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The estimated annual cost of caring for individuals with autism is US$268 billion (Leigh and Du, 2015). What is this buying? Beyond a general knowledge of setting and type of service provided (e.g. educational, mental health, speech therapy, and occupational therapy), we know very little about the type and quality of interventions being delivered. For several reasons, it is imperative that we be able to accurately and efficiently characterize the treatment that children with autism receive in their communities.

One reason for this urgency links treatment to our basic understanding of mechanism and subtype in autism. Most efforts to identify different kinds of autism, using either behavioral or biological measures, have been frustratingly disappointing. Yet there is still growing consensus that autism really comprises a set of phenotypically linked disorders, and that if we could distinguish among them, we could improve our understanding of their basic biology, leading to more targeted treatments and supports. An important unexplored strategy for subtyping autism may be to examine response to treatment. Thus far, we have examined predictors of treatment success; however, these have primarily been relatively gross measures of intelligence and language use (e.g. Ben-Itzchak and Zachor, 2011). A few studies have examined specific behaviors relating to response to specific, well-characterized treatments (e.g. Schreibman et al., 2009; Sherer and Schreibman, 2005; Yoder and Stone, 2006). However, these studies have not led to phenotypic descriptions that provide a better understanding of either the biology that may subtype the disorder or methods to prescribe treatment a priori (Stahmer et al., 2010; Vivanti et al., 2014). If we wish to examine this question, we will either have to standardize treatment for a very large and heterogeneous sample of individuals with autism—a very costly endeavor—or we will have to be able to measure the active ingredients of treatment in the schools and clinics in which treatment is delivered.

The second reason for characterizing intervention is the need to identify active mechanisms, with the goal of refining treatments (e.g. Kasari and Lawton, 2010; Schreibman et al., 2015). Due to the complexity of treatment of autism, many evidence-based interventions are packages composed of several components. Each of these components has a cost associated with implementing it, including the time it takes to train providers to accurately use each component. Evidence-based interventions with varying brand names may utilize similar components even when differing in overall theoretical orientation (Schreibman et al., 2015) and may lead to similar outcomes when implemented with high fidelity (Boyd et al., 2014). However, these interventions may also differ in important ways. Therefore, it is important to examine the relative contribution, mechanism of action, and necessity of each component of an intervention package to achieve optimal child outcomes (Lerner et al., 2012; Sanetti et al., 2009; Schulte et al., 2009). We know that community providers often pick and choose specific components of an intervention to fit their clients and setting rather than use the package as a whole (Stahmer et al., 2005). Examining the impact of individual components of an intervention will help determine whether their methods of modifying and combining treatments are likely to be both effective and efficient. If we could measure the delivery of each component accurately, we could dismantle components that are mostly associated with positive outcome.

The third reason to characterize interventions is that we can measure the quality of care individuals with autism receive. The service delivery infrastructure for individuals with autism has not kept pace with the dramatically increasing number of children diagnosed. Service providers rush to hang out shingles saying that they treat autism, but there are few licensure and credentialing practices in place. Although this has increased access to care, there continues to be extreme variability in service intensity and quality. Even if we measure the number of service hours, and perhaps the “type” of service, which may often include educational services, speech and language therapy, occupational therapy, parent-implemented intervention, and social skills groups, there is a huge range in the quality of intervention within these services. Families and payers have few ways of assessing the quality of the care individuals with autism receive. Similar to quality assurance and improvement procedures that have been put in place to assess the care provided for other health conditions, we need accurate measures that can be implemented with relatively little time burden to assess quality of care.

The measures currently available are narrow in scope, either focused on a specific intervention or a specific service setting. Typically, intervention developers will create a
protocol to guide implementation or a tool for assessing fidelity of implementation. Developing accurate, low-cost fidelity measurement is in many ways more challenging. The process of measuring fidelity involves several elements: (1) identifying important treatment components, or “key ingredients”; (2) developing an instrument that allows for valid and reliable measurement of these components; and (3) identifying a system for assessing the components, including methods for providing feedback to providers (Schoenwald et al., 2011). The fidelity process must measure the key ingredients of an intervention and be both psychometrically sound (effective) and usable in clinical care (efficient). Researchers in children’s mental health have validated fidelity measures for clinicians and supervisors in community settings for individual evidence-based practices (e.g. Multi-Systemic Therapy; Schoenwald and Henggeler, 2003); however, most methods of rating fidelity in autism have primarily been used for research.

There have been some important, recent efforts to characterize program quality without focusing on a specific intervention. For example, the Autism Program Environment Rating Scale (APERS), developed by the National Professional Development Center for Autism, is a tool to guide professional development and coaching efforts in educational settings. However, measures developed so far are typically setting specific, time consuming, and require significant clinical expertise to ensure accuracy (e.g. Hume et al., 2011; Mandell et al., 2013). Developing methods for measuring quality indicators in usual care for ASD across service systems (i.e. education, mental health, and affiliated care) and interventions (e.g. behavioral, developmental, and environmental) that are efficient and accurate will require a targeted and coordinated effort among intervention researchers and community collaborators.

References


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