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Original research article

Factors influencing the (non) use of social services – from the point of view of family members from selected municipalities of the Moravian-Silesian Region who provide care and guardianship for a loved one with an intellectual disability

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Abstract
Introduction: Despite the fact that caregivers see social services as an important form of support, in the Czech Republic we are increasingly encountering situations where a person with a disability lives together with their parents in the same household until the caregiver becomes elderly or dies. These families use the bare minimum of social services or none at all.
Goal: The goal of this paper is to present factors identifying the (non) use of social services from the perspective of family members from selected municipalities of the Moravian-Silesian Region who provide care and guardianship for a relative with an intellectual disability.
Methods: The data was obtained through field research, which was carried out in 2021 in six municipalities in the Moravian-Silesian Region. Twelve individual and five group semi-structured interviews were conducted with 22 communication partners. The data analysis was performed using constructivist grounded theory.
Results and discussion: Most of the communication partners prefer caring for a loved one in the form of home care. The reason for refusing to use social services is negative previous experience with social services, namely dissatisfaction with the quality. The issues that family members deal with when providing care and guardianship are: coping with demanding care, fatigue, isolation, loss of social contacts with friends and family, dealing with missing social relationships, the future housing of a loved one, and maintaining contact with the cared-for person.
Conclusions: To be able to take into account the individual wishes and possibilities of each client, it is necessary to focus on the coordination and networking of support at the community when planning social and follow-up services. Person-centered planning should be offered as a suitable starting point. A newly developed form of support for people with disabilities and caregivers, which could effectively supplement the network of social and follow-up services in the community, is homesharing (a form of respite care based on community assistance).

Keywords: Guardianship; Informal carers; Intellectual disability; Social services

Introduction

Průša et al. (2021) draw attention to the fact that caregivers believe the role of social services is irreplaceable. Despite the existence of many types of social services and tools to support the care provided by informal caregivers, in the Czech Republic it is sometimes very difficult to meet the needs of people dependent on the help of others (Čtvrtník and Tomášková, 2021: 65).

We can see that the capacities of residential services are insufficient at the present time, outreach services are developing very slowly, there is a shortage of social workers and their salaries are very low. These are all factors that lead to people with health problems needing the help provided by family members or loved ones (Průša et al., 2021: 306–307).

In the Czech Republic, we increasingly encounter a model where caregiving parents and a person with a disability live together in the same household until the advanced age or death of the caregiver. This is very often the result of a lack of high-quality services in the vicinity of these families, or the necessary services are not present at all (Uhlířová and Latimier, 2013: 10).

With regard to the suitability and availability of services, the situation of families caring for disabled children is more favorable than that of families caring for an adult/aging dependent person (Kotrusová et al., 2013: 16).

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The research of Geisler et al. (2015a) found that most caregivers prefer to share care with a professional service. The identified barriers include financial costs in combination with the poor financial situation of caregivers, insufficiency of informing caregivers about the existence of services, their inaccessibility in terms of time and location (lack of services in remote locations and small communities, the inflexibility of available hours, e.g., in case of the illness of caregivers), overloaded capacity, and the impossibility of transport to the service. These factors mean that caregivers use social services to a minimal extent.

There are not many services that directly support loved ones in caring for people with disabilities and carers. In a questionnaire survey that focused on the situation of people caring for persons with intellectual disabilities (Uhlířová and Latimier, 2013: 51), caregivers were asked what services they use. 79% did not answer or answered that they did not know about any services, 8.9% said they used social counseling, and 5.7% used respite services.

Hubíková (2017: 8, 2021: 85–86) and Votoupal and Krystek (2019: 105) refer to informal caregivers as "non-established" or the "invisible" clientele of social work. According to Hubíková (2021), social workers are not led to view family caregivers as their clients.

Chmelová (2021: 54) points out the fragmentation of social services, indicating there is no connecting link between them that would support and accompany family caregivers as a system with its own specifics (long-term caring and psychologically exhausted parent, older children in the family, upbringing methods, partner problems, complexity of the job classification of parents, etc.).

Wood (2018) draws attention to the high burden of elderly caregivers of people with intellectual disabilities. In the event that they perform the function of guardianship in addition to caregiver (which adds another significant role) then they assume legal responsibility for the person being cared for. This situation can last for many years.

The research of Mazák et al. (2021: 15–30) shows that services that can contribute to respite for parents by helping them with providing care and giving them some extra time were rarely used by the interviewed parents. 62% of respondents did not know about the existence of the respite care service, or the service was unavailable to them.

Only 5% of respondents regularly used respite care, and 12% of respondents used social services irregularly. 60% of respondents did not know about the possibilities of childcare services to enable them to work. 63% of respondents did not use help in arranging leisure activities.

Geisler (2021) also draws attention to informal caregivers' minimal use of respite services. Her research found that only 7% of caregivers had experience with the use of respite services.

Geisler (2021: 59) states: *"The use of support intended directly for caregivers is rather marginal. In addition to consultations with health professionals or social workers, 14% of caregivers turned to a health professional to solve their medical issues that arose or significantly worsened due to the provision of care. Only a minimal number of caregivers have experience with other types of support (e.g., 9% of caregivers have encountered support from non-profit organizations that provide care, 3% of caregivers have experience participating in a self-help group, 4% of caregivers have experience with educational activities, and 5% have used the help of a psychologist)."*

The questionnaire survey of the SPMP in the Czech Republic (Uhlířová and Latimier, 2013) carried out among caregivers of people with intellectual and combined disabilities, revealed the following reasons for not using social services: insufficient offer of social services (32% of respondents), unaffordability of services (21%), low quality of services (26%).

The research results of Geisler (2021: 58) also demonstrate that a significant proportion of informal care takes place outside the social support system. Only 43% of people are granted a care allowance when caring for their loved ones.

However, even in this target group, Průša et al. (2021: 307) indicate that more than 70% of care allowance recipients do not use any of the registered social services, and it is therefore necessary to emphasize the development of respite care, which will enable caregivers to receive the necessary rest.

The research of *The Quality of Life of Caregivers and Persons with Disabilities* (Michalík et al., 2018) shows that up to 26.62% of respondents had had no days off (i.e., days when they did not care for someone) in the last six months.

The availability of services for people with combined disabilities, e.g., for persons with medical disabilities and psychiatric illnesses, persons with mental disabilities and associated sensory disabilities, is also problematic. The fact that residential social services are generally less accessible and providers can themselves define the user group for their service leads to the fact that people with such combined diagnoses find placement very difficult (Geisler et al., 2015a; Uhlířová and Latimier, 2013).

Caregivers and service providers see a major obstacle in the setup of the social service system itself, where users have to adapt to the service (which is often not possible), instead of the services adapting to their possibilities and needs and thus being able to respond flexibly to sudden changes in the clients' situation (Geisler et al., 2015a: 71). Adamčíková et al. (2018: 135) draw attention to the problematic workings of social services, as defined in the Social Services Act, where, for example, parents with mental disabilities are often excluded from the circle of authorized users of a specific social service, which does not allow the social worker to provide adequate support to the family.

Kocman (2016) points to the fact that social services are currently focused more on direct user support than on mediating support through informal relationships. According to him, no single service can effectively work with the entire breadth of a person's needs and wishes, and therefore it is necessary to focus on the coordination and networking of support at the community level over individual services using person-centered planning.

Aging parents caring for a child with an intellectual disability all their lives face many difficulties. These include health problems that increase with age, both for the parents and their children. This is linked to the parents' constant worry about what will happen to their child when they are no longer able to take care of him or her in the future (Strnadová, 2009: 186).

The network of community services is often incomplete, social services especially for people with disabilities do not connect to services for a wider user group (care service) or to health services (Geisler et al., 2015b; Uhlířová and Latimier, 2013). For these reasons, many families put off thinking about their child's future until the last moment, and sometimes a crisis, such as the death or serious illness of one of the parents, forces families to make a decision. In such cases, it is usually too late and a person with an intellectual disability ends up in an environment that is not entirely suitable for them (SPMP, 2020).

The increasing demand for social services and support for the care of adults and elderly people with mental disabilities and increasing expenditures on social care abroad are pointed out, for example, in the research of Rojas-Garcia et al. (2020) and Woittiez et al. (2018).

This paper offers the results of field research carried out in 2021 among family members providing care and guardianship to their loved ones with mental disabilities in the Moravian-Silesian Region (in 6 municipalities: Karviná, Opava, Ostrava, Albrechtice, Havířov, Český Těšín) and whose partial research goal was to obtain answers to the questions: *In what areas of guardianship do family members identify their need of support? What support networks do family members use when exercising guardianship?*

The main part of the research section of the paper will be focused on the presentation of the factors that influence family members providing care and guardianship to a person with an intellectual disability in the (non)use of social services.

Materials and methods

A qualitative research strategy was used to achieve the partial research goal, where through the implementation of field research in the territory of the Moravian-Silesian Region, the following actions were carried out: 12 individual semi-structured interviews and 5 group semi-structured interviews with 22 communication partners from 6 municipalities (Karviná – 9 participants, Opava – 1 participant, Ostrava – 3 participants, Albrechtice – 1 participant, Havířov – 5 participants, Český Těšín – 3 participants). Three interviews were conducted online via video calls, 12 interviews were conducted in the home environment of communication partners. The characteristics of the research sample are shown in Table 1.

Table 1. Characteristics of the research sample

Designation of the communication partner	Age of guardian	Age of loved one with mental disability	Relationship	Period of guardianship	Shared household with ward
CPW1 (Ostrava) online interview	45 years old	49 years old	Brother	19 years	NO
CPW2 (Karviná)	83 years old	42 years old	Son	18 years	YES
CPW3 (Karviná)	69 years old	44 years old	Daughter	15 years	YES
CPW4 (Karviná)	60 years old	40 years old 38 years old	Sons	14 years	YES
CPM1 (Karviná)	50 years old	29 years old	Son	7 years	YES
CPW5 (Karviná) online interview	49 years old	24 years old	Daughter	3 years	YES
CPW6 (Český Těšín)	65 years old	43 years old	Son	26 years	YES
CPW7 (Český Těšín)	73 years old	52 years old	Son	14 years	YES
CPW17 (Český Těšín)	69 years old	44 years old	Son	26 years	YES
CPW8 (Opava)	65 years old	42 years old	Son	24 years	YES
CPW9 (Havirov)	70 years old	65 years old	Brother	10 years	NO
CPW10 (Havirov)	37 years old	80 years old	Family acquaintance	1 year	YES
CPW11 (Albrechtice)	68 years old	29 years old	Daughter	4 years	YES
CPW12 (Havirov)	60 years old	57 years old	Sister	7 years	YES
CPW13 (Havířov) CPM5 (Havířov) *Note: living in a partnership*	54 years old 55 years old	30 years old	Son	12 years	YES
CPW14 (Karviná) CPM2 (Karviná)	60 years old 62 years old	58 years old	Sister of husband	23 years	YES
CPM3 (Ostrava) online interview *Note: living in a partnership*	Not specified	Not specified	Father	Not specified	NO
CPW15 (Ostrava)	Not specified	Not specified	Sister	Not specified	YES
CPM4 (Karviná) CPW16 (Karviná) *Note: living in a partnership*	50 years old 47 years old	23 years old	Daughter	3 years	YES

Note: CPW – communication partner woman; CPM – communication partner man.

The original intention was to conduct interviews with family members providing care and guardianship to a loved one with an intellectual disability from other municipalities of the Moravian-Silesian Region (32 participants in total). In the spring of 2021, other representatives of the branch associations of the Society for the Support of People with Mental Disabilities operating in the cities of Břidličná, Bohumín, and Bruntál were contacted with a request to contact the communication partners, but they did not respond to the offer to participate in the research.

Electronic requests (with information leaflets) to address potential communication partners were also sent by e-mail to the managers of the Departments of Social Affairs of the cities of: Karviná, Havířov, Ostrava (ÚMOb South), Opava, Český Těšín, Frýdek-Místek, and Bohumín, Albrechtice. Despite the above-mentioned efforts, it was not possible to get other communication partners to participate in the research. The reason was, for example, the refusal of four contacted communication partners who had initially agreed to participate in the research, but subsequently declined due to concerns about the spread of Covid-19.

The research sample was selected using the method of purposive sampling through institutions (Hendl, 2005). The "snowball" method was also partly used.

In the research sample of 22 communication partners, 5 men and 17 women were represented. With the exception of three participants, the remaining communication partners lived in a shared household with a loved one who provided the function of guardianship and who also provided care for this person. In many respects, during the interviews the communication partners did not differentiate between the provision of activities connected with the exercise of guardianship and the provision of care for a loved one (similar findings have been pointed out in the *Explanatory Report on the Substantive Intent of the Public Guardianship Act* (Ministry of Justice of the Czech Republic, 2016: 9). Likewise, Wood (2018) draws attention to the intermingling of the roles of caregiver, guardian, and family member.

The average age of the communication partners was 59.6 years. The oldest communication partner who provided the guardianship function and care for a loved one (son aged 52) was 83 years old.

The fact that older generations participate in care more often than young people can also be seen in the results of Geisler's research (2021), where the average age of this group of caregivers (factoring in the entire population) was 48 years old.

The conducted semi-structured interviews were audio-recorded, and verbatim transcripts were prepared. A total of 380 pages of transcribed material were obtained. Data analysis was subsequently performed using the constructivist grounded theory (Charmaz, 2006), where two levels of coding were used. First, open coding (initial – line by line – coding) was carried in the MAXQDA program (Qualitative Analysis Data Software) version 2018, where initial codes were created, and then focused coding (separation, sorting and synthesis of data) was performed, from which five categories emerged to be further presented and discussed in this paper: 1. How can I cope with fatigue and make sure I get rest? – the need for respite services; 2. Reasons for the preference for home care; 3. Social isolation of the cared-for person and the caregiver; 4. The possibility of growing old together – maintaining contact with the cared-for person; 5. A vision of the future Housing of love one in residential care service.

Results and discussion

How can I cope with fatigue and make sure I get rest? – the need for respite services

The topics of conversation with communication partners were: the demands of caring for a loved one, the fatigue of the caregiver, and the insufficiently fulfilled need for sleep and rest. CPW7 (257–257): *"Then I would lie down and sleep for almost the whole day. I'm sleep deprived. Because I lie down in the evening and think..., we need to buy bread rolls..., we need to buy salami, we still need to deal with..., call the doctor at neurology, because we don't want to go there. It's just that it all comes together in the evening."* CPW12 (203–203): *"... I say I have to recharge my batteries a bit in nature or when I go out with my daughter somewhere... Among people, but otherwise..., I look forward to going to bed at night, I mean, when I lie down."*

The communication partners also stated that, in addition to providing round-the-clock care for a loved one, they also take care of another member of the household (they spoke of the so-called "double burden") and the demands of care. CPM2 and CPW14 (22–22): *"Daddy also got old... Her father came to help us, so we were able to move around quite freely... But two years ago, her health deteriorated to such an extent that she requires round-the-clock care almost all the time, and he can only leave her when she is in bed, like for just a while, yeah, maybe, I don't know... for an hour... So now we're learning how to cope with it with the help of our daughter... It's very difficult..."*

A frequent topic discussed by communication partners was the need for respite services. They thought about the scope of these services. The question was also the capacity, unaffordability and physical unavailability at the place of residence. CPW12 (197–197): *"When I felt that I was in a very bad way..., I agreed with my daughter, for example, that she would look after me for at least one day or something like that, or now I have put her in respite care for a week and got a little time off, because I felt that I needed it, but otherwise..."* CPW12 (123–123): *"Well, only respite care, but it is very expensive. My daughter pays for it about eleven hundred a day, which is a lot of money. I was in the spa last year and paid over twenty-eight thousand for it, and that's no joke..."* CPW2 (123–123): *"You can't get in. At all. I asked for it a while ago, but they were not able to accommodate me. I should have ordered it six months to three quarters of a year in advance. In December, already in September... So here we really lack such things."* CPW2 and CPW3 (120–120): *"It exists... but there's very little space and it's occupied a year in advance by retirees... Everything has already been planned in advance and you won't get in."* The communication partners also stated that they could not secure respite care in the event of an emergency situation – for example, during the period of hospitalization (CPW15).

The findings are consistent with the research of authors Uhlířová and Latimier (2013), Mazák et al. (2021), Geisler (2021), who draw attention to the insufficient capacity and availability of respite services for informal caregivers. The fact that families lack sufficient support in receiving respite care is also reflected in the discomfort of families, the perception of stress, and the evaluation of the quality of life of families (Jenaro et al., 2020). As evidenced by the results of the interviews, it is crucial to provide caregivers with the necessary rest by guaranteeing a sufficient supply and development of respite services (Průša et al., 2021). The communication partners also stated that they would welcome respite care being provided for a shorter period of time (without the need of an overnight stay), for example for half a day when they need to see a doctor or arrange some matters with officials. Uhlířová and Latimier (2013) also state the need to create a short-term respite service. One of the options that could offer respite to caregiving family members so that they have space and time to themselves is homesharing, a form of respite stay based on community assistance, which is new in the Czech Republic (Pudlovská et al., 2021).

Reasons for the preference for home care

Most communication partners preferred caring for a loved one in the form of home care. One of the main reasons they refused to arrange care during the day in the form of an outpatient service (e.g., visit to a daytime care facility) was the claim that social services are not adjusted to the individual needs of the client. Similar findings are also referred to by the research results of Geisler et al. (2015a) and Adamčíková et al. (2018). *"She went there as a child… her father used to send her to a daytime care facility. She had been going there for a long time, but over the years it happened that she didn't look forward to it. She didn't want to go there. Her father basically pushed her there and she resisted because she liked her peace and quiet and there were a lot of boys and they were quite noisy… He was blamed for not taking her there, but really, she wasn't able to function there at all, not in that way"* (CPW12: 121). *"Because she was in the facility like that for five days… we supported her to go home for the weekend so we could be in contact… but we had a meeting where we all recognized that they really couldn't handle her there anymore, that they weren't able to provide for her needs, so we took her home…"* (CPW14: 17).

Another reason for refusing to use social services was a previous bad experience with residential care services (which offered housing): *"There was such a facility in our community, this was during socialism, but she really didn't like going there, because there was…, I don't know. You really can't get inside of what goes on behind those walls"* (CPM2 and CPW14: 74). *"She had a bruise here and there, and no one knew how it happened… because it used to be taboo. Basically at that time you didn't talk about these problems, about these children"* (CPM2: 74). *"So when I see what's happening there, I'm just disappointed with social services"* (CPW4: 186).

Another surprising finding was the repeated negative evaluation of protected housing – the communication partners drew attention to the strict conditions in the setting of this social service or its insufficient quality. *"But quite often afterwards, I met the social worker when such 'bigger problems' were being solved, e.g., the non-observance of house rules, or even the fact that my brother did not quite fit into protected housing, because he has a mild degree of mental disability. I'm convinced that he belonged to that protected housing, but protected housing just started at the time and the conditions were terribly strict"* (CPW1: 25). CPW4 (154–154): *"Maybe I just don't like protected housing very much. Because, as I said, they actually pay…, they practically give a pension there, they provide care there* [author's note: care allowance] … *But where do they end up? Nowhere! Some services are paid. The kids don't do anything, because they stick everything under their noses, and it seems completely unnecessary to me."* In practice, we can see that the effort to create alternative models of care/services on the part of social service providers, which can prevent "people from being relegated to institutions", can encounter obstacles or the rejection of family members, where one of the reasons for not using social services is the criticism of their low quality (Geisler, 2015a; Uhlířová and Latimier, 2013).

The negative evaluation of protected housing by family members could also reflect a certain degree of their protectionism (overprotection of the person being cared for) or their concerns about the deterioration of the health condition of the cared-for person after leaving their home environment to another social service (which offers housing). CPW2 (125–125): *"For me, it would be important if my daughter was then somehow able to get transferred to protected housing, because we have had two experiences of girls who have been there for a long time and who changed psychologically so much that they didn't want to come home."*

Giertz (2018) points out that family guardians often seek to defend the interests of the family and not the clients, and it occurs when the family overprotects and restricts the person being cared for in everyday life. CPM2 and CPW14 (169–169): *"… a young girl, a social worker like, … now it was a big task to introduce this service there* [protected housing], *so she didn't hear our voice when we said that our daughter wasn't capable of it. From our point of view, we would be terrified, because we know that someone will just knock on the door and it will open and someone gets let in…, and they are supposed to live in a normal housing development. So it was a utopia for us."* The interviews also revealed communication partners' concerns about their adult children being able to manage independent lives, and concerns about their emotional distress in the social service (cf. Uhlířová and Latimier, 2013: 10).

Social isolation of the cared-for person and caregiver

Another topic the communication partners discussed was the need of support for their loved ones (mostly their adult children whom they cared for) in the area of social relationships. The communication partners talked about their unfulfilled needs in this area and that they substitute for the friends/peers missing in their adult children's lives. CPW4 (256–256): *"From what I noticed, the biggest problem they both had… but the older son suffered because he had no friends. The others have boyfriends, girlfriends…, he can't have a girlfriend. So I told him, choose a girl in the association, in the social services… Well, he doesn't want any girl there, because they are disabled. What can you say to that?"* CPM1 (258–258): *"Because young people always have certain groups. There's a group of friends doing some activities or something. There are some social services. But when you listen to what's there in the social service, it seems so strange to me. So artificial, so meaningless."*

CPW4 (179–179): *"I will always be a mother, even if we're just friends. Nobody tells me that and they look at me like that. That means, I know exactly when we're here…, they'll be sitting here like little girls, but God forbid, how are we going to get behind that door. And we're off."* [laughter] Strnadová (2009) and Uhlířová and Latimier (2013) point out that isolation often occurs among people with disabilities who live in the family but do not participate in public, social, and cultural life. Social isolation deepens in a situation where the parents are getting older, and the mobility and activities outside the family are decreasing. In the case of the death of a person who alone provided care for a loved one living for years only in the "safety" of his family, such a loved one person is then lonelier than a person who has lived in institutional care for years. Kocman (2016: 19) points out that people with complex needs and mental disabilities are particularly affected by the closure of social networks, because – as it emerged from research in countries with a long tradition of deinstitutionalization – these people still have limited opportunities for social contacts outside the three most common groups of people: family, other social service users, and social service workers.

In practice, missing relationships with friends are in some cases replaced by relationships with volunteers (Kocman, 2016) or relationships with workers in social services or public guardians (Giertz, 2018), where it is expected that these persons can also replace the function of a missing family member. The communication partners (CPW4, CPM1, CPW7) also talked about the need to find a friend for their adult son/daughter. According to Kocman (2016) "having social relationships" ought to become the goal of planning and the direct support of loved one person provided by social worker with the possibility of using volunteering, and it should be the subject of the reform of social services and their personalization.

The communication partners also reflected on whether, during the course of caring for a family member, they lost their own friends and network of relationships; the topic of conversation for them was their isolation and loneliness. Research by Michalík et al. (2018) indicates similar results. As many as 71% of the informal caregivers interviewed reported that their isolation from others increased during the period when they started caring for a loved one. Some of them stated that they lack contacts with friends, which, for example, are replaced by contacts with neighbors at their place of residence, or they solve loneliness by having pets, or they have tried to look for support – the opportunity to share their situation, experiences and emotions with the provision of care in the form of contact on social networks. They would also welcome the possibility of support in the form of a self-help group.

CPW7 (70–70): *"I can't find a girlfriend. Because I don't go anywhere, right? I'm with my son. I have to go to the store in a hurry. Just go shopping and go home, because he's waiting for me here." "So I've given up on girlfriends. Yes, just me talking to grandmas. I'm just another chatty woman, ain't I, I like to laugh. And I love dogs. I already have a fifth dog…"*

CPW9 (72–72): *"… because you're talking all day with a sick person and here's a woman…, I can talk to her and she knows what I'm talking about. That was the time when I would meet my co-workers and say, 'You girls don't know how much I love seeing you.'"*

CPW17 (128–128): *"For example, there's a group of parents of disabled children on Facebook, and they kicked me out in about a month, because it was just a family where they discussed how to get something, from foundations, from everything…"*

The communication partners also talked about the fact that they would welcome the possibility of support in the form of a self-help group. CPW1 (39–39): *"… I think it could be interesting if the social worker knew about some self-help groups. Where he could direct the guardian to… because he's such a mess sometimes. So if he knew, he could just go to someone, to some group. Yes, I would see it differently and maybe it would even motivate me to say to myself, 'but you can deal with it', or I would feel a certain support there."*

The possibility of growing old together – maintaining contact with the cared-for person

When solving the issue of the future housing of the cared-for person, maintaining contact with the cared-for person was an important topic for the communication partners (Uhlířová and Latimier, 2013: 45). Some communication partners talked about the vision (wish) of the possibility of living together with adult dependents in community housing.

CPW4 (152–152): *"I still have it, maybe it's naive. Maybe it's a dream. I know I'm not so young anymore. But I still hope that it will work out, some kind of community housing. Take five or six kids together, build them a home. The children have pensions, they have care and there will be one or two people, basically adults, or some founder who will lead the agenda. But I would like it in the form of community housing, with parents in the first house and children in the second. That means everyone will live separately, but they can be together, they can go out together and so on, and so no one would have to assume guardianship there, if possible. And basically, if, God forbid, someone dies, the other ones stay there, so they'll still be in some kind of contact with this sort of big family."*

CPW6 (128–128): *"He presented the case of how they took care of their children's future in Finland. The costs were covered by the company that built housing for their children…, it's by the sea, they have semi-detached houses that stand like this next to each other, all around. They have ramps there for those who need them. Well, amazing. I stared in disbelief. I mean, some parents know how to fight for their kids. But here, we simply can't do that."* [laughter]

CPW4 (160–160): *"Of course, it would have to be housing for children who are not in bed all the time. It would have to be set up so that the younger mothers would de facto keep an eye on the older ones. Just a community that would take care of itself."*

That people with mental disabilities can live in the community and participate in its life, which means, according to Esteban et al. (2021), a fundamental change in the provision of support that requires professional person-centered practices. There can also be a situation where, despite the fact that they live in a community environment where there are enough experts, they can spend a large part of their time alone without participating in activities that interest them.

A vision of the future Housing of love one in residential care service

The research also raised the question of why some communication partners saw the future of where their adult child will live more in a residential care, than with their relative at home, either with family or a family friend. The findings of other research shows that parents would prefer an adult member with an intellectual disability to live with another sibling or other relatives in the future. A total of 53 of the 100 research participants preferred this possibility (Strnadová, 2009). Another topic of the interviews was the problem of the unavailability of residential care services, especially for persons with a severe mental disability (cf. Klusáček and Adamcová, 2021; Uhlířová and Latimier, 2013). Some communication partners mentioned the choice of a future home in residential care service as the only option, because they did not see the possibility of handing over care to another person in the family.

CPW6 (28–32): *"I have been applying for a place for 12 years* [indicates a town in the Moravian-Silesian Region] *and we are still waiting for someone there to 'leave forever' so that the child can go somewhere… That's year-round housing for the mentally disabled… And that's a terrible feeling when you have to wait for someone there to vacate so that your child has somewhere to go. And there's no certainty that he'll go straight there right after someone dies, because there are others on the waiting list ahead of you. So the lack of placements within the Moravian-Silesian Region is a desperate situation."*

Conclusions

Social services play an important role in supporting family members in providing care and guardianship for a loved one with an intellectual disability. The findings from the field research, which was carried out in 2021 in 6 municipalities of the Moravian-Silesian Region with 22 family members who provide care and guardianship for a loved one with an intellectual disability, show that family caregivers have minimal opportunity to use respite services due to their lack of capacity, unaffordability or unavailability where they live. This results in their fatigue, the impossibility of getting enough sleep, or having the chance to rest and spend free time with their hobbies and enjoying contacts with friends. As reasons for preferring home care and rejecting the possibility of using social services, family members cited previous negative experience with social services and the fact that social services are not tailored to the client's individual needs. They also drew attention to their insufficient quality.

The communication partners also talked about their social isolation due to having to provide round-the-clock care and the impossibility of sharing that care with another person, as well as the insufficient network of social contacts of their loved one whom they care for, missing relationships with friends and peers. Caregivers replace missing relationships with friends, acquaintances, and other family members with occasional contacts with neighbors, or by looking for opportunities for support on social networks, or in the form of participation in associations they belong to. They also have the opportunity to share their experiences with other caregivers or spend free time with them, e.g., through participation in joint leisure activities or therapy stays.

Another important topic for family members was the question of safeguarding the future home of a loved one in the event that they are no longer able to provide the care themselves ¬– due to the deterioration of their health or death. The idea of safeguarding future housing reflected the wish (vision) of family members to grow old together with a loved one in the form of community housing and to have the possibility of contact. With regard to the current offer of social services and the lack of community or shared housing, the possibility of a future home for a loved one in residential social care was also considered.

The findings show the need to focus on the coordination and networking of support at the community level (rather than individual services) when planning social and follow-up services for people with mental disabilities. That way the individual wishes and possibilities of each client can be taken into account. Person-centered planning is offered as one of the possible solutions. A key aspect when planning support is to focus on shaping the social relationships of the person with an intellectual disability in the community. Home sharing (a form of respite care based on community assistance) is a newly developed form of support in the Czech Republic, which can significantly contribute to the support of caregivers and enable them to find time and space for themselves ¬– while also expanding the possibilities of people with disabilities in establishing natural relationships in the community.

Ethical aspects and conflict of interests

The authors have no conflict of interests to declare.

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Faktory ovlivňující (ne)využívání sociálních služeb – z pohledu rodinných příslušníků z vybraných obcí Moravskoslezského kraje zajišťujících péči a opatrovnictví blízké osobě s mentálním postižením

Souhrn

Úvod: Navzdory tomu, že jsou sociální služby z hlediska pečujících osob významnou formou podpory, stále častěji se v České republice setkáváme se situací, kdy spolu pečující rodiče a člověk se zdravotním postižením žijí ve společné domácnosti až do pozdního seniorského věku či smrti pečující osoby, přičemž jsou sociální služby jimi využívány minimálně nebo vůbec.
Cíl: Cílem příspěvku je představit zjištěné faktory (ne)využívání sociálních služeb z pohledu rodinných příslušníků z vybraných obcí Moravskoslezského kraje, kteří zajišťují péči a opatrovnictví blízké osobě s mentálním postižením.
Metody: Data byla získána prostřednictvím terénního výzkumu, který se realizoval v roce 2021 v 6 obcích na území Moravskoslezského kraje, kdy bylo uskutečněno 12 individuálních a 5 skupinových polostrukturovaných rozhovorů s 22 komunikačními partnery. Analýza dat byla provedena s využitím konstruktivistické zakotvené teorie.
Výsledky a diskuse: Většina komunikačních partnerů preferuje péči o blízkou osobu ve formě domácí péče. Důvodem odmítnutí využívání sociálních služeb je negativní předchozí zkušenost se sociální službou, nespokojenost s jejich kvalitou. Otázky, které řeší rodinní příslušníci při zajištění péče a opatrovnictví, jsou: zvládání náročné péče, únavy, izolace, ztráta sociálních kontaktů s přáteli a rodinou, řešení chybějících sociálních vztahů, budoucího bydlení a zachování kontaktu s opatrovanou osobou.
Závěr: Aby bylo možné zohlednit individuální přání a možnosti každého klienta, je nezbytné se při plánování sociálních a návazných služeb zaměřit na koordinaci a síťování podpory na úrovni obce nad jednotlivými službami. Jako vhodné východisko se nabízí plánování zaměřené na člověka. Nově rozvíjenou formou podpory lidí se zdravotním postižením a pečujících osob, která by mohla efektivně doplňovat síť sociálních a návazných služeb v komunitě, je homesharing (forma odlehčovacího pobytu založeného na komunitní pomoci).

Klíčová slova: mentální postižení; neformální pečující; opatrovnictví; sociální služby

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