

**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 18 MONTHS?

New findings and opportunities over the last 18 months 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 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 with ASD in the United States receive Medicaid-reimbursed services (Semansky et al., 2012).

Comment [A1]: Discussion Point: Is there any way to put a number on this increase?

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

A recent review of screening instruments and screening practice suggests 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 et al., 2011).

While the 2011 Strategic Plan 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 find 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 et al., in press). On a more positive note, models for a medical home for children with autism have been developed and have some preliminary evidence that they result in greater parent satisfaction, greater shared decision making, and fewer unmet service needs (Golnik et al., 2012; Perrin et al., in press). On the other hand, these models have not been widely disseminated (Hyman & Johnson, 2012). 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 3 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 2 years later than Canadian-born children and children living in rural areas were diagnosed 6 months later than children living in urban areas (Coo et al., 2012).

Wandering/Elopement

Wandering/elopement is a critical safety concern for many children with ASD, with parents of 49% of children with ASD reporting that their child had attempted to flee, and a quarter reporting that the child had been missing long enough to cause concern (Anderson et al., 2012).

Seclusion and Restraint

In March 2012, the Department of Education's Office of Civil Rights released data from 2009-2010 on seclusion and restraint. They report that 70% of the cases where students were restrained involved students with disabilities. 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. In May 2011, the Department of Education issued a resource document on restraint and seclusion in schools. The document provides 15 principles for policies around restraint and seclusion.

Mortality

Among the most compelling recent research findings is that mortality is elevated among individuals with ASD relative to the general population, with studies reporting standardized mortality ratios close to 3. Much of this excess mortality appears due to co-occurring conditions (Bilder 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

Findings are emerging about the causes of caregiver burdens in families of people with ASD. For example, British researchers found that the level of unmet need for young persons with ASD was associated with excessive caregiver burden (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 was poor (Zwi et al., 2011).

WHAT GAPS HAVE EMERGED IN THE PAST 18 MONTHS?

Most gaps that have emerged since last year stem directly from the new findings described above. Of particular concern are the effects on service access, delivery and 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 services.

The recent findings regarding the lack of quality and positive outcomes of community-based care suggested an urgent twofold gap. 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. Quality measures can 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 may be required to identify which active treatment components can successfully be implemented in community settings.

A third 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.

Findings regarding wandering/elopement suggest the urgent need to develop and test specific interventions to improve safety for individuals with autism, either by directly intervening with the individual, or indirectly, through training of first responders.

Additional research on effective models for supporting families is sorely needed.

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