

**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.

References:

Al-Qabandi M, Gorter JW, Rosenbaum P. Early autism detection: are we ready for routine screening? *Pediatrics*. 2011 Jul;128(1):e211-7. [[PMID: 21669896](#)]

Anderson C, Law JK, Daniels A, Rice C, Mandell DS, Hagopian L, Law PA. Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics*. 2012 Nov;130(5):870-7. [[PMID: 23045563](#)]

Bilder D, Botts EL, Smith KR, Pimentel R, Farley M, Viskochil J, McMahon WM, Block H, Ritvo E, Ritvo RA, Coon H. Excess mortality and causes of death in autism spectrum disorders: A follow up of the 1980s Utah/UCLA Autism Epidemiologic Study. *J Autism Dev Disord*. 2012 Sep 25. [Epub ahead of print] [[PMID: 23008058](#)]

Cadman T, Eklund H, Howley D, Hayward H, Clarke H, Findon J, Xenitidis K, Murphy D, Asherson P, Glaser K. Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *J Am Acad Child Adolesc Psychiatry*. 2012 Sep;51(9):879-88. [[PMID: 22917201](#)]

Coo H, Ouellette-Kuntz H, Lam M, Yu CT, Dewey D, Bernier FP, Chudley AE, Hennessey PE, Breitenbach MM, Noonan AL, Lewis ME, Holden JJ. Correlates of age at diagnosis of autism spectrum disorders in six Canadian regions. *Chronic Dis Inj Can*. 2012 Mar;32(2):90-100. [[PMID: 22414306](#)]

Eldevik S, Hastings RP, Jahr E, Hughes JC. Outcomes of behavioral intervention for children with autism in mainstream pre-school settings. *J Autism Dev Disord*. 2012 Feb;42(2):210-20. [[PMID: 21472360](#)]

Frazier TW, Shattuck PT, Narendorf SC, Cooper BP, Wagner M, Spitznagel EL. Prevalence and correlates of psychotropic medication use in adolescents with an autism spectrum disorder with and without caregiver-reported attention-deficit/hyperactivity disorder. *J Child Adolesc Psychopharmacol*. 2011 Dec;21(6):571-9. [[PMID: 22166171](#)]

Golnik A, Scal P, Wey A, Gaillard P. Autism-specific primary care medical home intervention. *J Autism Dev Disord*. 2012 Jun;42(6):1087-93. [[PMID: 21853373](#)]

Hyman SL, Johnson JK. Autism and pediatric practice: toward a medical home. *J Autism Dev Disord*. 2012 Jun;42(6):1156-64. [[PMID: 22411200](#)]

Mandell DS, Stahmer AC, Shin S, Xie M, Reisinger EM, Marcus SC. (in press). Outcomes and moderators of outcome in a randomized trial of two classroom-based interventions for students with autism. *Autism*.

Nahmias AS, Kase C, Mandell DS. Comparing cognitive outcomes among children with autism spectrum disorders receiving community-based early intervention in one of three placements. *Autism*. 2012 Nov 27. [Epub ahead of print] [PMID: 23188885]

National Conference of State Legislatures. Insurance coverage for autism. 2012 Aug. Available at: <http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx>.

Parish S, Magaña S, Rose R, Timberlake M, Swaine JG. Health care of Latino children with autism and other developmental disabilities: quality of provider interaction mediates utilization. *Am J Intellect Dev Disabil*. 2012 Jul;117(4):304-15. [PMID: 22809076]

Pickett J, Xiu E, Tuchman R, Dawson G, Lajonchere C. Mortality in individuals with autism, with and without epilepsy. *J Child Neurol*. 2011 Aug;26(8):932-9. [PMID: 21471551]

Semansky RM, Xie M, Mandell DS. Medicaid's increasing role in treating youths with autism spectrum disorders. *Psychiatr Serv*. 2011 Jun;62(6):588. [PMID: 21632723]

U.S. Department of Education. Restraint and Seclusion: Resource Document. 2012 May. Available at: <http://www2.ed.gov/policy/seclusion/restraints-and-seclusion-resources.pdf>

U.S. Department of Education, Office for Civil Rights. The transformed civil rights data collection (CRDC). 2012 March. Available at: <http://www2.ed.gov/about/offices/list/ocr/docs/crdc-2012-data-summary.pdf>

Woolfenden S, Sarkozy V, Ridley G, Coory M, Williams K. A systematic review of two outcomes in autism spectrum disorder - epilepsy and mortality. *Dev Med Child Neurol*. 2012 Apr;54(4):306-12. [PMID: 22348343]

Zwi M, Jones H, Thorgaard C, York A, Dennis JA. Parent training interventions for attention deficit hyperactivity disorder (ADHD) in children aged 5 to 18 years. *Cochrane Database Syst Rev*. 2011 Dec 7;(12):CD003018. [PMID: 22161373]