autism

Editorial

# Mental health across the lifespan

Autism
2020, Vol. 24(4) 805–808
© The Author(s) 2020
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1362361320912132
journals.sagepub.com/home/aut
SAGE

Prevalence estimates of mental health problems among autistic individuals range from "significant concern" to "epidemic." In a very few specific areas related to mental health, we have a strong literature base that extends to intervention science (e.g. adapting cognitive-behavioral therapy to address anxiety disorders in autistic children and adolescents; Reaven et al., 2012; White et al., 2010; Wood et al., 2015). Still, much work remains to address even the most widely studied of mental health difficulties. More concerning yet is the fact that mental health problems are both broad and deep in the autism population; they reach far beyond anxiety alone (into such difficulties as depression, post-traumatic stress, and schizophrenia), and we know relatively little about the complexity of presentations and effectiveness of treatments across the life course. We need to come together as stakeholders to figure out how best to help, and we need to do this, as they say, *yesterday*.

For several decades, the focus on understanding autism in terms of phenotype, intervention, and prevention seemed to leave little room for research on co-occurring mental health problems. Along the way, pioneering work (e.g. Lainhart & Folstein, 1994) kept reminding us that mental health symptoms, as distinct from features of autism itself, have been described in individuals on the spectrum from the days of Kanner's (1943) case studies. Autistic people and those who support them have worked with funders to push mental health in autism up to the top of the autism research agenda (Autistica, 2016; Cassidy et al., 2019). Per the sharp increase in the number of research publications on this topic over the last decade (see Figure 1 in White et al., 2018), the field of autism research is moving toward seeing autistic individuals holistically, and as having an important voice in directing researchers, funders, and services toward issues of mental health and quality of life.

While this movement is positive, the situation itself remains quite dire: Many people on the spectrum struggle daily with mental health problems—which often relate to the context of living as an autistic person in a world built for the neurotypical majority—with little recourse to treatment and support. Clinical researchers get frequent requests for referrals to mental health resources for individuals on the spectrum, yet stakeholders in all roles experience firsthand what Maddox and colleagues (2020) observed within this special issue: Clinicians in the community will not see autistic clients for most mental health concerns, often because of lack of training and misconceptions about working with autistic people. While pharmaceutical intervention is more accessible, we know of no randomized controlled trials for using selective serotonin reuptake inhibitors (SSRIs) specifically to treat mood problems in people on the spectrum.

We need to understand the presentation, epidemiology, moderators, and mechanisms that cause or contribute to mental disorders in autistic individuals. We need validated assessments and demonstrated-effective intervention, and we need to disseminate them in a manner that can reach real people in need. To do so, we must *act fast*—with short-term efforts, such as building awareness and improving access to what already exists—but we must also *think slowly*, about where to steer the ship, and how to apply cutting-edge scientific methods to long-term programs of research that will improve the mental health landscape in autism not just now, but 25 years from now.

Toward this long-term agenda, we advocate for more community-based participatory research (e.g. Benevides et al., 2020), making sure that programs of research unfold in response to the community-identified priorities. We also recommend cross-training professionals to position them to flexibly borrow methods from both landmark and cutting-edge studies currently underway to treat mental disorders. For example, future working groups and special issues might focus on integrating behavioral science with immunology, genetics, and neuroimaging toward the study of transdiagnostic mental health problems that most commonly co-occur with autism (Gadow, private communication). In addition to its potential to address an immediate clinical need, such work may afford new opportunities to study transdiagnostic mechanisms and may have scientific and clinical effects that reach beyond select groups. Now is the time to lobby researchers from other fields, as well as new trainees, to build awareness and interest in this crucial work.

This special issue dedicated to Mental Health across the Lifespan is not the start, because this work has been started already. It goes without saying that it is not the end. In this special issue, we focus on two continua: *breadth* of mental health problems and associated mechanisms, and *lifespan* approach to their study.

## Breadth of mental health problems and of the underlying potential mechanisms that drive their presentation

We attend to conditions that are very common in autistic people (e.g. depression and anxiety) and mechanisms that are relatively well researched (e.g. emotion regulation). We also highlight transdiagnostic mechanisms, conditions, and contexts that receive little research attention in this population, including obsessive–compulsive symptoms, post-traumatic stress symptoms, substance abuse, psychosis, inpatient populations, or undiagnosed adult women.

Research presented in this special issue helps build evidence for processes that affect many: For example, in a systematic literature review exploring symptoms of depression in autistic adolescents and young adults, results suggest that, for a subset of autistic people who are more socially motivated, social and communication difficulties (and associated loneliness) can contribute to depressive symptoms (Smith & White, 2020). Similarly, emotion regulation difficulties were found to predict anxiety, even after controlling for autism symptoms, in a very large community sample of autistic individuals 6–17 years of age (Conner et al., 2020). We continue to refine our understanding of these relatively well-studied concepts toward improved treatment precision and efficacy: For example, Tajik-Parvinchi et al. (2020) noted that greater baseline *somatic* symptoms of internalized distress in particular were associated with less robust responses to a cognitive-behaviorally based treatment of emotion regulation. Data from Mazefsky et al. (2020) suggest that autistic people may have difficulty disengaging from negative distressing stimuli, thus identifying a potential cognitive mechanism underlying the higher-order mechanism of emotional dysregulation in autistic adolescents.

This collection also informs our understanding of less well-studied groups: "Camouflaging" one's autism symptoms to fit into social contexts was associated with poorer mental health in a study of adult women with varying degrees of autistic traits (Beck et al., 2020). This finding has important implications in the long term, in terms of calls for societal acceptance over individual change, and in the short term, in terms of considering how best to support well-being holistically in the context of interventions that seek to improve adaptive and social functioning.

Northrup et al. (2020) demonstrate the feasibility of measuring emotional reactivity in psychiatrically hospitalized autistic individuals 5–20 years of age using standardized observational measures (as opposed to commonly used informant-based questionnaires), expanding the breadth of how mental health problems may be studied. Indeed, Santore et al. (2020) found that the source of information matters: Youth report, but not parent report, of obsessive–compulsive symptoms was associated with clinician observations of repetitive and restricted behaviors in youth, which the authors used to elucidate relations among obsessive–compulsive and autism symptoms.

Another group of papers explored mental health conditions which have been under-researched in autism. Psychosis is one such condition, with overlapping features between autism and psychosis potentially resulting in misdiagnosis. Wilson et al. (2020) demonstrated that a psychosis risk assessment tool, developed and validated for non-autistic people, showed promising evidence for face validity in autistic adolescents and adults. Importantly, response errors were associated with difficulties in understanding unclear questions regardless of diagnosis. Results from Ressel et al. (2020) suggest a limited evidence base (26 studies) exploring substance abuse in autistic people from childhood to adulthood. While the studies were of acceptable methodological quality, the wide variety of methods and the absence of validated tools available to identify substance abuse in autistic people made it impossible to estimate prevalence. Importantly, autistic people may be more at risk for substance abuse due to higher prevalence of known shared risk markers with the general population (e.g. social isolation), as well as unique factors (e.g. late autism diagnosis). Post-traumatic stress disorder (PTSD) may have a different presentation across autistic and non-autistic populations, which may mean that many autistic people remain undiagnosed and untreated. Haruvi-Lamdan et al. (2020) compared exposure to potentially traumatic life events and post-traumatic symptoms in 25 autistic compared to 25 non-autistic adults. Autistic adults reported significantly more potentially traumatic life events, particularly social events, than non-autistic adults, and a majority (60%) rated these social events as the most distressing. The rates of probable PTSD and post-traumatic symptoms were significantly elevated in autistic compared to non-autistic adults.

## A lifespan approach to mental health research in autism

Participants reflected in this special issue range from preschool children to those late in life. In a randomized controlled trial of a cognitive-behavioral intervention to improve emotion regulation in a school-age sample, the authors concluded that greater baseline internalizing symptoms were associated with less robust treatment response, implying that we need to focus on prevention at younger ages (Tajik-Parvinchi et al., 2020). Gaigg et al. (2020) provide evidence for the use of online self-help cognitive behavior therapy and online mindfulness-based therapy to address anxiety in autistic adults, and explore the feasibility of studying these effects using a randomized trial. Considering the needs of autistic adults, and ways of making supports accessible, is a key step to real-world effectiveness for mental health difficulties. In capitalizing on longitudinal design spanning from childhood to young adulthood, Stringer et al. (2020) found that while as a group autistic individuals show small but significant reductions in symptoms of mental health problems, many continue to demonstrate clinically meaningful severity levels across time points. Furthermore, mental health trajectories were associated with individual (e.g. adaptive functioning) and contextual (e.g. neighborhood deprivation) variables, which may inform ecological approaches to care, the identification of risk factors, and treatment planning.

This special issue encompasses different stages of the work about *breadth* and *lifespan*, from early reviews (e.g. Ressel et al., 2020), initial measurement evaluation (Wilson et al., 2020), and exploratory studies (e.g. Beck et al., 2020; Gaigg et al., 2020) to investigations of moderators of treatment outcomes in randomized controlled trials (e.g. Tajik-Parvinchi et al., 2020). Autistic voices are included as experts (e.g. Benevides et al., 2020), both as researchers and reviewers of this work, though we recognize that there is more work to do in this area.

We would like to suggest the following next steps, indicated by this special collection of articles:

1. Innovate how we *operationalize* and measure mental health, its underlying mechanisms, and its changes over time, including applying cutting-edge science from related areas to advance this work within autism.
2. Develop *validated measurement tools* to capture the unique presentation of mental health problems among autistic people in different contexts, rather than relying solely on "standardized" measures developed for other groups with no evidence of validity in autism. Ensure that these tools can be used with different kinds of responders to take into account autistic perspectives and those of family carers and clinicians.
3. *Build awareness in stakeholders* of all roles by developing task forces around mental health literacy, wellness, prevention, and promotion. It is crucial that autistic adults and their families are drivers in these efforts.
4. Aim to further understand which mental health *interventions* work for whom, and for what targets, recognizing that there is no one-size-fits-all approach across difficulties, characteristics, or contexts.
5. Develop low-cost ways to *educate community clinicians* about autism, including common misconceptions and treatment adaptations, so that existing resources become more accessible to this community even as we strive simultaneously to improve these resources or develop new ones.
6. *Recognize everyday trauma* and identify creative ways to *support meaningful social contact* in accepting environments.

In this age of crucial identity politics, when stakeholders struggle to reconcile different models and monikers for autism in daily life—from disease to celebrated difference—most of us would agree that the mental health problems prevalent in autistic individuals are NOT necessary to, or consistent with, autistic identity. Let us come together, then, in working toward improved mental health in autism.

## References

Autistica. (2016). *Your questions: Shaping future autism research*. https://autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf

Beck, J. S., Lundwall, R. A., Gabrielsen, T., Cox, J. C., & South, M. (2020). Looking good but feeling bad: "Camouflaging" behaviors and mental health in women with autistic traits. *Autism*, *24*(4), 809–821.

Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D., Hector, B. L., Morgan, L., Nebeker, L., Purkis, Y., Rankowski, B., Wittig, K., & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, *24*(4), 822–833.

Cassidy, S. A., Robertson, A., Cogger-Ward, H., Goodwin, J., & Rodgers, J. (2019). *Autism community priorities for suicide prevention*. https://sites.google.com/view/mentalhealthin-autism/projects/insar-policy-brief

Conner, C. M., White, S. W., Scahill, L., & Mazefsky, C. A. (2020). The role of emotion regulation and core autism symptoms in the experience of anxiety in autism. *Autism*, *24*(4), 931–940.

Gaigg, S. B., Flaxman, P. E., McLaven, G., Shah, R., Bowler, D. M., Meyer, B., Roestorf, A., Haenschel, C., Rodgers, J., & South, M. (2020). Self-guided mindfulness and cognitive behavioural practices reduce anxiety in autistic adults: A pilot 8-month waitlist-controlled trial of widely available online tools. *Autism*, *24*(4), 867–883.

Haruvi-Lamdan, N., Horesh, D., Zohar, S., Kraus, M., & Golan, O. (2020). Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions. *Autism*, *24*(4), 884–898.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, *2*(3), 217–250.

Lainhart, J. E., & Folstein, S. E. (1994). Affective disorders in people with autism: A review of published cases. *Journal of Autism and Developmental Disorders*, *24*(5), 587–601.

Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J., Arnold, S. R. C., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism*, *24*(4), 954–967.

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2020). "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism*, *24*(4), 919–930.

Mazefsky, C. A., Collier, A., Golt, J., & Siegle, G. J. (2020). Neural features of sustained emotional information processing in autism spectrum disorder. *Autism*, *24*(4), 941–953.

Northrup, J. B., Goodwin, M., Montrenes, J., Vezzoli, J., Golt, J., Peura, C. B., Siegel, M., & Mazefsky, C. (2020). Observed emotional reactivity in response to frustration tasks in psychiatrically hospitalized youth with autism spectrum disorder. *Autism*, *24*(4), 968–982.

Reaven, J., Blakeley-Smith, A., Culhane-Shelburne, K., & Hepburn, S. (2012). Group cognitive behavior therapy for children with high-functioning autism spectrum disorders and anxiety: A randomized trial. *Journal of Child Psychology and Psychiatry*, *53*(4), 410–419.

Ressel, M., Thompson, B., Poulin, M. H., Normand, C. L., Fisher, M. H., Couture, G., & Iarocci, G. (2020). Systematic review of risk and protective factors associated with substance use and abuse in individuals with autism spectrum disorders. *Autism*, *24*(4), 899–918.

Santore, L. A., Gerber, A., Gioia, A. N., Bianchi, R., Talledo, F., Peris, T. S., & Lerner, M. D. (2020). Felt but not seen: Observed restricted repetitive behaviors are associated with self-report—but not parent-report—obsessive-compulsive disorder symptoms in youth with autism spectrum disorder. *Autism*, *24*(4), 983–994.

Smith, I. C., & White, S. W. (2020). Socio-emotional determinants of depressive symptoms in adolescents and adults with autism spectrum disorder: A systematic review. *Autism*, *24*(4), 995–1010.

Stringer, D., Kent, R., Briskman, J., Lukito, S., Charman, T., Baird, G., & Simonoff, E. (2020). Trajectories of emotional and behavioral problems from childhood to early adult life. *Autism*, *24*(4), 1011–1024.

Tajik-Parvinchi, D. J., Farmus, L., Cribbie, R., Albaum, C., & Weiss, J. A. (2020). Clinical and parental predictors of emotion regulation following cognitive behaviour therapy in children with autism. *Autism*, *24*(4), 851–866.

White, S. W., Albano, A. M., Johnson, C. R., Kasari, C., Ollendick, T., Klin, A., . . . Scahill, L. (2010). Development of a cognitive-behavioral intervention program to treat anxiety and social deficits in teens with high-functioning autism. *Clinical Child and Family Psychology Review*, *13*(1), 77–90.

White, S. W., Simmons, G. L., Gotham, K. O., Conner, C. M., Smith, I. C., Beck, K. B., & Mazefsky, C. A. (2018). Psychosocial treatments targeting anxiety and depression in adolescents and adults on the autism spectrum: Review of the latest research and recommended future directions. *Current Psychiatry Reports*, *20*(10), Article 82.

Wilson, C. S., Anthony, L., Kenworthy, L., Fleischman, R., Demro, C., Andorko, N., Armour, A. C., & Schiffman, J. (2020). Feasibility of psychosis risk assessment for adolescents diagnosed with autism. *Autism*, *24*(4), 834–850.

Wood, J. J., Ehrenreich-May, J., Alessandri, M., Fujii, C., Renno, P., Laugeson, E., . . . Murphy, T. K. (2015). Cognitive behavioral therapy for early adolescents with autism spectrum disorders and clinical anxiety: A randomized, controlled trial. *Behavior Therapy*, *46*(1), 7–19.

**Katherine Gotham**
Rowan University, USA

**Sarah Cassidy**
University of Nottingham, UK

**Jonathan Weiss**
York University, Canada