

## RESEARCH

# Empowering Parents as Co-producers: Personal Assistance for Families with Disabled Children

Line Jenhaug and Ole Petter Askheim

Inland Norway University of Applied Sciences, NO

Corresponding author: Line Jenhaug ([line.jenhaug@inn.no](mailto:line.jenhaug@inn.no))

Personal assistance (PA) is seen as an important tool for empowerment, independence and participation for disabled people, traditionally for adults. In Norway, PA was extended to families with disabled children in 2006, but the extent so far is modest. The change meant that the parents could act as managers for their children's assistants. A central issue in this article is to what extent co-producing PA with the municipality empowers the parents as family managers. The empirical basis is a study among Norwegian parents with disabled children who receive PA. The data indicate that PA makes parents feel more empowered and improves their control and coping. It also gives their children the benefit of both parental care and increasing independence. However, in the decision-making process of granting and following up PA, the parents also experience that they are not regarded as equal co-producers by the municipal services.

**Keywords:** empowerment; co-production; personal assistance; disabled children

## Introduction

The empirical background for the article is a qualitative study among parents with disabled children in Norway who received personal assistance (Jenhaug 2014). Personal assistance (PA) is a result of initiatives and struggles among disabled people to achieve empowerment, independence and the right to participate in society on equal terms to those of non-disabled people (DeJong 1983; Barnes and Mercer 2006; Glasby and Littlechild 2009). From its origin in the United States in the early 1970s (DeJong 1983), personal assistance has diverse versions, and today it is established in most European countries (European Network on Independent Living 2013). PA is mainly developed as a scheme designed for disabled adults. A main reason was the rationale behind PA: the users should have optimal influence and control over the arrangement. Consequently, they should be at an age where they have the authority to decide over their own lives and how their services should be organized and implemented.

In some countries, PA is also available for families with disabled children. In these cases, the responsibility for managing the arrangement is transferred from the user to another person, typically the parents. If the parents did not have the benefit of PA, they would be dependent on assistance from other services, or they would have to take care of the children on their own. Because PA is a direct help for the parents in taking care of the children, the parents also become users of the service.

PA can be seen as co-production between the service users and the local authorities (Christensen 2016). With regard to families with disabled children, the direct communication with the municipal services is the responsibility of the parents, and PA mainly becomes a co-production between the children's parents (as the carers of the family) and the municipality.

Co-production is often closely connected to the concept of empowerment. Like empowerment, it expresses confidence in the users' resources and competence and confirms that they have assets that will improve the services. Needham and Carr (2009: 1) describes co-production as a 'potentially transformative way of thinking about power, resources, partnership, risks and outcomes', whereas Martin (2009: 286) presents the term in the following way:

Co-production seeks to go beyond an attempt to attune public services to the wishes of passive participants. Its aim is to empower users to take greater control over and responsibility for their lives.

In this way, co-production is described as a new way of thinking about public services with the potential to deliver a major shift in the way we provide health, education and other services (Boyle and Harris 2009). However, co-production is also referred to as a 'slippery concept' (Scourfield 2015: 544). Bowers and Wilkins (2012: 100) declare that 'as a

concept co-production is renowned for its “excessive elasticity” in terms of the ways in which it has been defined and interpreted’. Whether co-production will imply a transformation of power from the services to the users will therefore depend on how the term is defined and practiced.

If the disabled children are to achieve an optimal and inclusive development, as similar as possible to that of their non-disabled peers, it is important to examine if and how parents can be made capable through empowerment. We ask to what extent the parents can achieve these goals by being empowered as co-producers in the process of getting PA and when receiving PA on a daily basis.

## Background

### *Families with Disabled Children*

When PA is placed on the agenda as a scheme for families with disabled children, the main reason is that a disabled child often requires considerable efforts by the families (Helse- og omsorgsdepartementet 2005). Already in 1984, Ingstad and Sommerchild used the term ‘the disabled family’ to make clear that the birth of a disabled child had consequences for the whole family (Ingstad and Sommerchild 1984). A considerable number of studies document that the birth of a disabled child creates stress, health problems and a decreasing quality of life for the parents, and especially for the mothers (Fairthorne et al. 2014; Haugen, Hedlund and Wendelborg 2012; Cuzzocrea, Larcán and West 2013; Ansthele and Joseph 2006; Boström 2010; Norges Forskningsråd 2015). Parents, and especially mothers, often have to reduce their participation in ordinary working life (Lundeby 2008; Ridderspore 2003; Tossebro and Paulsen 2014).

As a main rule, the parents’ responsibility for the children’s adolescence is regulated in the Convention on the Rights of the Child, in Article 18 and Article 27 (UN 1989). When a child has an impairment, the parental autonomy is no longer so obvious because they have to adjust to the municipal services for support. Among the circumstances that create the most stress for the families are the relationships with the established services (Tossebro and Lundeby 2006; Lundeby 2008; Connors and Stalker 2003; Rogne and Hareide 2003; Rogne 2016). The parents experience that they have to fight to receive the necessary services and report continuing struggles, negotiations and tensions with the service providers over support and assistance. Parents often feel that they are left to themselves and have to find their own way through what they see as a complicated conglomerate of services (Kittelsaa and Tossebro 2014). They are critical to the thresholds and barriers they have to face and the degree of municipal willingness that is dependent on the attitude of the individual care workers.

To obtain the services, which they regard as the child’s right, the parents also often feel they have to emphasize the negative aspects of caring for a disabled child and to present themselves as victims, which they feel is an additional burden (Gundersen 2012). Some parents report a feeling of being suspected of using their child to swindle the welfare system. They experience implications that their care work is not valued and that their expertise as parents is not recognized (Murray 2000; Brett 2002). Flexible and family-centred support is seen as one of the strongest predictors for a family’s quality of life (Davis and Gavidia-Payne 2009). Dempsey and Dunst (2004) found that both the relationship with the helper and the opportunity for participation in the help-giving is important for the parental experiencing of empowerment.

When the children grow older, the parents’ role changes and creates other challenges for the families. Disabled adolescents will, like any other youngster, gradually wish to free themselves from their parents, and the parents will want more independent lives for their children. At the same time, these adolescents are in greater danger of being isolated because of lack of physical accessibility to arenas that their peers frequent and because of social stigmatization. Grue (1999, 2001) has found that disabled adolescents participated less in social activities and had more passive lives than their peers. Many disabled adolescents also expressed the view that the parents inhibited their development of independence by being present too much during their spare time.

### *PA for Families with Disabled Children*

The scope of the scheme is modest in the countries, which has opened up PA for families with disabled children. In the UK, PA (financed as direct payments) can be made for carers aged 16 or over, including people with parental responsibility for a disabled child.<sup>1</sup> However, the issue has received little attention from the local children services (Glasby and Littlechild 2009). In the Nordic countries, Sweden has no lower age limit for receiving PA. In 2013, 14% of the total number of PA users were children up to 14 years of age.<sup>2</sup> In contrast, Denmark and Finland have not opened their PA arrangements to children.<sup>3</sup> In Norway, PA is a municipal arrangement, regulated in the Social Services Act of 2000 (Helse- og omsorgsdepartementet 2000). Until 2006, PA was reserved for persons who were able to act as managers for their assistants. The target group was then extended to persons who were not able to act as managers on their own (Helse- og omsorgsdepartementet 2005). The government especially mentioned families with disabled

<sup>1</sup> <https://www.gov.uk/apply-direct-payments>.

<sup>2</sup> <https://www.forsakringskassan.se/wps/portal/statistik/funktionsnedsattning/assistersattning>.

<sup>3</sup> <http://sm.dk/arbejdsomrader/handicap/personlig-stotte/hjaelpordningen-bpa>. <http://www.finlex.fi/laki/ajantasa/1987/19870380>.

children as a group that could benefit from having their services organized as PA. In 2015, as few as 275 Norwegian children under the age of 18 had PA (SSB 2016).

Because the extent of PA for families with disabled children is small, there is also little research focusing on the experiences of PA for this group, and only a few studies have touched on the issue. Axelsson, Imms and Wilder (2014) have found that children with profound intellectual and multiple disabilities who received PA improved their participation in family activities. Some Swedish studies show that the families are mainly satisfied with the arrangement but also report problems and frustrations (Socialstyrelsen 1995; Olsson, Flygare and Roll-Pettersson 2012; Stenhammar 2006). The parents had to show considerable initiative and to invest great effort in order to secure the arrangement for their children, and some found it difficult to recruit good and supportive assistants. Some parents also report that they felt at times it was difficult to have the assistants so close to the family.

### ***Co-production as Empowerment***

The development of the theory of co-production in the public sector has taken two major directions. One has come from literature about the private sector (Alford 2009, 2015; Grönroos and Ravald 2011; Grönroos and Voima 2013; Osborne, Radnor and Nasi 2013; Osborne, Radnor and Strokosch 2016; Skålén et al. 2014; Vargo and Lusch 2008), and one has originated from public administration literature (Bovaird 2007, NESTA 2011; Needham and Carr 2009; Parks et al. 1981; Pestoff 2011, 2012). The traditions differ in their definitions. The private sector tradition defines co-production as a value creation taking place in the moment the employee meets the user in the service delivery. This co-production is implicit, and the grading of intensity has to do with the amount of contact. Literature developed from public administration tradition often includes other stakeholders as co-producers in addition to the service users, such as volunteers, the users' families and user organisations (NESTA 2011; Bovaird 2007). Planning the service is also regarded as co-production, and it tends to be more normative, grading co-production against the users' possibility of being an equal partner, or the degree of power sharing (Needham 2007; Needham and Carr 2009; NESTA 2011; Pestoff 2011, 2012). In this article, we lean on the tradition from public sector, which relates to co-production as a level of power-sharing, and where applying and planning in contact with the municipality is also considered as co-production.

Co-production is a term increasingly used in literature about welfare, and it is used in policy documents (Hunter and Ritchie 2007; Alford 2009). In Norwegian welfare policy, the term made its breakthrough in the Official Norwegian Report 'Innovation in the Care Services' [Innovasjon i omsorg] (NOU 2011: 11). Co-production is presented there as a main perspective for the development of the future care services. The perspectives are followed up in two white papers concerning care and public health in 2013 (Meld. St. 29 [2012–2013]; Meld. St. 34 [2012–2013]).

Needham and Carr (2009) distinguish between three levels of co-production in public services. At the lowest level, co-production is simply used as a *description* of how all services rely on some productive input from the users. This approach simply restates existing approaches to public services as co-productive, and it fails to acknowledge the potential for more effective uses of productive capacities among the users. At an intermediate position, Needham and Carr (2009) describe co-production as a tool of *recognition* for the people who use services and their carers, acknowledging their input, valuing and harnessing the power of existing informal support networks and creating better channels for people to shape services. This level of co-production offers a way of acknowledging and supporting the contributions of service stakeholders, although without necessarily changing fundamental delivery systems or the individual outcome. It is therefore a danger that it can be a device to legitimise existing approaches, helping people who use services to better understand the strains that providers face, rather than changing organisational cultures and improving service provision. Williams, Kang and Johnson (2016) find that these imbalanced power relations might lead to co-contamination, as a negative outcome from co-production. At the third level, which Needham and Carr (2009) describe as the most effective level of co-production, the approach involves a *transformation* of the services. The transformative level of co-production requires a relocation of power and control through the development of new user-led mechanisms of planning, delivery management and governance. It involves new structures of delivery that firmly establish co-production as a partnership, rather than simply ad-hoc opportunities for collaboration, and it brings service users and practitioners together in new ways. Needham and Carr (2009) thus emphasise the necessity of power sharing for obtaining quality in co-production for the users. The more empowerment to the users, the more quality in the co-production.

Even if definitions include family carers as co-producers, there has been little research on family carers' opportunity for empowerment in the co-production of public services. Pestoff (2012) has studied preschools and the opportunities for co-production for parents in different sectors, finding that both the public and the private sectors have a 'glass ceiling' that limits necessary power sharing, which is not present in the third sector (voluntary and non-profit organisations). He makes a distinction between what he calls co-production 'heavy' and co-production 'light', and he concludes that co-production 'heavy', which can be compared to Needham and Carr's third level, is only possible in the third sector. In this article, the possibility of empowerment in public sector will be examined further when discussing the parents' experiences with co-producing PA with the municipalities for their disabled children. The

co-production in this article takes place between parents and municipal case workers, and between parents and assistants.

### Methodology

The study is part of a wider examination of the municipal implementation of PA financed by the Norwegian Directorate of Health (Askheim et al. 2014).

A part of the study explored families with disabled children's experiences with PA and the process of getting the arrangement. The interviews took part in 2014, and eleven parents (four fathers and seven mothers) from nine families in five municipalities in Norway were interviewed. In this article, we analyse the empirical data within a theoretical framework of empowerment and co-production. We ask whether the parents experience the PA scheme as a tool for empowerment, making them more capable of supporting their children's inclusion and independence in society. The overall study was ethically approved by Norsk Senter for Forskningsdata (NSD; the Norwegian Centre for Research Data). The parents were recruited on the basis that they already provided PA arrangements for disabled children through the municipal department of granting services.

The criteria for participation were that the interviewees were parents or foster parents of children under the age of 18 who received PA, and that the children lived with them. The parents were recruited through a contact person in the municipality, and the willing parents then reported directly to the project.

Seven parents were interviewed in two groups of three and four, from two and three families, respectively. Four parents from four families in three municipalities were interviewed individually. The interviews were held in municipal locations, in a hotel or in the interviewees' home. The interviews were semi-structured, with an interview guide prepared in advance, and lasted between one and one and one-half hours. The issues concerned the parents' situation, how they considered the situation for the child and siblings, how they were able to take care of the child and their relationship with the municipal allocation office. Questions asked were, for example, 'Describe positive and negative aspects of being a manager for the assistants: How does PA influence own participation in paid work, and how do you consider the organising of PA?' The questions regarding the collaboration with the municipal caseworkers captured the interest among the parents, and they elaborated beyond the questions asked. All the interviews were recorded and then transcribed. The transcriptions were interpreted, categorised thematically and analysed further.

When analysing the transcriptions, the parents' focus made it natural to create two main categories, which were further categorized into subgroups. Translating the quotes from Norwegian to English was done by the authors of this article.

The families had children from two to 16 years old. Three children were in their teens; the others were younger. The children had a variety of impairments: physical impairments, neurological diseases and multiple impairments were represented, as well as both genders. To protect the children's confidentiality, the various impairments will not be described any further, their exact age will not be given and the gender will sometimes be changed. For the same reason, foster parents are also referred to as parents, and the parents' sex is sometimes interchanged. The parents are not referred to by name, but they are given an individual number in the citations, as parent number 1 to parent number 9 (P1–P9).

### Results

The parents' experiences take two directions, one concerning the daily running of PA and the other concerning the direct communications with the municipal allocation office. The first four headlines below refer to the daily running, and the last headline refers to direct communication when it comes to obtaining, maintaining and changing the arrangement.

#### *PA's Influence on Family Life*

Some parents explain the importance of being a 'family with a disabled child', and not a 'disabled family', to give the child a normal environment. The parents find PA important in order to be able to live a near-normal life and to get the opportunity to give their children the required parental care. For some families, PA helps to avoid conflicts between siblings, and it helps the parents with the extra tasks involved in running the household. The parents provided examples by presenting everyday situations:

P1: Now we can invite other people for dinner. When he gets ill, we can still eat like a family, and he can join us for a little while. Without PA, we have to invite people after he has gone to bed. Now he can take part in a normal family life in the way he can.

The assistants also help the families by directly taking care of the child or the siblings:

P2: Sometimes he only wants to stay with us, and then it's a good thing that the assistant can help the siblings with their homework, go out or go to the cinema with them.

When the families take part in activities, and the child or the adolescent wants to stay at home, he or she can stay with the assistant, and the trip can continue as planned with the siblings. One family has brought the assistant to a wedding, so that the child could also come. Some have brought assistants for holidays because it was the only way to be able to go as a family. As one mother summarises:

P3: Quality of life, dignity, the possibility of love, respect, warmth and family. That is what PA provides the opportunity for. It creates fewer conflicts. It makes it possible to have a family. And it makes it possible for the child to stay more at home than he could otherwise. He can be a part of the family.

When they have assistants in their homes, families naturally lose some privacy. Some parents say that at times, it can be strenuous to have the assistants so close to the family. Still, this is seen of minor importance because their children can now remain at home with their families. Some parents say that the most important factors to make PA a success are that the parents get along well with the assistants, and that they are able to trust them. The possibility of taking part in the hiring process can ensure this.

### ***Parents' Participation in Employment***

For these parents, a part of being a normal family is to be able to choose to work. Despite the fact that managing PA can be demanding, all the parents in the study agree that their participation in employment has increased since their child was granted PA.

In one family, the father stayed home for a period. In the first years, he received a cash benefit for care. However, when the family received PA, he began to work full time. One father said that when they were only offered respite care for their teenager, they opted out of employment for the mother in order to be able to help the child at home. As the father says:

P4: So it is obvious that a PA arrangement is necessary for us to remain in employment, when institutions would otherwise be the alternative.

In one family, both parents work full time, which they say is only possible because they can use PA for after school care.

Even if the parents work more with than without PA for their child, some wish for more assistance in order to be able to work more. A father says that both parents have higher education, but they cannot work full time because they do not receive enough PA. One of the mothers who has recently begun working would dearly like to work more, but she finds it difficult to get extra PA for the mornings.

P5: And who is the losing part? It is the family. Mother gets less income, Mother is a little unhappy because she would want to work more, but she is not able to.

The amount of assistance is thus important to be able to work as much as other parents can.

Another family is only granted PA as night watch, but the child is now healthier at night, and they would rather have assistance during the day in order to have better opportunities to take part in work.

Some parents have an arrangement at work that enables them to count sick leaves hour by hour so that they can participate in their children's appointments, such as training and therapy. They reckon that if they had more assistance, the assistants could participate more in these activities, and the parents would be able to spend more time at work.

### ***The Managerial Role***

The parents' role as managers for their children's personal assistants includes hiring assistants, finding substitutes when assistants are sick, working out schedules and giving instructions:

P6: We thought that we had enough with the care work, but when there was a possibility of assistants taking that part, and we could decide whom to employ, that decision was easy to make.... We are greatly satisfied with that part. I need to watch the time schedules and everything, but we are greatly satisfied.

However, some of the private PA providers also offer to take on some of the managerial tasks.<sup>4</sup> Some of the parents, from three different municipalities, have chosen a provider who assists them in employing assistants, finding substitutes and working out schedules. The parents then participate in interviewing potential assistants, and they give directions and

<sup>4</sup> Besides the municipality, the employment responsibility in Norway could also be left to a user-controlled cooperative, to a private company or to the individual user. In all cases, the municipality has the economical and granting responsibility.

inform the providers of their needs. The parents have chosen this type of help from the provider because they consider it as essential in order to be able to manage everyday life. 'It is really nice to have someone ensuring the legal part with confidentiality contracts and police certificates, and that everything is right.'

Most of the parents who carry out all the tasks find themselves able to cope with them, but they still present different experiences. Parents from two families had previously been managers in a work situation. They feel that they cope well with this responsibility, and they consider their earlier experiences in leadership as important to their being able to cope with their role as managers:

P3: From work, I am used to being a leader, and I believe that it has been essential to create a predictable situation. This is not a low-threshold service, and several people didn't understand how we managed. I believe that there is a big difference in whether or not you get overwhelmed by the situation.

Other parents say that they manage the role but find the situation stressful. One parent explains that he uses between eight and 10 hours a week to manage the PA arrangement, as well as having contact with other authorities regarding the child. That makes him too stressed and busy to find the time to apply for more assistance, even if he experiences that they have too little.

### ***The Significance of PA for the Children and the Adolescents***

There is a common view among the parents that they see PA as a tool that can assist them in enabling their children to act like and have experiences similar to their peers. However, their emphasis differs according to the age and the disability of their children. For the children who are not yet teenagers, the main significance is related to minimising the stigmatisation of the child, where the child can stay at home with the family and have experiences like other children of the same age, together with the assistant:

P2: The assistant can be there so that he can do what other children do at home, and he cannot manage when he is alone. Because when something is happening that is 'not inside the square', there is someone there who understands and can settle things. He could not go home or be at home without an assistant.

For the teenagers, the aim is to make arrangements that allow the adolescents to be more independent and venture beyond the family sphere. The parents find it less natural to assist their children in all activities, and PA is more directly aimed at the adolescent.

For two of the three teenagers in this study, their impairments are physical. They both have friends without impairments, and according to their parents, the assistance helps the teenagers to keep in touch with their friends and is a tool to give them more independence from their parents, like their peers:

P4: It isn't right if we must be with him all the time when he is with friends, at parties, bowling, and cinema... Normally children at that age are independent.

All these parents also see PA as important for helping their children to fulfil their ambitions at school and be able to work instead of receiving disability benefits as adults.

### ***The Relationship with the Municipal Allocation Office***

The municipal caseworkers at the allocation office are the ones granting PA and making decisions regarding extensions and expansions. However, the parents can complement these processes by giving input as experts on the child and the family's needs. How this is carried out has influence on the parents as co-producers and their experience of empowerment.

In spite of the parents' positive experiences with PA, a main conclusion from the study is that the arrangement was difficult to obtain. First, they found that most of the municipalities had a restrictive policy regarding the dissemination of information on PA, and the parents often had to find the necessary information themselves:

P7: No one came and told us about it, that it existed. We had to find out about it ourselves, but when we got the people from the municipality home, we got a lot of information.

Second, the parents experienced that the municipalities often wanted them to choose other types of assistance and tried to persuade them to choose solutions like respite care. They were given arguments like problems in finding assistants, their houses were too small and they probably would not be granted PA anyway:

P3: Then I converted this decision of respite care, of personal support and whatever else they came offering to PA hours. I told them, 'This would not cost you anything more, so I want PA instead. I can arrange it myself.' But no, of course I had to appeal [before receiving it in the end].

When they were granted PA, a number of the families received fewer hours than the parents had applied for, and they then had to fight to get what they considered would cover their needs. Some parents feel a lack of trust from the caseworkers regarding the amount of needed hours:

P9: We would not ask for more than we absolutely need for a minimum.... When I go to the municipality and say I need so many hours, it would have been nice if they had seen that. That he probably has not asked for too many, in order to lie down and have a sunbath. This would be what he actually needs.

The parents also experience that they have to consider how they behave so that they will more likely be able to achieve their goals:

P7: You learn in which meetings you can say exactly what you feel, and in which you have to rein yourself, even if you are so angry you can barely sit still.

Some parents say that they have to behave more rigorously and harshly than they are comfortable with in order to get what they need. They cannot be conscious of what the other party thinks of them when they are fighting for what they need.

The parents also describe the importance of predictability of the arrangement. Especially in one municipality, there is no communication with the parents until they receive a letter telling them whether or not the arrangement is supposed to continue in the same way:

P2: You get that letter anyway, if there is going to be a change or not. You have no prerequisite to actually know what they think.... I become so stressed when I see the name of the municipality on the envelope.... Predictability would have been like gold. If they had started now in March to ask if we should go through the decisions, and then this is our setting. And if we could have a little time before the changes were put in effect, that would have been nice.

These experiences differ to some degree from municipality to municipality. Other parents from another municipality feel that the predictability is good. They receive the letter months before the decision expires, and they know that it will run as before if they have not heard anything in advance.

### **Concluding Reflections**

The extent of the study is limited to the experiences of nine families. It still gives a clear picture of the positive experiences the families have with personal assistance for their disabled children. Although some parents experience loss of privacy as a consequence of the PA arrangement, and although some find the management role stressful, the parents, like the parents in the Swedish studies we referred to (Axelsson, Imms and Wilder 2014; Olsson, Flygare and Roll-Pettersson 2012; Stenhammar 2006), are essentially satisfied with the influence PA has for them and their families. The valued outcome could be summed up as the opportunity of living a normal life. The disabled child can live at home and gradually develop independence like other children. The parents can take part in typical activities like being able to work and having a normal income, going on holidays, having visitors at home and letting the siblings have normal lives.

Regarding co-production with the assistants, it seems natural for the parents that they are in charge. They feel that they are taken seriously as co-producers and are regarded as experts by being given the opportunity to be parents the way they think is the best for their disabled children. That is possible by deciding who to hire as assistants, to what degree they want to include them in their family life, and how much help they want from the providers in managing the arrangement. In other words, the possibility of empowerment due to taking on the manager role is important to experience normality.

In order to help the families achieving this normality, PA sometimes becomes the parents' assistance, rather than the child's—for example, when assistants are used for housekeeping and for taking care of siblings. But it also more directly supports the disabled children's independence when the child can stay 'home alone' with the assistant, and when assistance makes it possible to get to and from school like the other children. According to their parents, the adolescents especially will attain independence by having the opportunity to participate in society and being more independent from the parents. All in all, the parental empowerment is used to empower the children when they see it as expedient, as experts on their children's best interest.

In these managerial tasks, the parents generally do not need to have any contact with the municipal caseworkers. The parents are in control of the assistance, and the power is transferred from the municipal caseworkers to the parents, which corresponds with Needham and Carr's (2009) model for transformative co-production and the criteria for changing power relations in social services.

However, such a transformation seems to depend on that assistance being sufficiently provided. Especially one parent considers that the family has too little assistance, which they see as limiting their opportunity to live normal

lives. The possibility of empowerment when co-producing PA with the assistants seems to depend on the opportunity of being trusted in the co-production with the municipal case workers.

The exhausting relationship with the services that parents with disabled children experience (Tøssebro and Lundebj 2006; Lundebj 2008; Connors and Stalker 2003; Rogne and Hareide 2003; Rogne 2016) also applies when the children have PA. This is especially related to the issues of getting information about the arrangement, how much assistance they will receive and their involvement in decision making. Here, we see parents recounting experiences of withholding information, of a lack of teamwork in questions of extension of the arrangement and of not being heard regarding the needed amount of hours, which will also influence the possibilities for flexibility in managing the scheme. The parents are then in a limited way drawn into the process as co-producers. They experience that their values and competences are perceived as being unrecognised, and they feel instead that they are treated with suspicion. Instead of empowerment, the parents are left with a feeling of lack of recognition. On the other side, when parents from one municipality consider the predictability to be good, it is because they trust that the case workers will let them know and discuss the issue if any doubt about the existing arrangement should materialise. This indicates a co-production that leads to empowerment.

Compared to traditional care services for families, PA for children represents an innovation and a huge change when it comes to the ability for parents to be the experts of their children and their family life, and it has a great potential for user experiences of empowerment. By large, the possibility of empowerment seems to depend on what kind of co-production the arrangement allows when it is implemented in the municipality and in the family. In our study, we have located two levels of co-production regarding PA for families with disabled children. When the arrangement works and the power is transferred from the municipality over to the parents, it gives the parents direct democratic control, as Needham and Carrs' (2009) transformative level describes. In other words, it makes possible what Pestoff (2012) characterises as 'co-production heavy'. However, in the decision-making process of granting and following up PA, we find that the parents are not considered as equal co-producers. Rather, it seems like the co-production is amplified by rigorous practices of discretion, which hinder good relationship and participation. When Dempsey and Dunst (2004) confirm the need for both good relationships and participation in care services to allow parents' optimised empowerment, we see that these factors are only partly realised. Still, compared to the established municipal services, co-producing PA allows for a higher degree of empowering parents. We find that the severe limitations of parental co-production in public sector found by Pestoff (2012) are only partly present regarding the PA arrangement for children.

There may be different reasons for the municipal reluctance mentioned by the parents. One is that PA is a new arrangement for families with disabled children. In Norway, it did not appear on the agenda until 2006, and very few families so far have partaken in the scheme. The municipal caseworkers have therefore limited experiences with the scheme for this group. At the same time, it is an innovative scheme that shifts the control from the care services to the families. For the professionals, this kind of shift might appear threatening, representing a loss of control, and it could be considered a risk in the service provision.

According to Needham and Carr (2009), the lack of empowerment for the receivers will be a hindrance for change of care services. When the parents have to fight to achieve and maintain PA for the children, as well as receiving enough hours, we can also assume that some parents give up. Others are simply unaware of the scheme. The result might be that only the parents with the most resources end up receiving PA for their children, because they are the ones most capable of overcoming the thresholds that seem to exist. The change of care-service provision in general is thereby minimised because of lack of empowerment, despite the fact that it possibly improves the lives of the target group. A change of attitudes in the professional caseworkers, as well as a municipal cultural change, will therefore be a prerequisite for making PA for families with disabled children a more commonplace and accepted arrangement, and an even more successful scheme with respect to co-production.

By a change in the Patient and User Rights Act in January 2015, personal assistance was legislated as an individual right for persons with comprehensive and permanent needs for assistance—more than 32 hours each week (Helse- og omsorgsdepartementet 2015). Further research should be implemented to examine whether this change will have consequences for how personal assistance for families with disabled children will be practiced.

### Competing Interests

The authors have no competing interests to declare.

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