

IACC Services Town Hall Meeting

Sponsored by the IACC Services Subcommittee

July 24, 2009

St. Charles, IL

Summary and Analysis of Public Comments

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SUMMARY OF COMMENTS

1. A faculty member from the University of Southern California, who serves on the Autism Society of America's Spectrum Advisors Panel, requested more research examining subtypes of Autism Spectrum Disorders (ASD) and individualized treatment options.
2. A private piano teacher to people with ASD and other disabilities asked that more research funding be dedicated to validating the effectiveness of music and art therapy for people on the spectrum.
3. A parent of three children with ASD requested resource toolkits for parents of children newly diagnosed with ASD, as well as for health professionals and educators.
4. A program manager for an autism program and a parent of two children with ASD expressed concerns with the service delivery system in New Mexico. She said that families are struggling to access services because of the inadequate number of service providers in her state and that more funding is needed for workforce development.
5. An active duty army officer with an 11-year-old, non-verbal child with ASD raised significant issues with lack of education and medical services for military families that include a child with ASD. He felt that lack of services in particular geographic areas affects financial stability, job success, and military retention rates. He stated that only about 2 percent of the military families affected by ASD (900 out of 18,000 families) currently receive Applied Behavioral Analysis based (ABA) therapy via TRICARE.
6. A mother whose two adult sons and husband have Asperger's syndrome advocated for more effective research on how to obtain lifespan services and vocational supports in order to find and retain employment.
7. A mother of an 11-year-old child with ASD asked to involve gastroenterologists and immunologists in diagnosing autism and requested more information from the Department of Education on inclusion in order to help teachers.
8. A mother of a child with ASD, who also works for the military on special needs services, commented on the lack of continuum of services across the states, and indicated that there is a heavy resistance from the military to allow outside resources, such as ABA based therapy, to come into school settings.
9. A mother of a 13-year-old with ASD and an advocate for families with disabilities in South Florida said that there are an insufficient number of trained providers to meet the high demand for services. She also noted that home service provision may limit access to therapy centers.
10. A representative from the New England Center for Children, a private school for children with autism, urged the IACC services subcommittee to advocate the allocation of the limited available research funds to: 1) support ABA based therapies to improve the methods and curricula for teaching people with ASD and 2) improve dissemination of empirically-supported services and training of service providers.
11. A parent urged the IACC services subcommittee to integrate various plans to provide better services for people with ASD and to better disseminate the findings of evidence-based services research.

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12. A mother of a 9-year-old child with low functioning autism enrolled in the Medicaid program stated that her child receives ABA-based home therapy, but that the family struggles daily with obtaining other appropriate medical services.
13. A clinical social worker from Illinois stressed the importance of public service announcements to educate the general public on autism in order to prevent workplace discrimination. She requested expanding the services subcommittee to include members of State Boards of Education, integrating services for early diagnosis and assessment, and creating mandates for educational services.
14. A clinical psychologist from Idaho commented on the wide divide between services provided through Medicaid programs and private insurance for people with ASD. He also commented on the lack of qualified providers experienced in dual diagnosis of autism and mental illness and asked that Medicaid provide better care for autistic individuals with psychiatric disorders.
15. A mother of a 25-year-old man with ASD and a coordinator for transition into adulthood at Ohio Center for Autism recommended coordinating the variety of services available through different state agencies. She said that services are not reaching families despite the efforts made by various State departments and further noted that the definition of disability varies based on the program, which impacts eligibility and access to necessary services.
16. A parent of a 16-year-old son with high functioning autism from New Mexico had concerns about the lack of services for adults with high functioning autism and Asperger's Syndrome. She urged the committee to continue support for self-directed services.
17. E-mailed comment: "Why do you not require individual states to put federal matching Medicaid funds into where they are used and not into a State's general fund?"
18. A parent of a 25-year-old son with developmental disabilities, not on the spectrum, recommended building integrated systems of care. The mother, who works as the director of a program for children with special health care needs in Wisconsin, criticized "siloes" care and asked for the integration of different service sectors.
19. A mother of a child with ASD from Michigan suggested better integration of services, especially when transitioning to adulthood, for all children with disabilities and special needs. She said that adolescents with ASD need more career support and pointed to vocational software used in her son's school that did not present any options for people without high school diplomas. She praised supported employment programs like Program Search and TEACCH¹ (Treatment and Education of Autistic and Related Communication-Handicapped Children) and said that more programs such as these are needed.
20. A mother of a 29-year-old with ASD emphasized a need to include and support students with ASD in the classroom, keep learning centers open as alternative education options, and train additional service providers for children, youth, and adults with ASD.

¹ TEACCH program Web site: <http://www.teacch.com/>

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21. A mother of a child with ASD and a social worker for the Wisconsin Maternal and Child Health's special needs program for youth spoke about the GAO report on the use of seclusion and restraint and pointed out differences between state and federal legislation. She said that children receiving school-based Medicaid services are not subject to Medicaid's regulations on the use seclusion and she asked that committee investigate how early use of seclusion and restraint affects children as they get older.
22. A parent of an 8-year-old high functioning child and a training and outreach specialist with the State of Wisconsin focused on the importance of using a strengths-based approach to support the well being of families and communities in order assure the well-being of people with ASD.
23. A mother of a 19-year-old son with ASD and operations director of Dan Marino Foundation, addressed the feasibility of a successful summer program that teaches vocational skills to adolescents with ASD and suggested a need for more such programs to continue on a year-round basis. The program matches a qualified candidate with a paying summer job. She urged the committee to do more research into the feasibilities of such programs and address the need for continuation of services to youth with ASD who graduate with a high school diploma. The Foundation offered to collaborate with the committee to address these issues.
24. A brother and a guardian of an adult with ASD from the University of Maine's Center for Community Inclusion and Disability urged for more high-quality research into comprehensive interventions to answer "what works?" and "for whom?"
25. A mother of a 6-year-old boy with ASD told the committee about how her formerly non-verbal son learned to speak through intensive behavioral interventions (IBI). She asked the IACC to resoundingly affirm IBI as an effective evidence-based intervention and spoke about the need for affordable access to treatments and intervention.
26. A clinical psychologist and a father of a 29-year-old man from Philadelphia urged longitudinal and population based studies regarding divorce rates in families affected by autism and suggested investigating family variables.
27. A parent of a 16-year-old with ASD had concerns regarding the lack of services for the autistic children of low-income, non-English speaking families and middle-income families due to what she described as "systemic dysfunction" in the Santa Barbara special education system.
28. A Northwestern college student recommended developing toolkits for young people who wish to pursue careers as service providers for people with ASD.

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ANALYSIS: Common themes and concepts derived from the public comments that pertain to the critical questions of the IACC Strategic Plan:

Question 2: How can I understand what is happening?

1. A need for research on various ASD subtypes.
2. A need to research how the use of restraint and seclusion impacts brain and emotional development.

Question 4: Which treatments and interventions will help?

1. A need for training of additional providers of Applied Behavioral Analysis (ABA) based therapies.
2. A need to validate and document the benefits of music and arts therapies.
3. A need for research to affirm the effectiveness of specific ABA therapies.
4. A need for research into comprehensive intervention programs.

Question 5: Where can I turn for services?

1. A need for more training of service providers.
2. A need for improved coordination of services among states and among government agencies.
3. A lack of services for people with Asperger's and high-functioning autism.
4. A need to make families and providers aware of available services, including families living in remote areas and those serving in the military.
5. A lack of services for non-English speaking families in Santa Barbara, California.
6. A need for toolkits for parents, teachers, and physicians involved with children who have been newly diagnosed with ASD.
7. A need for toolkits targeted at young people who wish to pursue careers as service providers for people with ASD.
8. A need for teachers to be taught to effectively include children with ASD in a mainstream classroom.
9. A need for providers trained to treat mental health issues in people with ASD.
10. A need for modification of Medicaid legislation addressing the use of restraint and seclusion of children with ASD.
11. A need for research addressing the mental and emotional health needs of families affected by ASD.
12. A need to effectively communicate information about empirically validated services (e.g. ABA-based therapies, etc.).

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Question 6: What does the future hold?

1. The challenges of implementing a continuum of services for military families and transitioning adults.
2. The challenges of providing appropriate vocational skills training, including finding and retaining employment.
3. The challenges of accurately identifying and addressing family variables, such as divorce rates.