

Theses of Doctoral (PhD) Dissertation

Supporting background, caring practices and perceptions of care in narratives of parents of children living with autism spectrum disorder

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I. Aims and theoretic frames of the dissertation, overview of the topic

Care constitutes a fundamental aspect of life. Following the approach of care ethics, we are constantly in a state of caring, being cared for, and caring for others, thus creating a web of mutual dependencies that also serves as the basis for social functioning. Care is just as much action as it is knowledge, just as much work as it is presence and relationship. (Tronto, 1993). My dissertation aims to represent the perspective of care, examining the parenting practices of a particular group of parents, namely those who care for children living with autism spectrum disorder (ASD).

The analysis of the caregiving relationships surrounding children with autism spectrum disorder is closely related to the field of education, including special education, but also to the fields of psychology and social policy. At the same time, the literature on the various dimensions of parenthood has grown quite large in recent decades. Alongside this broad academic interest, there is also an intensive lay discourse on the practice of parenthood, which focuses on the various ways of achieving 'good parenthood'. After all, parenthood is an area that is almost naturally approached from the perspective of practices, i.e. the individual methods and strategies used in child-rearing, and the principles and trends that underpin them. However, in the field of autism research, work on the experiences of parents of affected children and their individual interpretations of their work as caregivers is rare. Thus, the topic of this thesis is related to a less discussed territory.

The parenting experiences of these parents are shaped by social discourses of care, disability, autism spectrum disorder and parenthood and the relating public interpretations.

Taking these into account, the conceptual fabric of the dissertation is determined by three theoretical threads: *the definition of care and the inequalities of care, the determination of parental autonomy experienced in caregiving, and the description of individual parental practices*. Let's see, how these threads form the theoretical pattern of this work!

Caregiving is related to its social context and bounded together with expectations and several culturally coded meanings. Based on my starting point, parenthood is one prototype of caregiving roles. It is a phenomenon made up of activities, feelings, emotions, and traditions surrounded by a

series of social expectations and norms. This perspective raises the question of how caring actors (in this case parents) relate to the current structures and conditions of care, how they act and decide in this space and how they form their self-definitions in it.

Hence caregiving is also an individual and societal resource, which is not evenly distributed among the members of society. Although caring is a universal need, there are large differences in the needs and opportunities for care between people and social groups in a moment and over the life course. The parental role and caregiving tasks of parents of children with ASD are strongly influenced by the lack of care, and the management of care deficit forms a significant part of their parental strategies and also does not leave their parental self-determination unaffected. The experience of parental competence and control over life are essential components of parental identity, directing my attention towards parental autonomy. How do these parents experience their autonomy in caregiving and how does this experience of autonomy manifest itself in their reactions to the lack of care? Care is a network of interdependencies, which is why I also examine the parental autonomy experienced in its relational context, as the relational autonomy approach suggests.

The theoretical reflections on care should embrace the autonomy debate between Disability Studies and care research, hence the social definitions of autism are embedded in the discourses of disability/ability, otherness/difference, dependency/autonomy and understandably do not leave parental experience untouched.

Social definitions of autism are embedded in discourses of disability/ability, difference/difference, and understandably do not leave parental experiences untouched. Therefore, among the theoretical reflections on care, the inclusion of the debate around the concept of autonomy in disability studies and care research in the conceptual web could not be left out. Nevertheless, the discourses of otherness/diversity also affect the social structures of care, so that they can be interpreted in the dimension of inequality.

The individual, everyday caring practices of parents are apt to shed light on the social structures and interpretations that define care that give the context of individual caring pathways. The way parents talk about their day-to-day caring work also shows their ideas and interpretations about their own parenting. This perspective is related to the approach of family practices, a model developed by D. H. Morgan. The model embedded into the theoretical tradition of social practice analysis, implementing this knowledge in the field of Family Sociology.

Taking all this into account, the theses of the thesis and the related research questions are as follows:

- 1. Parenthood, care deficit and difference.** Social inequalities of care are produced and re-produced in the family practices of parents in a variety of ways. The lived care deficit becomes part of the parental self-definition, a source of the experience of atypical parenthood. In developing strategies to compensate for the caring deficit, they can only partially rely on the generally available patterns and methods of parenting.

On this basis, the aim is to understand how care-related gaps and disadvantages are present in the everyday practices of parenting. Relating to caregiving stories of parents, this requires the identification and interpretation of examples of care deficit in parenting narratives. I will also examine the co-occurrence of care deficits and experiences of difference in the texts.

- 2. Meanings of the good parent.** Face with a lack of care, parents' images of good parenting are also constantly under scrutiny. The ideal image of caring is redefined depending on the gaps in care and its resources.

On this basis, the aim is to identify the points at which parents are reflecting on and modifying their images of good parenting.

- 3. Parenting role and care - resources and strategies.** A crucial part of parental caring practices is the management of the care deficit, i.e. the identification, accumulation and use of the necessary resources. I therefore consider the lived care deficit as a boundary-situation in which the resources and strategies of parents become visible. Caregiving itself can become capital that parents invest in maintaining or improving their own caregiving practices or in transforming broader structures of caregiving.

My aim is to understand how narrators construct their own role as caregivers and, related to this, how they present their responses to the lack of care. In line with the theoretical background, the examples of caregiving deficits are the breaking points of parental caregiving stories, and as such, they are boundary events in which parents' resources, crisis

management strategies and problem-solving routines become visible. The narrator's ideas about good care and inclusion/exclusion.

- 4. Parental autonomy and care as capital.** As a consequence of point 2, individual responses to the caregiving deficit also reflect forms of parental autonomy-maintenance or autonomy deficit.

Based on this, the aim is to understand how the experience of parental autonomy is represented in caregiving stories. That is, which scenarios of agency emerge in the parenting narratives and how parents harmonise and interpret care deficit and their care resources.

II. Methodological features of the research

Denzin and Lincoln, in their widely cited seminal work define qualitative research as an autonomous field of research encompassing a variety of data collection and analysis methods, trends and theories, which, as it has evolved over its history, has been increasingly characterised by a blurring of boundaries between methodologies and genres, and between the text and context of research.

These definitions have been the foundations on which I have built my empirical toolkit. The research process and the presentation of the results are essentially based on the criteria of Grounded Theory (GT). The choice of methodology is motivated on the one hand by the research topic, and on the other by my relationship with this topic and the investigated parental group. The position of the researcher defined by the duality of my researcher-parent role, required a bottom-up, field-based research logic, in which personal reflexivity had great role. Thus, the design and conduct of my fieldwork, the sampling method, the development of the analytical strategy, and thus the multi-level process of coding and interpreting the data followed the typical GT process (Mitev & Horváth, 2015).

One of the solutions that deviate from the methodological specificities of GT is the occasional switch between inductive and deductive data analysis methods. The data-driven approach of the analysis would prevail throughout the work, but for some topics (e.g. making sense of intergenerational supportive relationships) I used the theoretical models already known and widely used in the literature as a starting point. In my dissertation, I present the results of two

research processes in two different fields. The data collection phase of the work started in August 2020 and ended in June 2023. During this time interval, several intensive interviewing phases took place, separated by analysis phases. In the first stage, I visited a small settlement in Eastern Hungary, and I conducted semi-structured interviews with the affected parents living there, during personal and online meetings. After that, I contacted the members of a parent group related to a foundation in Budapest, and I continued to conduct interviews with them. A total of two fathers and fourteen mothers were included in the sample. Several conversations were made with two mothers during the research, so the entire database contains a total of 19 interviews. After the verbatim transcription of the interviews, the thematic analysis of the text corpus was performed using MAXQDA 2020 and 2022.

III. Findings

1. Parenthood, care deficit and otherness

The landscapes of care that emerge from the analysis of the interviews are strongly defined by the lack of care experienced by parents, which particularly linked to formal care. It is a prominent theme running through the parenting stories in all the interviews. There are greater differences in the informal support provided to parents. The surrounding family network has the strongest supportive role in the life of parents, while the wider network of friends, relatives and neighbours may be complementary to the former.

In the parental narratives, mothers are the primary caregivers, the majority of caring for and caring about responsibilities are related to them. Activities that express meaning of caring about are mediating, problem-solving, communicative roles. Based on the parental self-reflections and the sections on parenting strategies in the interview texts, fathers tend to associate their parental self-definitions with these. They define themselves as rational problem-solvers responsible for the foundations and stability in the family fabric. Mothers position themselves in a specific centre role. Here I identified three different self-interpretations: *the mediator*, *the bound maker-guide-organiser* and *emotional centre*.

Parents are likely to perform those caregiving tasks in their narrative that are problematised in everyday life. Among the caring for activities, assistance with eating and sleeping, the integration of child development tasks into family life, and home learning are the highly referred examples. Due to the non-typical developmental paths of children, therapeutic activities determine the period of early childhood. In several families there is a recognition that the parent-child relationship was defined by problematization these years. The hegemony of home therapeutic activities over shared time is clearly a source of otherness in parental experiences.

The themes of therapy and learning conducted at home are linked to the themes of finding the right professionals and the right institutions, and managing the child's metaphoric journey to school. The dominance of these themes in themselves highlights the dysfunctions of the support systems surrounding parental care, where most of the problems related to gaps in institutional care and support. Frequent changes in institutions, inadequate forms of support, workload and lack of capacity of professionals working with children, difficulties and constraints in accessing institutions are the main nodes of the problem map. Some parents report regular or prolonged conflicts at a particular stage of their child's pre-school or school career, often due to the two-sided exclusion of children with ASD. They are in a boundary-position: they are not fitting in the neurotypical world around them, while their difference is very difficult to decode for formal care institutions who mostly prepared for the service of ASD children with cognitive disabilities. They are excluded from mainstream institutions because of their autism, and from educational provision for children with autism because of their similarities to the majority. This poses a major problem in finding appropriate educational institutions, support and community spaces.

In parent-professional interactions dominated by conflict, the external rules of parenting and the internal image of parenthood are disrupted, making it difficult or impossible to represent the role of the parent.

In addition, the deficits of the secondary care relations are pushed on the primary sphere. Due to a lack of financial and relational resources, these burdens have to be overcome by parents with other capitals, which also acts as a barrier to the experience of parental autonomy. At the same time, the stories of parents living in small settlement communities also show that services are more locally embedded. The familiarity, subordination and more informal nature of relationships in the local community helps to access information and can improve the chances of accessing appropriate services. Drawing on the approaches to caring poverty presented in the theoretical section (Hill,

2022; Kröger, 2022), we can argue that the parents included in the research live in relative caring poverty, where their caring needs remain unmet to varying degrees. Care poverty is expressed in the absence of adequate formal care. Like caregiving, care deficit is bound up in a web of relationships. The caring needs of parents are intertwined with the caring needs of children, and the accumulation of care gaps in the relational web can further increase the range of caring responsibilities of parents. The increased caregiving work has to be covered by the already scarce caregiving resources of the participants, and the concentrated caregiving deficit may also narrow individual pathways to autonomy.

In addition to “caring for” type tasks, I recorded the “caring about” type activities, too, such as knowledge transfer, friendship management and helping others. These are to provide a kind of boundary crossing to guarantee the child with autism's entry into the mainstream world. The aim of these attempts is to rewrite the meanings and boundaries of otherness and to ensure the community integration of children, which is why I have linked these activities with Georg Simmel's concept of bridge-building.

Strengthening peer relationships, taking on community tasks and some forms of knowledge transfer about autism have such a bridge-building function. The latter is a two-way task. It can be aimed at informal education and 'sensitisation' of outsiders to autism, on the one hand, and at supporting parents in similar situations, on the other. This quasi-professional, advisory role can really be articulated in situations where the shared identity is reinforced in some way, since proximity does not automatically follow from the same life situations. In the search for common ground, parents must take into account that even in this micro-medium of everyday interaction, it is not possible to generalise one's own interpretative schemata, and therefore building bridges is not always possible. The consequence of misunderstandings is the reinforcement of boundaries, isolation and rejection, which is a loss in many ways: it strengthens the stigma of otherness and makes further help impossible.

In parental narratives, the meaning of otherness varies according to the situation. The meaning of ASD is typically not linked to the medical meaning of disability, and the term “otherness” is used in a positive sense, as a synonym for diversity, when talking about the characteristics of their children. In the institutional context, however, the child's autism is thematised as a problem, a difficulty, an obstacle in the dialogue with formal actors, and it also becomes the basis for the parental stigma of troubled, and difference. It is associated with the meaning of abnormality and

exclusion. In this sense, the meaning of ASD is constructed in the social discourses of problematisation, in which personal definitions of good parenting need to be reconstructed.

2. Meanings of the good parent

Based on the above, the various forms of care deficit are interpreted by parents as breaking points where established individual and institutional practices of care do not work and become a source of experiencing otherness. The experience of otherness can be reinforced and institutionalised by interactions between parents and other actors. For example, for parents, the lack of experiencing the *sense of Us* is linked to the image of troubled family reflected by institutions. As a result, personal reference points for good parenting become precarious. In conflicts with the institutions, parents feel they have to prove that they are good parents, or in extreme cases even that they are able to take care of their children. At the same time, they themselves have difficulties in understanding their child's world or in dealing with the specific problems of autism. As a response to formal care deficit, we see a shift in parental expectations from the ideal to the optimal solutions, and in some cases, participants redefine considerations of ideal care.

3. Parenting role and care - resources and strategies

The direct resources mentioned in the interviews relate to several areas, namely adequate formal care, information support, practical help and psychological support. Taking into account the content of the interview texts, adequate formal support, although very important, is not sufficient to make parents feel in control of their destiny and to act in accordance with their values and desires to achieve their goals. If forms of support are limited to a single area, parents are less able to use existing resources effectively in the care process. This may be explained by the fact that the wide inequalities in care lead to so many disadvantages in different areas of social life that this can only be counterbalanced by an interlocking system of institutional, emotional, practical and knowledge support.

Among the supportive relationships within the family, the role of grandparents, especially grandmothers, is the most important, but we must not forget that these are mutually supportive relationships that form the axis of care within the family. Therefore, by looking at the channels of intergenerational support, the main characteristics of parents' care attitudes, and the map of family resources are revealed.

Taking into consideration different factors of intergenerational family solidarity, the most well-balanced parent group is the one with *strong ties* to the older generation, with strong links to grandparents in all dimensions of solidarity, and a gap between them only in terms of knowledge and perceptions of autism.

Not too far from them we find parental stories expressing a close bond too. They show a close bond between parents and grandparents, but because of the death of a grandparent, the family moving away the narrators can no longer, or at least temporarily, rely to on the support of previously important intergenerational relationships. The loss of support is compensated for by other intergenerational relationships within the family (spouse's mother or father) or by redesigned parenting strategies. In this sense, the intergenerational relationship can be called *integrated*.

In the third group of parenting stories, norms governing intergenerational relations are strongly present, regulating the obligations towards older family members. Comparing to the uncertainty of the spousal relationship, the intergenerational link between parents and children is seen as a safe point. Strong emotional closeness is not inherently associated with this family-centred attitude, or even independent of it.

Those parents are the most distanced from strongly tied group who are perceived to be isolated within the family network. The loss or marginalisation of a grandparent who has been an important emotional or caring role before is not compensated. Parents are left alone with their tasks and difficulties, the family universe of care is uninhabited.

Resources are not only supportive factors that reinforce the parents' care within the family, but are sometimes used beyond the family too. Parental caregiving work can be invested in new forms of care that also serve to strengthen social relationships. One example of this is the role of quasi-expert, a recurrent motif in parental narratives, which is divided into two branches of meaning in the texts. The experiential expert knowledge is rooted in expertise in the upbringing and care of children with autism, and is dominated by the practical knowledge that arises from the use of the institutional system. The other strand is based more on an understanding and synthesis-critical

analysis of the theoretical-academic background of autism. Theoretical knowledge combined with lay experience is a capital that is used as transferable capital for parental care, self-care and caring about/for others. Conversion of acquired knowledge into caring for others, however, only occurs for mothers with a higher educational degree.

Other examples of care capital can be identified in the texts. Parents who have sufficient resources to compensate for the care deficit, beyond their individual caring roles, attempt to 'reprogram' the majority definitions of otherness associated with autism. They also seek to reorder the carescape map, for example by creating a new institution. But very few families have the capacity to do this. Through the example of a single interview, we see that the accumulated relational, material and knowledge capital also only allows for the 'export' of the care deficit, i.e. the new facility created creates gaps in care elsewhere.

4. Parental autonomy and care as capital

Several forms of autonomy behaviour can be identified in the texts, such as a sense of control and related self-discipline, self-control, flexible adaptation and creativity for successful problem solving, advocacy, standing up for personal causes and principles, and examples of innovation and entrepreneurship. In addition to all this, the experience of autonomy can be linked to a kind of negativism, i.e. it can be embodied in resistance, in rejecting, criticising and confronting stigmatising practices based on a tragedy narrative.

On the one hand, the social determination of autonomy is expressed in the way in which the social situation of individuals, their resources and the current social milieu shape their access to the resources of autonomy. In addition, these social patterns are also reflected in the perception of autonomy, which is constructed through interaction with others. An example of this is the phenomenon that I described as the *autonomy trap*. Those parents who appear to be 'well-trained' and knowledgeable managers during meetings with professionals, perhaps they are literally professionals in the field of ASD or education of children with special needs, are left alone with their problems because professionals working with children assume a level of knowledge or emotional preparedness that is not available to these parents. A stronger representation of parental

autonomy may mask the real parental needs in the supportive formal (or informal) relationship system.

In examining the relationship between the experience of parental autonomy and the lack of care, the interviews show that the care deficit does not only mean that a family or child does not have access to adequate formal or informal care. These gaps reach down into the deep layers of everyday parenting practices, permeating the temporal and spatial strategies of the caring parent and all family members, from experiencing home space, to family division of labour or future scenarios. As Bowlby and his co-authors point out in their concept of a caring landscape (Bowlby, 2012), parents compensate for these gaps by developing new spatial and temporal strategies. Based on the analysis of the interviews, we also see that their strategies include substituting missing actors, either in person or by mobilising informal relationships. Spatial, temporal and actor strategies, if successful, become a source of parental autonomy experience.

5. Conclusions

The results of the research show that the narratives of the parents are dominated by the narrative of the struggle between the families and the formal care system, even though these actors are mutually dependent on each other. Parents' advocacy work, their quasi-expert knowledge, seems to be little utilised in the formal care system for children. Yet the capital accumulated in parental care can help to alleviate the deficit in formal care. However, this would also require an understanding of parents' capacities and support needs when designing formal care. One possible way to strengthen the experience of parental autonomy is to provide services of relief. Such benefits could not only help to manage long-term care work of parents but could also reduce spatial inequalities and barriers to access to care. A common feature of adequate formal care was personalisation and the availability of a professional who could be contacted with day-to-day problems. Frequent changes in formal care make it difficult to develop a permanent parent-professional relationship based on personal trust.

An important conclusion for the field of educational research may be that there are some parental groups whose needs remain hidden, more invisible than others. Single parents, parents with multiple caregiving responsibilities are clearly among these, but the 'absence' of fathers is also

conspicuous both in terms of research and in terms of services to support affected parents. The literature on the experience of fatherhood is growing, but there is a lack of research on fathers of children with autism. Greater research attention to these groups could help to ensure that their needs and perspectives are reflected in wider social and policy discourses as well.



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List of publications related to the dissertation

Hungarian book chapters (1)

1. **Nagy, É.**: Fogytékossággal élő gyermekeket nevelő családok.
In: Társadalom, család, egészség : családtudományi alapismeretek. Szerk.: Feith Helga Judit, SE-ETK, Budapest, 84-100, 2018. ISBN: 9786155855054

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