

Commentary: Addressing stigma through relational research design

Neurodiversity
Volume 2: 1–7
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DOI: 10.1177/27546330241230428
journals.sagepub.com/home/ndy



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Abstract

The history of research on parenting autistic children is complicated by the inheritance of “mother-blaming,” which continues to occur, albeit indirectly or implicitly. Parents of autistic children often experience and internalize stigma, which arises from the messaging that suboptimal parenting can exacerbate a child’s autistic traits. This stigmatization is echoed by parents of other neurodivergent groups, including ADHD. For neurodivergent parents of neurodivergent children, this stigma may be compounded, since stigma is experienced both as a neurodivergent individual, and as the parent of a neurodivergent individual. Researchers have an ethical duty to pay attention to experiences of stigma when we study any vulnerable group so that stigma does not become a barrier to participation. In this commentary, I critically reflect on a study I designed, which did not adequately address parents’ potential stigma or sufficiently anticipate the impact of experiences of stigma on participation. I then outline the steps I took to modify the design, framed within a relational ethics of care, to acknowledge and account for the stigma that might have otherwise excluded parents of autistic children—especially parents who are autistic and otherwise neurodivergent themselves—from participating.

Keywords

Stigma, parenting, autistic children, research design, autistic parents

Submission date: 6 October 2023; Acceptance date: 18 January 2024

Introduction

The history of research on parenting autistic children is fraught. Since Bettelheim, following Kanner, popularized the notion of the “refrigerator mother” in the 1950s and 60s, research has been shaped by the debate over mother-blaming (Douglas & Klar, 2019). Even now, genetics, poor coping, and parenting choices are identified as potential causes or contributors to autistic “severity” (Courcy & des Rivières, 2017; Farrugia, 2009). While we no longer blame mothers for *causing* their child’s autism through withdrawal of affection, mothers are still cast as blameworthy through their failure to pursue every course of action to “normalize” their autistic child (Douglas & Klar, 2019; Waltz, 2015), or because their suboptimal parenting approach exacerbates a child’s autistic presentation (Blum, 2007; Fernández & Arcia, 2004). Such criticisms are similarly directed at parents of children with ADHD (Harborne et al., 2004; Leitch et al., 2019). Ultimately, parents of autistic and otherwise neurodivergent children can face judgement, reproach, and stigma from the multiple contexts within

which they parent their child—educational, therapeutic, medical, community, familial, and social (Broady et al., 2017; Gwernan-Jones et al., 2015; Kinnear et al., 2016; Mofokeng & van der Wath, 2017; Neely-Barnes et al., 2011).

Parents of autistic children experience stigma in different ways, including the socially constructed and perpetuated stigma of parent-blaming (public stigma), discrimination (enacted stigma), internalized prejudices and shame (self-stigma and internalized family stigma), and parent’s affiliation with their autistic child’s visible autistic traits (stigma by association) (Allen, 2017; Hurley-Hanson et al., 2020; Salleh et al., 2020; Turnock et al., 2022). Such varied experiences of stigma are also prevalent for

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parents of children with ADHD, with stigma by association and self-stigma cited regularly (Charbonnier et al., 2019; Koro-Ljungberg & Bussing, 2009; Lin et al., 2023; Özaslan & Yıldırım, 2021).

Few studies, however, have focused on *autistic parents'* experiences of stigma (Pohl et al., 2020; cf. Liao et al., 2019). It makes sense that when that parent is themselves autistic, the stigma they experience is likely to be amplified or compounded (Filax & Taylor, 2019). While non-autistic parents report feeling blamed for their child's autistic, atypical behaviors (Lodder et al., 2019), autistic parents carry the additional burden that they are directly liable for their autistic child's traits given the genetic inheritability of autism (Davis & Manago, 2016; Douglas & Klar, 2019; Lilley, 2013). Moreover, autistic parents may not only experience stigma because of their child's autistic presentation (as all parents of autistic children might), but also because of their own autistic identity and traits (Han et al., 2023; Rogers et al., 2017). Indeed, autistic parents report feeling perceived as a "terrible" parent (Heyworth et al., 2023, p. 29) or a "failure" at parenting (Dugdale et al., 2021, p. 1981) because they are autistic themselves; some even cite being afraid that their child will be removed because their own autistic identity makes them unfit parents (Filax & Taylor, 2019; Pohl et al., 2020).

For researchers, Bettelheim's hypothesis that disordered maternal attachment caused autism has often made it difficult to examine parenting autistic children in constructive ways (Briggs, 2020; van Rosmalen et al., 2020). As Ventola et al. (2017) point out, because of the "the historical complexities of discussing parenting in ASD, scientists shied away from the topic of parenting and ASD, as though it would (erroneously) imply that parents were 'to blame'" (p. 2). Thus, how one designs research to be responsive and nuanced to the discipline's historical underpinnings is an important question (Courcy & des Riveières, 2017), particularly since the experiences of stigma is often a daily lived reality for many parents of autistic children (Gray, 2002; Hurley-Hanson et al., 2020; Turnock et al., 2022).

As an autistic parent of autistic children myself, studying the nexus of parenting and autism seemed an obvious choice for my doctoral research. I am deeply aware of the research tradition that has shaped attitudes to parents of autistic children, both as a not-inexperienced researcher and through my own lived experience. So, I assumed that a study design that compared the experiences of autistic and non-autistic parents of autistic children would be straightforward and easy to implement. Yet, despite my own experience of being judged and stigmatized as an autistic parent of autistic children, I failed to recognize the potential for other parents to have similar experiences of being blamed, judged, and ostracized for their parenting choices. I also did not adequately recognize the possible impact that the stigma surrounding parenting autistic

children might have on parents' feelings of self-worth and self-efficacy.

Below, I describe my original research design, explore changes in my research approach, and consider the potential barriers and enablers to working with stigmatized populations. This commentary piece is thus a *discursus* in how research design can recognize stigma and respond to it in more mindful and proactive ways.

Study design: stigma as a barrier to participation

My original research design was a mixed-methods study, using both standardized questionnaire-based measures and a semi-structured interview. I had also proposed to use a standardized assessment within that interview, using video footage of child-parent interactions to anchor the interview.

When I began recruiting for the study, the interest was notable. This was unexpected. The recruitment material made clear that this project had a significant time commitment of around 3–4 h, would be primarily conducted online rather than face-to-face, and included a step in which parents would capture "selfie-style" footage of themselves interacting with their autistic child. According to a large-scale community survey of parents of autistic children, participant burden is a key factor in whether parents commit to a study, and face-to-face data collection is preferred (Fletcher-Watson et al., 2019). So, I was surprised when I had an enthusiastic response within 72 h of its launch, with around two thirds of interested participants identifying as autistic parents.

But quickly it became clear that there were barriers to participation. Of the around 60 consent forms I sent out in the first days, only a third came back. Other parents responded with questions that indicated specific barriers that prompted me to reconsider the fundamental design of my data collection.

The inaccessibility of quantitative measures

In my original design, the first step for consenting participants was to complete background demographics and standardized measures for the quantitative component. These included a range of questionnaires measuring the constructs of interest, largely validated on neurotypical parent samples. Over a 6-week period, only around half of those who had consented had completed this step.

For some participants, especially neurodivergent participants, this step was a barrier. While carers may generally prefer online surveys, many of my study participants are neurodivergent (primarily Autistic and/or ADHD). Given the executive function challenges associated with both autism and ADHD (Gargaro et al., 2011), completing such measures can pose challenges. Moreover, autistic participants often prefer to "be heard and understood as equal

and valued partners in research,” with insensitivity and inaccessibility cited as frequent inhibitors to autistic participation in research (Haas et al., 2016, p. 1803). Most quantitative measures—including those in my study—are not designed “by autistics, for autistics,” or for the people who support and love us (Jones, 2022). In choosing the measures, I had looked for those that were relevant for parents who may or may not be neurodivergent, and those which would be respectful of particularly autistic parents’ experiences of parenting their autistic children. Although I tried to modify language where I could without changing the measure’s psychometric properties (e.g. from person-first to identity-first language), the framing of the measures can remain grounded in stereotyped and pathologized understandings of mental health and autism (Jones, 2022; McConachie et al., 2020). Moreover, all parents, but particularly autistic parents, can find these standardized measures poorly representative of their experiences, and the questions themselves can be inaccessible without adequate context, nuance, or clarity, and with limited response possibilities (Stacey & Cage, 2022).

Parents of autistic children are also simply questionnaire weary. As one of my participants noted, after spending hours filling in the requisite forms for assessments, high school, homeschool, and government support services, “I just can’t do another form.” In Australia, where I am based, parents need to complete such questionnaires during the diagnostic process, to access funding for their child and themselves, for educational purposes, at therapeutic evaluations and at funding reviews. It is not surprising, therefore, that, for many participants, completing yet another swathe of questionnaires was neither feasible nor desirable.

These were not unexpected barriers, although I felt unsure how to reduce them. Most validated measures have been “retro-fitted” for the autistic or neurodivergent communities and our families. For example, to assess quality of life, autistic people are required to complete the “standard” WHOQOL-BREF measure first with additional disability-specific questions (WHOQOL-DIS plus ASQoL measures; McConachie et al., 2018). Measures that have been co-produced with families are not necessarily respectful of autistic parenting experiences or autistic neurology (for example, the Autism Family Experience Questionnaire uses wording like “fussy eating” which misrepresents the very real experience of sensory eating; Leadbitter et al., 2018). And co-produced disability measures which are designed from the outset by—and specifically for—the communities they purport to measure, are currently non-existent.

Fear of judgement: the reality of stigma

There were other barriers, too. After collecting the quantitative data, I then sent participants instructions directing them

to capture themselves “selfie-style” in naturalistic parenting contexts with their child (e.g. in teaching, playing, and caregiving). The footage was only to be used to prompt some specific reflections within the semi-structured interview (so it would only be shared between the interviewer—me—and the interviewee) before being deleted. Some parents expressed an expected concern about their child’s privacy. Some parents chose not to continue because their child would not consent to be videoed or they felt their child could not give informed consent. But many parents who were committed to participating just didn’t do the videos. In fact, over the first 6 weeks of the project, only a third of parents had submitted videos.

The question was why?

For some, at least, the answer was stigma. As one autistic parent—who did not continue with the study—communicated, their concern with the videos was “feeling judged,” which had the potential to be a “shaming experience” and to cause significant anxiety. Another autistic parent conveyed their anxiety that the videos would uncover that “I’ve been doing something detrimental to my kids without realising!” While most participants did not disclose why they found the videoing step difficult, and no doubt a combination of factors played into parents’ reticence (e.g. time), these interactions suggest that at least some parents were concerned about having their parenting appraised and found wanting, as they had in other contexts (Lilley, 2013; Neely-Barnes et al., 2011; Turnock et al., 2022). The inheritance of mother-blaming shapes the way that so many parents of autistic children view themselves (Gill & Liamputtong, 2011), and fuels an internalized self-stigma, undermining parents’ feelings of self-esteem, self-efficacy and parental effectiveness (Chan & Lam, 2018) and increasing feelings of inferiority, shame and isolation. On reflection, including this videoing step exposed this vulnerability. Indeed, it possibly prevented parents from participating at all since experiences of stigma often prompt families to *conceal*, rather than *reveal*, the source of that stigma (Moses, 2014). For autistic or otherwise neurodivergent parents, that vulnerability may be intensified. When you are a neurodivergent parent of an autistic child, the received stigma has increased impact, since it is not only your parental self-efficacy that is damaged, but your whole identity: the internalized message is that it is not only your parenting that is broken, but you are (Farahar, 2022).

I know firsthand the reality of being judged harshly for my parenting choices. I have undoubtedly internalized these judgements: for a very long time, I believed that I was not a good parent. But in designing my own research, I forgot that many parents—regardless of their neurotype—live with the weight of social judgement every day, received from therapists, schools, family, friends, peers, and colleagues (Kinnear et al., 2016; Robinson et al., 2015). And while I knew that I would never judge the participants in

my study because of my own experiences of being judged, potential participants could not know that.

So, in asking parents to capture moments of their parenting journey, I had not recognized the deep vulnerability in that task, or that the fear of being judged could be a barrier to participation.

I had expected that my autistic identity might overcome these barriers; I assumed that my status as “peer” would trump that of “researcher.” That was certainly the case in a previous project in which I was involved: autistic participants felt more easily able to disclose their experiences to an autistic researcher because of their shared neurology and common experience of late diagnosis. This commonality established a level of trust, connection, and mutual empathy, which was ultimately validating and liberating (Pellicano et al., 2022). I had anticipated my participants would feel a similar sense of trust and connection with me in my own research, and that being an autistic mum would foster openness and dissipate worries about being judged. When that didn’t eventuate, I had to ask why.

One key difference between that previous study and my PhD project was that, in the former project on late diagnosis, there was no quantitative data collection. Instead, the first contact with autistic researchers was in the form of an information session in which rapport was established with the interviewees (Lilley et al., 2021). By asking participants to complete quantitative data in my study first, I had missed the opportunity to build rapport and trust from the outset, and to collapse the inherent power differential that exists between researchers and participants, especially in quantitative research (Karnieli-Miller et al., 2009).

In fact, my process of collecting quantitative data first established me as another professional and judge in parents’ lives, confirming that power differential rather than minimizing it. And giving so much personal data to yet another unknown person, exposed another vulnerability and set me up as someone who was “studying” my participants by collecting their information in a transactional model, not learning from them by hearing their stories.

In response to these barriers, I fundamentally changed the research design. Now, I administer the interview first, and then ask participants to complete the quantitative step second. In starting with the interview, I develop rapport with participants, establish myself as their peer, and foster the belief that I deeply and personally, as well as professionally, empathize with their experiences. In the interview I am authentic, vulnerable and transparent, and there is more “semi” than “structure” in the interviews: the participants lead. In so doing, I hope to promote equity, redistribute power, and offer participants control over their story, their information. I also entirely removed the videoing step in the research so that participants now have increased autonomy over the experiences they choose to share and can set the agenda within the interview. I have recognized the

vulnerability in being stigmatized, and actively worked to destigmatize my research process.

Addressing the stigma: enacting a relational ethics of care in research design

My project has an advisory group, but it was not specifically the advisory group that led these changes: it was the participants themselves. My receptivity to their needs is integral to a relational ethic of care (Noddings, 2013) to which we, as researchers, should be committed. It might also mitigate some of the experiences of stigma, which might otherwise exclude people from the research process.

In my original design, I had attended to a model of person-oriented research ethics by addressing my participants’ communication, processing, and sensory needs, as well as the reality of diagnostic privilege (Cascio et al., 2020a). But I had failed to account adequately for the social context—to acknowledge the lived world and to focus on the researcher–participant relationship (Cascio et al., 2020a)—or “the everyday and relational aspects” (Cascio et al., 2020b, p. 3) of the research. Despite my desire to focus on each participant as a unique peer and equal (in the pursuit of individualization, empowerment, and respect for holistic personhood; Cascio et al., 2020a), I needed to do more to promote trust and rapport, and, vitally, to alleviate the effects of stigma.

I am glad I listened to the participants’ needs not just because my research will be stronger for it, but because now the participants have spoken about our interviews as being “cathartic,” “lovely,” “delightful and intense,” and “valuable.” I have now interviewed 80 parents—40 autistic and 40 non-autistic, with many identifying as having other neurodivergences and co-occurring conditions—and have nearly 6,500 min of interviews and a full quantitative dataset for all 80 participants. By attending to the ethical and political dimensions of parental care (Douglas & Klar, 2019), I was able to respond to participants’ needs with care, compassion and empathy (Ellis, 2017), and ultimately support the wellbeing and interests of my participants (Metz & Miller, 2016; Robinson, 2020).

For my part, I have realized how important relational, caring ethical design is to the research process, especially when we’re committed to co-production. Co-production doesn’t just require us to involve the community in the research lifecycle, it requires us to be responsive to our participants’ experiences and to their needs and vulnerabilities, to address power dynamics and right epistemic injustices (Groot et al., 2022). It requires us not just to be aware of the research power differential, but to find ways to overcome that hierarchy and to share power with our participants. When something isn’t working—like collecting quantitative data first or requiring participants to expose their deep vulnerabilities—we have a responsibility to our participants, and to our research, not simply to continue

because it's the way things are "usually" done, or the way we expected, or the easiest process. We owe it to the people who are sharing their lives and their journeys with us, to think creatively and to be flexible so that the research process is as valuable and worthwhile to them, as the answers it generates.

Acknowledgments: MH is grateful to the extraordinary generosity of the autistic and non-autistic parents who have shared their insights and experiences, and given so much of their time to contribute to this research study. MH also acknowledges her supervisors, Professor Elizabeth Pellicano, Professor Cathy McMahon, and Dr Diana Tan for their wisdom and guidance in navigating the study, and her advisory group members, who have offered such vital counsel and support.

Author Contributions: MH confirms sole responsibility for this perspective article, the analysis and interpretation of events informing it, and the manuscript preparation.

Declaration of conflicting interests: The author is the founder of an autistic-led charity, Reframing Autism, which provides educational opportunities to autistic individuals and to parents of autistic children (regardless of neurotype).

Funding: The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: MH is supported by Macquarie University Research Excellence Scholarship and is a paid employee of Reframing Autism, which provides some financial support to complete the research. The views expressed are the views of the author alone and do not necessarily represent the views of their organizations or funding sources.

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References

- Allen, H. (2017). Bad mothers and monstrous sons: Autistic adults, lifelong dependency, and sensationalized narratives of care. *Journal of Medical Humanities*, 38(1), 63–75. <https://doi.org/10.1007/s10912-016-9406-4>
- Blum, L. M. (2007). Mother-blame in the Prozac nation: Raising kids with invisible disabilities. *Gender & Society*, 21(2), 202–226. <https://doi.org/10.1177/0891243206298178>
- Briggs, J. (2020). The enduring fortress: The influence of Bruno Bettelheim in the politics of autism in France. *Modern Intellectual History*, 17(4), 1163–1191. <https://doi.org/10.1017/S1479244319000015>
- Broadly, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers lived experience of stigma: The voice of families with a child on the autism spectrum. *Health and Social Care in the Community*, 25(1), 224–233. <https://doi.org/10.1111/hsc.12297>
- Cascio, M. A., Weiss, J. A., & Racine, E. (2020b). Person-oriented research ethics to address the needs of participants on the autism spectrum. *Ethics & Human Research*, 42(5), 2–16. <https://doi.org/10.1002/eahr.500064>
- Cascio, M. A., Weiss, J. A., & Racine, E., & The autism research ethics task force. (2020a). Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities. *Autism*, 24(7), 1676–1690. <https://doi.org/10.1177/1362361320918763>
- Chan, K. K. S., & Lam, C. B. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 48, 44–52. <https://doi.org/10.1016/j.rasd.2018.01.001>
- Charbonnier, E., Caparos, S., & Trémolière, B. (2019). The role of mothers' affiliate stigma and child's symptoms on the distress of mothers with ADHD children. *Journal of Mental Health*, 28(3), 282–288. <https://doi.org/10.1080/09638237.2018.1521944>
- Courcy, I., & des Rivières, C. (2017). From cause to cure': A qualitative study on contemporary forms of mother blaming experienced by mothers of young children with autism spectrum disorder. *Journal of Family Social Work*, 20(3), 233–250. <https://doi.org/10.1080/10522158.2017.1292184>
- Davis, J. L., & Manago, B. (2016). Motherhood and associative moral stigma: The moral double bind. *Stigma and Health*, 1(2), 72–86. <https://doi.org/10.1037/sah0000019>
- Douglas, P., & Klar, E. (2019). Beyond disordered brains and mother blame: Critical issues in autism and mothering. In L. O'Brien Hallstein, A. O'Reilly, & M. V. Giles (Eds.), *The Routledge companion to motherhood* (pp. 205–214). Routledge. <https://doi.org/10.4324/9781315167848>
- Dugdale, A. S., Thompson, A. R., Leedham, A., Beail, N., & Freeth, M. (2021). Intense connection and love: The experiences of autistic mothers. *Autism*, 25(7), 1973–1984. <https://doi.org/10.1177/13623613211005987>
- Ellis, C. (2017). Compassionate research: Interviewing and storytelling from a relational ethics of care. In I. Goodson, A. Antikainen, P. Sikes, & M. Andrews (Eds.), *The Routledge international handbook on narrative and life history* (pp. 432–445). Routledge. <https://doi.org/10.4324/9781315768199>
- Farahar, C. (2022). Autistic identity, culture, community, and space for well-being. In D. Milton & S. Ryan (Eds.), *The routledge international handbook of critical autism studies* (pp. 229–241). Routledge. <https://doi.org/10.4324/9781003056577>
- Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, 31(7), 1011–1027. <https://doi.org/10.1111/j.1467-9566.2009.01174.x>
- Fernández, M. C., & Arcia, E. (2004). Disruptive behaviors and maternal responsibility: A complex portrait of stigma, self-blame, and other reactions. *Hispanic Journal of Behavioural Sciences*, 26(3), 356–372. <https://doi.org/10.1177/0739986304267208>
- Filax, G., & Taylor, D. (2019). Disabled mothers. In L. O'Brien Hallstein, A. O'Reilly, & M. V. Giles (Eds.), *The routledge companion to motherhood* (pp. 77–88). Routledge. <https://doi.org/10.4324/9781315167848>
- Fletcher-Watson, S., Larsen, K., & Salomone, E. (2019). What do parents of children with autism expect from participation in research? A community survey about early autism studies.

- Autism*, 23(1), 175–186. <https://doi.org/10.1177/1362361317728436>
- Gargaro, B. A., Rinehart, N. J., Bradshaw, J. L., Tonge, B. J., & Sheppard, D. M. (2011). Autism and ADHD: How far have we come in the comorbidity debate? *Neuroscience & Biobehavioral Reviews*, 35(5), 1081–1088. <https://doi.org/10.1016/j.neubiorev.2010.11.002>
- Gill, J., & Liamputtong, P. (2011). Being the mother of a child with Asperger's Syndrome: Women's experiences of stigma. *Health Care for Women International*, 32(8), 708–722. <https://doi.org/10.1080/07399332.2011.555830>
- Gray, D. E. (2002). Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, 24(6), 734–749. <https://doi.org/10.1111/1467-9566.00316>
- Groot, B., Haveman, A., & Abma, T. (2022). Relational, ethically sound co-production in mental health care research: Epistemic injustice and the need for an ethics of care. *Critical Public Health*, 32(2), 230–240. <https://doi.org/10.1080/09581596.2020.1770694>
- Gwernan-Jones, R., Moore, D. A., Garside, R., Richardson, M., Thompson-Coon, J., Rogers, M., Cooper, P., Stein, K., & Ford, T. (2015). ADHD, parent perspectives and parent-teacher relationships: Grounds for conflict. *British Journal of Special Education*, 42(3), 279–300. <https://doi.org/10.1111/1467-8578.12087>
- Haas, K., Costley, D., Falkmer, M., Richdale, A., Sofronoff, K., & Falkmer, T. (2016). Factors influencing the research participation of adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 46, 1793–1805. <https://doi.org/10.1007/s10803-016-2708-6>
- Han, E., Scior, K., Heath, E., Umagami, K., & Crane, L. (2023). Development of stigma-related support for autistic adults: Insights from the autism community. *Autism*, 27(6), 1676–1689. <https://doi.org/10.1177/13623613221143590>
- Harborne, A., Wolpert, M., & Clare, L. (2004). Making sense of ADHD: A battle for understanding? Parents' views of their children being diagnosed with ADHD. *Clinical Child Psychology and Psychiatry*, 9(3), 327–339. <https://doi.org/10.1177/1359104504043915>
- Heyworth, M., Brett, S., den Houting, J., Magiati, I., Steward, R., Urbanowicz, A., Stears, M., & Pellicano, E. (2023). I'm the family ringmaster and juggler': Autistic parents' experiences of parenting during the COVID-19 pandemic. *Autism in Adulthood*, 5(1), 24–36. <https://doi.org/10.1089/aut.2021.0097>
- Hurley-Hanson, A. E., Giannantonio, C. M., & Griffiths, A. J. (2020). *Autism in the Workplace: Creating Positive Employment and Career Outcomes for Generation A*. Palgrave Macmillan. <https://doi.org/10.1007/978-3-030-29049-8>.
- Jones, S. (2022). Measuring the wrong thing the right way? Time to rethink autism research tools. *Autism in Adulthood*, 4(2), 104–109. <https://doi.org/http://doi.org.simsrad.net.ocs.mq.edu.au/10.1089/aut.2021.0050> <https://doi.org/10.1089/aut.2021.0050>
- Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative Health Research*, 19(2), 219–289. <https://doi.org/10.1177/1049732308329306>
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942–953. <https://doi.org/10.1007/s10803-015-2637-9>
- Koro-Ljungberg, M., & Bussing, R. (2009). The management of courtesy stigma in the lives of families with teenagers with ADHD. *Journal of Family Issues*, 30(9), 1175–1200. <https://doi.org/10.1177/0192513X09333707>
- Leadbitter, K., Aldred, C., McConachie, H., Le Couteur, A., Kapadia, D., Charman, T., Macdonald, W., Salomone, E., Emsley, R., & Green, J., & The PACT Consortium. (2018). The Autism Family Experience Questionnaire (AFEQ): An ecologically-valid, parent-nominated measure of family experience, quality of life and prioritised outcomes for early intervention. *Journal of Autism and Developmental Disorders*, 48(4), 1052–1062. <https://doi.org/10.1007/s10803-017-3350-7>
- Leitch, S., Sciberras, E., Post, B., Gerner, B., Rinehart, N., Nicholson, J. M., & Evans, S. (2019). Experience of stress in parents of children with ADHD: A qualitative study. *International Journal of Qualitative Studies on Health and Well-being*, 14(1), 1690091. <https://doi.org/10.1080/17482631.2019.1690091>
- Liao, X., Lei, X., & Li, Y. (2019). Stigma among parents of children with autism: A literature review. *Asian Journal of Psychiatry*, 45, 88–94. <https://doi.org/10.1016/j.ajp.2019.09.007>
- Lilley, R. (2013). Crying in the park: Autism stigma, school entry and maternal subjectivity. *Studies in the Maternal*, 5(2), 1–28. <https://doi.org/https://doi.org/10.16995/sim.21>
- Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, S. R. C., Trollor, J. N., Yudell, M., & Pellicano, E. (2021). 'A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. *Autism*, 26(6), 1395–1408. <https://doi.org/10.1177/136236132111050694>
- Lin, P. Y., Chou, W. J., Hsiao, R. C., Liu, T. L., & Yen, C. F. (2023). Association of affiliate stigma with parenting stress and its moderators among caregivers of children with Attention-Deficit/Hyperactivity Disorder. *International Journal of Environmental Research and Public Health*, 20(4), 3192. <https://doi.org/10.3390/ijerph20043192>
- Lodder, A., Papadopoulou, C., & Randhawa, G. (2019). Stigma of living as an autism carer: A brief psycho-social support intervention (SOLACE). Study protocol for a randomised controlled feasibility study. *Pilot and Feasibility Studies*, 5(34). <https://doi.org/10.1186/s40814-019-0406-9>
- McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Developmental*, 48(5), 1596–1611. <https://doi.org/10.1007/s10803-017-3402-z>
- McConachie, H., Wilson, C., Mason, D., Garland, D., Parr, J. R., Rattazzi, A., Rodgers, J., Skevington, S., Uljarevic, M., & Magiati, I. (2020). What is important in measuring quality of life? Reflections by autistic adults in four countries. *Autism in Adulthood*, 2(1), 4–12. <https://doi.org/10.1089/aut.2019.0008>
- Metz, T., & Miller, S. C. (2016). Relational ethics. In H. LaFollette (Ed.), *The international encyclopedia of ethics* (pp. 1–10). Wiley-Blackwell.

- Mofokeng, M., & van der Wath, A. E. (2017). Challenges experienced by parents living with a child with Attention Deficit Hyperactivity Disorder. *Journal of Child & Adolescent Mental Health, 29*(2), 137–145. <https://doi.org/10.2989/17280583.2017.1364253>
- Moses, T. (2014). Stigma and family. In P. W. Corrigan (Ed.), *The stigma of disease and disability: Understanding causes and overcoming injustices* (pp. 247–268). American Psychological Association. <https://doi.org/10.1037/14297-013>
- Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family Social Work, 14*(3), 208–225. <https://doi.org/10.1080/10522158.2011.571539>
- Noddings, N. (2013). *Caring: A Relational Approach to Moral Education* (2nd rev. edition). University of California Press.
- Özaslan, A., & Yıldırım, M. (2021). Internalized stigma and self esteem of mothers of children diagnosed with Attention Deficit Hyperactivity Disorder. *Children's Health Care, 50*(3), 312–324. <https://doi.org/10.1080/02739615.2021.1891071>
- Pellicano, E., Lawson, W., Hall, G., Mahoney, J., Lilley, R., Heyworth, M., Clapham, H., & Yudell, M. (2022). I knew she'd get it, and get me': Participants perspectives of a participatory autism research project. *Autism in Adulthood, 4*(2), 120–129. <https://doi.org/10.1089/aut.2021.0039>
- Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism, 11*(3). <https://doi.org/10.1186/s13229-019-0304-2>
- Robinson, C. A., York, K., Rothenberg, A., & Bissell, L. J. L. (2015). Parenting a child with Asperger's Syndrome: A balancing act. *Journal of Child and Family Studies, 24*(8), 2310–2321. <https://doi.org/10.1007/s10826-014-0034-1>
- Robinson, F. (2020). Resisting hierarchies through relationality in the ethics of care. *International Journal of Care and Caring, 4*(1), 11–23. <https://doi.org/10.1332/239788219X15659215344772>
- Rogers, C., Lepherd, L., Ganguly, R., & Jacob-Rogers, S. (2017). Perinatal issues for women with high functioning autism spectrum disorder. *Women and Birth, 30*(2), e89–e95. <https://doi.org/10.1016/j.wombi.2016.09.009>
- Salleh, N. S., Abdullah, K. L., Yoong, T. L., Jayanath, S., & Husain, M. (2020). Parents experiences of affiliate stigma when caring for a child with autism spectrum disorders (ASD): A meta-synthesis of qualitative studies. *Journal of Pediatric Nursing, 55*, 174–183. <https://doi.org/10.1016/j.pedn.2020.09.002>
- Stacey, R., & Cage, E. (2022). 'Simultaneously vague and oddly specific': Understanding autistic people's experiences of decision making and research questionnaires. *Autism in Adulthood, 5*(3), 263–274. <https://doi.org/10.1089/aut.2022.0039>
- Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding stigma in autism: A narrative review and theoretical model. *Autism in Adulthood, 4*(1), 76–91. <https://doi.org/10.1089/aut.2021.0005>
- van Rosmalen, L., van der Veer, R., & van der Horst, F. R. P. (2020). The nature of love: Harlow, Bowlby and Bettelheim on affectionless mothers. *History of Psychiatry, 31*(2), 227–231. <https://doi.org/10.1177/0957154X19898997>
- Ventola, P., Lei, J., Paisley, C., Lebowitz, E., & Silverman, W. (2017). Parenting a child with ASD: Comparison of parenting style between ASD, anxiety, and typical development. *Journal of Autism and Developmental Disorders, 47*(9), 2873–2884. <https://doi.org/10.1007/s10803-017-3210-5>
- Waltz, M. M. (2015). Mothers and autism: The evolution of a discourse of blame. *AMA Journal of Ethics, 17*(4), 353–358. <https://doi.org/10.1001/journalofethics.2015.17.4.mhst1-1504>