Chapter 17
Autism in the COVID-19 Pandemic: Reflecting on Loss and Resilience

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For several years now, I have had a complicated relationship with the concept of resilience. Resilience can be defined as the ability to withstand and perhaps even grow from challenging circumstances or to have a better-than-expected outcome (Szatmari 2018; Sinclair and Wallston 2004). We all encounter struggles in life, though our positionality – the aspects of our identity that allow us privilege or are subject to marginalization – has a significant impact on the intensity and frequency of the struggles we encounter. This means that some of us are forced to be more resilient than others. The current global COVID-19 pandemic has only enhanced this dynamic.

It makes sense that as social workers, we like the idea of resilience. It is strengths-oriented. It offers a sense of hope both for us and for our clients, a belief that we have the strength to persevere. It is an essential ingredient in recovery (Hobbs and Baker 2012). Yet in my role at a university where we are charged with preparing students to be competent, anti-oppressive social work practitioners, I worry at times that we place too much emphasis on resilience. Much of our role, at least in clinical social work, is helping people maintain and strengthen resilience. We offer support and work to help our clients enhance coping skills in the face of challenging circumstances. However, I often caution students that this orientation toward individual resilience can have the unintended consequence of complacency. Challenging circumstances are virtually always the result of or enhanced by structures of oppression: racism, ableism, sexism, heterosexism, ageism, classism, etc. COVID-19 has been no exception. The pandemic itself may be a biological and environmental phenomenon, but the response in the United States reflects the American cultural emphasis on individualism. Such an orientation allowed this pandemic to grow,
disproportionality harming communities of color and those groups of people most impacted by the isms that are deeply embedded in the American social fabric. It is not acceptable that some people must beat the odds in order to survive. Yet, especially now, that is often our role: to help them survive and try to thrive through the challenges. Resilience offers hope, but it also comes with baggage. As a social work field, we cannot lose sight of this reality.

While we are all sharing the impacts of this pandemic, we are not all forced to be equally resilient. Our positionality dictates the risk factors and protections that foster resilience (Kapilashrami and Hankivsky 2018). My own field of practice and scholarship has been working to address the mental health needs of autistic people.1 Resilience has been a requirement for this community, long before the pandemic. You must be resilient to live as autistic, operating in a society that does not inherently welcome neurodiversity or difference. Fiorillo and Gorwood (2020) note that people “who are already vulnerable to biological and psychosocial stressors” (p. 1) are one group most at risk for suffering adverse mental health consequences as a result of the current pandemic. For most autistic people, the shifts necessitated by COVID-19 only add to the life stressors requiring resilience. This struggle is further exacerbated if an autistic person belongs to other marginalized identity groups, experiencing the impacts of racism, classism, etc. in addition to ableism.

**Autism, Mental Health, and COVID-19**

COVID-19 has brought about a mental health crisis or what Mortazavi et al. (2020) describe as a “psychiatric pandemic” (p. 225) that is only likely to grow as the new post-COVID reality continues over the course of months, if not years. Autistic people were already experiencing high rates of mental health struggles prior to the COVID-19 pandemic, while having limited access to clinicians trained to identify and offer clinical services to address these struggles which are often incorrectly dismissed as an inevitable part of an autism diagnosis (Fuld 2018). Historically, social work has relied on a medical model of understanding autism spectrum disorder (ASD) rather than interrogating the social structures which require conforming to certain neurological and social ways of being and interacting with the world (Meekosha and Dowse 2007; Roulstone 2012; Fuld 2019). As a result, our clinical treatment models are primarily behavioral – focused on helping an autistic person alter their behavior to look more like society’s expectation of normal. This critique is not to say that the ability to fit in cannot improve someone’s quality of life, but what is often missed is the validation and support of one’s identity. We know that validation is central to developing positive self-esteem and overall well-being for

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1 In this chapter, I am using identity-first language to describe autistic people. This choice in language is based on the recommendation of the Autistic Self Advocacy Network (n.d.). I want to acknowledge that this may not represent the choice that every autistic person or person with autism spectrum disorder may be most comfortable with in describing their identity.
the client and a hallmark of good practice for social workers. Discussing the impact of COVID-19, self-advocate Amy Louise Simmons (2020) speaks to this describing, “our lives are restricted by marginalisation, which is veiled by the social deficit model of autism and misinterpreted as the inevitable outcome of impaired social communication, and impaired social interaction” (p. 1011). In sharing this insight, Simmons (2020) makes the point that social distancing is not new for many autistic people. It has been an imperative because our sociopolitical structures create a context where autistic people face “overstimulation, social-exclusion, and stigma” (p. 1011). As social workers, if we are not attuned to this reality, we risk amplifying this experience and disaffirming autistic identity.

Research on implicit bias (Banaji et al. 2015) has been relatively clear: when we are tired, stressed, overwhelmed, or overworked, we tend to slip in our ability to intervene on unconscious bias. As social workers, we all are impacted by unconscious bias as a result of living in an ableist society with little recognition for and support of neurodiversity. In working with autistic people, this often plays out as an emphasis on behavioral goals and strategies that work toward normalcy, emphasize the goals of others (caregivers, schools, residential staff, etc.), and take an overly diagnostic, deficit-oriented approach in understanding ASD. As a result of COVID-19, autistic people, having already been struggling with mental health, might experience an exacerbation in symptoms (Centers for Disease Control and Prevention 2020) as they work to adjust to a world that is so off-balance. At the same time, social workers are sharing this trauma of a world unexpectedly altered. Many of us are facing significant losses in our own lives, while simultaneously needing to be emotionally present to support others who are struggling. This shared traumatic experience creates a perfect scenario for enacting bias in our work: we are stressed, anxious, and overwhelmed ourselves as we try to maintain well-being in an unwell social context. Meanwhile, our clients’ needs are likely to be greater than ever before. Acknowledgment is meaningful in preventing this dynamic. We must be mindful and use our own experiences, our own sense of instability, to build empathy and relate to autistic people with a shared sense of humanity and understanding of the depth of trauma a pandemic like COVID-19 has caused.

We are in uncharted territory here. There is little research on supporting mental health and well-being in autistic people and none yet that could address effective ways to do this during the current pandemic. Understanding the significant impact such events are likely to have on this group of people, many of whom were already struggling, can offer some guidance for social workers to be effective advocates, supports, and allies in this pandemic.

Acknowledging Trauma and Loss

Several government agencies, nonprofit organizations, and scholars have offered guidance for supporting autistic people struggling with the impacts of COVID-19 (Centers for Disease Control and Prevention 2020; Frankova 2020; Narzisi 2020;
National Autistic Society (2020). Most of these recommendations focus on establishing structure and routine, as well as behavioral mechanisms for stress reduction such as avoiding news outlets and setting up a relaxing (or sensory-friendly) physical space. These suggestions are helpful, but I worry that in all the focus on behavior management and regaining normality, we miss the emotional component of the current experience. As a result of an unconscious ableist bias, I believe we have a tendency to reduce this group of people to merely a set of behaviors rather than understanding the psychological and more importantly the emotional basis of those behaviors. A 2017 report on autistic people’s reactions to behavioral interventions sponsored by Autistic Self Advocacy Network (ASAN) and the Office of Developmental Primary Care at the University of California, San Francisco, speaks to this. The personal narratives contained in this report emphasize that there is a focus among therapists and professionals (including social workers) on changing appearance rather than promoting well-being, working toward identity-affirmative coping strategies, and maintaining sensitivity to the trauma many autistic people face growing up in a neurotypical-centric world.

Nyatanga (2020) emphasizes the importance of acknowledging the multiple losses associated with COVID-19 that each of us has experienced (or will experience) as a result of this virus and its impact on our lives. ASD is often characterized in part by a need for routine. Many autistic people have spent years working to find a place in their communities, find routine, and find stability. Expressing resulting sense of loss may be challenging as some autistic people have great difficulty with verbal communication, especially around social and emotional experiences. It is critical that as social workers and fellow humans we see grief for what it is and not let it get lost and labeled as merely “behavior.” In that label, we risk losing the true meaning and communication behind the actions we observe and also the humanity and the shared experience.

I have previously written about the lack of evidence-supported frameworks for trauma-informed clinical care for autistic people (Fuld 2018). Acknowledging this issue and working with the knowledge we currently have, I have suggested that clinicians can utilize the Substance Abuse and Mental Health Services Administration’s (SAMHSA) six principles of trauma-informed care (2014) to guide practice in this realm (Fuld 2020). The themes of this model include establishing safety; being consistent, trustworthy, honest, and transparent; finding opportunities for peer support or identity-affirmative role models; using a stance of collaboration and mutuality; shifting power dynamics to promote self-expression and choice; and staying attuned to the impact of culture, ableism, and other intersectional aspects of oppression. While these themes do not offer a clear roadmap for social workers, they do provide a therapeutic stance that will be essential in addressing the impact of COVID-19 on mental health in autistic people. Keeping these principles in mind can guide us in seeing beyond the behavior and structuring interventions that address the loss and trauma that is both acute and cumulative for the autistic community.
Resilient Coping

While resilience has been a popular field of study in the social sciences recently, there is a dearth of research on supporting resilience in autistic people (Szatmari 2018). Research associated with resilience and ASD has explored ways to support resilience among family members and caregivers, but resilience in the individual is often overlooked in favor of a behavioral focus. This oversight misses a potential strength: the term persevere is commonly used in reference to autistic people when describing the propensity for repetition and/or a singular intense focus on routine or on a particular topic. It is often used with a negative clinical connotation by professionals, but the term perseverate is directly related to perseverance, and perseverance is something we likely all need to cope in this pandemic.

Kocalevent et al. (2017) discuss the concept of resilient coping. Resilient coping refers to one’s skills for managing challenging situations in an adaptive way that allows for positive outcomes and potential growth (Sinclair and Wallston 2004). Sinclair and Wallston (2004) developed the Brief Resilient Coping Scale, which measures four characteristics indicative of resilient coping: ingenuity in adapting to challenging circumstances, confidence in one’s ability to control their reaction to challenging circumstances, a belief that positive growth can come from challenging circumstances, and an ability to recalibrate following loss. These features, which are mostly cognitive, might provide some clinical guidance for social workers looking to support autistic clients in strengthening resilient coping skills during the COVID-19 pandemic. This framework resonates for me as having potential in our current sociopolitical context because of its emphasis on adapting not just behaviorally, but also psychologically to this new post-COVID environment and addressing the experience of loss.

Final Thoughts

There are many additional questions that arise when thinking about the impact of a COVID-19 era on autistic people that seem important to pose even if they cannot yet be answered: What does social distancing mean for people who typically struggle in social situations? Could the adoption of new forms of communication that allow physical distance create space for neurodiverse ways of relating and connecting in our communities? There are still so many unknowns. Our increased reliance on technology for work and socialization could make both communal and professional spaces more accessible and less anxiety-provoking for some autistic people. Conversely, it could also enhance the challenge of reading social cues. An autistic person may need to learn a whole new set of unspoken norms (often referred to as the hidden curriculum) for these newer forms of social interaction.

It is also important that as social workers we understand that difficulty with social communication does not mean that most autistic people do not want close
social relationships and connection (den Houting 2020). Many struggle to create those connections but want them very much, which can foster a sense of isolation that is likely to be heightened by the social distance of COVID-19. Certainly, this sense of isolation and loss is shared among all of us. In working with autistic people during and after the COVID-19 pandemic, I am hopeful that we as social workers will tap into this sense of shared trauma, shared loss, and shared resilience. The acknowledgment and empathy that come from this shared experience have real potential to address the ableism that has existed in social work’s adherence to a medicalized understanding of ASD.

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