



User-Controlled Personal Assistance for Children— Does the Independent Living Ideology Translate to the Lived Life of Children and Youth with Disabilities?

RESEARCH

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STOCKHOLM
UNIVERSITY PRESS

ABSTRACT

In Norway, user-controlled personal assistance (UPA) is a right for children under the age of 18. Based on the independent living (IL) ideology, the intention of UPA is to provide the person with user control, independence and more. However, in order to receive UPA, minors need an external actor to be formally in charge. Through a qualitative approach, this article discusses whether the ideological principles governing UPA can be utilised as intended in families where the parent is expected both to care for and protect the child as well as act as an administrator providing opportunities for the child to enjoy the IL principles. The findings in this article suggest that there may be a need to revise the ideological framework in order to better encompass the reality of childhood. Instead of full user control at present, UPA could be viewed as an empowering tool in the process towards future independence.

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KEYWORDS:

personal assistance; independent living; children with disabilities; family institutions; self-determination

TO CITE THIS ARTICLE:

Snipstad, Øyvind Ibrahim Marøy and Stine Vik. 2023. "User-Controlled Personal Assistance for Children— Does the Independent Living Ideology Translate to the Lived Life of Children and Youth with Disabilities?" *Scandinavian Journal of Disability Research* 25(1):363–377. DOI: <https://doi.org/10.16993/sjdr.931>

INTRODUCTION

User-controlled personal assistance (UPA) is an arrangement developed by, and for, people with disabilities. UPA for people with disabilities is 'seen as a tool for liberation and a decisive instrument to realise their right to control over their own life' (Askheim, Bonfils & Hugemark 2014: 1). This involves transferring control from an external service provider to the person with disabilities, empowering them to administer their own arrangement by deciding when they want assistance, how they want to use it and who their assistants should be (Norwegian Ministry of Health and Care Services 2015). UPA emerged from the independent living (IL) movement that originated in the United States in the 1960s (Pelka 2012). The core ambition of IL was to fight the oppression and discrimination that people with disabilities faced in America during this period.

According to Ratzka (2012, para. 20), the IL ideology is founded upon five core values:

- De-medicalisation: People with disabilities are citizens, not patients.
- Cross-disability: Changing the views of people with disabilities from sick/injured to a group that is discriminated against in society. This further builds on the conception that a common experience of discrimination unites, whilst diagnostic descriptions separate.
- De-institutionalisation: Institutions that control the lives of people with disabilities need to be phased out. This also includes what IL defines as mobile institutions, a term which refers to health and care services provided in people's homes.
- De-professionalisation: External actors, public or private, should not control the lives of people with disabilities. Instead, IL demands the recognition of people with disabilities as the foremost experts of their own lives.
- Self-representation: People with disabilities should be given the right and opportunity to speak on their own behalf, both collectively and as individuals.

Emerging from the IL movement, UPA was intended to be founded on all the above-mentioned values and represent an alternative to traditional health and care services. This means that the person receiving UPA should decide what, where and how they wish to use their own arrangement (Prop 86 L 2013–2014). This stands in contrast to other public (or private) services where assistance or care is often provided at set times, where the recipient often has less control over who is providing the service to them and when they receive it. Traditional services for people with disabilities have been criticised by the IL movement and disability activists alike for focusing primarily on the health or care aspect instead of independence, self-determination and empowerment (Ratzka 2012; UPIAS 1975).

Askheim, Bonfils and Hugemark (2014: 1) refer to UPA as a 'contradictory ideological hybrid' because it attempts to combine two discourses that are often considered opposites. On the one hand, UPA is rooted in a social justice discourse, viewing disability as a concept that is produced and maintained by barriers in society (Barnes 2012; Oliver 1990; Ratzka 2012; Shakespeare 2014; UPIAS 1975). On the other hand, it builds on a neo-liberal discourse that emphasises marketisation and free consumer choice (Askheim et al. 2014; DeJong, Batavia & McKnew 1992). Within public services, the latter discourse is perhaps best illustrated through new public management (NPM), which can, in short, be described as a political ambition to organise services based on inspiration from principles governing the private sector (Denhardt & Denhardt 2011).

In Norway, UPA was first introduced for adults with physical impairments who were able to be in charge of their own arrangement (Norwegian Ministry of Health and Social Affairs 2000). In 2005, UPA became available as an alternative to children and others who required assistance in managing their arrangement (Norwegian Ministry of Health and Care Services 2005). Finally, when the Norwegian government defined UPA as a right through legislation in 2015, children were included (Prop 86 L 2013–2014; Norwegian Ministry of Health and Care Services 2020; Patient and User Rights Act 1999 § 2-1 d). In fact, as long as you have a need for assistance that extends beyond 25 to 32 hours per week over a period of two years or more and are under the age of 67, you can apply for and receive UPA in Norway (Prop 86 L 2013–2014).

By extending the ‘user group’ of those eligible for UPA, potential issues arose related to the IL ideology and consequently the political intention that UPA builds upon. As already mentioned, self-determination, independence, freedom, user control and self-representation represent important aspects of UPA. However, children and young people under the age of 18 years are dependent on an external actor to organise and lead UPA on behalf of or in cooperation with them in order to receive it (Prop 86 L 2013–2014). Consequently, having an external actor influencing day-to-day decision-making raises questions about how and in what ways UPA for this population is able to maintain the above-mentioned values advocated by the IL framework. Looking at the IL ideology and the principles governing UPA, these seem to be developed with an adult user group in mind (Ratzka 2012) with little attention given to children and young persons (Axelsson 2015; Jenhaug & Askheim 2018; Skär & Tam 2001).

This article is part of a research project focusing on UPA for children and young persons under the age of 18 in Norway. Through qualitative interviews with two cases, each consisting of the leader of the young persons’ UPA (in our project this was, in both cases, a parent) and the children/young persons who received the arrangement, complemented by pictures taken by the families over a three- to six-month period, our ambition with this article is to discuss the following:

Are the core values of the IL ideology as a foundation for UPA sufficiently adapted to the reality in which children under the age of 18 live their lives?

The purpose of this paper is not to state any general tendencies regarding how UPA is applied or utilised within families per se. Rather, this article seeks to illustrate empirical examples of potential issues that may arise when applying an ideological framework intended for adults with physical impairment, capable of leading their own arrangement, onto a childhood context. UPA has the potential to increase autonomy, integrity, influence and participation for adults with disabilities (Wadensten & Ahlström 2009). However, the values in the IL ideology intended to increase autonomy, integrity, participation and more, such as de-institutionalisation, de-professionalisation and self-representation (Ratzka 2012), may create challenges related to families where the child has UPA. This is because these values, as will be elaborated more in-depth below, do not necessarily conform directly to the idea of childhood and parenting.

UPA IN A SCANDINAVIAN CONTEXT

The Norwegian policy on UPA is similar to that in Sweden, where children and young persons under the age of 18 are covered by the same legislation as adults (NOU 2021: 11; LSS § 1 and 9, 1994). However, Sweden is considering moving away from offering UPA as a welfare service to children and replacing it with alternative services (NOU 2021: 11). Despite UPA being an arrangement that exists in all three Scandinavian countries, it is only in Norway and Sweden where persons under 18 have access to UPA (Norwegian Ministry of Health and Care Services 2020; LSS § 9 1994; Serviceloven § 95 and 96 2021). In Denmark, there is a strong emphasis on the notion that the person who receives personal assistance must also be able to manage their own arrangements, meaning in principle that minors are excluded from having their services organised as UPA (Serviceloven § 95 and 96 2021; NOU 2021: 11). There are also differences between the Scandinavian welfare states concerning how UPA is defined within the respective nation’s legal framework. In Norway, UPA is defined as a health and care service, whilst Sweden and Denmark define it as a social service. This implies differences between the countries regarding which needs UPA is intended to cover.

When UPA was introduced in Sweden and Norway in the 1980s and 1990s, the arrangements in both countries were firmly rooted in the IL ideology, whilst in Denmark the arrangement was argued to be both strict and paternalistic. In recent years, however, Askheim, Bengtsson and Richter Bjelke (2014) have argued that there has been a shift, where Denmark has gradually moved towards a more liberal interpretation of UPA by providing more control to the user, whilst in Norway and Sweden local and state governments have sought to attain more control over how UPA is organised.

UPA, when introduced, was intended to represent a radical alternative to existing services for people with disabilities. Instead of an external actor (i.e., the government, the municipality or private companies) controlling how, what and when the person receives assistance or care, UPA seeks to transfer this power to the person in need of assistance. Thus, rather than be treated as passive recipients of health and care services, people with UPA would instead be provided with the power to decide for themselves when they wanted assistance, what they wanted to use their assistance for and who the assistants would be (Norwegian Ministry of Health and Care Services 2015). Thus, self-determination is one of the multiple core values that UPA seeks to achieve on behalf of those who use the arrangement (ULOBA 2018). NPM and free consumer choice imply a certain understanding of freedom and self-determination, where it is suggested that people have the capacity to experience full freedom and exert full autonomy in their own lives (Ratzka 2012; ULOBA 2018). This view stands in contrast to the social model of disability, which could be used to argue that choices and decisions are influenced by the structures surrounding the individual (Oliver 1990).

Utilising user control and self-determination through UPA, as emphasised in the IL ideology, requires the ability to choose and make conscious decisions about what is in one's best interests (Snipstad 2018; Wehmeyer & Garner 2003). Self-determination and user control are closely related to one another as both refer to the control people have over major and minor decisions in their life (Ratzka 2012; Smith, Morgan & Davidson 2005; ULOBA 2018). There are, however, potential issues between how UPA and IL define self-determination and the reality in which children and young people under the age of 18 live their lives. Children are subjected to certain social restrictions that affect their ability to be self-determined, such as legal age limits that prevent them from making certain choices and family members who may choose to inhibit decision-making alternatives. Further, the ability to choose what is in one's best interests also relates to the experience of choosing, where choice could be considered to represent the ongoing interactions between individuals and the multiple environments they are subjected to (Abery & Stancliffe 1997). This implies that the ability to become self-determining is not a static state, as appears to be suggested by IL, but rather a process where self-determination competence is practised through gradual trial and error. The ability to choose is not only a question of cognitive capacity. In order to choose what is in one's best interest, one must become familiar with the variety of available choices and have gained experience in predicting their potential outcomes. A child, who lacks life experience, might not know which decisions are beneficial and thus may need adult supervision and guidance in the process of making decisions on their own behalf (Palmer et al. 2013).

Further, the UN Convention on the Rights of the Child (UN 1989: preamble) states that children are to be provided with the right to exert independence, autonomy and freedom. However, the Convention also states that children 'because of their age and considered immaturity are in need of extra protection and safeguard' (UN 1989: article 12). The UN Convention illustrates that at least two approaches to childhood need to be considered. Qvortrup (2009) argues that these approaches relate to the view of children as 'human becomings', where they are viewed as cognitively unready to utilise independence to the same degree as adults, or 'human beings', which underpins their right to independence, self-determination and freedom. Regardless of whether one views the ability to choose as a social skill or an innate feature, UPA for children and young people does complicate the ambition that the arrangement should provide full 'user control' and thus enable the person to be a fully self-determined and independent agent, since children and young people are often restricted by legal, normative and developmental barriers.

DE-INSTITUTIONALISATION AND DE-PROFESSIONALISATION

IL claims that people with disabilities need to be freed from institutions controlling their lives, which here refers to externally organised health care services provided at a physical institution or at people's homes (Ratzka 2012). With the person no longer dependent on a centralised service provider, the intention is that the person receiving UPA is provided with both power

and responsibility to make independent choices concerning what is in her/his best interests. Replacing institutions, i.e., traditional health care services, with free consumer choice reflects the neo-liberalist aspect of UPA (Askheim Bengtsson & Richter Bjelke, 2014). However, this causes potential issues when applied to children. Firstly, one can argue that the IL ideology has a rather narrow definition of institutions. It seems that the IL movement mainly refers to health care services when arguing in favour of de-institutionalisation (Ratzka 2012). However, what seems to be lacking in the IL definition in relation to the present is an acknowledgement of the family as a relevant institution. This is important because it might have consequences regarding how independence and freedom are understood and utilised. Perhaps more concretely, as there are different actors involved in the UPA/family institution (the child, the leader/parent and assistants), there might be a variety of perspectives that need to be taken into account, and these may affect how independence and freedom are exercised within UPA for children and youth. When translating the IL ideology to fit the framework of UPA to children, a potential paradox emerges in cases where the person formally in charge of the arrangement has a double role because (s)he is also a parent. Further, this point also appears relevant in relation to the IL ideology's argument of de-professionalisation, i.e., 'External actors, public nor private, should not control the lives of people with disabilities' (Ratzka 2012). Children/youth who are not formally in charge of their own UPA are in fact dependent on external actors in order to receive the arrangement in the first place as well as negotiate how it should be organised. Thus, it does not seem that the core values of IL ideology have been sufficiently adapted to UPA organised for children. Secondly, as a result of being a 'contradictory ideological hybrid', UPA emphasises the importance of consumer choice (Askheim et al. 2014; Bonfils & Askheim 2014), meaning the freedom to decide when to receive assistance, what the assistants should be used for and who they should be. However, there is one important question that appears to be overlooked in relation to UPA for children and youth: for whom is consumer choice intended—the child, the leader or both?

THE FAMILY INSTITUTION: APPROACHES TO PARENTING AND PARENTS' DOUBLE ROLE

As mentioned above, when UPA is arranged for children, it is often a parent or close relative who functions as the administrator/leader. In contemporary society, a parent is perhaps not to the same degree as before expected to be an authoritarian figure who demands respect and obedience from their children. Instead, norms regarding upbringing seem to expect that parents choose an authoritative approach, one characterised by a willingness to negotiate and be responsive to the child's needs (Baumrind, Larzelere & Owens 2010; Foros & Vetlesen 2015; Ulferts 2020). UPA, organised around the perspective of user control, self-determination, independence and freedom seems, to a degree, to support this idea of parenting (Askheim, Bonfils & Hugemark 2014; Pelka 2012; Ratzka 2012). UPA might conflict with parental approaches where parents take a more authoritarian approach. In contrast to an authoritative approach, parents using an authoritarian approach would generally place high demands on their child without being responsive to the child's needs, and would lack flexibility and be unwilling to negotiate on the rules their child has to follow (Baumrind, Larzelere & Owens 2010; Ulferts 2020). Here UPA might be viewed as a threat to the authority of the parents as it will challenge many of the mentioned values present in the IL ideology.

Further, it appears that UPA, as it is organised for children and young persons, also complicates the IL ideology's perception of the person as the foremost expert in their own life (Ratzka 2012). Thus, UPA organised in this way can come into conflict with the full self-determination and user control that the IL ideology advocates for because the parent/leader of the arrangement might have perspectives that differ from their child on what constitutes a beneficial choice for their child/youth (Axelsson 2015). In addition, since there is often a parent formally in charge of the arrangement, it may also create a conflict between the different roles this person has. For example, parents who are leaders in their child's UPA must balance a double role. On the one hand, they are leaders and administrators of UPA and are thus expected to ensure that the user benefits from the principles of user control and self-determination. On the other hand, however, they are parents that are expected to protect and care for their children, thereby ensuring that no harmful decisions are made.

The data in this study were collected using qualitative semi-structured interviews combined with photovoice. The fieldwork consisted of two cases. Each case involved a person under the age of 18 who had UPA and the person leading the arrangement. In both cases, the leader was the user's mother. The children/young persons in the two cases were at the time 16 and 17 years old. Both written and oral consent were obtained from the child and their parents. Invitations to participate in the study, accompanied by a letter of consent, were distributed through user-organisations and organisations facilitating for UPA in Norway. The letter of consent was signed by all participants, which included the parent/leader of the arrangement and the child with UPA. In order to ensure anonymity, the declaration of consent was addressed directly back to the researchers. This ensured that the researchers had no knowledge of who had received the invitation to participate. In the same way, the organisations that distributed the invitation letters had no insight into who had agreed to participate in the project. Oral consent was obtained from all participants at the beginning of both the first and second interview, and they were also provided with information about the project, their freedom to withdraw their consent, the option to skip any questions experienced as being intrusive or unpleasant, and their right to anonymity. The researchers made sure that this information was addressed both to the child and their parents.

Two interviews were conducted in each of the two cases. The time between the first and the second interview was, in Case A, approximately three months and, in Case B, approximately six months. All interviews lasted approximately one hour. Due to the ongoing COVID-19 pandemic, some adaptations were made when conducting the interviews. One interview was conducted with both researchers present at the informant's home. In two other interviews, one researcher was present whilst the other participated digitally. Finally, one was conducted digitally with neither of the researchers physically present. All interviews were conducted in the participants' first language, which was Norwegian. The data material was translated from Norwegian to English by the researchers afterwards.

The decision to have both the child and the parent present served different purposes. Firstly, this article is concerned with family institutions and the everyday lives of families with a child who receives UPA, and it was therefore crucial to gain voices from different actors in order to identify the variety of values, perspectives, experiences and so forth that might be affecting the arrangement. Secondly, having the parent present was also considered necessary for practical reasons due to the children's impairment. One child appeared to have some difficulties comprehending some of the questions asked by the researchers whilst the other had verbal impairments that caused the researchers some difficulties when trying to interpret her answers. In the first case, the parent played an important role as mediator where she would assist her child in understanding the researchers' question by rephrasing it or trying to make her child remember situations or contexts relevant to the question asked. In the second mentioned case, the mother served as a translator in cases where it was difficult to understand the child's answers.

There are some potential ethical issues arising from having a parent present during the interviews. Cuskelly (2005) argues that the power imbalance that occurs when studying children with disabilities is often greater than when studying children in general because they are often more dependent on external actors. We made various efforts to ensure that the presence of parents did not affect the answers given by the child. For example, the child with impaired verbal language skills was dependent on her mother to translate in order to communicate her perspectives. The researchers were aware of this issue during the interviews, and continuously made efforts to direct questions intended for the child to her alone. In addition, in cases where the mothers translated or in other ways spoke on their child's behalf, we asked both children whether they agreed with the answers given. In the interview guide, we also tried to make a clear distinction between the questions intended for the parent/leader and the questions intended for the child receiving UPA. Despite our efforts, we also acknowledged that the mere presence of parents did have potential impact on the child's answers.

At the end of the first interview, informants were provided with an iPad and were asked to go out and take pictures of their everyday lives. The second interview was structured around Wang and Burris's (1997) photovoice methodology. Photovoice has a number of benefits when

applied in research on the lives of children (Abma & Schrijver 2020) and persons with intellectual disability (Povee, Bishop & Roberts 2014). Photovoice can be an empowering tool because it enables the participant to have more control over the data collection process (Abma & Schrijver 2020; Povee, Bishop & Roberts 2014). The participants in our study both selected the motif and chose which pictures should be included in the second interview. In addition, photovoice can promote inclusion and accessibility, as conversing over a photo creates a concrete reference point for the conversation, thus reducing the demand for abstract thinking and reasoning often associated with traditional interviews (Ellingsen 2010). This methodology proved beneficial in both cases, as the pictures provided a relevant context which assisted in communication and reduced the aforementioned communicative barriers between the researchers and the young persons with UPA.

Based on the work of Wang and Burris (1997), the study applied photovoice as follows:

1. **Selecting**—allowing the informant to choose which pictures most accurately reflect important aspects of their life: The informants were asked to choose five to ten of the pictures that they had taken. During the second interview, they were asked to elaborate on what they had taken pictures of, such as who/what were in the pictures, and what they were doing.
2. **Contextualising**—asking the informant to tell stories about what the selected pictures mean to the informant. In this step, the informants were asked why they had chosen the photos they decided to show us, what was going on in the pictures, why they had taken these pictures, and what was taking place before and after each particular picture was taken.
3. **Codifying**—identifying together with the informant those issues, themes and theories that emerged from contextualising the selected photographs. Here the participants were asked to share their thoughts, perspectives, experiences, etc., concerning what was taking place in the pictures (Wang & Burris 1997).

The idea of combining traditional semi-structured interviews with photovoice is that the analysis begins together with the informants who share their interpretations of the pictures they take (Wang & Burris 1997). The themes that occurred when discussing the pictures were further analysed using a thematic case study analysis as presented by Creswell (2013: 190–191). This analytic approach consists of six steps that progressed as follows:

1. **Data organisation:** The transcripts from the interviews were sorted into separate files and imported into NVivo for further analysis.
2. **Reading and memoing:** The researchers read the transcripts from start to finish. Initial notes on potential themes were written down.
3. **Describing and organising the data into themes and codes:** Codes were developed based on the issues, themes and theories that emerged from the informants' answers and from topics that emerged during the process of reading through the data material.
4. **Classifying the data into codes and themes:** Text sources were placed into different codes that were established in step three. The same coding scheme was used for all interviews in both cases.
5. **Interpreting the data:** The codes were here compiled under broader themes such as independence, user control, self-determination, self-representation and more. Those mentioned here were considered especially relevant for this article.
6. **Representing and visualising the data:** The data included in this article are represented in ways that resemble the themes mentioned under step five, which are further operationalised in the results section under the headings 'Independence' and 'User control and self-determination'.

The child in Case B had impaired language skills, and some of the sound recordings were unintelligible. In the results, we have marked with parentheses those places where it was difficult to understand what the child said, i.e. (...).

The study has been approved by the Norwegian Committee on Research Ethics (NSD).

INDEPENDENCE

In Case A and Case B, both the mother (leader of the arrangement) and the child appeared to advocate independence as a core value that they wished to achieve through UPA:

Mother A: You (the child) think that it is important that you get to choose where you want to live?

Child A: Yes, I am very determined.

The mother in Case B shared similar views with the mother in Case A, claiming that UPA enables her child to get a job during the summer and to get her own flat when she turns 18, and it provides her with the opportunity to hang out with friends without the need for her parents to be present. To live independently from her mother was mentioned as important by the child in Case B as well:

Child B: It [UPA] makes it so that I can live alone. ... If I want to spend time with friends, my mum does not need to be present. When I [eventually] move out ... it will be very nice to be able to do things without having to be together with my family.

There do, however, appear to be some differences between the two mothers regarding how to provide possibilities for their children to live independently. The mother in Case A seemed to view a gradual reduction in UPA hours as a means to accomplish the goal of independence. In relation to this, assistants appeared to play an important role in developing the child's independence, thus also gradually preparing the child for a life without UPA:

Mother A: I think that the UPA arrangement should contribute so that she [the child] would need less assistance after each year, so we would reduce the number of hours [of assistance] each year. In our case they [the assistants] are not called assistants, they are called 'independence developers'.

Though sharing the same value of independence, the mother in case B had a different perspective on how they would accomplish independence through UPA:

Mother B: When she moves into her own apartment, we will apply for assistance 24 hours a day and then she would be able to travel a lot. It would become a completely different equation.

Though more apparent in Case B than Case A, both parents seemed to share the goal of enabling their child to live as independently as possible once they reached adulthood, and UPA was viewed as an important tool in that respect. In Case A, the mother said that the child was, among other things, practising taking the bus alone. However, before she would be allowed to travel by herself, she had to first practice together with one of her assistants.

Regarding Case B, the preparation towards an independent adult life appears to be a significant part and function of their UPA. The stated ambition from both the parent and the child is that the child will move into her own apartment after turning 18. In addition, they are gradually preparing a transition of power, where the child will eventually take formal responsibility for her own UPA. As part of this process, the mother gradually provided the child with more tasks related to hiring assistants and scheduling at what times she would like to receive assistance:

Researcher: How do you [the mother and the child] divide tasks and responsibility ... how are decisions made?

Child B: We are often together [in decision-making].

Mother B: When we are hiring new assistants, she [the child] always takes part and we discuss together and, well, really she decides. ... She sends messages herself if she wants to make changes to the assistants' work schedule. ... She has become quite good at, well, running these things herself.

The mother in Case B appeared to view the opportunity to enable her child to practise leadership in her own arrangement as a vital step towards becoming gradually more experienced in leading her own UPA:

Mother B: I gradually give her more tasks where she must reflect about things. For example, if we, if she is going to send a text to an assistant, we can discuss what she has written in the message, you know, what questions did they [assistants] have, what questions did they not have. I am trying to prepare her [daughter] to start thinking by herself how and in what way she needs to run the arrangement.

Gradually providing the daughter with more responsibility appears to relate to the above-mentioned ambition of one day moving out and running her own arrangement:

Mother B: The intention is that, when she, well she is very prepared to move when she turns 18 and get her own place. Then the intention is that she will be, that you become the leader of your own assistants.

USER CONTROL AND SELF-DETERMINATION

In both cases, there was a tendency for the mother to speak on their child's behalf. It did not become explicitly clear why the mothers tended to do so, but it seemed on occasions that the reason for this might be to 'fill in' the gaps or elaborate on the child's answers to compensate for impaired verbal language. For the child in Case B, the mother's elaboration and translation of the child's statements received fewer objections from the child as opposed to when the mother in Case A intervened or made claims on behalf of her child.

Mother B: it is not always easy to understand [the child]. If that is the case, she won't be mad or anything if you just ...

Researcher: If you help us to.

Mother B: Translate.

The quote above is an example of how this family communicated throughout the interviews. At no point during the two interviews did the child display discomfort with this way of communicating. In contrast, the child in Case A, appeared to often resist or disapprove of her mother's attempts to intervene or elaborate on the discussion, and the child seemed more determined to answer the questions herself. Two examples of this, illustrated in the following quotes, occurred when the child was asked about what she usually does together with the assistants:

Child A: I work with homework, yes, generally homework. ...

Mother A: And you [the child and the assistant] are preparing food.

Child A: Hush.

Mother A: you [child and assistant] are often on walks, and you often go to visit [assistant], you work out and you relax when you are over at [assistant] during the weekends.

Child A: Hush.

Regarding tensions or disagreement between the child and the mother/leader of the arrangement, there were also instances where the child and parent seemed to have different desires regarding how often assistance should be provided. This was most apparent in Case B. In this case, the mother argued that she was not overly fond of having people from the outside coming into her home and explained that she found this stressful. However, she also said that her daughter was very social and outgoing and claimed that if it were completely up to her daughter, they would have far more assistance at home:

Mother B: to have assistants come into your home, I do think that is ... I don't know if it is because I have been tired or if it is just me, but I almost can't stand having people in our home. [child] is very social and want things to happen around her. She is young, you know. It's been a, well, I think it has been difficult.

This is also underpinned in the second interview with the same family:

Researcher: Last time we talked, we talked about how it is to have assistants present in the house. How do you [child and parent] feel about this now? ...

Child B: For me it is no problem, but it is more difficult for ...

Researcher: Can you relate to this, mother?

Mother B: I notice that it is important for [child], but I think it is exhausting to have... I think it is exhausting to have multiple people around me that I need to 'raise'. In addition, I always need to have a clean home. ... Yes, I am tired of having people around me, I am, I am the kind of person that prefers being alone. So, it is incredibly exhausting, but I manage. I will manage a while longer.

Child B said that if it were up to her, she would prefer more hours of assistance: 'I want more, I want a few more hours each month.' The mother seemed to acknowledge this but stated that 'I cannot have people here 24 hours a day.'

The mother in Case B seems to struggle with the tension between her own preferences regarding how much time she feels comfortable spending with the assistants present in her home and her daughter's opportunity to receive the amount of assistance that she wants:

Mother B: She [child] does wish that things were better in regards to me having assistants here because me being tired also affects her [child]. ... We are negotiating things. I've said, you know, weekends are family time, but I think that, now that we have been together for the whole weekend it impacts on the atmosphere/energy here negatively.

Child B: Yes.

Mother B: Because she needs assistants, and I see that, and, yes, it is difficult being together [mother and child] without them.

Child B: I want more. ...

Mother B: Yes, she [child] wants more but she knows that it is not possible.

In Case B, there appeared to be a very clear difference in preference concerning UPA, i.e., regarding how much the assistant should be present in the everyday life of the child when at home. However, both the child and the parent seemed confident that this disagreement would be solved once the child moved into her own flat.

Regarding Case A, they did not report any major disagreement concerning how they would run the arrangement in a way that maintained the interests of both the child and the mother. However, the mother shared some reflections concerning the double role that she had as both a mother and a professional leader, in relation to both the child and the assistants:

Mother A: What has been a dilemma up until recently is that I am both a leader and a mother being present at the assistants' workplace and that can cause some insecurity. We also travel to summer-school in [anonymised place] you know, where the assistants live together with us. They have their own room and everything, but they are still present there. In this case, I am a mother and that is very, you know, we have an agreement about what is going to happen in advance, and we have briefly talked about things that, in a way, could turn out to be difficult. ... In these cases, I think that the responsibility as a mother is closely connected with being responsible for the arrangement. You know, [the child] having a drinking party [translated from the Norwegian phrase 'rølpfest'] is not within the Working Environment Act.

DISCUSSION

The results presented in this paper seem to illustrate the claim that the IL movement's ideological framework does not sufficiently translate to UPA as an arrangement provided to children and youth under the age of 18 in Norway. By restricting the definition of relevant institutions to traditional health and care services, rejecting any form of external actor's influence upon the arrangement and demanding full user control, self-determination, independence and freedom on behalf of the user (Ratzka 2012) does not appear to reflect the reality in which children and youth find themselves. However, the informants in this study appear to have adapted some of the principles in the IL movement's ideological framework in order to make it function within their family institution. This suggests, as will be further discussed below, that even though UPA

seems to have the potential to play an important role in the inclusion of children with disabilities in society, both at present and in the future, we argue that the ideological framework needs to be adapted by keeping a 'wider' user group, i.e., children, in mind.

THE FAMILY INSTITUTION

The double role that parents have in relation to their children when they also function as an administrator/leader in their child's UPA was demonstrated in both cases on an explicit and also seemingly implicit level. The mother in Case A argued that she was aware of the potential insecurities that being both a mother and a leader could cause and stated that it was not always easy to separate the two roles. On a more implicit level, she argued that having a party involving alcohol was unacceptable as it was not within the Working Environment Act. Though this might be the case, it can also be argued that ensuring that your underage child does not consume alcohol is part of the protective role one is expected to have as a parent. In Case B, the mentioned double role was perhaps most evident in the feeling that the mother shared towards having assistants present in their home. On the one hand, she appeared to acknowledge that having assistants was important for the child, but on the other, she claimed she struggled with having external people in her home. Consequently, she even occasionally overruled her child's preferences by saying that she does not allow assistants to be present on weekends. The issue raised by the mother in Case B is relevant in relation to acknowledging the importance of family institutions when it comes to UPA organised for this group. Similar discussions are also present in Axelsson (2015), where the author argued that the preferences of parents or other family members affects the opportunities that the receiver of UPA has regarding when and where they wish to receive assistance. Hence, it underpins the argument that it is important to take the family institutions into account when discussing children's possibilities to apply the core values advocated in the IL ideology in their everyday life with UPA.

The parents in both cases appear to take a somewhat authoritative approach to their children. Despite sometimes appearing to mix their roles as a parent and as a leader, and occasionally choosing to overrule their child's preferences in favour of their own desires, both parents seemed to be responsive to their child's needs and willing to negotiate and explain their position to their child (Baumrind, Larzelere & Owens 2010; Ulferts 2020). Viewing this in light of the IL ideology and neo-liberalist perspective of personal independence (Askheim et al. 2014), it seems that neither an authoritarian nor an authoritative parenting approach is directly translatable to the personal independence, freedom and full user control advocated by the IL ideology and mediated through UPA (Pelka 2012; Ratzka 2012). However, of the two approaches, an authoritative parental style appears to work best in relation to the IL framework. This is because parents who are responsive yet demanding and willing to explain their position to and negotiate matters with their child seem able to maintain their protective and caring role as parents whilst at the same time empowering the child to enjoy a degree of user control, self-determination and independence (Baumrind, Larzelere & Owens 2010; Ulferts 2020).

PREPARING FOR INDEPENDENCE

The ambition of this paper is not to question the values of the IL movement. The quest for independence, freedom and self-representation has been vital in relation to inclusion in society for people with disabilities (Barnes 2012; Oliver 1990; Ratzka 2012; Shakespeare 2014; UPIAS 1975). However, this article relates to how these aforementioned important values can be adapted in order to encompass the wider group of people currently qualified for UPA in Norway (Norwegian Ministry of Health and Care Services 2005). In the current IL framework, there seems to be a discrepancy between how independence, self-determination and freedom are expected to be utilised by the user and the reality of how children and youth live their lives. Part of this issue relates to the family institution and norms about childhood in society, where it is not solely up to the child to decide what, how and when the arrangement should be used.

In examining the results and the parental approach that appears to be present in the two cases, these mothers seemed to have adapted the principles developed by the IL movement. By combining their role as a mother with the role as leader, these families seem to use UPA as a tool to practice independence competencies. This means that full user control, freedom, self-determination and independence are not things that are necessarily practised to the full

extent at present but instead something that UPA could help achieve for the child in the future. For example, the mother in Case A claimed that they defined assistants as ‘independence developers’, implying that the core function of the assistants was to support the child towards becoming gradually more independent. The mother in Case A exemplified this by describing how her daughter practised taking the bus with her assistants with the ambition that she would one day be able to do so herself. The mother in Case B seemed to hold the same view by claiming that she was gradually providing her child with more tasks and responsibility with regard to managing her own arrangement, with the end goal that her child would one day move into her own flat and lead her own UPA. However, the parents in Case A and B had different perspectives on how independence was to be achieved, where one claimed that independence meant gradual reduction in the need for assistants whilst the other argued in favour of more hours for UPA. Despite this, it appears that through an authoritative parenting approach, where the role as a caregiver and protector is combined with negotiation, sharing responsibility and so forth, both parents chose an alternative strategy with respect to independence that is slightly different from the intentions communicated in the IL ideology.

CONCLUSION

The main research question discussed in this article is as follows:

Are the core values of the IL ideology as a foundation for UPA sufficiently adapted to the reality in which children under the age of 18 live their life?

Based on the results, this article has discussed how two families appear to have adapted their UPA in order to make the core values of the IL movement, such as independence, work in combination with caring for the child and ensuring that they do not make unwise or inexperienced choices in life. In order to discuss this, the article has focused on whether the formulation in the IL ideological framework as a foundation for UPA sufficiently includes minors with disabilities. The findings in this study provide a useful starting point for further research into how UPA could be successfully implemented in the life of children with disabilities.

The core values of IL as they are presented through the works of Ratzka (2012) and Dejong, Batavia and McKnew (1992) emphasise de-institutionalisation, de-professionalisation and self-representation. As IL constitutes the ideological foundation for UPA, it is perhaps no wonder that the arrangement in both Norway and elsewhere was initially intended for an adult population capable of leading their own arrangement. This, in turn, seem to have created a rather narrow definition of what is considered to be a relevant institution, consequently overlooking family institutions which are undoubtedly important when discussing UPA as an arrangement for minors. Family institutions do in fact inflict limitations and restrictions on the life of children and youth, which ultimately hinder them in utilising independence as defined by the IL movement. The same is also true with other IL values, such as de-professionalisation and self-representation. We do agree with and acknowledge the fundamental rights of children with disabilities to state their opinions and influence matters concerning them, as stated in the CRPD (UN 2006, article 7-3). However, research suggests that parents, in addition to being responsible for their child’s needs and wishes, must also be able to set clear boundaries on behalf of their child. Thus, there are limits concerning the degree to which all children and youth can be freed from control by external actors, which in turn impacts their ability to represent themselves and be independent.

That being said, UPA is an arrangement that represents something fundamentally different from traditional health and care services provided to children and youth, and it does seem to contribute with increased possibilities for people with disabilities to participate in society. However, relatively few children and youth receive UPA in Norway compared to other age groups (Jenhaug & Askheim 2018; ULOBA 2018; NOU 2021). Therefore, asking what it would take to increase the number of children and young people receiving UPA is an important question. As the current formulation of the core values of the IL ideology does not seem to sufficiently reflect the situation of children and youth, it may cause state and local authorities to be reluctant to present UPA to families. Parents themselves may also be reluctant to apply for UPA on behalf of their children because they might consider it too difficult to combine the principles advocated by the IL movement with the expectations that follows from being a parent.

More research is needed to present concrete suggestions for how the IL framework could be reworked to better encompass children and youth. However, when these core values are to be translated to a user group consisting of minors, the uniqueness of the structures influencing their life, such as the family, need to be taken into account. One potential way to go about this is to view independence, de-institutionalisation, self-representation, user control and freedom as *processes* where the child develops towards gradually becoming more independent, rather than as a state that the individual should benefit from in the present. Thus, it might perhaps be that assistants in UPA for children are not merely assistants but also ‘independence developers’.

COMPETING INTERESTS

The authors have no competing interests to declare.


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TO CITE THIS ARTICLE:

Snipstad, Øyvind Ibrahim Marøy and Stine Vik. 2023. "User-Controlled Personal Assistance for Children— Does the Independent Living Ideology Translate to the Lived Life of Children and Youth with Disabilities?" *Scandinavian Journal of Disability Research* 25(1):363–377. DOI: <https://doi.org/10.16993/sjdr.931>

Submitted: 27 April 2022

Accepted: 26 October 2023

Published: 24 November 2023

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Scandinavian Journal of Disability Research is a peer-reviewed open access journal published by Stockholm University Press.

