### **ORIGINAL ARTICLE**



# Active adult lives for persons with learning disabilities—The perspectives of professionals

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### **Accessible Summary**

- The government says that all adults should have the opportunity to live active adult
- Many people with learning disabilities need support from professionals to realise living active adult lives.
- We asked some professionals what active adult living means and they believed it is about self-determination and making healthy choices.
- Some of those we talked to said it was necessary to have more time to support active adult living in people with learning disabilities.

### **Abstract**

Background: Living active adult lives is both a value and a right, but the right to do so is associated with restrictions among adults with learning disabilities. This research aimed to capture professionals' understanding and perception of active adult living for people with learning disabilities living in clustered housing in a Norwegian

Materials and Methods: Field notes and transcripts of interviews were analysed by systematic text condensation based on Giorgi's psychological phenomenological analysis, with focus on the professionals' own expressions about their experiences and not an exploration of deeper meanings.

Results and Discussion: The analysis identified four main themes: (i) active adult life as independent living and self-determination, (ii) choice of lifestyle, (iii) accommodation and privacy and (iv) the role of professionals. Results are discussed against concepts like dependence, independence and interdependence.

**Conclusion:** The role of professionals and structural conditions for support and care is crucial for how active adult living is realised for people with learning disabilities. The results highlight the need for further discussions of conditions for active adult living in people with learning disabilities.

### **KEYWORDS**

active adult lives, interdependence, professionals, residents, self-determination

### 1 | INTRODUCTION

To be regarded as adults has proved to be very important for individuals with learning disabilities (Umb-Carlsson & Lindstedt, 2011). However, there are indications that people with learning disabilities often have to struggle to be recognised as adults (Kittelsaa & Kermit, 2015). In this article, we focus on the notion "active adult living," including the rights of residents living in clustered housing to be perceived as adults who are active and self-determined and can make their own choices about their lives. This article explores how professionals supporting people in their homes define what adult living means and whether their support practice is performed in ways that support the rights of residents to act as adults.

For people with learning disabilities, adulthood might imply lack of autonomy and being controlled by others. In addition, because of their cognitive impairment and their support needs, people with learning disabilities may be experienced as not being wholly adults, but as people continuously living in transition: as biologically mature, but not fulfilling their expected roles as adults (Priestley, 2003). In the service system, people who need assistance are often met with paternalistic attitudes and are given few opportunities to make personal decisions (Christensen & Nilssen, 2006; Gjermestad, Luteberget, Midjo, & Witsø, 2017). Thus, living active adult lives is often realised in a tension between individual choice, control and responsibility.

This article is based on findings from a larger study in Norway exploring and developing professional practices in services for people aged under 67 who need extensive services in their homes. In health and social care systems in Norway, there is a strong focus on the individual's right for self-determination (NOU, 2016;17). A strong focus on self-determination may contribute to individual choices and control for adult living on the one hand, but may also lead to an inability to act in professionals on the other. This may put professionals in demanding positions when they are assisting people with activities they are not able to do by themselves without the professionals taking control or making decisions on their behalf. Balance is a concept often used in descriptions of professional work in other people's homes. This balance has been described as a living conflict between the responsibility for others and their integrity, self-determination and personal traits (Eliasson-Lappalainen, 1999). How professionals deal with this balance can be seen as a litmus test for individual experiences of the possibilities to be an active participant in one's own life. This means that professionals can be experienced as both facilitators and barriers for people's possibilities of living active adult lives.

Concepts such as autonomy, self-determination and independence are commonly promoted as the antithesis of dependency and as universally desirable goals (Fine & Glendinning, 2005). Researchers within the disability field have argued that achieving independence is always blurred and that independence masks a complex, entangled pattern of dependency (Brisenden, 1989; Power, 2008). However, the concept of dependency often connotes deficiencies on the part of the person that needs help (Shakespeare, 2000). Shakespeare draws on feminist ethics on care and argues that the concept of dependency should be replaced by a recognition of basic social conditions of interdependence among people (Shakespeare, 2000). Smith (2013) suggests that understanding people as interdependent "allows agency, autonomy and choice to be promoted as a matter of degree for everyone, recognising how complex social structures and institutions facilitates this process for all" (p. 29). According to Power (2008) models of interdependence acknowledge that everybody has dependencies in living their lives, and represent emancipatory potential for both cared-for and carers, because it recognises reciprocity and mutuality in caring relationships.

Thus, to recognise interdependence is not to deny but to acknowledge relations of dependence (Fine & Glendinning, 2005). Further, the interdependence concept allows for recognising the notion of emotion work, such as motivation and advocacy, which is often downplayed in disability writing (Power, 2008).

Interdependence includes the notion that development of autonomy and self-determination among persons with learning disabilities rests not only on the person's ability to exert it and on environmental opportunities to practice it, but in addition on the support they receive from professionals, including the manner in which they communicate and interact with them (Wehmeyer & Bolding, 2001), Finlay, Walton, and Antaki (2008) and Williams (2011) have shown that for people with learning disabilities, self-determination depends heavily on the interaction skills and behaviours of others in their environment. Thus, everyday interactions can be both supportive of adult living and selfdetermination as well as empowering for persons with learning disabilities (Williams & Porter, 2017). According to Johnson & Johnson (1989), interdependence exists when persons share common goals and when the persons' outcomes are affected by the actions of the others. Despite the acknowledgement of the importance of understanding and promoting caring relationships as interdependent, research has shown that it can be challenging to support active adult living and self-determination in people with learning disabilities (Finlay et al., 2008; Pilnick, Clegg, Murphy, & Almack, 2010). One of the obstacles that professionals face is a lack of knowledge of what autonomy and self-determination means and how to promote it (Pelletier & Joussemet, 2016).

### 2 | METHODS

This article is based on data from two clustered housing facilities (houses) for residents with learning disabilities. Six residents in their late twenties and early thirties lived in the first house and three residents in their late thirties and four in their forties were living in the second house. In the first house, the residents had recently moved from their parents' homes, while the residents in the second house had lived in their apartments from three to five years. One of the houses had a shared living room. In both houses, staff members were located close to the residents in order to assist them on an individual basis.

The overall methodological approach in the larger study was Practice Research (Marthinsen & Julkunen, 2012; Uggerhøj, 2011) including a variety of methods: participant observations, individual and focus group interviews, document studies, dialogue conferences. The study was ethically approved by NSD (Norwegian Centre for Research Data). This article derived data from five participant observations and field conversations and four focus group discussions with a total of 11 professionals working in the two different houses. The focus group discussions (Wibeck, 2000) were led by one researcher while another took notes. A tape recorder was used in order to support the written notes. In the group discussions, we asked the professionals to define what they meant by active adult lives for residents. Themes discussed were work experiences, challenges, relations to residents and how

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**TABLE 1** Gender, age, education and years in present work

Gender	Age	Education and participant number	Years at present work	House no
Female	50	Nurse assistant	6	2
Male	45	Health assistant 1	1.5	1
Female	26	Disability nurse 1	3	2
Female	52	Disability nurse 2	4 months	2
Female	25	Disability nurse 3	1.5	2
Female	57	Teacher	6	2
Female	26	Health assistant 2	6	2
Female	45	Disability nurse/MA 4	3	1
Female	43	Disability nurse 5	2	1
Female	30	Occupational therapist	1	1
Female	55	Social worker	1	1

professionals' work facilitated adult living for residents. The Table 1 below shows professionals' gender, age, education, number of years in present work and the two housings.

The municipality administration had accepted to take part in the study. This meant that professionals could not refuse to be observed, but had the possibility not to take part in interviews and not to be described in notes from observations. All professionals were informed about the project, their rights and that they consented on participating by accepting to take part in conversations and interviews.

Five observations (Fangen, 2004) were performed in the first house and three in the second during a period of five months. Most observations took place during afternoons when the residents were home from work, and a few during the day because some of the residents had one "home-day" a week. The researches only visited the individual apartments when invited in by the residents. In the apartments, we observed daily life routines such as cooking or cleaning and talked with the residents about household chores and their experiences from living in their own apartments. In addition, we observed what was going on elsewhere in the houses, as in the joint living room. We looked for daily routines, what was done and by whom and whether residents were mostly in their own apartments or in the shared living room. Besides, we observed interactions and patterns of interactions: between residents, between staff members and residents and between staff members. We did not take part in the practical work in the apartments or in the houses as such, but talked with residents and staff members about what was going on and how they felt about it. Themes of such field conversations could be daily life activities, likes and dislikes, social relations and experiences of living or working in this particular housing arrangement.

Notes were not taken during the visits, but were written down shortly after the visits, following recommendations from Emerson, Fretz and Shaw (1995) about writing ethnographic field notes. During the observations we tried to memorise; the atmosphere, the people, special episodes or comments, and afterwards, we wrote down what we remembered by making "jottings," which is a way of writing catchword, as basis for writing out the field notes.

Our total data material finally consisted of notes and transcripts from the interviews and field notes from the observations. The data were analysed by systematic text condensation (STC) (Malterud, 2012). The method is based on Giorgi's psychological phenomenological analysis but is not strictly phenomenological. Malterud (2012) describes STC as a descriptive approach. This means that focus is on the participants' own expressions about their experiences and not an exploration of deeper meanings. The analysis was done in four steps. First, we read the data material several times to attain an overall picture of the data. Then several preliminary themes were drawn from the text, and the text was reread and coded based on themes and meanings relevant to the research questions. In step three, we condensed significant meanings from the codes into substantial content, grouped and categorised parts of the text and quotations with the same meanings. In step four, the data were re-conceptualised and organised into four main categories:

- 1. Active adult life as independent living and self-determination.
- 2. Choice of life style.
- 3. Accommodation and privacy.
- 4. The role of professionals.

# 2.1 | Findings

Overall, active adult living was by the professionals referred to as independence, self-determination and choice of lifestyle, and they talked about their own role in promoting adult living, about organisational frames and a lack of resources as barriers to self-determination and choice.

# 2.2 | Active adult life as independent living and self-determination

A common trait across study contexts was the professionals' strong focus on the residents' right to self-determination.



(Being adult) is about taking the responsibility that you are able to. I used to tell some of the residents: 'You are grown up, you must decide for yourself. You are not a little girl any more'.

(Nurse assistant)

At the same time, the professionals complained that they lacked the time and resources to support self-determination and choice. It was, for instance, not possible for the residents to choose activities that required the professionals to follow them around. The professionals therefore explained that they did not have the capacity to guide only one person in his or her individually chosen activities. If the residents chose to go out, they often had to do so in groups. This was a recurrent problem. Every resident had a formal right to one individual activity per week. If they wanted to do more, they had to wait and see whether someone from the staff would be able to follow them or if other residents wanted to do the same activity. The professionals described this as a significant problem during weekends because of the reduced number of professionals on duty.

When talking about adult living for the residents, some professionals who worked with residents, who had recently moved from their parents' home, were overall concerned with expectations and dilemmas of independent living and self-determination. "They have to learn to live by themselves and to take control of their everyday life." (Disability nurse 5)

It turned out that the professionals found it challenging to facilitate active adult living in the residents. They engaged in questions such as when is the right time to act on residents' bad habits, how to systematically motivate and support the residents to make wise choices, relating to, for example, diets, an increase in weight, hygiene, getting oneself to work, sleeping, gaming and romantic relationships.

## 2.3 | Choice of lifestyle

Another recurrent theme was the residents' relationship to food and healthy living.

Deciding what to eat is very important for this group of people who have moved from their parents' homes.

(Occupational therapist)

On the one hand, the professionals expected residents to act independently in their everyday life.

It is important that they do what they can (what they have capacity to perform).

(Disability nurse 4)

Professionals in both houses also emphasised that residents should develop skills to become more and more independent over time. However, they identified barriers to independence within the individuals. Residents are not always motivated to do a lot by themselves independently, and although we try to supervise and motivate them, in the end they decide for themselves. (Disability nurse 5)

Some explained that it was not always possible for them not to "step over." This phrase was defined as sometimes deciding too much for the residents. One example is when they went shopping and the residents wanted to buy sweets. One solution to try to prevent this was to remind them of the shopping list and say "... we have to stick to the list" (Health assistant 1). He continued and explained "this is the easiest way, but it is to go too far." To prevent bad decisions being taken by the residents, the professionals said that they kept hold of the residents' bank cards for food shopping, while the residents were allowed to control their pocket money themselves. When asked what they did if the residents made bad decisions, the answer was that they supervise. The reasoning behind this was that most residents knew what is right because parents, professionals and sometimes doctors had been talking to them about it (e.g., nutrition, sleep). According to the professionals, some residents would get a guilty conscience when they knew that they were doing things that were not recommended. They argued that the residents were adults and must have the opportunity to decide for themselves. However, "It is not easy when so many others deal with what you do and when you experience pressure from many others." (Disability nurse 2)

### 2.4 | Accommodation and privacy

The professionals were concerned about how the accommodation itself affected the residents' possibilities for living active adult lives. The professionals expressed the opinion that owning one's own flat promoted an active adult life for some of the residents, like taking care of their home, engaging in furnishing it and running their home life. In addition, they believed that the ownership could lead to positive attitudes towards respecting the residents' privacy:

You know, it is more their own homes, than our workplace.
(Disability nurse 1)

When asked about how they related to the notion of "home," the professionals were quick to state that they respect the privacy of the residents:

We always knock on the door before we enter, and we go out if they [residents] ask us to.

(Nurse assistant)

However, the professionals across houses were concerned with other aspects of ownership and privacy, too. For some of the residents, the way of living could lead to social isolation and engaging in imaginary worlds at the sacrifice of keeping a job, having daytime activities or socialising with others. The professionals talked about these issues as



dilemmas, including the conflicting needs of the residents—who wanted to exercise the right to decide for themselves and to have privacy—and their parents—who wanted the professionals to exercise control and take action.

One dimension of privacy was romantic relationships. In house 1, the professionals had initiated and encouraged the residents to participate in joint seminars about relationships and sexuality. The professionals thought that for some of the residents romantic relationships were mostly superficial, and something they had because it is common and valued in society. Others had relationships that were more serious. Overnight stays and boy/girlfriends represented some concerns in the professionals:

Overnight stays should preferably happen at weekends, because we are worried about late evenings during the week making it difficult for the residents to get up in the morning and go to work.

(Disability nurse 5)

However, she reflected a second and said; "Well, it gets late anyway. One of the residents follows her boyfriend to the bus stop late at night, and then he could probably just as well have stayed over."

## 2.5 | The role of the professionals

The professionals were concerned about their own roles in the residents' lives and feared that too much focus on motivating and the unfortunate consequences of full self-determination would harm their relationship with the residents. However, across the group of professionals, there seemed to be a common concern that a strong focus on fulfilling the right of self-determination combined with a strong focus on keeping up friendly relationships with the residents could lead to inability to act among the professionals, resulting in unfortunate ways of adult living in the residents.

I believe we should have tightened up a bit. You know, when they buy candy every day and don't eat proper food. It has gone too far.

(Health assistant 1)

Our role is to do what is determined. It is important to be conscious about being professional, but sometimes one gives too much, and then one loses some of one's professionalism. Sometimes I hear myself talk like a mother....

(Disability nurse 4)

Overall, it seemed that the professionals recognised that their own responsibility might represent a barrier for promoting adult living in the residents.

Our professional platform should have been more coordinated. We work in different directions, you see. We have

our discussions, but I miss professional directions and more time for reflections together.

(Social worker)

In contrast, the following remark could indicate that the professionals sometimes blamed the residents' behaviour for the challenges they experienced.

You know, the residents, they try to set us up against each other. They try to choose one before the other of us – we can't accept that kind of behavior! It will make it impossible to stay here as professionals.

(Health assistant 1)

Another description of work in house 2 supports this view:

It (the work) can be intense and demands a lot of you. You are not tired physically, but mentally tired from working here. Residents can be very intense and they tie themselves to individual professionals. In a way, we are regarded as a relative or next of kin, even if they [the residents] also respect our rights to a private life.

(Disability nurse 2)

### 3 | DISCUSSION

Among the professionals, active adult life was primarily related to dilemmas of realising self-determination and independency in the residents. Overall, the findings touch upon conditions related to the dichotomy dependency and independency. The professionals' emphasis on self-determination as important for living active adult lives may mirror the strong focus on self-determination in political documents and legislation both internationally (UN, 2006) and in Norway (NOU, 2016;17).

Overall, the findings in the present study show that the professionals strived to realise self-determination and independence in the residents. In their daily interactions with the residents, they placed heavy emphasis on relational and care aspects. They found it troublesome to interfere when the residents made bad choices regarding everyday living such as eating too much, gaining weight or staying up all night. The professionals were concerned about avoiding conflicts with the residents in order to uphold good relationships with them. A recent study by Witsø and Hauger (2017) found that people with learning disabilities emphasised relational qualities like friendliness as an important interactional skill in their support staff. Interestingly, the friendliness in staff could be experienced as a barrier in everyday life, too-a way of ignoring their message, a barrier for action and, hence, could render their messages harmless. Thus, relationships with the professionals missing directions may create feelings of frustration—and represent a barrier to realising active adult living. Among the professionals in the present study, it turned out they were neither very specific nor united about what a relational approach included. Hence, one may question if their relational focus was sufficiently reflected, and how the professionals' variety of understandings might influence the residents' possibilities to live active adult lives.

One may argue that central dimensions of active adult living are social inclusion and community participation (Verdonschot, de Witte. Reichrath, Buntinx, & Curfs, 2009). Surprisingly, these dimensions did not have equal emphasis as self-determination and independency among the professionals in this study. However, this finding is in line with studies finding that support staff tend to rate care tasks as having higher priority than social inclusion tasks and that a strong focus on care may lead to overprotection explained by vulnerability in people with learning disabilities (McConkey & Collins, 2010). In contrast, other studies argue that self-determination in many people with learning disabilities should be understood as interdependent processes, depending heavily on interactions, skills and behaviours of others in the environment (Finlay et al., 2008; Williams, 2011). People with learning disabilities are often dependent on professionals to make strategic choices (Williams, Ponting, Ford, & Rudge, 2009), and Williams (2011) shows how everyday interactions can be both empowering and supportive of autonomy and adult living, arguing that making one's own choices is about being trusted and being able to trust yourself, in order to say what you want. It does not simply mean doing things that you might choose to do at this moment. A person's ability to reflect on constraints and outcomes is a natural part of wise decision-making. A professional's job may in that respect be to coach people about those outcomes so that they can make wise decisions for themselves (Williams, 2011), which may include emotion work, such as motivation and advocacy (Power, 2008). In these processes, clear information about the possible pros and cons of different alternatives is essential. It is also important to notice that people with learning disabilities experience lack of information as an obstacle to living active adult lives (Bjørnsdottir, Stefansdottir, & Stefansdottir, 2014). Thus, one may question if a strong focus on self-determination and relational aspects like friendliness and avoiding conflicts, as found in the present study, may lead relationships in directions where professionals offer insufficient information and supervision.

In line with staff experiences described by McConkey and Collins (2010), the professionals felt that their professional role was under pressure within the surrounding structures. They were concerned about how the organisation of services and accommodation influenced the service provision in the residents' daily lives. They tried to supervise individuals in making healthy decisions and promote living more active lives. Environmental aspects, including working hours, number of staff, disagreements and leadership, were described as influencing the conditions for promoting active adult lives in the residents. Because of reduction in the number of professionals, they were concerned about increased group orientation at the sacrifice of personalised support. Their concern is in line with studies showing that people with learning disabilities find that support staff treat them as a group, when they want to be treated as individuals with different needs and interests (Deguara, Jelassi, Micallef, & Callus, 2012). The professionals identified lack of time for reflection on the professional role as

a barrier to promoting active adult lives in the residents. McConkey and Collins (2010) claim that the social marginalisation of many people with learning disabilities may be a systemic aspect of present service models with blurred direction and guidance from service leaders and managers.

In line with Williams and Porter (2017), one may question if instead of envisaging people with learning disabilities as individual choice makers, we perhaps need to turn to the implications of interdependence and focus on how interactions among professionals and people with learning disabilities influence the possibilities for living active adult lives.

### 4 | LIMITATIONS

A limitation of this study is the small sample size. In addition, participants were recruited from only two clustered housings within the same municipality. Including professionals from other clustered housings with more variety in municipalities, residents and organisation of services would have been beneficial. Thus, further research is needed to examine how professionals across different contexts understand and define active adult living for people with learning disabilities.

### 5 | CONCLUSION

In this study, the professionals primarily related active adult living to dilemmas of realising self-determination and independency in the residents. We argue that living active adult lives includes more than self-determination and independency, and may contribute to identifying processes of social inclusion and community participation, too. Active adult living may represent a suitable perspective to explore and understand the interdependent everyday lives of adult people with learning disabilities. As we have seen in this study, there may be a risk that professionals' concern and strong focus on fulfilling the right to self-determination may represent an approach that creates an inability to act. However, when relationships between residents and professionals are based on trust, professionals should provide clear information about the possible pros and cons of different alternatives, engage in motivation and emotion work with residents, and in these ways promote self-determination. Further, in order to promote active adult lives in persons with learning disabilities, service leaders and organisations should recognise the need for and prepare for professional reflection and training of support staff in how to understand and practice interdependence perspective in the field of learning disabilities.

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