

## **2012 INTERAGENCY AUTISM COORDINATING COMMITTEE STRATEGIC PLAN UPDATE: QUESTION 5 WHERE CAN I TURN FOR SERVICES?**

### **WHAT IS NEW IN THIS AREA, AND WHAT HAVE WE LEARNED IN THE PAST TWO YEARS?**

New findings and opportunities relating to autism spectrum disorder (ASD) services over the last two years stem from both research findings that incrementally advanced understanding of issues affecting the service system and new legislative initiatives that have the potential to dramatically affect the way individuals with ASD access and pay for services.

#### **Access and Payment**

The 2011 addendum to the *IACC Strategic Plan for ASD Research* discusses the Affordable Care Act passed by Congress in 2010 and the Mental Health Parity Act implemented in 2010, both of which have the potential to expand service coverage for individuals with ASD. The importance of the Affordable Care Act was recently highlighted in a report estimating that as much as 45% of children (206,330 children in 2011) with ASD identified as having autism through the U.S. special education system receive Medicaid-reimbursed services (Semansky, Xie & Mandell, 2012).

Not mentioned in that addendum is the proliferation of private insurance mandates passed by state legislatures. Between 2008 and the present, 31 states have passed legislation requiring private insurance plans subject to state regulations to cover ASD-related services (National Conference of State Legislatures, 2012). These mandates range greatly in the types of services covered and the maximum dollar amount allowed, but all have at their core the coverage of behavioral treatments for young children with ASD. All of the mandates address service needs for children, with none mandating service coverage for individuals greater than 21 years of age.

#### **Translating Research Into Practice**

The most important goal of services research is translating the results into practice. A recent review of screening instruments and practices suggested that current screening instruments do not meet established quality criteria and thus are not suitable for widespread dissemination. The current healthcare and education systems are not prepared for the influx of children that would result from more reliable and valid screening (Al-Qabandi, Gorter & Rosenbaum, 2011).

While the *2011 IACC Strategic Plan for ASD Research* mentions the lack of implementation of proven-efficacious treatments in community settings, it cites no research examining these issues. Recently, a number of reports have emerged that conclude that community-based behavioral and pharmaceutical treatment implementation does not resemble evidence-based practice and outcomes do not mirror those found in research trials (Eldevik et al., 2012; Frazier et al., 2011; Mandell et al., *in press*; Nahmias, Case & Mandell, 2012). On a more positive note, models for a medical home (a team-based healthcare delivery system that delivers comprehensive and continuous medical care) for children with autism have now been developed. Preliminary

evidence indicates that these medical homes result in greater parent satisfaction, greater shared decision making, and fewer unmet service needs (Golnik et al., 2012). On the other hand, these models have not been widely disseminated (Hyman & Johnson, 2012), although some efforts to study the implementation of evidence-based care have been funded and are underway.

### **Disparities**

Recent research suggests that the lack of quality care is exacerbated among traditionally underserved minority groups. For example, compared with parents of white children with ASD, parents of Latino children with ASD were 1.5 times as likely to report difficulties getting needed referrals, twice as likely not to have a usual source of care, and almost three times more likely to have unmet routine healthcare needs (Parish et al., 2012). In a Canadian study, foreign-born children were diagnosed an average of two years later than Canadian-born children, and children living in rural areas were diagnosed six months later than children living in urban areas (Coo et al., 2012).

### **Wandering/Elopement**

Wandering/elopement is a critical safety concern for many families with children with ASD. Forty-nine percent of parents of children with ASD reported that their child had attempted to flee, and a quarter reported that the child had been missing long enough to cause concern (Anderson et al., 2012). As a result of the IACC focus on wandering/elopement, an ICD-9 medical subclassification code was proposed and accepted to characterize wandering with developmental disabilities. This code adds the potential to track autistic wandering through healthcare data systems.

### **Seclusion and Restraint**

The use of seclusion and restraint continues to be a concern for parents of children with ASD. In March 2012, the Department of Education's Office of Civil Rights released data from 2009-2010 on seclusion and restraint in which they reported that 70% of the cases where students were restrained involved students with disabilities (U.S. Department of Education Office of Civil Rights, 2012). This is the first time that seclusion and restraint data have been collected on such a large scale, and serves as the foundation for future research. Additionally, in May 2012 the Department of Education issued a resource document on restraint and seclusion in schools (U.S. Department of Education, 2012). The document provides 15 principles for policies around restraint and seclusion.

### **Mortality**

Among the most compelling recent research findings is the observation that mortality is elevated among individuals with ASD relative to the general population. Studies reported standardized mortality ratios (ratio of observed deaths in the study group to expected deaths in the general population) close to 3 for the ASD population, which means that persons with ASD are about three times more likely to die than an age-matched individual in the general population. To a large extent this increase in mortality in the ASD population appears to be due to co-occurring conditions (Bildler et al., 2012), such as epilepsy (Woolfenden et al., 2012; Pickett et al., 2011), rather than ASD itself. Researchers hypothesize that when individuals present with ASD, health care professionals may overlook other co-occurring conditions.

## **Family Support**

New knowledge is emerging about the causes of caregiver burdens in families of people with ASD. For example, British researchers found that when young persons with ASD had needs that were not met by the education or healthcare service system, it resulted in increased strain and stress for caregivers (Cadman et al., 2012). A 2011 systematic evidence review found that parent training may reduce parental stress and enhance parental confidence, but the quality of the studies reviewed was deemed to be poor (Zwi et al., 2011).

## **WHAT GAPS HAVE EMERGED IN THE PAST TWO YEARS?**

Most gaps that have emerged in the last two years stem directly from the new findings described above. Of particular concern are the effects on service access and delivery as well as the quality of the autism insurance mandates. It will be important to determine how state mandates will interact with the Affordable Care Act. Given the recent finding regarding the large proportion of children with ASD who are served through Medicaid, it will be similarly important to estimate how the Medicaid expansion under the Affordable Care Act affects autism-related services.

The recent findings regarding the lack of quality and positive outcomes of community-based care suggested an urgent twofold gap. First, autism researchers should borrow models from dissemination and implementation science to test methods to improve implementation of evidence-based treatments. Implementation science can help identify which components of effective care are the most feasible to implement in community settings. Second, quality measures should be developed to help monitor progress in improving care and outcomes for people with ASD. Research that examines the effects of specific treatment components rather than more complex comprehensive intervention packages, combined with community-based partnership research, will be required to identify which active treatment components can successfully be implemented in community settings.

Another gap relates to the disparities in care that have been extensively documented. This growing body of research now should be paralleled by research on strategies to ameliorate these disparities. Additional research on effective models for supporting families is also sorely needed.

Findings regarding wandering/elopement suggest the urgent need to develop and test specific prevention strategies and interventions to improve safety for individuals with autism, by both directly intervening with the individual and intervening indirectly, through training of first responders, healthcare professionals, educators, and the broader community.

Although progress has been made in services policy and services research during the past two years, significant gaps remain. Moving forward, greater focus is needed in these areas to improve the lives of those with ASD and their families.

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