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To better meet the needs of autistic people, we need to rethink how we measure services

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Services can be critically important to supporting autistic individuals in reaching their full potential. Diagnostic services can open doorways to autism-related services and to treatments for co-occurring conditions, early intervention and school-based services can set the stage for learning, therapeutic services (e.g., occupational therapy, speech and language therapy, mental health services) can encourage skills building and mental health, and a variety of services related to home and community-based living (e.g., job coaches, transportation services) can support independence in adulthood. Research suggests that when autistic individuals receive services, they often demonstrate improved school and post-school outcomes (e.g., Burke et al., 2019; Taylor et al., 2016).

In addition to being supported by research, the importance of services is an area of consensus among stakeholders in the autism community. In a literature review about research priorities identified by autistic individuals, families of autistic individuals, researchers, and practitioners, research about services was one of the top-rated priorities (Roche, Adams, & Clark, 2021). Autistic self-advocates report that research is needed to examine which types of services truly benefit autistic individuals (Autistic Self-Advocacy Network, 2022). Families report that information about ways to access formal services is needed to improve outcomes for their autistic family member (Aleman-Tovar et al., 2022). Researchers, practitioners, and policymakers similarly report that, to better serve autistic individuals, rigorous research is needed that examines which services are most effective for improving quality of life and other valued outcomes (e.g., Lord et al., 2022; Interagency Autism Coordinating Committee, 2020).

Given the general agreement on the importance of services for supporting autistic individuals, one might think that there would be rigorous methods to measure appropriate *and* beneficial services across the lifespan. Unfortunately, this is not the case. A common way to measure services is by examining service receipt—specifically, through dichotomizing whether or not a service is received and counting the number of services (e.g., Ishler et al., 2022; Kaya et al., 2018; Burke et al., 2016). This approach to measuring services assumes that more services are better, but such a premise may not be true. A count of services also implies that each service is equally impactful, an assumption that may be false and could point toward inefficient use of resources. Further, the dichotomization method ignores several of the nuances that are important to understanding whether and when services are beneficial, including the intensity of services (e.g., how many weeks or days is the service received?); duration of the service (e.g., how many hours is the

service received?); and content of the service (e.g., does the service reflect evidence-based practices?; what are the specific practices that are embedded in the service?). In further detail in another manuscript (Burke et al., submitted), we outline additional ways in which extant service measures are insufficient.

Measuring services in a way that moves beyond a count of services received and considers the aforementioned nuances has the potential to make research more impactful in informing practice and policy. Studies of mental health services may provide a good model for how to think about measuring nuance. It is relatively common in mental health services research to measure the type of service (e.g., inpatient, outpatient), setting of the service (e.g., psychiatric hospital, clinic, school), number of times the service was used, and benefits of the service (for an example, see the Services Assessment for Children and Adolescents, Horwitz et al., 2001). It is much less common to see comprehensive measurement of developmental disability or autism services – especially as an autistic person moves from adolescence into adulthood. For example, a study may assess whether vocational rehabilitation services are/are not received and whether the receipt of that service is related to a greater likelihood of employment; but for research to inform practice and policy, it is likely helpful to measure the number of hours of vocational rehabilitation services, the length of time the services are received, who is performing the services, and what specific practices are being implemented. Such a detailed and comprehensive assessment can provide the information needed to understand the circumstances wherein services are effective in meeting an individual's needs.

A measure to understand when and how services are beneficial to autistic individuals will also need to assess unmet service needs and, perhaps most importantly, identify the barriers to not receiving needed services. The number of unmet service needs has been used in research about adults with intellectual and developmental disabilities, including autism, to gauge service access (e.g., Burke & Heller, 2017; Laxman et al., 2019). Using an unmet service needs measure has provided important information, not only about which services are received but also about which needed services are most frequently *not* received. However, without identifying why needed services are not being received, a services measure cannot meaningfully inform service interventions. Put simply, without identifying the barriers to service receipt, neither interventions nor policy can be developed to overcome barriers. Thus, a measure of services not only needs to comprehensively reflect the services received but also document the reasons why needed services are not received.

Barriers to services can be found at the level of the service system or specific to individuals and families. The type of barrier can inform the solution to accessing effective services. Common systemic barriers to services include not having enough service providers in an individual's geographic area and governmental services that are complex and/or are underfunded (McBain et al., 2020; Dimian, Symons, & Wolff, 2021). Systemic barriers may point to the need for legislative advocacy to reform the service system (e.g., Burke et al., in press). Common barriers impacting individuals or families include lack of financial resources or time to navigate complicated service delivery systems (Xu et al., 2019). Barriers can also include lack of knowledge about services, feelings of disempowerment, and underdeveloped advocacy skills (e.g., Burke et al., 2019). Such barriers point to interventions

that target logistical obstacles in accessing services or to programs that educate autistic individuals and families about services, empower them, and equip them with advocacy skills to effectively work within service systems (e.g., Taylor et al., 2017). Studies that have examined barriers often look at barriers to services in general, but this information may not be actionable as different barriers may impede access to certain types of services. By identifying barriers to specific services, targeted interventions can be developed to overcome the barriers for that service.

There are two additional considerations that are relevant to all of autism research, but are especially important to address when measuring whether an individual's service needs are met. First, it is critical to partner with autistic individuals, their families, and practitioners to inform the development of a services measure. By including the input of the end users (i.e., autistic individuals) at the beginning of developing a measure, we can ensure that the measure accurately reflects access to services and captures aspects of services that matter to autistic individuals (Pukki et al., 2022). The input of autistic individuals should also be central when defining service needs and what it means for a service to be beneficial. Relatedly, families of autistic individuals should inform the development of a services measure. Services, regardless of the context, are often difficult to navigate. Autistic individuals may rely on people in their lives, often parents, to help identify, apply for, and access services (Sanderson et al., 2017) – including into adulthood. Thus, families can provide valuable insights to inform a services measure. Finally, it is critical to involve practitioners. Individuals who work for service provider agencies (e.g., schools, respite care, vocational rehabilitative services, social security) have unique perspectives of not being the user of the service but rather having an “insider” perspective in providing a service. Having individuals with diverse perspectives sharing their lived experiences in accessing, supporting, or providing services is a critical first step in developing a services measure.

Second, it is important for the measure to be responsive to marginalized populations impacted by service disparities. Research clearly shows that services are not evenly distributed across the population of autistic individuals. Latinx (vs. White) autistic children (especially those from monolingual, Spanish-speaking families) and those from racially minoritized groups are less likely to receive needed services (Magaña et al., 2013; Smith et al., 2020; Zuckerman et al., 2017). Autistic individuals from lower-income (versus higher-income) families, whose parents have less education, and who live in rural (versus urban) areas are also less likely to access needed services (McBain et al., 2020; Smith et al., 2020; Thomas et al., 2007). Gathering input from populations that have the greatest challenges in accessing services will help ensure that a service measure is responsive to the needs of a wide group of individuals and circumstances.

In sum, we propose a call to action to develop measures of services for autistic individuals across the lifespan that reflect intensity, duration, content, and barriers to receiving needed services. Research is needed to ensure that the service measure reflects the needs of multiple stakeholders (e.g., self-advocates, families, practitioners) and is responsive to the populations least likely to access those services. While the development of such a measure may be daunting, it is necessary. Only with rigorous and responsive measurement

of services can we identify barriers to service receipt, solve service disparities, and gauge the effectiveness (or lack thereof) of services for autistic individuals.

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