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Thematic Article

Supporting Background, Caring Practices and Perceptions of Care in Narratives of Parents of Children Living With Autism Spectrum Disorder

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Abstract

This study explores the childrearing practices of parents raising children with autism spectrum disorder (ASD), using D. H. Morgan's family practices framework (Morgan, 1996, 2001, 2002, 2004, 2011), the concepts of care capital and Bowlby's thoughts on caringscapes (Bowlby, 2012, 2017, 2019). It also addresses questions of care and autonomy within the context of disability. The author's dual role as both researcher and parent plays a significant part in the research process. Using Grounded Theory methodology, the study involved 19 interviews with Hungarian parents of children with ASD. The findings reveal that parenting practices are shaped by the lack of formal care. Deficiencies in institutional support shift additional care responsibilities to the primary sphere of care (Lynch, 2007), intensifying parental care burdens. Parents are forced to stretch already limited resources, which can restrict both their own and their child's experience of autonomy. Furthermore, the availability of formal care alone does not ensure a sense of agency or control for parents. Some parents with greater resources extend their roles beyond individual caregiving. They challenge dominant perceptions of autism and strive to reshape local caringscapes, effectively "rewriting" societal understandings of otherness and disability.

Keywords: parenthood; care; care deficit; autonomy perception; children living with ASD; insider research

Introduction

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 encompasses action and knowledge alike; it is both labour and relational presence. According to the popular care-definition "a species of activity that includes everything we do to maintain, contain, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment" (Tronto, 1993, p. 103). The various care-definitions consistently underscore inherently social character and cultural embeddedness of care. At its core lies the relationship between the caregiver and the care recipient. However, once care is set into motion—transformed into concrete action—the intricate network of caregiving is revealed, consisting of mutually interdependent care relationships. Within this network, the caregiver's personal disposition is shaped not only by their value system related to helping and altruism and by their socialization, but also by a culturally and socially encoded system of norms governing mutual solidarity (Broese van Groenou & De Boer, 2016). Parenthood is one prototype of caregiving roles, a phenomenon that embraces work, emotions, competency, memories and traditions. Adopting this complex care perspective, I examine the parenting practices of a specific group of parents, namely those who care for children living with autism spectrum disorder (ASD).

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This topic remains underexplored in existing literature, as the complex care-perspective is rarely used in understanding the experiences of parents of children with ASD within the scientific realms of educational sciences or autism research. The analysis of caregiving relationships involving parents of children with ASD naturally intersects with educational fields, particularly special education. 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 parenting, which focuses on the various ways of achieving 'good parenthood'. After all, this is an area that is almost routinely 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. (Daly, 2017; Betz et al. 2017; Lee et al., 2014). However, with the help of conceptually rich term of care, the horizon of understanding can be further broadened in understanding parental practices and positions.

The theoretical framework of my research is based on three pillars that represent the main conceptual fields: care theory and its interference with disability theory; the capital approach of care inequalities; and notion of autonomy in parenting and family practices. Based on the connections between the aforementioned theoretical realms, the following correlations were formulated, which determined the conceptual direction of the study.

(1) The social definitions of autism are embedded in discourses of care and disability/ability, difference/difference, and understandably do not leave parental experiences untouched. The care of children with ASD is basically thematised in the social discourses of exception and “trouble” (Kittay, 1999; Goddard et al., 2000, Francis, 2012, 2015; Morgan, 2019). Even the language of last decade scientific research on families and disability mirrors the burden-narrative, that is rooted back to the tragedy approach of medical model of disability (McLaughlin, 2020). Among others, source of exceptionality emerges from the confrontation with the challenges inherent in caregiving (often rooted back to the lack of support and secondary care (Lynch, 2007), during which normative parental ideals of 'good care' are problematized. This occurs as a consequence of the destabilization of the balance between intra-familial informal care and the external, institutional or community-based spheres of caregiving.

(2) Nevertheless, the discourses of otherness/diversity also affect the social structures of care, so that they can be interpreted in the dimension of inequality.

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, can be considered capital, which is not evenly distributed among members of society. Although caring is a universal need, there are large differences in the requirements of, access to, and opportunity for care between people and social groups in a moment and over the lifetime. Care as a capital and other forms of capital (e.g. social capital) can be converted to one another, and its redistribution is occurring alongside the power-relations of society (Lynch, 2007; Huppatz, 2009; O’Brian, 2009; Brisson, 2009; Nica, 2022). Care deficit (Hochschild, 1995) and care poverty (Kröger, 2022) affects different segments of society, and we can identify its unique patterns in families raising children with ASD. The parental role and caregiving tasks of parents of children with ASD are strongly influenced by the experience of care deficit. Its management forms a significant part of their parental strategies and also shapes their parental self-determination. The individual moral aspect of care is strongly tied together with care related social inequalities.

(3) 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 (Mackenzie & Stoljar, 2000; Ells et al., 2011). To put it to another way, our interconnectedness is a prerequisite of autonomous action and choice, and at the same time, we recognise ourselves as autonomous actors through our relationships with others.

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, expresses competencies and sources of autonomy. This perspective is related to the approach of family practices, a model developed by D. H. Morgan (Morgan, 1996, 2001, 2002, 2004a, 2004b, 2011a, 2011b). 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, my research questions are as follows:

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

Based on these assumptions, my first research question is: *How are care-related gaps and disadvantages manifested in the everyday practices of parenting?* Focusing on parents' caregiving stories, 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.

2. Meanings of the good parent. Faced with a lack of care, parents' images of good parenting are also constantly under scrutiny. The ideal image of care may shift depending on the gaps in care and its resources.

Accordingly, my second research question is: *At what points do parents reflect upon and modify 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 consider the lived care deficit as a liminal moment, when a rupture emerges in everyday practices of care, and the resources and strategies employed by parents of children with ASD become visible. Caregiving itself may be conceptualized as a form of capital - an investment parents make to sustain or enhance their own caregiving practices. In some cases, it may also serve as a means to challenge or reshape broader caregiving structures.

Building on this, my third research question is: *How do narrators construct their own roles as caregivers, and how do they describe their responses to the lack of care?* In line with the theoretical background, the examples of care deficit are breaking points in 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. Following from point 2., individual responses to caregiving deficit also reveal forms of parental autonomy-maintenance or autonomy deficit among parents.

Referring to the theory of care capital and its correspondence with parental autonomy my fourth research question is: *How is parental autonomy represented in caregiving stories, and which scenarios of agency emerge in these narratives?* That is, which scenarios of agency emerge from the parenting narratives and how parents harmonise and interpret care deficit and their care resources.

Hungarian context of ASD and parental care

Although autism research in Hungary dates back to the 1980s, little attention has been given to the experiences of parents raising children with ASD. A comprehensive study was conducted in 2009 on the needs of individuals with ASD and their families, as well as their access to healthcare, social, and educational services. As part of this project, Tobak analysed the sociodemographic characteristics of families raising children with ASD. She found that mothers were typically primary caregivers, and the proportion of single mothers was slightly higher than in the general population. Families with higher educational attainment were overrepresented in the sample, which can largely be explained by the fact that individuals with higher qualifications are more easily mobilised and more adept at asserting their interests (Tobak, 2012).

Over the past decade, scientific interest in families raising children with ASD has grown. The work of the Autism in Education Research Group, established by the Hungarian Academy of Sciences and ELTE University, is considered a milestone in this field. Among other topics, the group has examined the quality of life and psychological well-being of children with ASD and their parents. In addition to online questionnaire surveys, the researchers also conducted interviews, compiling a heterogeneous sample that considered age, socioeconomic status, place of residence, and the age and support needs of the affected children. Their findings show that the quality of life and psychological well-being of parents raising children with ASD are significantly lower than those of parents raising neurotypical children, especially for those caring for children with high support needs or for adult children. Moreover, the quality and distribution of services provided by the care system vary widely and are often difficult to access. Satisfaction with services strongly influences parental quality of life—much more so than in families raising neurotypical children (Stefanik, 2021; Volgyesi-Molnar et al., 2025). Given the growing number of individuals with ASD in Hungary (KSH, 2022), inequalities in access to care are also expected to increase, widening the gap between families.

Research design and methods

Denzin and Lincoln, in their widely cited seminal work define qualitative inquiry 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 (Denzin & Lincoln, 2005).

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 (Corbin & Strauss, 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. 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 conducted in-person and online semi-structured interviews with the parents living in an Eastern Hungarian village. Their children attended the same special education primary school which was run by a local NGO. After that, I contacted the members of a parent group related to an NGO in Budapest, and I continued to conduct interviews with them. Parents of both samples have children with ASD with average intellectual abilities. A total of two fathers and fourteen mothers were included in the sample. More than one interviews were recorded with two mothers, so the entire database contains a total of 19 interviews. Only one parent per family was interviewed, and siblings and children with ASD were not interviewed. After the verbatim transcription of the interviews, the thematic analysis of the text corpus was performed using MAXQDA 2020 and 2022. A total of 1904 minutes (about 30 hours) of audio material was collected during the data gathering phase. All the interviewees gave their written consent to the recording of the interview, and we also jointly recorded in writing the form in which the interviews could be used.

The interview protocol was organized around seven principal thematic domains. Each interview started with a brief self-introduction, followed by an overview of the family's current circumstances. Parents were then invited to relay how they felt when their child received an ASD diagnosis and to reflect on how they would go about parenting, including their interpretations of family life, intra-familial relationships, and parenting practices in the context of ASD. Subsequently, participants were asked to discuss issues of help and support, addressing their perceived needs, available resources, and forms of reciprocal exchange, as well as their connections with secondary care networks, such as neighbours, friends, and the local community. Considerable attention was also devoted to the role of local services and institutional actors, which parents identified as significant determinants of their support experiences. Within this domain, they were asked to describe their children's educational pathways and to reflect on their interactions with professionals throughout the school careers of their children. Finally, the interviews concluded with a forward-looking component, in which parents were invited to articulate their future plans, expectations, and prospects.

In addition to the traditional interview format, in one case I also used a reflective interviewing technique, the photo interview method, which helped me to ponder important events that took place between two meetings with the same mother. Three longer interviews were conducted with her over a two-year period. The year between the second and third interviews was a very busy time in the family's life, with many changes and challenging transitions. It was therefore agreed with the mother that we would discuss the events of the past year with the help of a review of her photographs stored on her mobile phone. Documenting interesting or significant events of the day in pictures and sharing the pictures with each other was an important channel of communication for the mother and her husband, so the narrative through the photos was not unusual to her. Prior to the interview, she selected the most relevant images, arranged them in order, and during the interview she went through them, explaining the background of their creation, their meaning and significance. The resulting visual recollection and the built-on personal narrative gave the mother the opportunity to look back at the events of the period, but also to cut these events away of their particularity and to place them in a broader context of the parenting experience.

The coding process started with the identification of three main structural dimensions of the parental narratives: spatial (places, spaces, geographical aspects, etc.), time (past, present, future, milestones, ruptures in time) and actor (formal and informal participants) references. I afterward defined codes and code-categories going sentence by sentence in the interview texts following the focal points of my research questions. In the iterative process of coding the most important thematic nodes were the next: parenthood, agency, support for parents and resources, problems, interpretations of otherness, time, spatiality, caring work of parents, actors. This code-structure has been improved throughout the analytical process; however, it signifies dominant themes and their relationships in the interviews.

Results

Sociodemographic status of the parents

To understand the context of the interviews, it is worth reviewing the main sociodemographic characteristics of the two subsamples. In terms of parental status, the Budapest-sample is more homogeneous comparing to the rural sample. In this group, all parents work full-time, except for one mother who, although she has a regular job, is unemployed from time to time because of the lack of childcare in the family. One of the ten parents has a high school diploma; the others have a university degree. Of the six parents in the rural sample, only one father was working full-time, one mother was on maternity leave at the time of the interview and did not plan to return to work because her child with ASD was studying with her at home. In this parent group, one participant has higher education degree, two have a high school diploma, and three parents have a vocational qualification without a high school diploma.

Three mothers of the rural sample are divorced and raising their children alone, the fathers are not or only very little present in the family's life, their role is completely peripheral. Three of the parents are married, one of whom is currently in her second marriage. In the Budapest sample, three parents are separated, one of them is divorced, but the former partner takes a very active role in the upbringing and care of the children. The majority of families do have more than one child: the proportion of only children is higher in the Budapest-sample (four out of ten families, compared to one in six in the rural sample), where two families have a sibling living with ASD. In the rural sample, three families have three or more children, but in two cases one of the siblings is an adult and does not live in the parental household. Among the families with ties to Budapest, there is one family with three children. In this group, parents are slightly older (median age 47, youngest parent 41, oldest 61; in the rural group, median age 40, oldest parent 53, youngest 40), with a higher median age of parenthood (rural sample 31, Budapest sample 35.8). The age of children is also higher in the Budapest-sample (median age 5 years in the rural sample, 12.5 years in the Budapest sample).

Based on status characteristics, the group of parents in the rural sample is not only more heterogeneous, but also more vulnerable. Labour market uncertainty, difficulties experienced due to single-earner households and single-parent families intersect for several cases in this group. In addition, the theme of financial deprivation is also more prevalent in these texts.

It is important to mention that the patterns of parental educational attainment and socioeconomic status align with previous Hungarian research results, suggesting similar trends in parental activism and mobilization. At the same time, socioeconomic inequalities may predict the presence of gaps in available care services and resources.

Dimensions of research questions

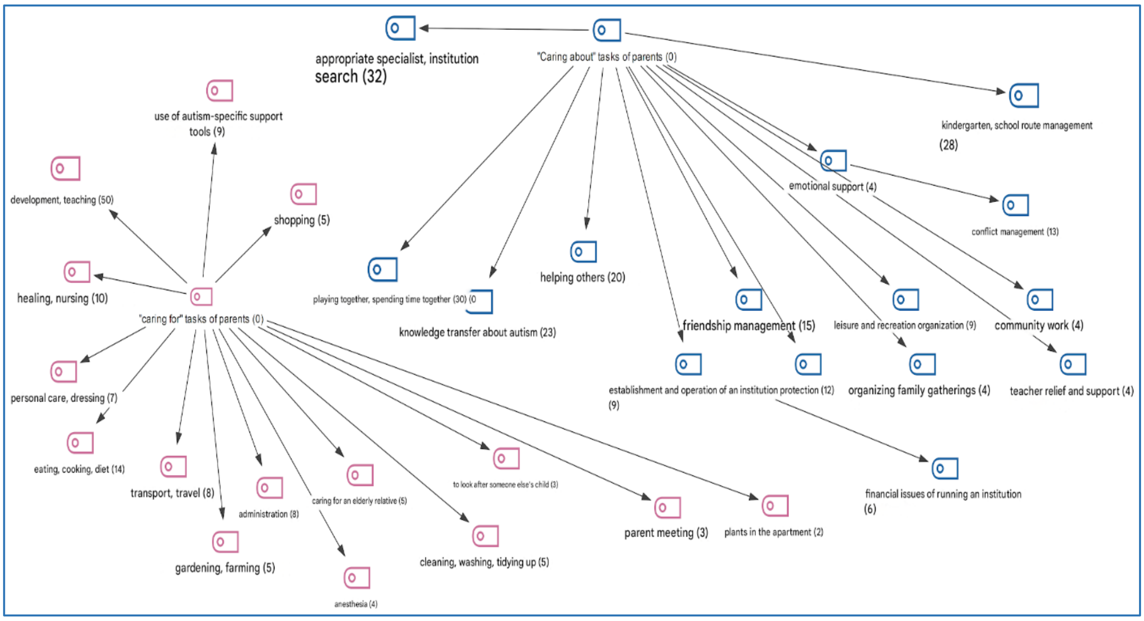
Parenthood, care deficit and otherness

The landscapes of care that emerge from the interview analysis are strongly shaped by the lack of care experienced by parents, particularly in relation to formal care. This theme runs prominently through all the parenting narratives. Differences are more noticeable in the realm of informal support: while the immediate family network plays the most supportive role in parents' lives, the broader circle of friends, relatives, and neighbours tends to offer only complementary support.

In the parental narratives, mothers are depicted as the primary caregivers, with the majority of both "caring for" and "caring about" responsibilities falling on them. Activities reflecting "caring for" - such as everyday housework, feeding, bathing, dressing, and administering medical care (see pink-highlighted words in Figure 1) - are typically physically demanding and involve bodily contact. In contrast, “caring about” encompasses roles involving mediation, problem-solving, and communication (see blue-highlighted words in Figure 1). Fathers often associate their parental identity with these latter roles, portraying themselves as rational problem-solvers responsible for maintaining family stability. Mothers, by contrast, tend to describe themselves at the centre of caregiving, fulfilling one of three key roles: mediator, bond-maker/guide/organizer, and emotional anchor.

Parents most often perform caregiving tasks that have become problematic in daily life. Among “caring for” activities, assistance with eating, sleeping, integrating developmental tasks into family life, and helping with homework are frequently mentioned. Given the atypical developmental trajectories of many children, therapeutic activities dominate early childhood and often redefine the parent–child relationship during these years. The overwhelming focus on home-based therapy frequently eclipses opportunities for shared time, reinforcing a sense of otherness in parents' experiences (Figure 1).

Figure 1. Codes of caregiving tasks mentioned by parents (by frequency of codes)



Themes related to therapy and home learning are closely tied to the challenges of finding appropriate professionals and institutions and managing a child's daycare or school trajectory. The dominance of these issues highlights dysfunctions in the support systems surrounding parental care. Problems include institutional instability, inadequate support, professional burnout, limited access, and bureaucratic obstacles. Parents often report prolonged or recurring conflicts with institutions, frequently caused by the dual exclusion of children with autism spectrum disorder (ASD). These children occupy a liminal space: they do not fit easily into neurotypical environments, yet their differences are difficult for formal institutions—primarily designed for children with cognitive disabilities—to interpret and accommodate.

These children are often excluded from mainstream schools due to their neurodivergence yet are simultaneously not accepted into special education programs designed primarily for those with intellectual disabilities. As most ASD-specific schools open to children with cognitive impairments, those with average or above-average learning abilities are left without appropriate options. This creates serious barriers to inclusive education, community belonging, and long-term support. The resulting conflicts often revolve around rejection, stigma, and the struggle for recognition.

In parent–professional interactions characterized by conflict, both the external norms and internal image of parenthood are disrupted, making it difficult or impossible for parents to enact or defend their parental roles. Furthermore, the deficits of secondary care systems shift the burden onto primary caregivers. Without sufficient financial or relational resources, parents must compensate using other forms of capital—creating additional barriers to experiencing autonomy in their roles.

Notably, parents in smaller communities often describe services as more locally embedded. In rural settings, the familiarity and informality of social relations can facilitate access to information and increase the chances of finding appropriate support. Drawing on the concept of care poverty (Hill, 2022; Kröger, 2022), we can argue that these parents live in a state of relative care poverty, in which many of their caregiving needs go unmet. Like caregiving itself, care deficits are embedded in relational webs. The unmet needs of children and parents are interwoven, and accumulating care gaps can expand parents' responsibilities. These demands must be met with already scarce resources, further narrowing the pathways to parental autonomy. In extreme cases, isolation can become so severe that it depletes parents' mental reserves.

"And then came Covid. And then this quarantine period started. Well, that was another horror for the child, because she had needed the company of other children since she was very small, and suddenly she was cut off from everyone. And we couldn't keep in touch with anybody—everyone just went numb. She was literally going crazy, and we didn't get any help. So this online education… whenever I hear that word, my brain explodes. Nothing worked. The teacher didn't do anything; she just sent me a page of numbers: 'Do this!' That was online education. Nothing else. And all this while I was working online myself. I had to work and teach the child somehow. I was so freaked out I literally threw and broke a chair. My brain was shattered" (Renata, Pos. 63).

"Caring about" type caregiving tasks include knowledge-sharing, friendship management and helping others. These often serve as boundary-crossing practices, enabling children with autism to enter the mainstream world. Such activities aim to redefine the meanings and boundaries of otherness and promote inclusion, echoing Georg Simmel's concept of bridge-building (Simmel, 1994).

Strengthening peer relationships, taking on community tasks and some forms of knowledge-sharing 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. However, this quasi-professional role is only effective when a shared identity exists. Commonality in life situations does not automatically lead to connection, and parents often find that their interpretive frameworks are not easily generalizable, making bridge-building a complex process. 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 with other parents is not always possible.

"My husband once got into such a difficult situation at the playground, there was a kid downstairs running around like crazy and he (the husband) approached this mum and asked her kindly what was wrong. He was completely just wanted to know, that .... finally, a kid like mine - and the mum - she was affected probably - freaked out at how my husband was talking. And then we vowed that now if it didn't develop into a "your kid too" kind of thing on its own, we wouldn't initiate it" (Erika, Pos. 318).

Such misunderstandings reinforce boundaries and deepen isolation. They also perpetuate stigma, making mutual support more difficult.

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 stigma of troubled, and different. 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.

Meanings of the good parent

As discussed above, various forms of care deficit are perceived by parents as critical breaking points -moments when established individual and institutional practices of care fail. Exclusion from adequate care becomes a source of otherness - a feeling of not belonging - which may be reinforced and institutionalized through interactions between parents and other actors. In parental narratives, the absence of a "sense of Us" is closely tied to the image of a "troubled family" (Francis, 2012) as mirrored back by institutions. As a result, personal reference points for what constitutes good parenting become unstable. In conflicts with institutions, parents often feel compelled to prove that they are good parents - or, in extreme cases, that they are even capable of caring for their children.

"And then we ended up going to S., because even in K. they thought we were completely stupid, because no matter how much I explained, they always read the papers, believed what was written there, that it was true, and that I was lying" (Laura, Pos. 51).

“I tell you, she is aggressive because she imitates, because she sees that this is the you survive. And still, it fell on deaf ears. You're constantly being questioned, and we ended up in such a fight with the school because of it” (Renata, Pos. 55–57).

“Well, when I received the letter, it was just sitting in the mailbox, telling me to be prepared for an inspection at any time. They cited the law and the complaint. Uh-huh. That was a very bad experience. I knew, in my mind, that I hadn’t done anything wrong - and that if someone came to the house - even though my husband and I were divorced and the children were in joint custody - both of us were clean, responsible parents with well-adjusted kids. A super, social and materially stable family. So really, there was no child endangerment whatsoever. I knew they wouldn't find anything, but I was still very scared. (...) I don't know, it's like... it must be some primal fear - a primal fear of exclusion, or even just the possibility... the possibility that I could be questioned about whether I’m providing adequately for my children as a mother. It was horrible” (Lívia, Pos. 77).

At the same time, they themselves have difficulties in understanding their children's world or in dealing with the specific problems of autism. In response to the formal care deficit, we observe a shift in parental expectations from the ideal to the optimal solutions, and in some cases, participant redefine considerations of ideal care.

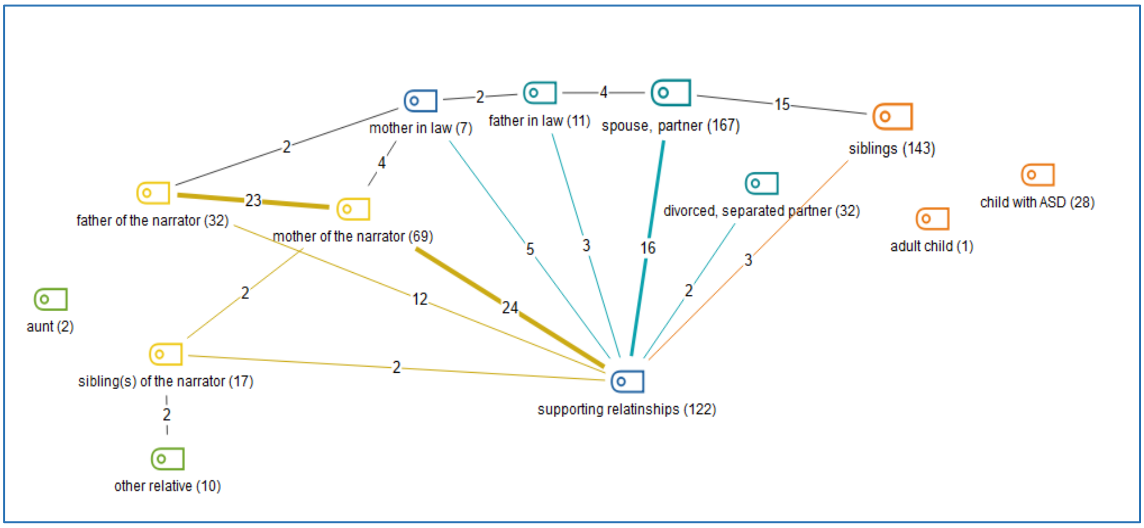
Parenting role and care - resources and strategies

The interviews reveal that the direct resources available to parents relate to several key areas: adequate formal care, informational support, practical assistance, and psychological support. While adequate formal support is undeniably important, it alone is not sufficient to enable parents to feel in control of their circumstances or to act in alignment with their values and aspirations. When support is limited to just one of these areas, parents often struggle to use available resources effectively in the caregiving process.

This may be due to the fact, that significant inequalities in care give rise to multiple disadvantages across various aspects of social life - disadvantages that can only be mitigated through an interconnected system of institutional, emotional, practical, and informational support.

Within the family, supportive relationships play a vital role, with grandparents - particularly grandmothers - often providing key support. However, it is important to emphasize that these are mutually supportive relationships, forming the core axis of care and solidarity within the family unit (Figure 2).

Figure 2. Supporting relationships of parents



An examination of intergenerational support channels reveals key characteristics of parents’ caregiving attitudes and provides a broader map of family resources.

Among the various forms of intergenerational family solidarity, the most balanced group of parents are those with strong bonds to the older generation - particularly to grandparents. These ties extend across all dimensions of solidarity, with the only notable gap being in knowledge and perceptions of autism.

Close behind them are parental narratives that also reflect strong emotional and practical ties to grandparents. However, in these cases, support has become unavailable - either due to the death of a grandparent or family relocation. Although parents can no longer rely on these previously crucial intergenerational relationships, the loss is often mitigated through other forms of familial support (e.g. from the spouse's parents) or by adopting revised parenting strategies. These relationships may be described as integrated - demonstrating flexibility and adaptation within the broader family network.

In the third group of parenting narratives, intergenerational norms play a central role. These norms dictate obligations toward older family members, often emphasizing duty and respect. In contrast to the uncertainty of spousal relationships, the parent–child intergenerational link is seen as a stable point. However, strong emotional closeness is not necessarily a feature of this model.

At the other end of the spectrum are parents who appear isolated within the family network. In these cases, the loss or marginalization of a grandparent who once played a significant emotional or caregiving role is not compensated by other relationships. These parents are left alone with their responsibilities and challenges - their family's universe of care is effectively uninhabited.

Resources, however, are not confined to intra-family support. They can also be extended outward. Parental caregiving efforts are sometimes invested in new forms of care that simultaneously strengthen broader social ties. A key example is the role of the quasi-expert - a recurring theme in the narratives. This role takes two main forms. The first is experiential expertise, grounded in hands-on caregiving and the navigation of institutional systems. This knowledge is primarily practical. The second form reflects a more analytical and theoretically informed understanding of autism - an integration of academic knowledge with lived experience. This hybrid of lay and scholarly insight becomes a transferable form of care capital, benefiting not only the family itself but also wider networks of support and advocacy.

However, this transformation of knowledge into outward-facing care - caring for others- is primarily observed among mothers with higher levels of education.

Other instances of care capital also appear in the narratives. Some parents, when sufficiently resourced to compensate for formal care deficits, go beyond individual caregiving. They attempt to challenge dominant definitions of otherness associated with autism and reshape the caringscape - for example, by creating new institutions or services. Yet only a small number of families possess the capacity to do this. Even then, as illustrated by one interview, the accumulation of relational, material, and knowledge capital may only allow for a relocation- rather than a resolution -of the care deficit. The newly created service may fill a gap for some, but it can simultaneously create new gaps elsewhere.

Parental autonomy and care as capital

The interviews reveal several forms of autonomous behaviour, including a sense of control, self-discipline, self-regulation, flexible adaptation, creative problem-solving, advocacy, standing up for personal principles, and even examples of innovation and entrepreneurship. Alongside these expressions of agency, the experience of autonomy can also manifest in a form of negativism - expressed through resistance, rejection, criticism, and confrontation of stigmatizing practices rooted in tragedy-based narratives of ASD.

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. One illustrative example is what I describe as the autonomy trap. Those parents who appear to be 'well-trained', competent and knowledgeable managers during meetings with teachers, psychologists, etc., perhaps 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 always available to these parents. A stronger representation of parental autonomy may mask the real parental needs in the supportive formal (or informal) relationship system. When examining the relationship between parental autonomy and the lack of care, the interviews demonstrate that care deficits extend beyond the absence of adequate formal or informal services. These gaps penetrate deeply into the everyday fabric of parenting, shaping the spatial and temporal strategies employed by parents and other family members. The effects range from how families experience and inhabit domestic space, to the internal division of labour, and even to the way they imagine future life scenarios.

As Bowlby and co-authors emphasize in their concept of the caringscapes (Bowlby, 2012), parents respond to care deficits by developing alternative spatial (improvement in spatial mobility, establishment of new supportive spaces), and temporal strategies (flexibility in time management, structuration of time, time harmonisation between family members). Our interview analysis also supports that many parents compensate for absent actors by mobilizing informal relationships or substituting their roles in other ways. When these spatial, temporal, and relational strategies are successful, they not only help manage caregiving challenges - they also become a meaningful source of parental autonomy.

Discussion

According to the findings of the interview analysis, an important takeaway is the extent to which parental narratives are shaped by an ongoing struggle between families and the formal care system - even though informal and formal care actors are inherently interdependent. As shown in the stories shared, parents' advocacy efforts and their quasi-expert knowledge are rarely recognized or effectively utilized within formal care systems. Referring to the results of second research question parents often feel compelled to prove their capability of caring for their children, so the identity of parenthood is shaped by the often-conflicting interactions with the formal caregiving institutions.

Relating to the answers to the third research question, yet the capital accumulated through parental caregiving - emotional, practical, and knowledge-based - has the potential to help alleviate gaps in formal care. Realizing this potential, however, would require formal systems to acknowledge and integrate parents' capacities, experiences, and support needs into the design and provision of services for children with autism. For instance, the cumulating caring roles of parents, and the ways in which caregiving responsibilities are distributed within families, are often overlooked. Parenting training programs and peer support groups organized outside of the state care infrastructure can offer valuable foundations for building a peer-based parental support network. However, many parents lack the time, energy, or financial resources to participate in such initiatives consistently and sustainably.

In accordance with the findings relating to the fourth research question, one possible reinforcement of parental autonomy could be the relief of burdens, which the parents concerned can only count on if there is someone in the informal network of contacts who can offer help from time to time. Relief services can help affected parents and their children not only to cope with concentrated and long-term care tasks. Inequalities and barriers in spatial access to care could also be reduced if services were available to help with transport, travel, nursery and schooling for affected children. Parents' spatial and temporal strategies highlight the effort that is often required to travel a distance of 20 - 30 km, especially for families in already vulnerable situations, where the whole family's time and rhythm of life is determined by the transport of the child with autism, in the absence of a car or adequate public transport. As demonstrated above mostly mothers are the primary caregivers, with the majority of both “caring for” and “caring about” responsibilities falling on them, especially management of teaching and logistic of educational background of their children. Relating to the first research question, the gender-specific patterns of caring work shed light on intra-family care deficit, too.

A common feature of the formal support that parents found was its personalized nature and the presence of a professional who could be contacted for everyday practical concerns. While most parents reported receiving some information at the time of diagnosis, few had continued access to a professional who could monitor their child's development and support them beyond that initial stage. Such ongoing, adaptive support was typically found only in private care settings, where professionals were more likely to be familiar with the family's broader circumstances and responsive to their evolving needs.

Some parents are even more invisible than others, and their situation, needs and experiences are even more hidden. Single parents, parents with multiple caring responsibilities are clearly included, but the 'absence' of fathers is also noticeable, both in terms of research and in terms of services to support affected parents. Greater research attention to these groups could help to bring their particular needs and perspectives into wider social and policy discourses.

The limitations of this study also related to the problem of invisibility of various parent groups. The findings of this paper reflect only a specific segment of parental life situations, owing to the overrepresentation of mothers with higher educational attainment and middle-class backgrounds. According to the results, low socioeconomic status (SES) profoundly influences parents' options and decisions; however, the sample's lack of greater diversity restricts deeper insights into these effects and prevents generalisation of the results. More focused research on these factors could refine our understanding of parenting strategies among families raising children with ASD.

Conclusions

The primary aim of this paper is to illuminate the unique caregiving experiences of a group of parents raising children with special needs. The conversations, narratives, and parenting journeys shared in the interviews revealed that the experiences of typical and atypical parenting are not separate. Instead, they can form a shared horizon - one that holds the potential to become a source of mutual strength, if we are willing to cross the boundaries of difference. One way to achieve this is through the exchange of diverse parenting perspectives, which lies at the heart of this work.

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Appendix

Table 1. Main characteristics of the participants

Fictitious name	Interview recording time	Area Sample	Gender and age of the affected child
Laura	April 2021	Rural sample	Boy, 9 years old
Ancsa	Aug 2020	Rural sample	Boy, 13 years old, two interviews
	Aug 2022		
Erzsi	March 2021	Rural sample	Boy, between the ages of 5 and 6, three interviews
	Aug 2021		
	Aug 2022		
Vanda	March 2021	Rural sample	Boy, 9 years old
József	Aug 2020	Rural sample	Boy, 11 years old
Brigitta	March 2021	Rural sample	Boy, 4 years old
Zita	Aug 2022	Budapest sample	Boy ,9 years old
Erika	April 2023	Budapest sample	Girl, 9 years old
Lili	April 2023	Budapest sample	Boy, 13 years old
Renáta	May 2023	Budapest sample	Girl, 9 years old
Valeria	May 2023	Budapest sample	Two boys 14, 16 years old
Melinda	May 2023	Budapest sample	Two boys aged 14, 17
Lívia	May 2023	Budapest sample	Girl, 12 years old
Zoltán	May 2023	Budapest sample	Boy, 14 years old
Patrícia	May 2023	Budapest sample	Boy, 13 years old
Anna	June 2023	Budapest sample	Boy, 13 years old