

When motherhood is not enough.

Challenges of children with disabilities' personal assistants

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“There is a new breed of human being now taking its place in the cosmos. It is a creature of the 21st century and as it blinks and looks around in the bright light of the unfamiliar day it is already beginning the search for its fellow travellers on planet disability. This modern creation has devised a support system for itself known as a Direct Payment and uses that means to surround itself with worker creatures often referred to as Personal Assistants” (Vasey, 2000).

Abstract

The present research aims to investigate the perception of the parent - personal assistant on his/her profession, but also on his/her personal life, with the aim of identifying the challenges, but also the opportunities that this status brings in the lives of the parents. Starting from the purpose of our research, two objectives were pursued, namely to identify the challenges and opportunities of the personal assistant position and to analyze the parents' perception regarding the decision to become a personal assistant. The study was designed as a qualitative research approach, the interview method was considered the most appropriate to serve the research objectives. The research took place in a day center that offers recovery services to children with disabilities in Timișoara (Romania), the subjects of our research being exclusively mothers. The research revealed that the decision to become a personal assistant for the child with disabilities is dictated by the affection for the child and the sense of duty towards him as a parent, despite the financial well-being previously ensured by a well-paid job. What impacts the respondents' lives is not the new job, but the confrontation with the child's disability. If in some cases the disability was accepted relatively easily, the parents offering each other support, the level of cohesion increasing and benefiting of help from the extended family, we also identified a situation where the family fell apart. The only need claimed by the parents is that of counselling, the respondents complainings were on the difficulties they have to manage with regard to stress, fatigue and lack of free time.

Keywords: disability; personal assistant; resilience; quality of life; satisfaction.

Introduction

The founding of a family and the birth of a child are major changes in an individual's life, which can profoundly impact the quality of his/her life. The role of parent brings many satisfactions, dissatisfactions, frustrations, both towards the children, but also towards the parents themselves (Batool et al., 2019, 34).

Depending on the severity of the disability, following the socio-psycho-medical evaluation, the need to establish a personal assistant for the disabled child can be decided. The personal assistant is, according to Law 448/2006 on the protection and promotion of the rights of disabled persons in Romania, "*the person who supervises, provides assistance and care to the child or adult with a severe disability, based on the empowerment-rehabilitation plan for the disabled child, respectively the individual service plan of the disabled adult*" (Art. 5, paragraph 6). The personal assistant provides support to the person (child) with disabilities both at home and in society. The same document includes provisions related to the criteria to be met, the rights and obligations of the personal assistant (Art. 38-50).

Most of the time, the personal assistance of the disabled child is provided by a family member, one of the parents (usually the mother) being the first option in this case. Caring for a child with disabilities, many times permanently, throughout the day, represents a considerable effort made by the family, with negative consequences on their quality of life. The longer the period of time allocated to the care of the disabled child, the lower the quality of life of the people who take care of him/her (Shan & Li-Tsang, 2003, 19-20), and there is a danger that the quality of life of the child may suffer (Greco et al., 2017, 502).

A series of studies (see Çolak & Kahrman, 2021, 13 and Salehi et al., 2017, 170 with bibliography) specifically looked at the quality of life of mothers of children with disabilities, their conclusions being that in the case of mothers the quality of life is below that of fathers, as a result of the fact that the care of the child falls predominantly in the care of the mother (Kartal, Melekoğlu & Yenioğlu, 2021, 333). This situation is due to the fact that the family is, according to the systemic theory, a dynamic, interconnected system, in which family members affect each other. The involvement of parents in the education and care of children influences not only the well-being of the child, but also that of the parents. In the condition where the main actor in the upbringing, care and management of the child's disability is the mother, it is expected that in her case the level of stress and psychological load will be higher, while her quality of life will be lower (Zeng et al., 2021, 600).

Analysis and results

Problem statement

The present research approach aims to investigate the perception of the parent - personal assistant on his/her profession, but also on his/her personal life, with the aim of identifying the challenges, in terms of needs and difficulties, but also the opportunities that this status brings in the lives of the parents.

A deeper look at the impact of disability on parents and implicitly their families could have a utility, not only academic, but also practical, for families, communities, local authorities and institutions empowered in this regard. In a society that wants to be inclusive, that promotes genuine tolerance of disadvantaged categories, including people with disabilities, a study of the impact that disability has on those nearby could contribute to a better understanding, at a social level, of what disability means and entails, beyond evidence, stereotypes or prejudices.

Objectives

Starting from the purpose of our research, two objectives were pursued, namely:

Ob1. Identifying the challenges and opportunities of the personal assistant position (satisfaction, development, professional needs).

Ob2. Analysis of the parents' perception regarding the decision to become a personal assistant, its impact and implicitly the impact of disability on the parent and the family.

Research design

The present study was designed as a qualitative research approach, the interview method being considered the most appropriate to serve the research objectives. Consideration was given to the emotional impact the research might have on the subjects, both parents of children with disabilities.

In order to fulfill the research objectives, a semi-structured interview guide was designed and subsequently applied, which aimed to investigate the following aspects: the reason behind the parents' decision to become a personal assistant of the disabled child; the challenges of professional reconversion; the impact on the personal and family life of the parent – personal assistant and, last but not least, the professional needs of the parent – personal assistant.

Participants

The sensitivity of the subject led us from the beginning to choose a qualitative research approach, but also to identify with considerable difficulty parents - personal assistants willing to participate in such research. For this purpose, we addressed a day center

that offers recovery services to children with disabilities in Timișoara, identifying with the help of the center's staff a number of 10 parents (mothers) willing to answer our questions.

The 10 people who agreed to participate in our study are mothers of children with various disabilities, aged between 30 and 54 years. With one exception, a stay-at-home mother who worked as a day-care cleaner, all others had a stable job prior to their personal assistant job. Even if we didn't set out to make a profile of the respondents, given the fact that we made a qualitative study, not taking into account the need to integrate some factual data, from the answers of the 10 mothers we could see that previously holding the position of personal assistant they occupied jobs in execution positions, such as tailoring, baking or in various factories, which suggests an average standard of living. Another aspect that we believe is important to consider is the presence of siblings, at least two mothers recalling the fact that they also have other healthy children in their care, while one of the mothers is a personal assistant of two children with disabilities.

Data collection and analysis

The interviewing of the subjects took place between July and August 2021. The interviews took place individually, face to face, in the day center where the parents - personal assistants accompanied their children to the specific therapies. Parents were asked to sign an informed consent regarding the processing of personal data, being assured of the guarantee of anonymity. Subjects' responses were recorded, transcribed and later analyzed using the hermeneutic method (the choice of method was determined by the small number of subjects participating in the study).

Results

Following the application of the interviews, we were able to establish that the decision to become a personal assistant of the child with disabilities has, at least in the case of the subjects of our study, strong affective reasons. For the ten mothers interviewed, it was the only viable option, the alternative of an assistant hired from outside not being discussed:

"I was thinking that I am the person who will show the strongest interest in my child and I am the most able to occupy this role" (B.C.)

"He's my only child, I didn't really dare to think about not staying with him. Having problems as well, it was very important for me to know that I could give him my full time and attention. Anyway, a stranger would never be like mother" (V.V.)

"I didn't even think about this option. That seems logical to me. I just think that only a mother can understand why you want to stay with him all the time and give up everything so that you can devote yourself only to him" (P.I.)

From the answers we can also deduce the presence of a strong sense of duty towards the child, expressed for example by S.A. (*"I made them, I take care of them"*), P.I (*"It seems logical to me"*) or P.C (*"I thought it was logical, to be me for my child"*).

The answers received also outline the duties of the personal assistant in the view of the mothers. His/her role would be to take care of the child, to *"give his/hers interest"*, *"to give him/her all the time and attention"*, or, as P.I states, *"to stay with him/her all the time and give up everything so that you can devote yourself only to him/her"*

In the answers provided by two of the mothers, an important aspect is invoked, namely the financial one, which could have constituted an important impediment in making the decision to become the child's personal assistant (it is known that, according to Law 448/2006, art. 37, paragraph 1, letter a, regarding the protection and promotion of the rights of persons with disabilities, the personal assistant benefits from a salary corresponding to a social worker with secondary education who works in the budget sector, with an average net value of approximately 1500 lei). The fact that they benefit from financial support from the family (one of the interviewees mentioning the father's role in this regard) was an important argument in favor of the decision to become the child's personal assistant:

"Honestly, I didn't even think about this option. As a mother in this kind of situation you cannot think of not staying with the child. Perhaps the only situation in which I accepted to go to work and have a personal assistant take care of the child was when we could not manage financially" (A.E.).

"Anyway, I would have stayed at home for her no matter what the situation was. Our luck is that financially the husband helps us" (R.C.).

The workplace gives the interviewed mothers a sense of satisfaction, primarily as a result of the time they can spend with the child, the financial benefits and those conferred by the employee status being a secondary reason:

"I am happy that I can stay at home with him and take care of him. It's a good opportunity when you know your child needs you non-stop. Financially I could not say that I am not satisfied. It's better than nothing" (D.P.).

"I am very satisfied, I don't think there are many people in my situation who appreciate this opportunity from so many points of view. I have a job card, I have financial aid, I have medical insurance, I have many things that I didn't have when I was working without a job card, all this in addition to what was most important for me, to be able to stay with her as much as possible" (P.N.).

The level of satisfaction is influenced by the standard of living and the previous economic situation of the interviewed mothers, the results of our study practically highlighting its limits. It is possible that the perspective of mothers who previously

benefited from a well-paid job or career that they had to give up is different from what we captured here. This situation was also stated by C.D.: *"I am satisfied because it also comes with a financial aid, and when I was working I cannot say that I was making enough money, so the financial discrepancy is not a big one. Probably if I had a very well-paid job it would have made a difference, but in my situation it's good"*.

For the people interviewed by us, this job was an opportunity, both from a personal and professional point of view: *"The thought of staying at home scared me, I was thinking how we would manage with the money, I didn't earn much before, but even so it was something. The position of personal assistant really helped me" (A.E.). "I was on maternity leave for the first child and I stayed at home longer than I anticipated, the second came, it was necessary to stay at home again and when I gave birth to her and found out that she had problems, it really turned out well that I could be his personal assistant. I really would have needed a little help" (R.C.). "The fact that I was able to be their personal assistant came like this, as a helping hand in being a mother" (S.A.).*

From the answers of the mothers, we can learn that this job does not require a (re) qualification, following professional training courses being optional and at the parent's decision. An important factor is also the child's disability, which may require certain knowledge or the learning of essential techniques for his care. As P.N. tells us, *"I didn't take any course because it wasn't necessary. I asked mothers in similar situations and talked to some who did all kinds of courses, but I saw that it depends on the child and for my child it was not necessary"*.

Other mothers learned various techniques and methods from the therapists with whom the child works in the center, such as V.V.: *"No. We do muscle exercises at home and that's about it. I came with him to the center and saw how he does the exercises with him and I do the same with him at home."*

The answer provided by P.N. raises a problem that we did not intend to investigate here, namely the support network of these parents - personal assistants, their sources of information and support, in which, as we can see, other parents in similar situations occupy an important role.

The child's needs, the mother's need to provide him with appropriate care, to be able to manage various situations in optimal conditions, to support the child in the recovery process (where this is possible) are the reasons for following specialization courses, and not the job requirements: *"Yes, I did a course on caring for people with severe disabilities and managing the relationship with them(...) It was interesting, but I can't say that after taking the course I have other methods with children. I thought it would help me more, yes, it's good that I tried" (S.A.). "I did an assistant course for people with severe disabilities. I did the course to be able to monitor his health all the time and feed him properly, that I learned there and what I should feed him to benefit*

him, how to talk to him, that is, how to recognize his signs or the expressions. It's more complicated, I think it depends on each individual child" (D.P.).

Professional development for the parent taking on the position of personal assistant for his child cannot be seen as a strength. Although there are courses, trainings and internships that the parent has the option to follow, depending on the degree of disability and the possibility of recovery, the parents did not see this as a possibility for career development, but only as a possible help if they felt they needed it. Parental instincts and information about their children's disability were sufficient for them to successfully exercise the position of personal assistant for their children.

To the question "Do you consider that your family's life has changed in any way after you became the child's personal assistant (from a social point of view - relations with the extended family, with friends; from an economic point of view; from the point of view of the relationship with couple)?" the answers given were extremely diverse. For some of the families, the mother's decision to become a personal assistant (and possibly to give up her previous job) did not bring significant changes: *"Nothing has changed. I spend much more time at home, my husband goes to work as usual, and with family and friends no change. Maybe I could say that we don't spend so much time with friends anymore, but it's not a big difference, they visit us every chance" (A.E.).*

Behind the decision to become a personal assistant is the child's disability, therefore we can find in the parents' answers a reference to its impact on personal and family life, as we could see in the case of the answer given by A.E., who talks about the time she spends at home, but also about reducing visits to friends.

The impact of the diagnosis on the family and the need to accept the situation, which came along the way and as a result of the time spent with the child, were also mentioned by other respondents, such as R.C: *"Not much has changed. Maybe we were a little more changed when we had her, in the first few months. It was quite a shock, but we got used to it easily. Our relatives and family friends love her as well as her siblings. I don't feel any difference and change".*

Mothers perceive as positive the time they have available for the child and family and the beneficial influence on family cohesion: *"There were not many changes. We are more united as a family, but otherwise there were no major changes" (P.N.). "We didn't notice many changes except that all our attention was directed only to them and all our interest. But there were no major changes that I could notice" (S.A.)*

The main negative consequence of the mother's job change was the financial one: *"Only from an economic point of view, I think. My previous salary was a big, big help, I wouldn't be able to compare what I was earning then to what I'm getting now. It*

was a big change and a financial difference that made us recalculate our expenses month after month until we got used to the discrepancy from my old salary” (P.I.). “It only changed financially, that we had a salary that was really great, but we manage. Otherwise, nothing has changed” (D.P.).

One of the answers mentioned the negative impact that the child’s disability had on the couple’s relationship: *“Yes. Well, the husband decided that it was too much for him and left us, although he was going to work and I was the one who stayed with the child. Everything that happens when you have a child with problems is much harder for a mother than for a father. From here I started having financial problems and getting by harder and harder. I was lucky to have parents who help me even now. It’s good that I was able to be a personal assistant anyway. In my situation it really helped me a lot” (V.V.).* The position of personal assistant was a support for this mother, who also benefited from the support of the extended family.

Regarding the impact of the decision to become a personal assistant on the mother’s life, our respondents mainly complained about the lack of free time, fully allocated to the child, and the fatigue:

“Yes. I’m at home more all the time and I’m much more tired. All I do now is strictly to help them” (S.A.)

“Yes. I am much more involved in his life than if I had another job. Because of the time I have with him and I’ve been able to since I’m his personal assistant” (P.I.).

“My life has changed. I’m much busier. I have a lot more things to do and the fact that I have to be non-stop after her is extremely demanding, this in addition to the fact that I have another child” (P.N)

“Well, I’m at home all the time and I don’t do anything but stay with him. When he is at the center I have time to cook and clean the house. But otherwise I am with him day and night, only for him” (D.P.)

For some of the mothers, not the position of personal assistant, but the disability was the factor that profoundly marked and changed their lives, the psychological burden being considerable:

“It changed because I had to learn to be a mother in a different way than I was used to. It’s much more demanding, much harder, I’m much more stressed than I was before, I worry much more in any situation, but that’s changed since I gave birth to him, not since I became his personal assistant” (C.D.)

“Maybe I could say that the change came to me. I am much more tired and much more mentally exhausted many times, but there is nothing I can do. It’s hard, especially since there are three of them. I can’t say it’s changed since I’ve been a personal assistant. As a mother it’s like being a personal assistant and something else” (R.C.)

The life of the parent taking on the role of personal assistant for her child changed, at least according to the views expressed by our respondents, the moment they received the child's diagnosis, rather than the moment they began to take on this role. We find the same situation in the case of family life. The most felt changes were from an economic point of view, as a result of the lower salary level offered by this position. The change is of little relevance to the parent's satisfaction with the time and care allocated to the child. From a social point of view - the relationship with the extended family, with friends - no significant changes were noticed. Some changes were found in the couple's relationship, either through greater involvement of the partner in terms of financial support or emotional support, or through the breakup of the family through divorce, the partner not being able to face this challenge.

On a professional level, the respondents claim the need for counseling services. From the answers received, these counseling services would address not only the assistant, but also or rather the mother behind the personal assistant of the disabled child, since, as R.C states for example: *"I think that only counseling could help me when I feel like I can not take it anymore. I have moments like that, but I've gotten used to getting over them in my own ways."* For C.D. the support offered by mothers in a similar situation takes the place of professional counseling: *"I wouldn't really believe it. I do the counseling when I meet with the mothers of the children at the center. I talk to them and we listen and encourage each other and that's it."*

Discussions

A special child, with a congenital, developed during childhood or acquired disability, represents a major challenge for the family and a factor that determines fundamental changes in the family's life, whether we are talking about social or economic aspects, the state of health of the parents or couple relationships. Regardless of the type (intellectual/physical) and its degree, the child's disability leaves its mark on the family life (allocation of resources, time management, intra- and inter-family relations, social relations).

Studies have revealed that families in which there are one or more disabled children are affected by stress, face financial problems as a result of low income, social isolation, a deteriorated physical and mental health and not infrequently with family breakdown (separation or divorce) (Muir & Strnadová, 2014, 922). The highest levels of stress is recorded at the time of diagnosis. The higher the child's dependence on the family, the lower the family's energy, the more social isolation increases and their private lives are affected. Couple relationships suffer, spouses no longer manage to spend quality time together, and not infrequently parents end up blaming each other for the child's condition (Kumar et al., 2021, 43).

These conclusions can also be found in the case of the study undertaken by us, from the answers given by the ten respondents, mothers of disabled children, and at the same time their personal assistants, revealing the challenges they have to overcome and the problematic situations they face, regarding fatigue, lack of free time, financial difficulties, affecting social and sometimes couple relationships.

Receiving a diagnosis that confirms the child's disability represents for a parent the beginning of major changes, primarily of emotional nature, each parent seeking to do what is best for her own child. Quitting the job before the time of diagnosis is an instinctive decision, the child and its needs being a priority, as we were able to ascertain from our research. None of the respondents considered the possibility of an external personal assistant, even if this decision meant a decrease in income and an increase in the family's financial effort.

Being a personal assistant to a disabled child means, at least for the respondents of this study, "*being a mother and something else*" (R.C.), the child's condition and not the job being the causes of fatigue, lack of time (complained by most mothers) or changes from the family routine (reducing trips to friends).

The results of our study are in agreement with the conclusions of Poston et al. (2003), who found that parents of children with disabilities report a lack of free time to meet personal needs and a high level of stress.

We also agree with the study of Matthews et al. (2022, pp. 311-312), citing previous studies, claiming that parents of children with disabilities face the need to achieve a balance between child care, daily activities and interfamily relationships, often a difficult and stressful endeavor, leading to a deterioration in the mental and physical health of family members and social isolation. The same study shows that families with children with disabilities face financial difficulties, lack of free time, interference in accessing specialized services or limited access to information.

The lack of free time and the financial impact of disability, without major consequences on the family, are information that can also be found in the answers received in our research.

Research approaches on families with children with disabilities have generally started from the assumption that disability has a negative impact on families, in terms of stress levels, depression or psychological burden. The main limitation of these approaches is that it only took into account the psychological impact of disability, which leaves its mark in a much more complex, multidimensional way on family life. This traditional deficit model emphasizes stress and psychological burden as the defining elements of caring for a person with a disability (Howson & McKay, 2020, 307).

The meta-analysis by Iacob et al. (2020) on 26 studies on the resilience of families in which there is a child with a developmental disability (within the autism spectrum disorder) highlighted the fact that there is a significant, directly proportional relationship between resilience and the social support given to these families. A negative, inversely proportional correlation was recorded between resilience and stress, anxiety or depression.

Some studies have instead highlighted that disability can have a positive impact on the family, especially in terms of communication, cohesion, flexibility, roles and coping strategies, hence the research hypothesis that disability has an exclusively negative impact on life family is not validated in all cases (Summers et al., 2005, 778). Parents who manage to adopt a positive, realistic attitude and accept their child's disability can end up developing a sense of reconciliation and contentment, of love, understanding, friendship and a better understanding of life (Savari et al., 2021, 2).

One can thus speak of a "paradox of disability", by which we mean the discrepancy between the objective limitations and suffering caused by a certain disability and the good quality of life of the people who face that disability. The basis of this situation can be the different way in which these people choose to respond and behave when faced with the negative consequences of disability, completely changing their value system, expectations, standards and way of relating to life (Carona et al., 2013, 971). The presence of positive perceptions does not exclude their coexistence with negative perceptions, with a high level of stress or a high psychological load (Ferrer et al., 2017, 904).

Ferrer et al. (2017, p. 913) concluded, following their study, conducted on a sample of 327 families with children with intellectual disabilities, that in families where parents perceive the child's presence and contribution within the family as positive, and also perceive that they have control over their life, the level of quality of life and family well-being is higher, parents are more satisfied, manage their emotions better and have a better level of health.

Resilience in the families of children with disabilities must be understood as a process, which goes through three stages: coping with the disability (seen as bad luck, trauma or a passing event); gathering the resources (including specialized services) and the forces necessary for optimal functioning; the return from the confrontation with the disability, in the sense of adapting to it. This process is dynamic, the family undergoing, depending on the context, destructions and restructurings, adaptations and repeated adjustments.

The family's resilience is based on the resources it has and the energies it can involve (in these categories the individual characteristics of the family members, the beliefs, attitudes and abilities of the family members, access to and use of the necessary resources can be integrated) (Muir & Strnadová, 2014, 924-925).

The most important individual characteristics that can contribute to achieving resilience are the ability to be flexible, to have hope and emotional strength, and to find meaning in the events of our lives. In terms of family skills, the most relevant are: problem solving, openness, ensuring a balance within family relationships (here being understood including the possible siblings of the disabled child) and financial management (Muir & Strnadová, 2014, 925-926).

We learned about the positive impact of disability and resilience, as we could see, from the answers given to us by some of the mothers, such as *"We are more united as a family"* (P.N.) or *"Not much has changed. Maybe we were a little more changed when we had her, in the first few months. It was quite a shock, but we got used to it easily. Our relatives and family friends love her as well as her siblings. I don't feel any difference and change"* (R.C.).

A factor that can leave its mark on the quality of life of those who care for a child with disabilities is the social support received (Lin et al., 2009, 1454), both formal (from qualified institutions or specialists), but also informal (from other family members or friends, other parents). Support can take different forms, from emotional support, physical help, in carrying out daily activities, material/instrumental (financial support offered to the family), or informational. Social support refers to participating in activities within the community, including recreation and leisure, maintaining relationships with relatives and friends to avoid social isolation and ensuring the building of a support network that can protect and support the family (Muir & Strnadová, 2014, 926).

From the answers received, we can conclude that financial support in the case of our respondents comes especially from the partner (*"Our luck is that the husband helps us financially"* (R.C.)), and in his absence from the extended family (*"I was lucky with my parents who help me now"* (V.V.)). Emotional support is provided by parents in similar situations, who are also an important source of information, as we could see in the case of the answers provided by P.N. (*"I have asked mothers in similar situations and talked to some who have done all kinds of courses, but I saw that this depends from child to child and for my child it was not necessary"*) or C.D.: *"I do the counseling when I meet with the mothers of the children at the center. I talk to them and we listen and encourage each other and that's it."*

Conclusion

Our research aimed to investigate the perception of the parent - personal assistant on this profession and on his/hers personal life, with the aim of identifying the challenges, in terms of needs and difficulties, but also the opportunities that this status brings in the lives of parents.

In this sense, two research objectives were formulated, namely: Ob1. Identifying the challenges and opportunities of the personal assistant position (satisfaction, development, professional needs), respectively Ob2. Analysis of the parents' perception regarding the decision to become a personal assistant, its impact and implicitly that of disability, on the person and his/her family.

In relation to the first objective of our research, from the answers provided by the ten respondents, we could conclude that the position of personal assistant gives them many reasons to be grateful, from the time they can allocate, to child care (from mothers' point of view, a personal assistant should care of the child permanently), to the financial support, the opportunity to have a stable job, with the advantages conferred by it (work card and medical insurance). Mothers - personal assistants claim at most the need for counseling services, but, as we could see, these respond to a personal need and not a professional one. The personal assistant job does not require training or specialized training, and the respondents stated that they attended such courses as a personal option, out of the need to adequately care for their children, not as a job requirement.

The decision to become a personal assistant to the child with disabilities that the parent (in the case of our research the mother) makes is dictated by the affection for the child and the sense of duty towards him as a parent. These are above the financial well-being previously ensured by a well-paid job. Even so, this decision did not impact personal or family life, with families identifying alternative solutions (either by involving the partner or the extended family). But what influenced the lives of families and parents - personal assistants was the disability. They had to go through a process of acceptance, adaptation and identification of solutions for managing the situation and the child's condition. The permanent care of the child during the whole day is difficult, the parents complain of fatigue and lack of free time. In some cases the disability was accepted relatively easily, the parents offering each other support and benefiting of help from the extended family, we also identified a situation where the family fell apart due to the divorce of the parents, with the mother receiving support from the extended family. However, as other studies show (Summers et al., 2005; Savari et al., 2021; Carona et al., 2013; Ferrer et al., 2017) disability can also have positive effects, by increasing the level of cohesion of the family.

We can conclude that, at least for the respondents of our study, the position of personal assistant is identified with the status of mother, coming in addition with the benefits of employment (work card, salary, medical insurance). What impacts the respondents' lives is not the new job, but the confrontation, as a mother, with the child's disability. It's the child's needs that motivate (or not) the parent to take courses, not the job requirements. The only need claimed by the parent, again personal and not professional, is that of counselling, the respondents complaining of the difficulties they have to manage with regard to stress, fatigue and lack of free time.

Limitations of research

A first difficulty in conducting this study was related to the identification of the subjects. The sensitivity of this topic contributed to the low number of respondents, for some of the parents who face this problem, opening up to a stranger is embarrassing. Carrying out a large-scale study, with a mixed methodology and a larger number of respondents, the possibility of a representative sample, would allow a complete picture of this population category and would open the opportunity to outline measures and social policies to support them.

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When motherhood is not enough.

Challenges of children with disabilities' personal assistants

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