10 It is supposed to be a home

Barriers to everyday life decisions in group homes

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In a group home with several apartments along a corridor we noticed that at midday many of the residents' doors were open, meaning that everybody who walks along the corridor of the group home could see into the apartments and see what the resident did. We noticed that there are many scheduled support services during this time and asked the staff members why the doors are open. It is because it is easier to provide support.

Imagine that it is time for you to move to your first apartment. You are very excited and have probably planned this for a long time. You have been thinking about which area to move to, how big an apartment you want or can afford, and perhaps you have looked up who already lives in the same area so that the neighbours are nice. The choice of area and apartment is yours. Now, imagine that instead of your own choice, you are assigned an apartment of two rooms and a kitchen in an area that you have not selected, and that you will live very close to neighbours with whom you must hang out, even if you don't like them. In addition, you have a variety of people to help you in your everyday life. People that are with you in your most private sphere, but you have not been allowed to choose them for yourself. Now, you are probably thinking that you would never accept that, but this is the reality for people labelled and diagnosed with intellectual disability. It is a reality that encompasses hierarchical power relations, diminished decision-making and normative codes of conduct for residents in group homes. This chapter aims to elucidate barriers for everyday life decisions that, we argue, can by extension, also underpin inaccessibility to societal community for people with intellectual disability. The chapter takes as its point of departure Erving Goffman's notions of institutions and their characteristics and focuses on group homes in Sweden.

Group homes

The home is one of the most fundamental aspects of independence, privacy, freedom of choice and the construction of identity. People living in group homes may experience barriers to accessibility in their own homes because of

normalising codes of conduct that guide residents to that which is considered right and appropriate behaviour. Group homes in Sweden are not institutions, however, they can have institutional characteristics, with organisational scheduled social care and ideas of fostering residents towards doing what one should do to be 'normal' (Svanelöv, 2019). The Swedish legislation concerning Support and Service for Persons with Certain Functional Impairments (LSS), which aims to facilitate equal living conditions, societal community participation and accessibility, has the support service of housing with special services, so-called group homes, available for people with intellectual disability (SFS, 1993: 387, §9). These group homes often consist of smaller apartments gathered around common areas with support staff available at all times. The group home is a unique residential setting as it is an institutional living arrangement, the private home of the residents, as well as a workplace for staff (Clement & Bigby, 2010; Svanelöv, 2019). Staff in group homes play an influential role in everyday life decisions for residents and how support is organised (Berlin Hallrup, Kumlien & Carlson, 2018; Talman et al., 2019). That said, staff members are also influenced and restricted by institutional notions of daily life in group homes and everyday decisions about their scope of action.

Public and private spaces, recreational and sports areas, cultural facilities, digital arenas and other physical and digital environments are often constructed with strong ideas of accessibility. However, accessibility for some can be inaccessibility for others and these spaces, areas, facilities and arenas often lack accessibility for people with intellectual disability (Lindqvist, 2020). Swedish disability policies and legislations (SFS, 1993: 387), as well as the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2016), stipulate that everyone should have access to the physical environment, transportation, information and communication, public facilities and services, and cultural and recreational activities. However, inaccessibility persists in every corner of society, both physical and psychological, as well as societal. Inaccessibility can take the form of the lack of a ramp to a museum entrance, or too-small text with long, complicated sentences used to convey important societal or welfare information (see also Liz Adams Lyngbäck, Mia Larsdotter & Enni Paul's chapter in this book). It may also take the form of normalising practices that label people with norm-breaking functionality as disabled and deviant (Sanmiquel-Molinero & Pujol-Tarrés, 2020). How would it feel to be labelled as deviating from the norm, with the possibility to make choices that affect your life taken away, and living in an institutionalised daily life which explicitly and implicitly tells you how to live your life? Norm-breaking functionality becomes a label of disability for people who require help and support in everyday life; support that is often necessary and good, but which also limits freedom of choice and self-determination. Inaccessibility in the wider community relates to barriers to accessibility in everyday living. That is, to have adequate and satisfying accessibility to the wider community outside the group home, it is important to first have accessibility in making everyday life decisions inside one's own home.

To understand life in group homes it is vital to observe the contextual environment, with its activities, symbols and interactions. This chapter relies upon data from group home observations in two separate municipalities in Sweden. These are ordinary group homes, one targeting people with mild or moderate intellectual disability and one targeting people with profound intellectual disability.¹ The first had 15 residents aged between 27 and 83 years, each with their own apartment, a shared common/living room and a kitchen (there was also a kitchen in the apartment). There were also rooms for staff. In total, 50 hours of observations were conducted in residents' apartments, common areas and staff accommodation. The observers stayed in the background and did not interfere or interact with residents or their activities. After a situation was observed, the residents were engaged in conversations about it.

There were six residents in the group home for people with profound intellectual disability, but two had mild or moderate intellectual disability and were not observed. Each resident had their own apartment (open-plan living room/kitchen, bedroom and bathroom). This group home also had a shared common/living room, a kitchen and some accommodation for staff. The four residents observed were aged between 27 and 55 years. The observers' most common role was observer as participant, since the focus was on collecting data rather than participating in the observed activity. We also conducted discussions with staff members concerning questions raised during the observations (Burgess, 1984).

Notions of disability

Barriers to accessibility reside in the social construction of disability. Disability support services and its practice, for example within group homes, should work to reconstruct societal structures and promote accessibility. However, the historical labelling of people with intellectual disability and the contemporary institutional characteristics of group homes can foster discourses of inaccessibility (Mallet & Runswick-Cole, 2015; Svanelöv, 2019). Today's group homes derive from the institutions discussed by Goffman (1990) but have come a long way from the total institutional setting of that time. However, today's group homes still have institutional characteristics which construct and co-construct societal views of disability.

Disability can be viewed in various ways and historically medicalised models of disability have long reigned in the social discourse. Medicalised models of disability, also called individual models, frame certain bodies and minds as atypical, different or defective, and focus on individual flaws and incapacities. In this diagnostic and functional model, disability practices are about correcting or normalising the pathological individual (Kafer, 2013; Lindqvist, 2020). As a reaction to the medicalised model of disability, a social model has emerged in which disability is viewed as socially structured through environmental inaccessibilities and hindrances (Shakespeare, 2017). For example, a person is paying for groceries in a shop but has trouble giving the

right amount to the cashier. In the medicalised model of disability, the problem is that the individual cannot count, differentiate between different-coloured notes or that she or he gets stressed by the queue forming behind. However, in the social model of disability, the problem may reside in the money's appearance – its colour or shape – or the store's organisational policy which only allows one check-out counter and leads to a longer line of customers.

Our view of disability departs from the social and medical models. We view disability as environmental-relational, that is, as residing in environments and social patterns that marginalise and stigmatise individuals due to normative labelling. Disability is reproduced in all social and cultural settings through language. Thus, to say, write or sign is to *do* something in the constructing of disability. Furthermore, we do not view disability and ability as dichotomous, but as mutually dependent in defining one another (Goodley, 2017; Lindqvist, 2020). Disability does not reside in an inability or deficit in the body, but in the inaccessibility of the environment and spaces, and in public attitudes – while there is much talk about disability, it is through the lens of ableism (see also Elisabet Apelmo & Camilla Nordgren's chapter in this book).

No matter the individual or societal view of disability (as social, cultural or relative), disability support service assessments are often based on diagnoses and a medicalised model (Meekosha & Dowse, 2007; Altermark, 2017). Thus, needs assessments can derive from an individual view of disability that constitutes disability support services and legislative interventions as *preventing inaccessibility* rather than *promoting accessibility*, and which view disability support services (such as group homes) as a way to compensate for individual impairment (Thomas, 2002; Goodley, 2017). However, even if needs assessment can be based on medicalised views of disability, the aims of these services are often rooted in ideas of self-determination, citizenship and social inclusion (Lewin, 2019), and the imperative to reform power structures from institutional settings to individual autonomy and equal rights (Altermark, 2017). That being said, there are still institutionalised practices in disability support services that can alter the expected outcomes of the services (Svanelöv, 2019).

Institutional practices are distinguished by restrictions, limitations, fostering, codes of conduct and labelling. These practices can contribute to structural security, but also have an oppressive outcome. Goffman (1990) defines the 'total institution' as 'a place of residence and work where a large number of like-situated individuals, cut off from the wider society [...] lead an enclosed, formally administered round of life' (p. xxi). Characteristics of institutionalised settings include hierarchal authoritarian power and a breakdown of social barriers. People in such settings tend to be viewed as a homogenous group, with diminished privacy, and the activities of daily life are often scheduled and carried out with other residents within the institution. The hierarchal authoritarian power in institutionalised settings can also give rise to codes of conduct (Foucault, 1995) and judgement of desired behaviour

and symbols (for example clothing). On the other hand, institutions can also be a place for identity construction, and the places from where individuals draw their social status, for better or worse. Today's group homes are, hopefully, not often total institutions in the sense that Goffman (1990, 1958) defines or the hierarchal power settings that Michel Foucault (1995) discusses. Instead, living in institutionalised settings or receiving support or services based on an assessment of intellectual disability can be a vital help and promotor of independence and participation in the society. Yet, it can also be an undesired 'otherness' or label which constructs individuals as different and which problematises access to certain domains outside institutionalised settings such as the labour market or recreational activities. Goffman (1958: 51) argues that disobedience or misbehaviour in one institutionalised setting (for example in daily activity services) often impacts on another (for example in group homes), as different institutions share aspects of fostering and supervision based on normative assumptions of what and how daily life should be.

Accessible inaccessibility

This section discusses how barriers for everyday life decisions underpin inaccessibility for societal community participation, taking as its theoretical departure Goffman's notions of total institutions. The section describes various aspects of group homes with different notions of accessibility, and how these different views of accessibility can construct inaccessibility. Thus, making inaccessibility accessible.

Barriers to accessibility

Accessibility, our observations suggest, has different meanings and understandings for different people in varied power relations as well as in disability policies. Accessibility is related to the societal community and much of the work within group homes is focused on creating opportunities for the individual to be part of society. However, what that community is, and what accessibility is intended for, varies. Goffman's (1958) ideas of institutions encompass control through physical restrictions, for example walls and closed doors, of homogeneously categorised groups of people. Today's groups homes are more open and aim to create a good home for residents; however, they constitute other kinds of barriers where the line between home and the workplace can be hierarchically determined. This can be seen if we go back to the observation at the start of this chapter where open doors to make it easier to provide support make the group home more of a workplace than a home.

In the group homes there are normative ideals of what are considered the 'right' activities and what 'accessible' constitutes. The empirical material shows that residents could ask staff members about activities they wanted to do which were not on the daily agenda. This means that residents explored activities that were accessible or not. Which particular activities were

accessible was ingrained in the organisational culture of the group homes, meaning that the residents' conceptions of accessibility could be regarded as barriers and not fitting with the group homes' notions of accessibility. Group homes can be viewed as 'social hybrids, part residential community, part formal organization' (Goffman, 1958: 48) which can hinder accessibility of certain activities.

'Can we go to the graveyard today? I want to put flowers on the grave' was a question posed by a resident to a staff member. The answer given by the staff member was that there was no time to go to the graveyard today because there were other planned activities or support services for other residents at the group home. For example, the same evening, a joint TV-watching session was planned.

The strict timeframes and structural planning of activities at the group homes rest on binary, albeit mutually dependent and interchangeable, institutionalised normative views of accessibility and individual experiences of inaccessibility. The group home staff work with the intention of providing good support for the residents and to facilitate social interaction, but the work is based on organisational notions of what is considered a 'normal' way of living. Thus, the group home's prevention of inaccessibility is confined to certain ways of doing which can create barriers to accessibility. Residents' experiences of accessibility, that is, what the individual wants to have access to and what it leads to, can be obstructed by the undesired activities organised by the group homes' structures. Questions like 'Can we go to the graveyard?' or, as other residents asked staff members, 'Can I go to the toilet?' or 'Can I have a shower during the day instead of the evening?', describe practices of accessibility based on institutionalised and time-fixed practices. Practices of accessibility also limit staff members to certain ways of doing in their work to prevent inaccessibility for residents. That is, accessibility of activities must go in line with the group homes' agenda and, as Goffman (1958) writes, 'seeing to it that everyone does what he has been clearly told is required of him' (p. 49).

Sometimes activities that the residents want to do are acceptable to some staff members even if they are not on the daily agenda. But, for the activity to be accepted as desirable and accessible, it seems to us that staff members have to be interested in the activity. In the following observation we see an example of an activity being cancelled due to staff disinterest.

The observation that was planned to be done on a public holiday was cancelled due to illness. One of the residents had planned to go to church to listen to a music concert and then she, along with a resident from another group home, would have gone to a restaurant to have dinner. The activity had to be cancelled when the staff who was going to accompany her was sick. We ask why they had cancelled and the staff member who

called me up said that it does not work with substitute staff, it gets so messy then. We wonder for whom it gets messy but understand that it is for the staff members primarily because she says that they cannot send a substitute with the resident and 'I do not want to go'.

From our observation notes it seems that the activity that the resident wanted to do could not affect routines at the group home. Accessibility is then bound to the staff and the organisational agenda. So, maintaining routines at the group home became more important than residents' needs – another interpretation of why inaccessibility arises within these organisations. A characteristic of institutional settings may be to allow residents in group homes a sense of control by allowing them to choose activities from the group homes' scheduled agenda (Goffman, 1958). However, in the observation above, the sense of individual control can be diminished by lack of interest in residents' activities and explained by organisational regulations such as understaffing.

Organisational inaccessibility

The group homes we observed are structured with different institutional characteristics that formed the organisational support practice and, by extension, the residents' community accessibility, which is key to being part of the society. Yet, the support can also be a barrier for accessibility. An example of inaccessibility we observed was the residents' restricted access to certain common areas, such as kitchen and living room – areas that were created to be accessible for all but are structured by institutional regulations on access or egress:

A resident walked up to the support staff accommodation room and wanted to have breakfast. The resident was told that breakfast is not served at this time. The resident then asked if he/she could wait in the kitchen (the common area) until it was breakfast-time but was told to wait in his/her apartment.

We would like to highlight three points in this example. First, common areas are constructed as inaccessible areas that are used at specific times, often when there are scheduled activities for all residents of the group homes, for example, watching TV in the evening or eating dinner together at the weekend. Thus, common areas can obstruct accessibility and form residents into a homogenous group through shared institutional activities and timetables that limit the development of individual identities. As Goffman (1958) argues, institutions can utilise scheduled collective activities, such as watching TV with other group home residents in the evening, which aim to take the resident 'out of himself, making [them] oblivious for the time to his actual situation' (p. 64). Second, as residents articulated, the group homes' institutional structure is ingrained in the culture, with defined codes of conduct.

That is, the group homes 'allow' or encourage how and when activities occur. The institutional structure within the group homes' common areas implies that they are formed by controlling (albeit caring) power. The institutional timetable is invisibly visible, meaning that the residents know or 'feel' what is considered 'appropriate' behaviour and move more cautiously towards that which they know or feel deviates from the constituted timetable. This means that the residents are guided by codes of conduct; one does not necessarily know what is considered right, but one has a sense of what is right, and a feel for what is expected in a given situation (Foucault, 1995). Consequently, the institutional characteristics may construct a contextual community based on normative and organisational codes of conduct. Third, not only are common areas inaccessible, but the residents' apartments can be a place of banishment. When residents do not have the freedom to access areas in the group home designed to be open to all, and are subjected to institutional constraints and timetables, the home itself can become a symbol of inaccessibility.

This leads us to ask, for whom are common areas created, for whom are they designed and what kind of community do they support? These questions may seem easy to answer, as Swedish disability policy documents describe common areas as having the purpose of strengthening and facilitating social interaction and of being a meeting place for residents, with the group home staff committed to ensuring comfort and structure (National Board of Health and Welfare, 2018). This means that common areas are supposedly created for the residents as a group and designed for individual residents, with institutional controls for creating community. However, the structure of common areas in group homes aims to prevent inaccessibility rather than promote accessibility. With this, common areas can become controlling and, in some cases, are only ostensibly accessible. The institutionalised purpose of ensuring comfort and structure within group homes, specifically within common areas, can be positive as it creates opportunities for social interaction between residents and staff members which may not have happened otherwise. However, the character of, and time frame for, activities in common areas can be exercised as an institutionalised way of preventing inaccessibility. The problem is that, according to our interpretation, what is considered inaccessible derives from normative assumptions about individuals who are homogenously grouped together and labelled.

Sometimes, even the use of one's own apartment is restricted due to the organisational structures of the group homes, as we see from the observation that opens this chapter. Similarly, in the group home in the observation notes below, there is only one staff member on duty at night, and that staff member is allowed to sleep during the night shift if the residents are asleep. Therefore, the main purpose for the afternoon staff members seems to be to make it easier for the night shift staff instead of meeting the needs of the residents.

Me and the two staff who work this day (a regular and a substitute) are sitting in the common area drinking coffee when the regular staff

discovers that one of the residents has disappeared. She asks the substitute where the resident is, and the substitute says: he is in his apartment resting on his couch. The regular staff member answers: he is not allowed to do that, because then he will not sleep tonight, and it becomes difficult for the staff member who works nights to sleep if he is awake. The regular staff goes to the resident's apartment to wake him up.

Under the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (SFS, 1993: 387, §6), necessary staff must be available to provide the support and care needed to create good living conditions (see also Barbro Lewin's chapter in this book). LSS also states that the aim of this legislation is for individuals to have the opportunity to live like others do (§5). Something that others quite often do is to take a nap in the afternoon or in the evening, and often this means that they choose to go to bed later. But this may not be possible when one lives in a group home, since the institutional structures focus on staff members' needs instead of residents' needs. Thus, residents may be fostered to internalise appropriate norms (Goffman, 1958). However, what is considered appropriate differs depending on group homes' resources and where they focus their attention. For example, it may be important that the resident does not eat too much too close to lunchtime, but it might not matter that the resident lies in bed too long. Another example of institutional structures in the group home that affects residents relates to staffing, which is seldom customised to the needs of residents, as the observation note below shows.

We arrive at the group home at 8.30 am. Two of the residents are up and clothed and they are waiting for their taxis to take them to their daily activities. Two staff members are also waiting; they cannot help the other two residents who are going to their daily activities until these two have left. The other two residents are scheduled to leave at about 9.30. One of the residents has a home-day (every resident has this once a week for washing, cleaning and shopping) so he must stay in bed whether he wants to or not as the staff does not have time to pick him up until all the other residents have left. The second set of residents leave at 9.45 am and the staff members then go to the resident who has a home-day to help him/her get up and have breakfast. The staff discuss how many sandwiches the resident should have for breakfast and agree that one sandwich is enough because the resident slept so long it is almost time for lunch. The resident eats the sandwich very fast and seems really hungry. We wonder if the resident might have wanted another sandwich.

Here the institutional structures of staffing and the staff members' normative notions of what time to eat breakfast and what time to eat lunch is stronger than the residents' needs. In the group homes there are sanctioned ways of behaving, both for residents and staff, which rest upon a normative

structure. Support services aim to help residents in their daily life, but with organisationally regulated resources that lead to specific codes of conduct being internalised by both residents and staff members (Foucault, 1995).

Conclusion: barriers to constructing a home

Group homes are not total institutions in the sense that Goffman (1958) writes about. However, group homes in Sweden do have institutional characteristics in the form of scheduled support, normative codes of conduct internalised by both residents and staff members and hierarchal power relations that restrict access to activities outside the group homes' agendas. There are also different aspects of accessibility within the group home context, where the group homes' strong organisational power relative to that of the residents takes precedence. If institutional structures in one's home are barriers to accessibility, for example through inaccessible common areas, decision-making processes and possibilities to run errands outside the group home, the social community outside the group home becomes inaccessible.

Activities that do not fit into the group homes' agenda of support are often omitted, with explanations of what is considered normal in a given situation and context. To receive the disability support service of housing in group homes the individual must uphold specific disabilities that are established and confirmed by medical diagnosis. Thus, residents in group homes are labelled as having norm-breaking functionality, but the group homes' institutional characteristics form support as normative and hold individuals to specific codes of conduct that give precedence to specific kinds of accessibility. However, just as residents are constrained by institutionalised norms of accessibility, so too are staff members. Often, staff members aim to facilitate residents' independence and well-being, but do so unintentionally (and perhaps intentionally), through the scope of structural and organisational limits.

The group homes and legislated disability support services are intended to promote accessibility to community and society at large, however, their institutionalised character can itself create barriers and inaccessibility. As our observation notes show, many barriers remain to accessibility in everyday life. To increase accessibility, the organisational focus of the group homes should be the promotion of accessibility in scheduled and unscheduled activities, and to reformulate notions of normative and appropriate behaviour. Otherwise, the accessibility of the societal community for residents in group homes can be difficult to achieve. Thus, inaccessibility in everyday life underpins the inaccessibility of societal community. Goffman (1990) argues that individuals are tied to social entities with obligations, expectations, and desired and undesired outcomes. However, if individuals experience barriers in one of the fundamental aspects of daily life – the home – due to its institutional characteristics how can individuals be part of, and have access to, other social entities?

Note

- 1 All empirical material was preceded with approval from the Ethical Board of Uppsala, Sweden (2015/39/1; 2013/375), and followed the Swedish Research Council guidelines for good research practice (2017).

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