https://doi.org/10.1371/journal.pone.0119630>

Report to the Storting nr. 45 (2012-2013) *“Freedom and Equality”*. Ministry of Children and Equality.

Scott S (2009) *Making Sense of Everyday Life*. Polity Press. Cambridge.

Scott M, Foley K-R, Bourke J, et al. (2014) "I have a good life”: the meaning of well-being from the perspective of young adults with Down syndrome." *Disability and rehabilitation* no. 36 (15):1290-1298.

Statistics Norway (2016/13) Homebased services target groups and organization. Report.

Tøssebro J and Søderstrøm S (2014) *Goals fulfilled or visions cut off?* Report. NTNU Social Science Research. Trondheim.

Tøssebro J and Kittelsaa A (2011) *Large shared housings for people with intellectual disabilities. Some consequences.* Report. NTNU Social Science Research. Trondheim.

UN (2006) *The Convention on the Rights of Persons with Disabilities*. Joint Committee on Human Rights.

Verdensschot MML, de Witte LP, Reichrath E, et al. (2009) Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research*, 53 (4), 303-3108.

Weimand BN, Hedelin B, Sällström C, Hall Lord ML (2010) Burden and health in relatives of persons with severe mental illness: A Norwegian cross sectional study.

*Issues in Mental Health Nursing*. 31.pp.804-815.

Williams V, Ponting L, Ford K and Rudge P (2010) Skills for support: personal assistants and people with learning disabilities. *British Journal of Learning Disabilities*, 38, 59-67. 10.1111/j.1468-3156.2009.00570.x.

Williams V and Porter S (2017) The Meaning of ‘choice and control’ for People with Intellectual Disabilities who are Planning their Social Care and Support. *Journal of Applied Research in Intellectual Disabilities*, 30, 97–108.

World Health Organization (WHO) (2001) International Classification of Functioning, Disability and Health. WHO, Geneva.