Why live together? The stories of co-living parents and adult children with intellectual disabilities

Kristina Engwall

Published online: 16 Apr 2018.

Submit your article to this journal ↗

Article views: 361

View related articles ↗

View Crossmark data ↗

Citing articles: 2 View citing articles ↗

Routledge
Taylor & Francis Group

Why live together? The stories of co-living parents and adult children with intellectual disabilities

Kristina Engwall

FoU Södertörn, Tumba, Sweden

ABSTRACT

Independence is highly valued in Swedish disability politics. Consequently, most adult people with intellectual disabilities live in group homes. Yet there are also adult people with intellectual disabilities who live with their parents. Why? In this study, eight parents with adult children in the home and three adults with intellectual disabilities who live with their parents are interviewed. These families deviate from the discourse on how support and service to people with disabilities should be carried out. There is a mixture of formal and informal support as well as paid and unpaid support. It diverges from norms attached to how Swedish families with adult children should be constructed and how relationships between parents and adult children should be expressed. In contrast to other studies, the parents are quite satisfied with the societal support they get. Instead, the parents' reasons for living together are related to a sense of duty and the ability to give their children 'a good life' and a social context. Another motive might be that the parents don't ascribe their grown up children the status of adulthood.

Introduction

The intention of Swedish disability policy for full participation in society includes the right for adults with intellectual disabilities to have a home of their own. With social support and special group housing, everyone must be given the opportunity to have his own housing. Living independently of parents as an adult is consistent with social norms in Sweden, where very few adults remain in the parental home. Under disability policy, housing is regarded not only as a way to enable private life, but also as the platform for participation in community life. Housing is one aspect of the integration process. In spite of strong social and disability policy norms that adults should live independently, a minority of adults with intellectual disabilities still live with their parents.

This article is based on interviews with eight parents whose adult children with intellectual disabilities live at home, and three adults with intellectual disabilities who live with their parents. The article focuses on the reasons they give for living together, their views on social support and how their situations are perceived by others.

CONTACT Kristina Engwall ✉ kristina.engwall@fou-sodertorn.se

From institution to a home of one's own

The deinstitutionalization process that began in the 1960s in Sweden when institutions for people with intellectual disabilities were shut down was completed in the 1990s (Tössebro 2016). Children with disabilities should grow up with their families and then move into a home of their own. Moving away from home also signals a coming of age. This transition to adulthood aligns with the Nordic 'normalisation principle', by which people with disabilities should be able to experience life course stages such as childhood, youth, adulthood and old age (Nirje 2003). Separate housing is also a marker of autonomy and independence – important goals of Swedish disability policy. This was also clarified in the law aimed at people with severe disabilities and substantial needs for support and service 'LSS' (SFS 1993:387) in 1994. The law specifies ten different types of support and service for which individuals can apply, including separate housing. Opportunities are provided to have a separate apartment linked to a service apartment where staff members are available, or a group home, where the residents' flats are grouped around staffed common areas.

LSS takes a clear stance against institutions as a form of housing. One of the ambitions behind the closure of the institutions was greater social integration for various groups, including people with intellectual disabilities (Tideman 2004; Tössebro 2016). Laws and ordinances help constrain institutional tendencies, physically and in terms of content. There are, for example, limits on the maximum number of residents permitted in a group home, statutes that prohibit different kinds of social housing in the same building, requirements that activities should be based on the individual's wishes and not the group's, etc. LSS repudiates collective groupthink, and yet we are currently seeing a whittling away of these rights and, increasingly, local authorities are being fined for not implementing decisions or being criticised for non-compliance with national rules (Tössebro et al. 2012; Socialstyrelsen 2015). Policy ambitions, however, go much further than merely separate housing and physical integration. It was hoped, as it still is, that social integration would be achieved by living in the community along with everyone else (Tideman 2004).

Even though people with intellectual disabilities are no longer hidden away in institutions, their everyday lives are still characterised by separate organisation. They live in special housing together with other people with disabilities. They work in sheltered workshops and their leisure time is also shaped by separate organisation (Lövgren 2013; Tideman 2015). A large part of the day is thus spent in the company of other people with intellectual disabilities and social workers. Physical integration has not led to full social integration (Tideman 2004; Bigby 2008; Tössebro 2016) and the lack of social integration appears to be significant to parents who choose to allow their adult children to remain at home.

Adults living with parents is unusual

In Sweden, as in the other Nordic countries, young people usually leave home at an early age. The average age for moving away from home in Sweden was 21 for women and almost 22 for men in 2013 (Statistics Sweden 2015a). The proportion of young adults in Sweden who still live at home at age 30 is about 1 percent for women and 3 percent for men (Statistics Sweden 2008).

Most adults with intellectual disabilities in Sweden live in separate housing and not with family. Housing is the second most common service provided under LSS, after daily organised activities programmes (Statistics Sweden 2015b). There are no statistics on the number of adults with intellectual disabilities who live with their parents, but two local studies show 10 and 19 percent, respectively (Eriksson and Tideman 2010; Umb-Carlsson and Sonnander 2005).

As an adult with an intellectual disability, living with one's parents in Sweden thus violates social norms and disability policy ambitions. Co-living also concerns the issue of relationships between parents and the adult child with a disability. The move away from home can facilitate the process in which a family transitions from a relationship where the child was dependent upon the parent to a relationship between two adults (Aquilino 2006). When such a process never happens and the adult

child with an intellectual disability remains with their parents, the relationship can be described and perceived in many different ways – from oppressive to enriching (Walmsley 1993; Watson et al. 2004). Hutcheon and Laschewicz (2015, 55) talk about 'the complexity of negotiating family life and disability'.

Study design

In this study, we meet eight Swedish parents who can be described as firmly established in Swedish society. They all have adult children with intellectual disabilities living with them, but they use other forms of social support. What are their reasons for letting their adult children to remain living at home? How do others react? We also meet two men and one woman with intellectual disabilities who live with their parents. Why do they live with their parents and how do they feel about it?

Earlier international research that has studied why adults with intellectual disabilities still live at home have often noted that the housing on offer is of such poor quality that parents do not consider it a realistic option (Mansell 2006; Miettinen 2012). The parents interviewed for this study do not justify their positions on the basis of poor quality of services offered; on the contrary, they are mainly satisfied with the social support they receive. Their stories are instead informed by fears of loneliness and loss of control over creating a good life.

On the empirical level, the article touches upon the reasons that parents and adult children with intellectual disabilities live together and their views on social support. On a more general level, this raises questions about the duty of care and relationships between adult children with disabilities and their parents.

The informants

The study is based on qualitative interviews with seven mothers and one father whose adult children with intellectual disabilities still live at home. Five of the parents worked, of whom two worked as paid personal assistants to their adult child. The other three were retired (>65) but had previously been employed within the care and service sectors. All had their own homes, and several owned their homes. Their adult children all had an intellectual disability, but to varying degrees; this was evident in their descriptions of daily life, where a child might have to be fed, lifted, etc., while others were able to use public transportation, heat food in the microwave, and so on. In all but two families, there were siblings who had moved away from home. The experiences of the siblings who had left the family enhanced comparisons with the adult child who still lived at home. In two families, there were younger siblings who still lived at home.

All of the families receive service and support under LSS. All individuals with intellectual disabilities are in organised daily activities programmes, which make it possible for the parents to work outside the home (Knox and Bigby 2007; Miettinen 2012). The adult children have stayed in short-term respite housing at one time or another, but at present, five are not using this service. Several have community contact persons, companion service, and go to summer camp. The parents have specifically declined housing, but otherwise take advantage of the social support and service available.

The study also includes qualitative interviews with two men and one woman with intellectual disabilities who live with their parents. Two of them have parents who are immigrants. All three work in an organised daily activities programme and one occasionally stays in short-term respite housing.

Summary of informants

Parents

Parent	Employment	Marital status	Child's age
Mother	Personal assistant	Married	27
Mother	Shop-assistant	Married	28
Mother	Retired (care-assistant)	Married	28
Mother	PA	Partnered	29
Mother	Civil servant	Partnered	31
Father	Care-assistant	Married	34
Mother	Retired (care-assistant)	Married	47
Mother	Retired (shop-assistant)	Widowed	55

Adults with intellectual disabilities

Adult with ID	Employment	Marital status	Age
Man	Daily activities	Single	27
Woman	Daily activities	Single	32
Man	Daily activities	Single	37

Method

The informants were reached via staff in daily activities programmes and LSS caseworkers. The invitation to participate was thus made via staff, which meant that I was dependent upon them to query relevant informants. Members of staff were provided with written invitations to participate, which they distributed. The process of getting informants was very slow and I spread my invitations in many different professional contexts. My dependence upon staff means that I have no information on how they spread the invitation or to how many.

Half of the interviews were held in various cafés and half were held by phone. The adults with intellectual disabilities were interviewed at their places of work. The interviews lasted between 35 and 90 min, with most lasting about 50 min. All interviews were recorded and transcribed. My experience from using both face-to-face and phone interviews was that they were equally rich in content and depth as well in time (cf. Sturges and Hanrahan 2004). An additional benefit of phone interviews was that they further protected the anonymity of informants.

The interviews were semi-structured and covered the themes of everyday life, allocation of household chores, treatment and attitudes from others, the reasons that the adult child lived at home, attitudes towards social support and thoughts about the future.

The transcribed interviews were read several times and conventional, qualitative content analysis was used (Hsieh and Shannon 2005). Initially, I used empiricist categorisations of a number of themes connected to motives and experiences of living together. An important analytical starting point is that the societal context is mirrored in the narratives. Views upon shared living is a social practice characterised by a varying social and cultural context, therefore I have tried to go beyond the individual descriptions in order to find the structural frames which influence co-habitation. The themes were analysed in relation to current research in the later phase of analysis as well as the overarching disability ideology characterised by autonomy and independence.

Ethics

Acquiring informants via others has ethical implications. I was unable to control how the question about participating in the study was asked, which may affect the clarity of information about the voluntary nature of participation in the research. I did, however, stress that participation was voluntary both when we made an appointment for the interview and when the interview began. Another disadvantage refers to the right to anonymity, as the staff knew who had been asked to participate in the study. I also discussed this with the informants, none of whom found this a cause for concern. For ethical reasons, I did not interview more than one person in the same family, to avoid putting statements in opposition to each other. I have made every effort to anonymize the informants in the text. The study was submitted for ethical review and was approved (2012/1999-31/5).

Why live together?

The following section reports the reasons parents give to explain why their adult children still live at home and the adult children's reasons for living with their parents. First, though, a discussion of how the decision, or non-decision, to remain in the parental home is made.

Who decides?

There is an awareness among the parents that their adult child will move house sometime in the future. Not least importantly, the parents' own ageing and, ultimately, death, will affect the ability of their children to live at home. However, there are no clear strategies for when or how the move will be accomplished. As other research (Hole, Stainton, and Wilson 2013; Lunsky et al. 2014) has shown, the oldest parents are the most resistant to planning the future: 'I am too old to think five years ahead', says one of the oldest mothers (Interview 2).

   Other research also shows that parents play an important role in the decision that the adult child should move away from home (Olin 2003; Dyke et al. 2013). The decision and preparations for the move are under the parents' control. People must apply for a place in a group home and wait in a queue, and a trustee and/or a parent plays a crucial role in this process.

   The parents sometimes have vague plans for the future, related to how a change in their own housing will also lead to a move for the child. They have thought about selling the house and moving to an apartment, or having the children take over the current home while the parents find new accommodation. There are no definite plans in terms of time and in practice, decisions are put off, and can be connected mainly to the age, capacity and inclination of the parents. 'When I feel ready', says one mother (Interview 8).

   None of the adult children informants express having the power to decide whether or not to move. That is a decision they leave up to their parents, or their parents may have told them that the local authorities are unable to arrange suitable housing for them. Nevertheless, some of the parents describe the situation in the interviews as that they are waiting for the child's decision to initiate a move away from home. 'I am waiting for him to say it, 'I want to do like others do" (Interview 3). Another parent sometimes asks her child whether she would like to move: 'she always says no, I want to wait a year, I want to wait' (Interview 7).

   Adults with intellectual disabilities lack many of the reasons others have for wanting to leave the parental home. While many young people move out to travel, study, work or move in with a partner, these incentives are perceived as not relevant to them (Walmsley 1993; Curryer, Stancliffe, and Dew 2015). As Veronica Lövgren (2013, 140) describes, talking about the future also requires the ability to 'relate to past experience and accessible interpretive frameworks'. This can be difficult for people with intellectual disabilities because so much in their lives is decided by others, and they are rarely afforded the opportunity to practice making choices and decisions. When the parents shift the responsibility

for initiating a move onto the adult children, they are ascribed influence that is hard for them to manage in practice.

The reasons

When the parents describe why their adult children live at home, the arguments can be put into four categories. The first is a sense of duty, and the second is so that they can give the children what they define as 'a good life'. The ability to give their children a social context and social interaction is the third reason. The fourth reason is mentioned more in passing, and has to do with the job as a personal assistant. The adult children argue that they need support from their parents in daily life due to their disability. This involves concrete things such as help waking up in the morning, taking medicine, or help if they have an epileptic seizure.

Responsibility and duty

In some of the families, the parents and adult children live together out of a sense of duty. The responsibility for the child is perceived to be so great that they simply do not consider the alternative of allowing the child to move out. This argument may be influenced by the parent's generation; among the oldest parents, past experiences of being encouraged to put the child in an institution may be significant (Knox and Bigby 2007; Whitaker 2013; Engwall 2017). The oldest informant has a daughter born in the early 1960s, a time when parents of children with a disability could still be advised to put the child in an institution. The parents chose to keep their daughter at home, however, and the mother refers several times in the interview to how she and her husband had promised to take care of their daughter: 'so, we were set on taking care of her as long as we could and things have worked out fine so far' (Interview 5).

But the younger parents for whom an institution was not an option during childhood also feel responsible for their children. One mother tries to answer the question of why her daughter still lives with her: 'I think, I feel it somewhere inside that this is my responsibility. And that if you give up, you somehow fail as a parent' (Interview 1).

Better at home

Some parents claim that their children develop more in the parental home than in a group home: 'As long as I feel it is better for him to live at home than to live in a group home, then I will, then I want it to be that way. And he has a better chance of developing at home' (Interview 4). Or as one mother says: 'You want him to be ready to leave the nest. And we wanted him to settle in with the daily activities first' (Interview 5).

Others say that the range of activities is better at home than in a group home. Some of the parents talk about a full life for their children at home, with many different activities. They are aware that these resources would not be available in a group home. A move away from home would also reduce the parents' capacity to control their children's lives. There are mixed feelings about the higher degree of autonomy that separate housing would bring, such as worry that the son would get obese because no one would be controlling what he ate any longer. There are also horror stories about people who lived in group homes and travelled to Thailand on their own initiative and died there because they were unable to take care of themselves.

One senses the parents' worry about greater autonomy increasing the chances that the children will make the 'wrong' decisions. The parents' ability to control their children's lives also indicates that the renegotiation of power and relationships that usually occurs in families as the children grow up and become adults simply does not occur (Priestley 2003). The parents seldom refer to their sons and daughters as adults, expressing the situation thusly, for example: 'It's a little hard to think of X as an adult. He knows he is on paper, sure, but I have a very hard time thinking that' (Interview 2).

Social interaction

Because the children live at home, the parents also have the ability to provide them with social interaction. When asked whether their children have friends of their own, the answer is often no, or that they might have a friend or two. The adult children need support to be able to get together with friends. One mother says: 'Well, sort of, but you know all of that [with friends] is pretty hard going' (Interview 5).

The friends mentioned by the parents are usually workmates in the organised daily activities programme. One parent relates that their child is the only one in the daily activities programme who is able to speak, but that there is a workmate her daughter cares about: 'a girl she likes that she recognises from preschool, so they know each other and so on. She likes her' (Interview 6). Another parent declares that their son has finally made a friend at work: 'And it's actually almost the first time in his life that he feels like he has a buddy. He has had a very hard time with that, so to speak' (Interview 3).

Some talk about friends outside the organised daily activities programme, who are often former schoolmates. One parent says that some of the children who grew up in the same neighbourhood sometimes suggest getting together '… sort of on the spur of the moment, when it suits them' (Interview 7).

The parents report that their children have few or no friends of their own, but the children are included in family contexts. One mother relates: 'She has no friends, really. That is what is so sad. But she is so happy when we have family get-togethers. And she is over the moon when all the cousins come to visit' (Interview 8). The same mother says: 'So, I usually tell her cousins, remember to come and see her when I die' (Interview 8).

In the discussions of a possible move to a group home, the parents are worried their children will be lonely. They are concerned the children will have the wrong neighbours, worried they will be left alone in their apartments and anxious that social workers will not understand their children's needs.

The biggest problem with group homes, according to the parents, is getting the right neighbours. The neighbours should be about the same age and at about the same level of functioning. Parents of children who speak would prefer the children's future neighbours to also be able to communicate orally. One parent turned down a group home because:

> He is pretty active, you know, reads newspapers and has good language skills and so on. And many of the people who were going to live there did not. I want the very best for him, of course, and for him to live where he has the greatest opportunity to further develop and feel happy in a group (Interview 3).

The other risk is being left alone in a large apartment. One mother says that a separate one-bedroom apartment entails greater risk of loneliness than earlier institutions where residents only had their own bedroom and a shared kitchen and living room. '[the daughter], she isn't one to reach out to others. She is going to be very lonely' (Interview 6). The same mother claims that she knows several parents who would prefer things the old way, with more common areas. She declares: 'But the politicians have other ideas' (Interview 6).

There is also worry about disengaged social workers who do not initiate activities: 'That they don't just sit around in their room doing nothing. That is horrible, absolutely horrible' (Interview 2). Parents are afraid that social workers will not understand alternative, supplementary communication. One parent makes a comparison with siblings who have already moved away from home and notes that this daughter will never be able to phone home and tell them how things are going. She will be entirely dependent upon social workers interpreting her signals in order to make herself understood.

Yet, the parents also appreciate the possibilities that a group home may offer when it comes to chances to make friends and participate in activities. A group home is preferred before an ordinary apartment. They have confidence in the collective way of living which hopefully is going to offer both activities and friends.

The woman who lives with her parents says several times that she absolutely does not want to live alone. The alternative for her is to get married and live with a spouse like her relatives have done. One of the men feels lonely even though he lives with his parents. His social interaction seems limited mainly to companion workers and the community contact person, and he longs for a girlfriend. He says that

he would prefer a group home to an apartment of his own with assistants, with specific reference to the opportunity to make friends.

Social interaction – for parents as well

But the adult children are not the only ones who gain companionship by living with their parents. It is also obvious that adult children can be company for the parent. This is most apparent in families with an older parent whose partner has died, become ill, or no longer has the energy or inclination to engage in social activities. In these families, the child has an important social role (Engwall 2017). Without exception, these parents talk about the joy of having their children with them. 'He is a feel-good factor' (Interview 4). The adult children also say that they mean a great deal to their parents. Research has previously talked about 'interdependence' between parents and adult children (Christensen 2009; Brennan et al. 2016). This may refer to practical chores where adult children can support ageing parents, but also to the social exchange between them.

Co-living becomes a strategy for the parents to provide the child with social interaction and good living conditions. For the adult children, living with parents provides a sense of security in social terms, but still they wish they had more friends.

Job opportunity

Two of the parents work as personal assistants to their children. These parents have switched from one low-wage job to another. Only one parent talks about her job situation and the changes it would entail if their daughter moved to a group home: 'So, it is not only that she would move away from home, but that my job will end and I would have to get another job' (Interview 1). For this particular parent, such a job switch would not be problematic.

The complexity of being employed as a personal assistant to one's own child is not problematized in the interviews. In such a relationship, the job role is mixed with the parent role and sometimes with the assignment as the child's trustee. Paid care work is performed in parallel with unpaid work. Gender aspects also come into play, as the job of personal assistant is often performed by women due to traditional gender labour division (Selander 2015; Olin and Dunér 2016).

The reactions of others

The lives of these families challenge a strong disability policy discourse on autonomy and independence that raises questions of how support should be provided: paid–unpaid, public–private, formal-informal. Sweden is characterised by a dual-provider norm where it should be possible to access care services for children, the elderly or people with disabilities through social services and support. The parents' responsibility and care for their adult children in these families illustrates a collision between two rationalities, where support should be provided through the public sector, not through the family. The complex relationships between social support and family support are most clearly manifest when family members work as (paid) personal assistants to their adult children (cf. Selander 2015; Olin and Dunér 2016). How are these parents treated when they encounter the social workers who are exploring avenues to provide support and service to their adult children with intellectual disabilities? How do the people in their personal networks, and others in general, react?

Social support

All of the families in this study benefit from the social support offered, according to LSS. All of the children attended special school, for example, and when their schooling ended, all were given places in organised daily activities programmes. Many of the adult children have also had community contact persons, companion service and stayed in short-term respite housing. Most of the parents are satisfied

with the social support they receive: 'I have never had to complain; I am given what I need and society in general is very disability-friendly' (Interview 1). The one who expresses the greatest discontent says that the local authority has cut the number of hours for a community contact person. She also has difficulty combining her full-time job with caring for her son when he is ill. Otherwise, the parents are content. One parent thinks that many others complain unnecessarily: '… I think everyone complains. Sometimes it feels like you almost can't socialise with people who have disabled family members. If you do, you just get dumped on and they do nothing but complain' (Interview 1). Another parent thinks support has improved over time and believes this is because she understands the system and knows how she needs to argue her case. Another parent relates that at the latest meeting 'she [the social worker] asked whether they could add any new services to make our situation easier' (Interview 3).

The positive attitude towards social support sets these parents apart from informants in other studies. Parents who have tried to transfer total responsibility for adult children with disabilities report that no one is willing to accept it (Whitaker 2013). Could the explanation be that the parents have not yet tested the boundaries of social support? A Norwegian study shows that parents of young children think applying for support is arduous, but that the support itself is good (Tössebro and Wendelborg 2015).

I asked whether the issue of housing arrangements came up in connection with the children leaving school. Some remembered that the issue was brought up, but others could not recall that it did. 'And the local authority hasn't brought it up [the housing issue] with us in any way, either' (Interview 3). The oldest mother says: 'nothing like that was ever in question. Except, no, we never asked for anything like that' (Interview 5). One mother remembers that many people were 'forced' to move away from home when they finished school: 'we knew some Chilean folks and their boy … His parents were so sad: 'Oh, now he has to move away. They are forcing us to move. And now he is going to live over there and we have to live here. Why is that?" (Interview 4). Some say that the issue comes up in annual conversations with social workers, who are mainly interested in connection with the local authority's plans for housing construction.

Some parents, however, believe that some of the willingness to grant various types of services that make life easier may stem from the fact that it is cheaper for the local authority if their children live at home rather than in group housing. 'It is actually the case that it is cheaper for the local authority to have him live with us instead of putting him in housing' (Interview 3). Another parent also believes there is some flexibility based on the fact that the child lives at home: 'so that if we talk to them and say that we want her at home, but we want this service, maybe have people who come and live in our home and take care of her. So, they are open to those suggestions too' (Interview 1).

The parents thus do not feel any particular scepticism from the social services office, but one parent claims that she encounters greater, more structural opposition: '… you do get the feeling from the society that no, this is not what you are supposed to do […] you sort of feel that you are breaking some kind of rules there' (Interview 4). This parent used to be actively involved in a disability organisation but quit because she felt that their choice of housing arrangements was contrary to the organisation's view. Another parent also expresses a sense of unease about the disability association she belongs to and only attends meetings if she can take her son with her.

Personal relationships

Adult children living with their parents violate social norms, although it can be accepted as an aspect of financial support to adult children who are studying, for example. In other cases there are tendencies to judge co-living as an example of over-protective parents (usually mothers) who are standing in the way of their adult children's self-determination (Knight 2013; Brennan et al. 2016; Olin and Dunér 2016).

How do others treat parents with adult children living at home? One parent answers that no matter what you do, people have opinions: 'they go both ways. There is a lot of that 'oh, you are so fantastic,' and then the others, 'you are just going to wear yourselves out" (Interview 1). Family members are the most opinionated, such as adult siblings who think the parents should think more about themselves and the grandchildren. Some parents have the feeling that older relatives think they should have given

up the children at birth. Others answer: 'they think it is stupid, or they are actually envious that they don't have the strength to take care of their own children' (Interview 2).

The few informants with intellectual disabilities represent two diametrically opposed opinions on the matter of other people's views on their housing arrangements. The woman and one of the men live in an ethnic context in which people live with their parents until they marry. In their circles, living with parents is not unusual and they know many adults who still live at home. The man of ethnic Swedish background feels otherwise. He avoids telling people that he lives with his parents and only gives his address if someone asks where he lives. He says, 'when you are 37 years old, you, how should I put it, you don't want to seem like a little boy' (Interview 10).

Co-living that breaks norms?

In this study, we have met eight parents who live with their adult children with intellectual disabilities and three adult Swedes with intellectual disabilities who live with their parents. Co-living violates Swedish norms in several areas. It deviates from how Swedish disability policy has organised support and service to people with disabilities with an emphasis on autonomy and independence. It deviates from social norms about how Swedish families with adult children should be constructed. It deviates from norms attached to how relationships between parents and adult children should be expressed. What reasons do the informants in this study give for living together?

Reasons

Unlike in other studies of why parents live with their adult children, the parents in this study are not too worried about the quality of the housing offered and do not lack confidence in the organisation (Mansell 2006; Miettinen 2012). There is nevertheless some scepticism about group housing. The criticisms of the housing in particular involve (1) risks of loneliness, (2) risks, such as weight gain, associated with giving up control over the daily lives of adult children, (3) risks that staff will not understand the children's communication. The co-living arrangements continue as a result of these risks, combined with the parents' ability to provide the children with a social network, make sure 'the children live a good life' and interpret their child's communications.

The adults with intellectual disabilities talk more about the concrete support that their parents give them as a reason for living together. Their parents have sometimes told them that social support cannot give them what they need. Nor does the idea of living alone in an apartment appeal to them.

The fear that the adult child will be lonely and not have many friends is not unjustified. The research that exists in the area of social interaction for people with disabilities shows that their social networks are smaller than those of others (Tideman 2004; Kittelsaa, Wik, and Tøssebro 2015; Tøssebro 2016). Parents are very important to the social network for people with intellectual disabilities (cf. Lövgren 2013). The worries about loneliness also show that the disability policy's faith in the physical integration of housing for people with disabilities has not automatically fostered social integration, which the parents have understood (cf. Tideman 2004; Bigby 2008; Tøssebro 2016).

However, parents and adults with intellectual disabilities do believe that a good group home can lead to social interaction. As long as the neighbours are right – of the right age and with similar functional capacity – the group home can be an arena for friendship and activities. Research also shows that many residents of group homes benefit from their neighbours (Tideman 2004; Söderström and Tøssebro 2011). In the parents' hopes for a good group home, there is thus faith in the collective with regard to both activities and interaction.

Swedish disability policy has been striving to move away from the collective for a long time, instead focusing on the individual and self-determination. The parents emphasise the collective option as something positive. It is within the separately organised world for people with disabilities that social life outside the family is found now and will be found in the future. The acceptance of the separate organisation in which the adult children live and are expected to continue living in aligns with how

the parents regard their daily lives, where the children require a great deal of support. The conditions for these children cannot be compared with their siblings' move away from home. The differences are perceived as major and as a reason for the parents to treat their adult children with intellectual disabilities differently by continuing to live together.

Breaking norms attached to care and support

The goals of Swedish disability policy concerning 'autonomy' and 'independence' are implemented through the provision of social service and support. The publicly financed support provided to people with disabilities in the Swedish welfare state has replaced family care and reduced the relationships of dependency within the family, according, at any rate, to the public rhetoric. In practice, there has been little study of how much support is provided to peoples with disabilities by family carers in Sweden, and there are no incentives to foreground this issue (Grassman, Whitaker, and Taghizadeh Larsson 2009). These principles of publicly financed support are challenged when family members perform care work, whether paid or unpaid. In addition, in a Swedish disability policy aiming at independence, these parents are questioned about their abilities to empower their adult children and to carry out their role as supporters of self-determination (cf. Curryer, Stancliffe, and Dew 2015).

The complexity of the issue is exacerbated when parents work as paid assistants to their adult children, as it can be difficult to draw a boundary between the job role and the family role (cf. Olin and Dunér 2015; Selander 2015). In the cases discussed in this study, the individuals cannot independently supervise their assistants and there is risk that they belong to the group of assistance recipients whom Giertz (2012) designates 'objects of care'.

Breaking norms attached to the family

Continuing to live together breaks social norms regarding modern Swedish family relationships. It is often said today that family is something that is 'made' – there is no self-evident or ready-made unit that can be called a family. Such criticism applies, for example, to the 'nuclear family', but norms and values still exist, such as that adult children should not live with their parents. Statistics also shows that parents co-living with adult children are rare in Sweden (Statistics Sweden 2011). In addition to 'making families', there is a theoretical talk of 'displaying families' (Finch 2007). The more a family constellation deviates from conventional notions of what a family should be, the more 'family practices' must be noticed by others to be acknowledged. This has often been discussed in connection with reconstructing families due to a relationship breakdown or in relation to families headed by same-sex parents. Displaying the family triggers a process of defusing and normalising the different in order to be acknowledged.

Several of the informants are aware that their way of living together is norm-breaking, but instead of displaying their family, they avoid certain situations. Parents who were once active in disability organisations quit. A man with an intellectual disability avoids telling people that he lives with his parents. The families are most closely scrutinised by their extended families – that is, in contexts where it is difficult to avoid display. This avoidance of displaying the family may be interpreted to mean that they see few opportunities to be acknowledged.

Breaking norms attached to parenting adult children

Over time, families change; relationships between family members are recreated as the members age, some relationships are broken, or new family members arrive. In the fluidity of family relationships, power structures are also renegotiated (Finch 2007). That which departs from the norm in families with adult children living at home is the absence of changes in power relationships. According to social norms, it is customary for the parent/child relationship to move towards a more equal relationship between two adults (Aquilino 2006). Such a process does not occur in these families. One reason for

this is that the parents do not perceive their children as adults, but rather as lacking the attributes associated with adulthood (Engwall 2017). The adult children's situation gives reason to reflect over the significance of expressing age, where Laz (1998) emphasises the link between the individual's ability to enact and perform age and structural factors that constrain or facilitate the creation of age. The absence of being ascribed adulthood may explain why parents claim the right to decide where their adult children should live.

These parents choose to accommodate the difficulties of integrating people with intellectual disabilities in the community through an individual solution in which they allow them to remain in the parental home. There is a price to be paid for this kind of solution in the form of being perceived as a norm-breaker with regard to how people should make a family, and with regard to the goals of Swedish disability policy. Another price is paid by some of the adult children, who are denied the opportunity to try creating an adult life in a home of their own.

Disclosure statement

Funding

References

Aquilino, W. S. 2006. "Family Relationships and Support Systems in Emerging Adulthood." In *Emerging Adults in America: Coming of Age in the 21st Century*, edited by J. J. Arnett and J. L. Tanner, 193–217. Washington, DC: American Psychological Association.

Bigby, C. 2008. "Known Well by No-one: Trends in the Informal Social Networks of Middle-Aged and Older People with Intellectual Disability Five Years after Moving to the Community." *Journal of Intellectual & Developmental Disability* 33 (2): 148–157.

Brennan, C., R. Traustadóttir, J. Rice, and P. Anderberg. 2016. "Negotiating Independence, Choice and Autonomy: Experiences of Parents who Coordinate Personal Assistance on Behalf of their Adult Son or Daughter." *Disability & Society* 31 (5): 604–621.

Christensen, K. 2009. "In(ter)dependent lives." *Scandinavian Journal of Disability Research* 11 (2): 117–130.

Curryer, B., R. J. Stancliffe, and A. Dew. 2015. "Self-Determination: Adults with Intellectual Disability and their Families." *Journal of Intellectual and Developmental Disability* 40 (4): 394–399.

Dyke, P., J. Bourke, L. Gwynnyth, and L. Leonard. 2013. "The Experiences of Mothers of Young Adults with an Intellectual Disability Transitioning from Secondary School to Adult Life." *Journal of Intellectual & Developmental Disability* 38 (2): 149–162.

Engwall, K. 2017. "'I'm Too Old to Think Five Years Ahead'. Parent Carers of Adult Children with Intellectual Disabilities in Sweden." ALTER, *European Journal of Disability Research* 11 (3) : 155–167. doi:10.1016/j.alter.2017.05.005.

Eriksson, H., and M. Tideman. 2010. *Levnadsvillkor idag och jämförelser med 1990-talet: En studie om barn, unga och vuxna med utvecklingsstörning och autism samt vuxna med förvärvad hjärnskada i Halmstad kommun* [Living Conditions Today and Compared with the 1990s]. Halmstad: Högskolan i Halmstad.

Finch, J. 2007. "Displaying Families." *Sociology* 41 (1): 65–81.

Giertz, L. 2012. *Erkännande, makt och möten. En studie av inflytande och självbestämmande med LSS* [Recognition, Relations and Power. A Study of Influence and Self-Determination in LSS]. Växjö: Universitetet.

Grassman, E.J., A. Whitaker, and A. Taghizadeh Larsson. 2009. "Family as Failure? The Role of Informal Help-Givers to Disabled People in Sweden." *Scandinavian Journal of Disability Research* 11 (1): 35–49. doi:10.1080/15017410802253518.

Hole, R. D., T. Stainton, and L. Wilson. 2013. "Ageing Adults with Intellectual Disabilities: Self-advocates' and Family Members' Perspectives about the Future." *Australian Social Work* 4 (4): 571–589. doi:10.1080/0312407X.2012.689307.

Hsieh, H. F., and S. E. Shannon. 2005. "Three Approaches to Qualitative Content Analysis." *Qualitative Health Research* 1 (9): 1277–1288. doi:10.1177/1049732305276687.

Hutcheon, E. J., and B. Laschewicz. 2015. "Are Individuals with Disabilities and their Families 'Resilient'? Deconstructing and Recasting A Well-Intended Concept." *Journal of Social Work in Disability & Rehabilitation* 14 (1): 41–60. doi:10.1080/1536710X.2015.989560.

Kittelsaa, A., S. E. Wik, and J. Tøssebro. 2015. *Levekår for personer med nedsatt funksjonsevne: Fellestrekk og variasjon* [Living Conditions för People with Disabilities]. Trondheim: NTNU.

Knight, K. 2013. "The Changing Face Intellectual Disability and Some Concerns." *Disability & Society* 28 (5): 660–673. doi:10.1080/09687599.2012.732540.

Knox, M., and C. Bigby. 2007. "Moving Towards Midlife Care as Negotiated Family Business: Accounts of People with Intellectual Disabilities and Their Families 'Just Getting Along with their Lives Together." *International Journal of Disability, Development and Education* 54 (3): 287–304.

Laz, C. 1998. "Act Your Age." *Sociological Forum* 13 (1): 85–113.

Lövgren, V. 2013. *Villkorat vuxenskap. Levd erfarenhet av intellektuellt funktionshinder, kön och ålder* [Conditional Adulthood: Lived Experience of Intellectual disability, Age and Gender]. Umeå: Universitetet.

Lunsky, Y., A. Tint, S. Robinson, M. Gordeyko, and H. Quellette-Kuntz. 2014. "System-Wide Information About Family Carers of Adults With Intellectual/Developmental Disabilities-A Scoping Review of the Literature." *Journal of Policy and Practice in Intellectual Disabilities* 11 (1): 8–18.

Mansell, J. 2006. "Deinstitutionalisation and Community Living: Progress, Problems and Priorities." *Journal of Intellectual & Developmental Disability* 31 (2): 65–76.

Miettinen, S. 2012. "Family Care of Adults With Intellectual Disabilities: Analysis of Finnish Policies and Practices." *Journal of Policy and Practice in Intellectual Disabilities* 9 (1): 1–9.

Nirje, B. 2003. *Normaliseringsprincipen* [The principle of Normalisation]. Lund: Studentlitteratur.

Olin, E. 2003. *Uppbrott och förändring. När ungdomar med utvecklingsstörning flyttar hemifrån* [When Youths with Intellectual Disabilities Leave their Parental Home]. Göteborg: Universitetet.

Olin, E., and A. Dunér. 2016. "A Matter of Love and Labour? Parents Working as Personal Assistants for their Adult Disabled Children." *Nordic Social Work Research* 6 (1): 38–52. doi:10.1080/2156857X.2015.1099116.

Priestley, M. 2003. *Disability. A Life Course Approach*. Cambridge: Polity.

Selander, V. 2015. *Familjeliv med personlig assistans* [Family Life with Personal Assistance]. Stockholm: Universitetet.

SFS. 1993:387. '*LSS*' *Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments*.

Socialstyrelsen. 2015. *Kartläggning och analys av vissa insatser enligt LSS. Delredovisning av regeringsuppdrag* [Survey and Analysis of Certain Actions According to LSS].

Söderström, S., and J. Tøssebro. 2011. *Innfridde mål eller brutte visjoner? Noen hovedlinjer i utviklingen av levekår og tjenester for utviklingshemmede* [Some Trends in the Development of Living Conditions for People with Intellectual Disabilities]. Trondheim: NTNU.

Statistics Sweden. 2008. "Leaving home." Demographic Reports 2008: 5.

Statistics Sweden. 2011. "Housing Situation in Europe." Living Conditions Report 121.

Statistics Sweden. 2015a. "Leaving the Nest. A Description of Young People Moving from Home." Demographic reports 2015:3.

Statistics Sweden. 2015b. *Statistics – Social Welfare, Persons with Certain Functional Impairments – measures specified by LSS 2014*.

Sturges, J. E., and K. J. Hanrahan. 2004. "Comparing Telephone and Face-to-Face Qualitative Interviewing: A Research Note." *Qualitative Research* 4 (1): 107–118.

Tideman, M. 2004. "Socialt eller isolerat integrerad?" [Socially or Isolated Integrated?] In *Integrering och inkludering*, edited by J. Tøssebro, 121–140. Lund: Studentlitteratur.

Tideman, M. 2015. "Education and Support for People with Intellectual Disabilities in Sweden: Policy and Practice." *Research and Practice in Intellectual and Developmental Disabilities* 2 (2): 116–125. doi:10.1080/23297018.2015.1067868.

Tøssebro, J. 2016. "Scandinavian Disability Policy: From Deinstitutionalisation to Non-Discrimination and Beyond." *Alter European journal of disability research* 10: 111–123. doi:10.1016/j.alter.2016.03.003.

Tøssebro, J., and C. Wendelborg. 2015. "Ordinary or not? Families of Children Growing up with Disabilities." In *Childhood and Disability in the Nordic Countries. Being, Becoming, Belonging*, edited by R. Traustadóttir, B. Ytterhus, S. T. Egilson and B. Berg, 199–215. Basingstoke: Palgrave Macmillan.

Tøssebro, J., I. Bonfils, A. Teittinen, M. Tideman, R. Traustadóttir, and H. Vesala. 2012. "Normalization Fifty Years Beyond - Current Trends in the Nordic Countries." *Journal of Policy and Practice in Intellectual Disabilities* 9 (2): 134–146.

Umb-Carlsson, Õ., and K. Sonnander. 2005. "Comparison of the Living Conditions of Adults with Disabilities in a Swedish County and in the General Population." *Journal of Policy and Practice in Intellectual Disabilities* 2 (3/4): 240–248.

Walmsley, J. 1993. "Contradictions in Caring: Reciprocity and Interdependence." *Disability, Handicap & Society* 8 (2): 129–140.

Watson, N., L. McKie, B. Hughes, D. Hopkins, and S. Gregory. 2004. "(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model." *Sociology* 38 (2): 331–350.

Whitaker, A. 2013. "In the Shade of Disability Reforms and Policy – Parenthood, Ageing and Life-Long Care." In *Ageing with Disability. A Lifecourse Perspective*, edited by E. J. Grassman and A. Whitaker, 91–108. Bristol: Policy Press.