

Draft Recommendations for Secretary Sebelius based on the IACC Services Workshop – November 8, 2010

Where We Are Today and Where We Want to Be in 10 Years

- Conduct services research in real-world settings and give due weight to the experience of parents and service providers. Translate findings into a format that is understandable and usable for the public. (Dr. Bill East)
- Increase collaboration between stakeholders on all levels to share resources, develop policy, and resolve issues. (Dr. Bill East)
- Identify a federal agency to collaborate with state developmental disability agencies to provide ongoing support and assist in personnel training. (Ms. Nancy Thaler)
- Provide federal support for families living with adult relatives with ASD. An increasing number of people receiving services and supports for intellectual/developmental disabilities are living with family members. These individuals report better quality of life than when living outside the home and overall expenditures are much lower on average for adults in family-based settings (\$25,072 annually for individuals living with their own family versus \$128,275 for individuals in Intermediate Care Facilities for the Mentally Retarded [ICF/MR]). (Dr. Charlie Lakin)
- Create an entitlement to fund services for people with ASD after they have finished their education entitlement. Improve transitional services and increase the use of vocational rehabilitation. (Dr. Charlie Lakin)

Self-Direction

- Follow models of self-direction and self-determination such as those used by the Michigan Department of Community Health. Self-direction empowers people with ASD and other disabilities to play a role in managing the services and supports they receive, which results in a greater level of autonomy and improved quality of life. Several cost studies have found that self-directed services also decreases total cost. (Mr. Michael Head and Dr. James Conroy)

Standardized Assessment

- Adequately understand the needs of people with disabilities so that appropriate services are provided. Standardized assessments can streamline the process and ensure that people with similar support needs receive similar levels of service. (Mr. Donald Clintsman)

Prevention and Reduction of Seclusion and Restraint

- Significantly reduce the use of seclusion and restraint with the ultimate goal of eliminating its use entirely. The policies and procedures outlined in the Six Core Strategies developed by the

National Technical Assistance Center have been proven effective in preventing violence and seclusion/restraint use in mental health and other settings. Direct service personnel and other staff need to be trained to use these strategies to diffuse potentially violent situations without resorting to seclusion or restraint. (Ms. Kevin Ann Huckshorn)

Direct Service Workforce Training

- Reward Home and Community-Based Services (HCBS) programs with quality training programs. Develop better mechanisms to pay for training through Medicaid programs and offer financial incentives (e.g., higher federal match, higher reimbursement rates) to states and employers that provide competency-based training. (Ms. Carrie Blakeway and Ms. Erika Robbins)
- Strengthen partnerships between DHHS and the Department of Labor/Workforce Infrastructure. There are opportunities through Registered Apprenticeship Programs and the High Growth Jobs Initiative. (Ms. Carrie Blakeway and Ms. Erika Robbins)
- Take a cross-population, cross-program, holistic approach in all training efforts. Only fund workforce/training programs or initiatives that benefit workers in all public programs and all consumer populations. (Ms. Carrie Blakeway and Ms. Erika Robbins)

Housing Options

- Fund, develop, and recruit other state and federal resources that could support supportive housing models similar to the Shelter Plus Care program. Existing data should be used to develop evidence-based best practices. (Mr. Sheldon Wheeler)
- Examine other populations that are at risk for homelessness (e.g., former inmates, people recently discharged from hospitals) that may benefit for permanent supportive housing. Provide future support for a longitudinal study of this cohort currently underway. (Mr. Sheldon Wheeler)
- Work with the Department of Housing and Urban Development to create housing vouchers for people with ASD. Stable housing has been shown to be critical to receiving appropriate health services and significantly reduces costs. (Mr. Sheldon Wheeler)
- Create opportunities for individualized housing. Create relationships with non-profit organizations in the community that can help with this effort. (Mr. Joseph Wykowski)

Peer Supports

- Establish peer-support networks at local schools, where typically developing students serve as peer mentors for their classmates with ASD. Existing peer-support programs have been shown to improve the social skills and feeling of acceptance for students with ASD while increasing awareness about ASD among the peer mentors. (Dr. Lisa Crabtree and Ms. Julie LaBerge)

- Incorporate autistic peer mentor programs (those where people with ASD mentor others with ASD) into existing support programs. These programs must be run by autistic people and training must be provided by autistic individuals. (Mr. Jim Sinclair)
- Encourage people with ASD to pursue degrees to become special education teachers. Create scholarships for people with ASD and provide professional support for autistic adults. (Mr. Jim Sinclair)

Systems Integration

- Encourage the Centers for Medicare and Medicaid Services to partner with states to incentivize training, flexibility (creating single waivers to meet multiple needs throughout the lifespan), inclusion (providing services in a natural environment), and long-term relationships. (Mr. John Martin)
- Send a strong message about the dangers of segregating students with ASD in self-contained classrooms. Engage in a national discussion about the value of educating children with ASD in a main-stream classroom and the dangers of segregation. (Mr. John Martin)