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Supporting resilience for autistic children and their families: appreciating the roles of grandparents

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Autistic children are confronted with many challenges in their daily lives. These include coping with sensory sensitivities, managing emotional regulation, and navigating social interactions. When their difficulties are misunderstood, autistic children can be stigmatized and marginalized, and this may lead to anxiety, stress, and unhappiness. The wellbeing of autistic children is of particular concern, as mental health problems are more common for autistic young people than for the general population. We contend that grandparents are an under-recognized resource to support resilience for autistic grandchildren and their families. This perspective piece combines the story of one Italian grandmother with evidence from international research about grandparents of autistic grandchildren. Drawing upon concepts of intergenerational family solidarity, we look in turn at the resilience of autistic children, parents, and grandparents themselves. We call for acknowledgement of the role of grandparents in recognizing and supporting the resilience of autistic grandchildren and their families.

KEYWORDS

autism, family, grandparent, intergenerational, solidarity

Introduction

The argument presented in this perspectives piece is that involved grandparents can play an important role in promoting the resilience of autistic grandchildren and their families. This claim is rooted in understandings of the importance of multigenerational relationships. In families that are emotionally close and interact frequently, intergenerational solidarity is characterized by mutual psychological and practical support between family members of different ages. This includes parents assisting their adult children and grandparents playing active roles in the lives of grandchildren (Bengtson, 2001). Such reciprocal support can foster a sense of belonging, strengthen family ties, and provide a safety net when crises occur. We consider that intergenerational family solidarity may be of particular importance in families of autistic children (Chaki and Faran, 2024; Kahana et al., 2015; Prendeville and Kinsella, 2018; Trindade et al., 2020).

Resilience is broadly characterized as the capacity to adapt, function, rebound and progress in the face of risk and adversity; with most theorists and researchers in agreement that resilience involves complex dynamic interactions between individuals and their environments (Pearson et al., 2025; Raheli and Abdalla, 2022; Southwick et al., 2014). Vrastia and Michelsen (2017), who explore the relationship between concepts of resilience

and solidarity within the field of political theory, point out that the vulnerability associated with a perceived need for resilience is often the result of depletion of rights. This can be applied to autistic children and young people, where calls for them to become more resilient should be placed alongside the ableism and exclusion that they and their families face on a daily basis (Autistic Girls Network, 2025; Beadle, 2024). Similarly, although highlighting the potential importance of grandparents, we do not argue that responsibility for resilience should be placed upon the family (Gunty, 2021).

The global prevalence of autism is 1%–2% of the population and in the UK, where we are based, 1.76% of children are formally assessed as autistic (Roman-Urrestarazu et al., 2021). Therefore, there is around a one in 50–100 chance of a grandchild having autism, a neurological and developmental condition that results in differences in the ways that an individual interacts with others, thinks, feels, and experiences the environment around them. The focus here is on the roles of grandparents in families where one or more grandchild is autistic. International research studies show that, in these families, grandparents often contribute practical, emotional and financial support, that may be ongoing and is vital for family well-being (Hillman, 2016; Li et al., 2025; Margetts et al., 2006; Novak-Pavlic et al., 2021; Prendeville and Kinsella, 2018; Yang et al., 2018).

Autistic children vary in their support needs; with expressive language difficulties, dietary restrictions, struggles with self-care skills, and sleep disruptions often causing stress for parents (Galpin et al., 2018). Delays in diagnosis, social stigma, and limited provision of support services can all affect the well-being of children and families (Frigerio et al., 2024; Shah et al., 2026). In this context, parents can feel overwhelmed and isolated and available social support networks can make a positive difference to parental quality of life (Derguy et al., 2018; Shah et al., 2026). Parents who do not receive any help in caring for their child may have more negative perceptions of their child's abilities and needs (Asahar et al., 2021). The presence of intergenerational solidarity, particularly supportive relationships and practical assistance from grandparents, can be vital to sustain the family (Chaki and Faran, 2024; Kahana et al., 2015; Prendeville and Kinsella, 2019; Trindade et al., 2020; Zakirova Engstrand et al., 2023).

Grandparents are not always available to provide support, and can even be a burden to families and a source of conflict, for example, where there are differences in understandings of autism and disagreements about how best to support the child (Fiske, 2017; Hillman, 2007; Li et al., 2025; Novak-Pavlic et al., 2021). There may be particular difficulties in cultural contexts where grandparents feel shame due to negative perceptions of people with disabilities (Raheli and Abdalla, 2022; Trindade et al., 2020; Wang et al., 2023). Tensions may occur in cultures where family interdependence is highly valued yet emphasis on family reputation hinders the acceptance of an autistic grandchild (Li et al., 2025). Some grandparents may want to help but not be trusted to care for the autistic child or might lack the skills and physical strength (Baena et al., 2024). All grandparents of autistic grandchildren may experience complex and sometimes conflicting emotions, including joy, grief, guilt, and concern for both their grandchild and their own adult child (Hillman et al., 2017; Kahana et al., 2015; Margetts et al., 2006; Zakirova Engstrand et al., 2023).

In support of our argument that grandparents can be a source of resilience, we present a small case study in the form of a positive narrative from one grandmother of an autistic grandchild. This

unique story is taken from our wider Italian research project, in which grandparents participated as co-researchers to consider the roles of grandparents in the 21st century (Mangione et al., 2024). It is embedded within the cultural expectations and traditions of the south of Italy, where family bonds are central, informal caregiving is provided by family members to compensate for gaps in community services, and grandparents play an important part in family life. Taking this hopeful case study as a starting point, we draw upon extant research to highlight three literature-informed viewpoints, those of the autistic child, the family, and grandparents themselves. Our discussion and conclusions then call for more recognition of the potential support that can be offered by grandparents for autistic children and their families.

Claudia's story—a case study from Italy

One of my daughters is the mother of a little girl who is autistic. When the child's father decided to move away from his partner and daughter, they came to live with us, because my daughter could not cope alone with a child with additional needs. I supported my daughter in her role; sometimes I was forced to stand in for her, especially in meetings with external institutions. She didn't feel like a "mother." I had to help her understand how to empathize with the child. She didn't kiss her, she didn't "sing songs" to her, she even neglected her day-to-day care. I encouraged her to see a psychologist, with whom she had several sessions. She wasn't even financially independent.

Several years have now passed. My daughter cannot imagine living without her child. She wanted to find stable, permanent work in another city because she wanted to be independent in managing her life and that of her daughter. I helped her with this project with enormous sacrifices, both organizationally and emotionally and financially. I wasn't sure I'd helped my daughter well. I feared that, away from me, she'd go back to being that cold, unsympathetic mother she was. But I understood that if I didn't let her go, neither she nor my granddaughter would ever live their own lives. I stayed with them until she found independent housing and enrolled her daughter in full-time school. In their free time, mother and daughter enjoyed some quality time together, managing to handle the moments of "problem behavior."

I deeply miss my granddaughter, the times when I sang her songs, the times when, in those few moments, she would come to hug me, leaving her world behind. It seemed like my little songs weren't reaching her, but one day, she and I were in the car, and I heard her singing a little song that was her morning wake-up call: "Wake up, little girl, the sun has risen, the rooster has already crowed.." I cried with emotion. How I cry now, when I video call her, and she seems not to pay attention to me, but a smile appears on her face and I sense she's happy. I feel that my daughter has finally become aware of herself, of being the mother of a special child. I follow my daughter and granddaughter from afar. I wanted to share my story, to provide an "example of life" in these complex times. A grandmother's giving,

supporting her daughter and granddaughter, for their growth in affection, relationships, and independence.

(Mangione et al., 2024 pp. 92–93, translated).

Autistic children and their grandparents

Autistic children may face many difficulties in a society that is created mainly by, and for, people who are not autistic. Negotiating daily life, including education, can be overwhelming and cause stress and anxiety. Even from a young age, stigma and bias can be internalized with negative effects on the child's confidence and self-esteem (Scheerer et al., 2024). The steady presence, understanding and unconditional love of grandparents can make a positive difference (Magro, 2025; Raheli and Abdalla, 2022). We can see that Claudia fostered a meaningful relationship with her granddaughter, with songs and shared routines, and maintains this now via video calls. As a grandmother, Claudia accepts and values her granddaughter for who she is and the main priority is her granddaughter's happiness. The hugs and hearing the granddaughter sing the morning song are special moments but there is no pressure for her to participate in the video calls just glimpsing a smile is enough.

From the earliest study about grandparenting autistic children, grandparents are found to hold positive and optimistic views of the child (Harris et al., 1985). Like Claudia, grandparents engage in radical acceptance of their autistic grandchildren (Hillman et al., 2017) and appreciate the child's small achievements (Fiske, 2017; Novak-Pavlic et al., 2021; Yang et al., 2018). Maternal grandmothers are the most frequent grandparent caregivers for autistic grandchildren (Baena et al., 2024; Glasberg and Harris, 1997). Interviews with 14 grandparents, in Utah, US, revealed maternal grandmothers' high levels of involvement with first-born grandchildren, with meaningful, regular connections fostering close relationships (D'Astous et al., 2013). Similarly, interviews with parents and grandparents in Ireland (Prendeville and Kinsella, 2018) showed that maternal grandparents were knowledgeable about the abilities of their autistic grandchild and made personal sacrifices to provide them with physical and emotional support.

Parents, families and grandparental support

As shown in Claudia's story, the whole family can gain from 'a grandmother's giving'; benefitting from the emotional, practical and financial support provided by a grandparent. Grandparents are often very aware of the difficulties that parents face and develop protective bonds with their adult child and autistic grandchild(ren) (Margetts et al., 2006). They express concern for their adult child's wellbeing and also admiration for their strength and approach to parenting (Baena et al., 2024; D'Astous et al., 2013; Hillman et al., 2016; Kornilaki and Kypriotaki, 2024; Prendeville and Kinsella, 2018). Maternal grandparents are found to be especially empathetic to their daughters and offer support within close relationships (Glasberg and Harris, 1997; Prendeville and Kinsella, 2018). Similarly, emotional support from mothers-in-law is found to improve the

life satisfaction of Bedouin mothers of autistic children (Chaki and Faran, 2024).

Claudia offers practical support, first of all opening her home to her daughter and granddaughter and meeting their physical needs and later helping her daughter to establish her career. The emotional support is exemplified in role modelling a caring parental role, until the mother could bond with her child, and also in reaching out to professional counsellors to meet the mother's psychological needs. There is additional financial support when helping the daughter to gain independence. There is self-sacrifice here, too, in accepting the need for her daughter to establish a life on her own terms, even if it means them moving away to another city. Grandparents like Claudia prioritise support for their adult children and, while doing so, may suppress their own emotional responses to the diagnosis (Miller et al., 2012). With Claudia's support, her daughter was able to move from being completely overwhelmed to an independent life and a positive experience of parenting.

Grandparents' joys and challenges

Claudia's story reflects the 'double burden' of caring for two younger generations (Margetts et al., 2006, p.569) and 'the double grief of their grandchild's disability and their own child's pain' (Naseef 2012, p.367). For the sake of her daughter and granddaughter, Claudia looks after both of them until they can become more self-sufficient. Such resilience in grandparents is an important resource for families (Raheli and Abdalla, 2022). Grandparents may face challenges, though, especially as the self-sacrifice required is quite different from the experience of grandparenting children without disabilities (Kornilaki and Kypriotaki, 2024). They may struggle to accept that their grandchild is autistic (Raheli and Abdalla, 2022). Claudia seems to communicate instinctively with her little granddaughter but some grandparents find communication with an autistic grandchild difficult and struggle to understand and respond to their behaviors (Baena et al., 2024; Raheli and Abdalla, 2022).

Nevertheless there is personal satisfaction to be gained from meaningful involvement when supporting younger generations of the family, building a relationship with an autistic grandchild and finding joy in their grandchild's achievements (Baena et al., 2024). Claudia takes pride in her daughter's independence and self-awareness and the happiness of her granddaughter. This corresponds with the results of a questionnaire-based study in Indonesia that found a positive correlation between the role played by grandparents, in families of an autistic grandchild, and their experience of higher psychological well-being (Densingrum, 2018). Additionally grandparents may recognize personal growth and empowerment in their own increased coping strategies, empathy and better understanding of disability and diversity (Baena et al., 2024; Raheli and Abdalla, 2022).

Discussion

Claudia's story highlights the importance of intergenerational family solidarity for resilience building; and this is supported by the linked research-based reflections from the viewpoints of the autistic

child, the family, and the grandparents. As Bengtson (2001) emphasized, changes in family structure due to separation and divorce have reduced the capacity of families to provide the support and nurture that family members may need. This can increase the importance of assistance from grandparents. In all types of families, the social and economic resources that grandparents provide can contribute to stress reduction and family resilience (Chaki and Faran, 2024; Kahana et al., 2015; Prendeville and Kinsella, 2018).

Existing studies show that grandparents contribute to family resilience via financial contributions, to help meet therapeutic needs, and by acting as caregivers (Hillman, 2016; Novak-Pavlic et al., 2021; Yang et al., 2018). They can offer strong emotional support, too, empathizing with the challenges that parents face and being there when needed (Margetts et al., 2006; Prendeville and Kinsella, 2018), and displaying love, acceptance and encouragement towards their autistic grandchild (Yang et al., 2018). This assistance from grandparents can strengthen the family system, benefitting children and parents and increasing well-being (Prendeville and Kinsella, 2019). Whereas in families of children without disabilities demands may reduce over time as children gain independence, the grandparents of autistic children may find that their caring roles and responsibilities persist, or even increase (Li et al., 2025).

Trew (2025) identifies a need for more qualitative research that attends to positive aspects of family life, when a family member is autistic, and recognizes the importance of resilience, connection and well-being. In their Australian study, interviews with autistic adolescents and members of their immediate family showed that families may face stress and tension but can work to maintain and strengthen close family bonds and foster resilience (*ibid.*). This type of project could be extended to explore the importance of relationships with the extended family, beyond the nuclear family unit. Such research could inform service providers in the development of family-focused services and support for all family members, including grandparents (Prendeville and Kinsella, 2019).

We recognize that in this paper we have focused upon a unique positive example. Whilst Claudia, her daughter and her granddaughter faced challenges, they were able to work together to overcome these. Not all families have this capacity to support one another, and family support should never be taken for granted. In some cases grandparents may perceive the autistic grandchild as a source of tension and heightened stress within the extended family (Fiske, 2017; Novak-Pavlic et al., 2021), particularly when issues of unequal attention among grandchildren arise (Miller et al., 2012). Baena and colleagues (2024) found that some grandparents do not have the physical capacity to care for their autistic grandchildren and sometimes parents are reluctant to accept help from grandparents. Hoang and Kirby (2020) suggest that grandparents caring for neurotypical grandchildren can cause parental stress due to conflicting child-rearing attitudes, communication barriers and excessive grandparental control. Similar difficult family dynamics can be encountered by parents of autistic children and these can be exacerbated by an additional challenge when grandparents struggle to understand or accept the child's disabilities (Hillman, 2007; Wang et al., 2023).

There are problems, too with placing all responsibility for resilience on the family (Guntz, 2021). Much stress within the

families of autistic children stems from lack of support from the wider community and outside agencies. For example, in England there are very long waits for pediatric assessments to formally identify autism (NHS England, 2025) and similar delays in the creation and approval of Education and Health Care Plans to support children at school (Adams and Ofori, 2024). Availability of advice and suitable therapies can be very limited, too. There is only so much that families can do in the face of these unmet needs.

Where grandparents are prepared to assist within the family, they themselves may have significant information and support needs. These include understanding the child's autism diagnosis, managing behaviours that challenge, adapting play and communication, navigating services, and coping with family stress (Raheli and Abdalla, 2022; Zakirova Engstrand, et al., 2020). Interventions specifically designed for grandparents, could reduce barriers to involvement and help more grandparents to support autistic grandchildren and their families (Hillman, 2007). Insights can be gained from the Swedish context, where grandparents of young autistic children were offered a group-based psychoeducation intervention that was positively received. The participating grandparents gained more knowledge about autism, learned skills and strategies to support their grandchildren, and appreciated the opportunity to meet and share experiences with other grandparents (Zakirova Engstrand, et al., 2023).

Given that grandparents are under-recognised, despite their often vital caregiving role, integrating them more intentionally into autism-support ecosystems could lead to improved outcomes for autistic children, their parents, and extended families. Family-centered provision that focuses only upon the nuclear family may limit understanding of a child's support needs. Where service providers acknowledge the role of grandparents, additional insights could be gained to support the care and education of autistic individuals (Li et al., 2025; Prendeville and Kinsella, 2019). The caregiving role that grandparents provide to families could be more formally recognized within policy frameworks and by professionals, for example: allowing grandparents access to summaries of key meetings and updates on grandchildren's education (with consent); giving opportunities to participate in meetings; providing dedicated support groups (Prendeville and Kinsella, 2019); and offering culturally sensitive training such as caregiver skills training designed for families (World Health Organisation, 2022).

Conclusion

In this contribution we have focused on the potential importance of the role of supportive grandparents in building the resilience of autistic grandchildren and their families. This implies not only practical help, such as financial contributions and caregiving, but also wider elements that contribute to intergenerational family solidarity. Positive relationships across generations, specifically in this context among a grandmother, her daughter, and granddaughter, were key aspects. Claudia's story exemplifies how resilience may emerge in the presence of intergenerational tensions, and raises the importance of acknowledging and respecting the boundaries within family roles and expectations. Resilience is promoted through dialogue, respect and trust, encouragement, mutual affection, emotional

closeness, and empathy; it is also reinforced by reciprocal support between family members and encouragement towards independence and the pursuit of individual life trajectories. Emotional closeness and connection can be maintained despite geographical distance through frequent communication via digital technologies.

There is scope for more work to be done in this important area. In-depth exploration of the theoretical concepts of intergenerational family solidarity and resilience, in families of autistic children and young people, could inform new ways of working with and for families. Additionally, qualitative research involving autistic children, parents and grandparents could further illuminate family dynamics and assist in understanding how each generation perceives the others and what family members can do to support one another. Claudia's story is from the south of Italy, where family values are deeply rooted. Future research on this topic should also take account of the enabling factors and the barriers to grandparents' support in diverse cultural contexts with varying social expectations.

In summary, the positive contributions of involved grandparents should be more widely recognized and appreciated. Grandparents can play a vital role in nurturing resilience for autistic children and their families, offering unconditional love, understanding, and many forms of support that help everyone to navigate day-to-day challenges with greater strength and confidence.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Anglia Ruskin University Arts Humanities Education and Social Sciences Faculty Research Ethics Panel. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

PL: Writing – original draft, Conceptualization, Writing – review & editing. DM: Writing – review & editing, Project

administration, Conceptualization. MK: Conceptualization, Resources, Writing – review & editing. MD: Resources, Writing – review & editing, Conceptualization.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declared that generative AI was not used in the creation of this manuscript.

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