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## Accelerating research on treatment and services for transition age youth and adults on the autism spectrum

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Outcomes such as employment, social relationships, independence, quality of life, and life expectancy are all quite poor for adults on the autism spectrum (AS) (Bishop-Fitzpatrick et al., 2016; Hirvikoski et al., 2015; Howlin and Magiati, 2017), despite the findings that social interaction difficulties and restricted and repetitive behaviors decrease in severity in adulthood (Howlin et al., 2014; Moss et al., 2015). Research on transition age youth and adults with autism is in its infancy. Less than 20% of all published autism research literature and about 2% of all autism research funding in the United States target these populations, and there are large deficits in related services (Interagency Autism Coordinating Committee, 2016; Government Accountability Office (GAO), 2015). Despite these challenges, there are many opportunities to capitalize on lessons learned from previous research in related areas. Opportunities for research on adults with autism will reach a new height over this next decade as the first large cohorts of children diagnosed with autism have now reached adulthood (Bishop-Fitzpatrick et al., 2017; Gerhardt and Lainer, 2011). The time is ripe for our research community to conduct effective and efficient research and swiftly translate research findings into services to improve the lives of this growing population.

Two large bodies of literature can guide investigators: (1) research on children with autism and (2) research with adults with other neurodevelopmental conditions, such as schizophrenia. Three key lessons learned from this literature could accelerate research for adults with autism. Our hope is that this editorial and the original research published in this special issue will provide examples and guidance in this area.

### Lesson 1: Apply prevention and early intervention theories

One important lesson from previous research is that access to intervention services is vital to improved outcomes (Bryson et al., 2003; Hume et al., 2005). Our service system for children is developed to the point that some children receive early intervention as young as infancy. Adults with autism, on the other hand, find it extremely difficult to access appropriate services (GAO, 2017) and available services often dramatically decrease as they transition to adulthood. This extreme shift is often referred to as the “service cliff” (Roux et al., 2015). Existing services for adults frequently only enroll those with more significant needs such as intellectual disability, psychiatric disorders, or medical problems (Lorenc et al., 2017). Individuals with autism spend significantly more time of life within the adult service system

compared to the child system. So why is there such a large discrepancy in research, interventions, and services across the life span?

Child services have grown due to a recognition of the importance of early intervention, which is derived from the theories of neurodevelopment and neuroplasticity. Neurodevelopmental theory postulates that by defining and targeting neurodevelopmental mechanisms early in the course of development, the results can be lifelong effects. Neuroplasticity refers to the brain's ability to change in structure and function, and an emphasis has been placed on perceived limited "windows" of opportunity for change in childhood. However, more recent findings have revealed that adults have a substantial capacity for neural and developmental growth, and this growth can have lifelong positive impacts (Campos et al., 2016; Valkanova et al., 2014).

Interestingly, the adult schizophrenia literature makes use of both neurodevelopmental and neuroplasticity theories and has emphasized early or preventative interventions for adolescents and adults (Bora, 2017). In fact, schizophrenia research over the past decades has demonstrated that early intervention positively affects adult neural connectivity and functional skill levels, resulting in more positive life outcomes (Buonocore et al., 2017; Lee et al., 2012; Ramsay and Macdonald, 2015). Additionally, schizophrenia researchers have developed and tested neurological interventions, such as cognitive rehabilitative and compensatory training prior to or in combination with vocational training, secondary education, or supported employment (Bell et al., 2008; Eack, 2017; Eack et al., 2009).

Adult autism research also could take a prevention approach by intervening "early," prior to meaningful life transitions, such as transitioning from primary education, transitioning into independent living, or transitioning into the workforce. Several studies in this special issue focus on key transitions. Hume et al. report on the study of a multi-informant assessment of transition-related skills. Hillier et al. present an intervention for supporting university students during that transition period to secondary educational settings. Ross et al. describe an innovative line of research considered early intervention to independence by measuring the attitudes toward driving among adolescents and adults with autism.

When using this prevention and early intervention lens to examine the life course, it is also important to identify and target the developmental skills needed during the transition and incorporate neurodevelopmental approaches. For example, in this issue, Baker-Ericzén et al. target a key adult life transition of gaining and maintaining employment. The transition from school to employment has been an area of particular vulnerability for adults with autism, with the majority unemployed or underemployed (Shattuck et al., 2012). Baker-Ericzén et al. pilot test an innovative intervention that targets vocational soft skills, which are key neurodevelopmental skills necessary for successful employment. These skills are exactly the neurocognitive and social cognitive skills that affect employment outcomes for adults with autism. Hedges et al. use technology as a support tool for increasing meaningful life outcomes for adolescents with autism. Their study explores an innovative approach to treatment research that could include technology as a mechanism for increasing neurodevelopmental skills at that life stage.

## Lesson 2: Focus on the multiple service systems that could support adults with autism

A second lesson is to attend to multiple service systems, interagency collaborations, and barriers to accessing care within and across these systems. Like children, adults make use of multiple service systems: developmental disabilities, health, vocational, educational, independent living, social services, transportation, and mental health. Decades were spent on creating systems of care for children and establishing models for interagency collaboration. Adult service systems can apply similar methods. There are some applications of these child approaches for adolescents, such as the Federal Partners in Transition (FPT) interagency workgroup in the United States, which is composed of Education, Health & Human Services (HHS), Department Of Labor (DOL), and Social Security Agency (SSA), as well as a joint research grant initiative called the Promoting the Readiness of Minors in Supplemental Security Income (PROMISE) that focuses on improving the life outcomes of youth with disabilities by supporting improved coordination of services across DOL, Department of Housing and Urban Development (HUD), SSA, and Education (GAO, 2012). The few collaborative models used in services for adolescents and adults stand in stark contrast to models serving adults with serious mental illness. Mental health services research has focused on interagency collaborations and systems of care approaches over the past decades (Barreira et al., 2000; Oades et al., 2005; Woltmann et al., 2012). As stated in the US Government Accountability Office Interagency Autism Coordinating Committee (IACC) Report, adolescents and adults with autism “need to be able to access services that are individualized, timely, equitable, and community- and evidence-based, among other things” (GAO, 2017).

Research on barriers to accessing care is equally important (Dern and Sappok, 2014). Recent research data reveal high rates of medical conditions and early mortality for adults with autism and co-occurring health complications (Croen et al., 2015; Hirvikoski et al., 2015; Schendel et al., 2016). Saqr et al. (this issue) describe medical comorbidities and medication use in adults with autism in primary care, as well as barriers to care from the perspective of the adults, including aspects of the waiting room experience and waiting times. Identifying these barriers to care can lead to interventions to address them.

Child autism services research, as well as mental health services research more broadly, have documented the gap between evidence-based interventions developed in clinical research settings and community-based services delivered in routine care (Baker-Ericzén et al., 2010; Garland et al., 2013). Applying implementation science frameworks and methods (e.g. Aarons et al., 2011; Proctor et al., 2011) to develop and deploy interventions for adolescents and adults with autism can accelerate the delivery of effective interventions in the multiple service systems involved in caring for this population. An alternative to the traditional unidirectional model of intervention development is to design clinical interventions at the outset to fit with the targeted services context and maximize uptake. Partnering with community providers and consumers can facilitate research toward practice-relevant services interventions and avoid some of the pitfall and barriers to evidence-based practice implementation (Brookman-Frazee et al., 2012). There are a few examples of this approach

for children with autism in early intervention services, mental health services, and schools (e.g. Wood et al., 2014) that hold promise for research on adults with autism.

Another important area to attend to in services and intervention research is the role of hybrid effectiveness and implementation research. Implementation studies extend effectiveness research, which focuses on individual outcomes, to include outcomes at the provider, organization, and service system levels (Aarons et al., 2011). Applying implementation research frameworks would lead to examining feasibility of intervention delivery, provider fidelity, intervention cost, penetration, and sustainment in existing community service settings (Proctor et al., 2011) and determinants of these implementation outcomes. The recent growth of this research conducted in AS child services (Locke et al., 2016) highlights the relevance to adult AS research.

### **Lesson 3: Attend to outcomes and measurement tools**

Another lesson from previous research is the importance of defining outcomes and developing psychometrically strong measurement tools. One recent review of interventions for adults with autism, including those targeting various life outcomes (employment, social relationships, daily living, quality of life), found that in the 20,584 articles screened, only 32 were studies of interventions; more than 50 outcome measurement tools were used among the studies with very little consistency across measures (Lorenc et al., 2017). The authors reported that meta-analyses could not be conducted due to the heterogeneity of intervention content, outcomes, and outcome measures. Even more concerning was that few studies used validated measurement tools (Lorenc et al., 2017). This same challenge of lack of consistency across outcomes and measurement tools has been reported in numerous review articles. The need for psychometrically sound treatment outcome measures has been identified as a key priority for adult autism research (Bolte and Diehl, 2013; McConachie et al., 2015).

Again, research on adolescents and adults with autism can learn from the trials and tribulations, as well as advances and solutions found by research on other populations. The US National Institutes of Health (NIH) tool-box offers an instructive example. Schizophrenia researchers played a major role in advocating for a mechanism by which outcome tools would be accessible to researchers of all types (genomic, biological, neurological, interventions, services) so that results could be integrated, compared, and interpreted. As a result, since 2011 there has been a large battery of validated, open-sourced measures for research use. Unfortunately, those measures only partially meet the needs of adult autism researchers. Autism researchers can collaborate to describe, define, and measure meaningful outcomes. Individuals, families, and the community should also be involved in this process. A study by Sosnowy et al. (this issue) has begun this research and gathered parent and young adult perspectives on transition outcomes.

### **Conclusion**

In the young field of adolescent and adult autism research, we can learn a great deal from our predecessors in child autism and adult neurodevelopmental disorders research. In

particular, we can capitalize on the tremendous value of early intervention by intervening with adolescents and adults as early as possible and giving more attention to research in neurological development (i.e. cognitive and social cognitive functioning), developmental life course interventions (i.e. educational, vocational, social, independent living), coordinating adult community services, outcome measurement, and implementation research. In this way, we can truly make a difference in the lives of individuals with autism across their life span.

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