

Journal of Intellectual & Developmental Disability

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/cjid20

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To cite this article: Petra Björne (2020): *As if* living like others: An idealisation of life in group homes for people with intellectual disability, Journal of Intellectual & Developmental Disability, DOI: 10.3109/13668250.2020.1793451

To link to this article: https://doi.org/10.3109/13668250.2020.1793451

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As if living like others: An idealisation of life in group homes for people with intellectual disability

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ABSTRACT

Background: People with Intellectual Disability (ID) in Sweden should be enabled to live like others. This life like others is realised in group homes that have little in common with the typical home. **Method:** A reading of Appiah's *As if* is used to discuss how people with ID are supported in Sweden. Current national data are presented within the framework of idealisation, the use of (useful) untruths to navigate a complex context.

Results: Small group homes should allow people with ID to communicate their preferences and exert real influence over how support is provided. Instead, times of budget austerity require the efficient use of resources in ever larger settings, where normalisation of deviance is prevalent. Conclusions: Although the stated aim is that people with ID live like others, the idealisation is rather that they live as if they live like others. This is generally not discussed, possibly due to dedifferentiation.

KEYWORDS

Intellectual disability; group homes; idealisation; normalisation of deviance; de-differentiation

Background

Social services for people with Intellectual Disability (ID) in Sweden are based on the tenet of equal citizenship. The aim for disability services is to enable people with ID to live like others. The Act concerning support and service for people with certain functional impairments was passed in 1993 to protect the rights of people in need of wide-ranging support (SFS 1993:387, henceforth the Swedish abbreviation LSS will be used).

The majority, approximately 88%, of those who access services according to this act are people with ID and/or autism (National Board of Health and Welfare, henceforth abbreviated NBHW, 2019). Services provided according to LSS include, among others, supported living and daily activities, as well as respite care and personal assistance. Supported living is generally offered in two forms. Persons with higher support needs usually live in group homes with small apartments grouped around shared areas, such as a living room and kitchen, staffed around the clock. Those with lesser support needs live in ordinary apartments either grouped in a house or dispersed in the community, and with access to staff as needed.

LSS states that the service user should be given the opportunity to exert real influence over how services are provided, and the design of support ought to enable independence, self-determination, and integrity. Services should be accessible and predictable (Government bill 1992/93:159). Physical, mental and social care should be provided in a manner that strengthens the service user's sense of self-sufficiency (NBHW, 2002).

The Swedish legal system further underpins that people with ID are equal citizens by making no allowances for coercive or restrictive measures in community services. The Instrument of Government protects the fundamental rights and freedoms, and states that no person can be subjected to restrictions in mobility, involuntary medical interventions or other coercive or restrictive measures unless such measure is supported by legislation (Chapters 2, 6 & 8 §\$). Accessing social services constitutes no such exception, thus people with ID who live in group homes are protected from the use of undue restrictions and coercion.

Normalisation

The development of the Swedish support for people with ID was greatly inspired by the concept of normalisation (Nirje, 2003; Wolfensberger, 1972). The concept of normalisation could be interpreted as highly normative, that people with ID should live as normally as possible, even that they should be normal. However, in Nirjes use of the concept, normalisation refers to the context, not the person with ID. That is, normalisation is not translated into "being normal," but rather as having access to the full range of opportunities available to everyone, regardless of disability. Thus, being able to make choices and explore preferences and thereby living like others.

This life in a "normal" context is generally assumed to be implemented, albeit in a setting of supported living quite different from typical housing. In Appiah's (2017) terms this would be an idealisation: a simplified model that serves a political purpose, known to be false, yet used as if it were true. In Appiah's work, such untruths are strategic or dangerous, and either recognised or unrecognised.

The aim of this paper is to explore the as ifs of the current policies and practices in support for people with ID in Sweden.

As if

Appiah (2017) draws on the work of Hans Vaihinger, a German philosopher active at the turn of the twentieth century. An idealisation can, according to Appiah, be a useful or a dangerous untruth. It can further be recognised or unrecognised. Appiah points out that an idealisation is not about the usefulness of telling a lie, saying something that is (knowingly or purposefully) untrue and deceiving. An idealisation is a model of the world, a model that disregards some aspects, while including others. This is done to handle the complexity of the world, which would otherwise be too cognitively demanding.

Such models or representations of the world are not equal to the "true" world. We cannot access "truth," and, therefore, there will be a gap between "truth" and what is useful to believe as if it were true. The features included in the model are not selected to replicate the "true" world as closely as possible but chosen dependent on context. The application of the idealisation is equally dependent on context. That is, the intent is to enable us to get by for a certain purpose or aim. Importantly: "In believing that it is as if something is so, I dispose myself to act in a certain way, but only in certain contexts and for certain purposes" (Appiah, 2017, p. 22).

An example would be how people tend to understand a computer as a filing cabinet, regardless if they have consciously put this into words or not. Most people know a computer is not a filing cabinet, but they interact with the computer as if it were, with real documents and folders. And for the purpose of organising documents and finding them later, in the context of handling them in a digital world, the behaviour that follows from acting as if the computer were a filing cabinet is

(usually) successful. We aim to control the handling of, e.g., written text or pictures, and what we intend to happen usually does: documents are saved, and we all tend to find them again. Most often this idealisation works, although it is strictly speaking not true (there are no drawers, shelves or folders in a computer), because it was designed to appear as if it were. Therefore, if I dispose myself to interact with the computer as if it were a filing cabinet, I can predict actions and interactions, and successfully reach my goal.

For me, an average user of a computer, interacting with the full complexity of its machinery or programs would be cognitively too taxing. However, a computer is not really a filing cabinet. Interacting with the computer as if it were such a cabinet for some other purpose, in another context, could lead to unintended results. In the context of building a computer or programming a new interface, the idealisation so useful for some of us would prevent a successful outcome. And today, when we no longer save our documents locally on the hard drive or usb, but in "clouds," the filing cabinet may no longer be a viable fictionalisation for anyone.

Although it may be useful to act as if an untruth were true, other untruths may be dangerous. Vaughan (1996) coined the concept of "normalisation of deviance" when analysing what had led to the Challenger disaster. According to Vaughan, NASA had a thorough safety protocol in place, but necessary safeguards at various steps were missed or ignored. A row of consecutive signs that should have been interpreted as warnings were normalised, which led to the final disaster. Highly qualified people behaved as if the protocol were in place and did protect the project from potential mistakes and dangers.

Other examples of untruths that are have proven dangerous are models of people as "utility-maximising rational agents," commonly held among some strands of economic research. To build a predictive economics, the philosopher Adam Smith assumed that people acted purely from egotistic reasons. He knew this assumption to be untrue, but it served its purpose in a specific philosophical context. Modern research, as pointed out by Appiah (2017), shows that people tend to act on seemingly irrational and biased information. Economic and political decisions not recognising the untruth in Smith's assumption has led to turmoil and several crashes. Another example of dangerous untruths is the supposed existence of Nations and Peoples with specific characteristics, leading to reduced opportunities, slavery, and war (Appiah, 2018).

An idealisation can, therefore, have the impact of an illusion (Alvesson, 2011), changing and shaping the world in a way that can be detrimental to the outcome.

While an idealisation is used to get by in a complex world, the goal of an illusion is to uphold an image that does not necessarily have any relation to the core task of an organisation. Pseudo-activities, -happenings, and -structures are used to create an image of a successful organisation, but such activities do not arise from what is identified as critical to solve the core task of the organisation. They are used for window dressing, to make the organisation seem legitimate among other comparable organisations or to members of the organisation. This leads organisations to imitate what other organisations do, leading to isomorphism between and within organisations. Alvesson (2011) differentiates between normative isomorphism, whereby organisations gain legitimacy by not deviating; and cognitive isomorphism, where organisations rely on what others do when they do not really know how things could be done. However, organisations tend to imitate an image, that which is presented as legitimate, successful or knowledgeable, while not taking local structures or other contextual factors into account. In such organisations, functional stupidity may be prevalent, where avoiding complexities and not challenging what is generally taken for granted may be advantageous (at least short term) to the members of the organisation (Alvesson & Spicer, 2016).

Are there, then, useful or dangerous, recognised or unrecognised untruths in the service provision for people with ID?

Living like others

As outlined, the intention of the Swedish legislation is to enable people with ID to live like others (LSS 5§). There is an initial paradox built into the legal system, in that social services are provided conditional on a medical framework of diagnoses. Other legislation that regulates social services focuses on the needs of a person, generally without reference to diagnoses. LSS is a rights-based act, that grants people with certain disabilities a higher degree of secure and predictable access to services. Thus, only people with specified diagnoses borrowed from the medical realm can apply for social services according to LSS, and the process of application requires that the diagnosis is thoroughly documented. To live like others, a person, therefore, has to prove that (s)he is not like others, but more vulnerable, in need for the protection and security of a specialised legal act.

Further, the intention to enable people to live like others is specified by the legislation to be realised as support in a group home or service home. The support should promote the possibilities of people with ID to

lead self-determined lives and they should have the opportunity to exert real influence over how services are provided. People with ID should be enabled to fully participate in community.

However, the specified service of a group home quite literally says that the person with ID cannot really live like others, if we in the concept of living like others include the physical and social design of a home. Thus, people with ID are offered services that set them off from the rest of society. A minority will be supported by personal assistants of their own choice in their own home. The majority of adults with ID in Sweden live in group homes; i.e., live communally with people they have not chosen, and are supported by staff employed for them, not by them. People with ID are generally excluded from the labour market, and, therefore, rely on daily activities in centres or sheltered workplaces with little or no compensation. The Swedish National Association for People with Intellectual Disability (abbreviated FUB) published a report in 2020 that concludes that the majority of people with ID live in lifelong poverty. They have very few opportunities to change their financial situation by earning money or make anything resembling a career. Many are poor and have no possibilities to change this fact (FUB, 2020). Their opportunities to choose how to live their lives and with whom, are quite circumscribed. For those living in a group home, there is very little real self-determination and influence about who will provide support, even in the most intimate situations.

As if living like others

The legislation, then, holds two incompatible views. If the legislators' aim is that support should enable people with ID to live like others, one must assume that legislators express the belief that people with ID can live like others. That is, that they (in some sense, at least) are like others. Simultaneously, the same act expresses a belief that people with ID are not like others. They have to prove that they have a certain diagnosis that makes them different, granting them the right to apply for and access services, which other people (the majority) cannot. It is, as Appiah points out, not uncommon that we hold incompatible systems of beliefs. They are incompatible when lined up together, but not when applied in their different contexts, and as long as they are kept apart. It causes more of a problem when simultaneously present in a rights-based legislation.

One way to make sense of this is to consider *living like* others as an idealisation intended by legislators to be a recognised useful untruth: we should understand living like others as the idealisation that people with ID can

be supported as if living like others. This idealisation would then dispose service providers, managers and direct care staff to act as if people with ID live like others, possibly with the positive impact of opening up opportunities and spaces for people with ID to access generally available contexts.

Is such an untruth useful, opening possibilities for people with ID, or is it a dangerous untruth, contributing to excluding practices? Given the current development, I would hold the latter to be true.

A regulation by the National Board of Health and Welfare (NBHW, 2002) states that a group home should be built for three to five persons, with an additional person if quality can be guaranteed. Almost half of the group homes are larger, managers are responsible for several services, and hiring staff with relevant competence is a challenge (NBHW, 2020). Although each service user in a group home has an apartment, these are usually not of the kind other people live in most of their lives. Many apartments are small, with a kitchenette, and do not allow for much social life. The presence of other people has a continuous impact, as they are heard and seen in the communal areas.

It will be difficult to provide individual, personcentred support with a high degree of self-determination and influence in a context that has an institutional character. For example, not all group homes can support leisure activities after 9 pm if staff is required (NBHW, 2020). Service users adapt their everyday lives to the schedules of staff (Lövgren, 2013). And if people with ID need to be supported in their family life, they seem to be required to find a partner with ID, as services allow live in partners, but only if the partner also is granted support according to LSS (NBHW, 2020).

The fact that persons living in group homes do not feel safe in their own home, either being afraid of other service users or of staff is of greater concern. Further, the use of coercive and restrictive measures is not uncommon even though they are illegal (Health and Social Care Inspectorate, 2020). These facts should lead to a lively discussion about the very assumption that group homes are suitable services for vulnerable people, when inadequately staffed, and led by managers who cannot be present as they often manage several services (Berlin Hallrup, 2019; NBHW, 2020). Is the aim of policies and legislation truly to enable people with ID to live like others? I believe we should recognise that the aim rather is as if living like others, and being an unrecognised untruth turns out to have detrimental consequences.

In the present context, *living like others* is possibly an unrecognised untruth that allows services to support people with ID to live lives that resemble or mimic as if living like others, physically and socially. There currently seems to be a strong development towards reinstitutionalisation, proving the idealisation to be akin to an illusion.

De-differentiation

De-differentiation is the view that people with ID face the same socially construed problems as others with the lived experience of a disability (Clegg & Bigby, 2017). Although there are some advantages in de-differentiated policies and social service systems, there are a number of important disadvantages, e.g., within social services and mental health provision (Clegg & Bigby, 2017).

In the Swedish legislation that secures the access to certain services, it is taken for granted that living like others is desirable. Although people with ID are identified as vulnerable, in need of a rights-based legislation that guarantees them the security of services of good quality, I would hold that the full impact of facing the cognitive complexities resulting from an ID is not acknowledged. There is always the dilemma between describing people with ID as being different, on one hand, and describing their lives in ordinary terms, on the other, thereby ignoring their lived experiences with conditions that are not the same as others' (Lövgren, 2013).

De-differentiation serves as an idealisation, as if people with ID share the lived experience with people with other disabilities. However, as pointed out previously, the majority of those living in group homes, with restricted opportunities and circumscribed quality of life, are people with ID. This must be recognised, to be able to address a service delivery that might contributes to victimisation (Sheerin, 2019). For some purposes, an idealised picture of people with ID, as if they can and do live like other citizens, can serve as a useful model. However, as the gap widens between the idealised model and the services provided, de-differentiation threatens to mask a development away from the desired outcome.

In a specific area, training of direct care staff and health providers, de-differentiation has had a direct impact in Sweden. In the years following de-institutionalisation not only specialised healthcare but also training for direct support staff in community services was abandoned. General healthcare and psychiatry should support people with ID as it supports all others. Why training for direct care staff in social services was abandoned is somewhat unclear but has changed to some extent in recent years with higher vocational training available. This may have contributed to the fact that more staff today know how to use cognitive and communicative aids (Health and Social Care Inspectorate, 2020; NBHW, 2020).

There is no comparable change in healthcare provision. The general physical and mental health is poor among people with ID, and health needs of people with ID are often unrecognised. Prescription of anti-psychotic medication is prevalent, especially among those who present with behaviours that challenge services (NBHW, 2020). This is concerning, as such medication can have serious side effects for those with an ID (Sheehan et al., 2017). The intention of normalisation was that people with ID should access general healthcare. In Sweden, there are no learning disability nurses, and specific challenges in healthcare for people with ID are not taught at medical schools, i.e., there is still no specialist training for health care staff at any level. This has probably an impact on observed health inequalities as well as mortality (Ng et al., 2017).

Clegg and Bigby (2017) also address the fact that people with intellectual disabilities often are represented by those with mild cognitive difficulties. The Swedish focus on living like others may contribute to this, in service provision as well as research. In a series of workshops held for direct care staff on communication in people with profound ID, it was obvious that staff found it difficult to translate concepts like self-determination, preferences, influence and participation to be applicable to people who communicated by other means than speech. Allowing and supporting the narrative of those in need of extensive interpretation to make their voice heard requires some rethinking (Björne, 2016).

In a review of research on behaviours that challenge, the National Board of Health and Welfare identified few Swedish papers, and none of them on methods such as PBS or Active Support (NBHW, 2015). The same was true in a project on participation (NBHW, 2017). Studies that involve adults with ID through the use of interviews and surveys are not uncommon in Sweden. There are, however, few studies that involve adults with profound ID, their lived experiences and how to support adult life in a group home in Sweden. That is, how do we translate the core task of supporting a selfdetermined life, with person-centred services that allow a person with extensive support needs to live, if not like others, then as if like others? This translation is largely left to direct care staff who are not sufficiently trained nor supported.

I would argue that one consequence of de-differentiation is that there is very little, to say no research on how to support adults with ID in their everyday lives in a Swedish context. There are excellent studies on lived experiences in a group home (see e.g., Jormfeldt, 2016; Lövgren, 2013), and on staff and organisations (Berlin Hallrup, 2019). There is, however, an obvious lack of studies on how to support adults to live self-determined lives and to enable their full participation in community, by using certain methods and/or communicative aids. Nor are there studies on how to support people who are challenged by services, and, therefore, who present with behaviours of concern.

Conclusions

Living like others, the main aim when supporting Swedish people with ID could be interpreted literally, intended to enable people with ID to have the same range of choices and opportunities as their neighbour. This would, of course, require substantial political engagement and resources.

However, I conclude that a literal interpretation of living like others was never intended, that it is rather an idealisation: as if living like others. Many of the complexities and irrationalities of the non-idealised world are lost in an idealisation. So are important details when translated into the everyday support in a group home. It is currently left to (largely) unqualified staff to translate the idealisation back into their work. Staff who may not recognise that translation of an idealisation is part of their everyday work.

The reason for concluding that living like others is an idealisation is firstly the very construction of the legislation. LSS specifies services such as group homes, a form of living that is almost exclusive for people with ID. That is, people with ID are not expected to live as others, in their own home, but in congregate settings apart from people without ID.

Secondly, in recent times, group homes are becoming larger in Sweden, which is tacitly accepted. Group homes were an instrumental part in the de-institutionalisation in the 1980s and 1990s, and possibly the best solution in times when large institutions were still widely in operation. The main assumption was that living together in smaller groups, in near to normal settings, would allow for people with ID to communicate and express their preferences. In such services, staff would be able to listen to those preferences, and provide adequate support.

One could, of course, claim that living in a group home is one of the many possible variations of living like others, as some "others" do live in group homes. This interpretation of living like others was probably not intended, as the guiding forces of service development were normalisation and equal opportunities. And if it once were, the current discourse and practice in

which as if living like others is obvious as an unrecognised untruth, what was once achieved is threatened. There is a stepwise normalisation of deviance, which allows larger group homes, located in close proximity with other services; exclusion from society and the labour market; and the prevalent use of coercive and restrictive measures. This development is possibly driven by the stark realities of budget (NBHW, 2020): larger services, located close to each other would allow for the efficient use of resources such as staff and managers. These larger services do not resemble total institutions, such as depicted by Goffman (2007), but something unique of its own (Sandvin et al., 1998). Whatever the reason, the current trend leads toward re-institutionalisation in the form of larger services. Thus, the life of persons with ID is set ever more apart from what is generally considered as typical. These facts are described but not debated.

It is necessary to ask the question if people with ID are like others, and to what extent they are not. Is living like others in the literal sense a desirable goal? And who are the others? People without ID, with or without other disabilities? Do people with ID share the challenges of people with other disabilities? When maintaining that they are no different, we gain the opportunities that lie in our shared experience of being human. We might, however, ignore potential challenges unique to people with ID due to specific vulnerabilities, requiring, e.g., specialised knowledge about physical and mental health to meet their needs. We might also ignore the heterogeneous group lumped together under the category of people with ID and focus on those with mild ID as proxies for the whole group.

Currently, it is not possible to properly answer this question. People with ID live in oppressive settings that recreate disability (Sheerin, 2019). We must explore (at least) two paths simultaneously. On the long term, living arrangements need to be reconsidered and changed. Group homes were the best we could think of at the time of de-institutionalisation. New and certainly more diverse forms for support must be developed. On short term, people with ID should be supported in exploring their preferences, gaining access to a whole range of opportunities, to find out how they really want to be supported.

As pointed out by Clegg and Bigby (2017), supporting people with intellectual disabilities requires wider thinking than the application of one or two "methods." It requires that we embrace the complexity of human beings living in diverse social structures. We must allow for a group home to be exactly that, a home, and recognise that living in a group home is not literally living like others. There needs to be a wider discussion of

the impact of an idealisation on service development. An idealisation might not be for the worse, if it is recognised and understood in a useful manner. Idealisations as useful untruths can serve an important purpose in developing support for people with ID, when the idealisation functions as an incentive to act as if it were true.

I would argue, however, that the idealisation of as if living like others is not recognised as an untruth that could be useful when applied in the proper context and with the intended aim. Given the current development in Sweden, I hold that the concept of living like others rather turns out to be an unrecognised and dangerous untruth that obscures the lived experience of people with ID. The idealisation, which might have prompted action to change the oppression model of service delivery (Sheerin, 2019) now functions as an illusion (Alvesson, 2011), partly maintained by functional stupidity (Alvesson & Spicer, 2016), partly by the stark realities of austere

We must truthfully answer the question: is as if living like others really the best we can do when supporting people with ID? Or should we explore an alternative phrasing; maybe the main goal of support for people with ID should shift to living with others? That would then require of "us" to "decide whether or not we are the kind of people who want to share our lives with disabled persons" (Reinders, 2008, p. 44).

Note

1. I will not delve further into the philosophical discussion about "the true world" and if we have access to this or not. Suffice it to say that we need shortcuts to get by in a complex world.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by FORTE (Forskningsrådet om Hälsa, Arbetsliv och Välfärd), the Swedish Research Council for Health, Working Life and Welfare [grant number 2018-01336].

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