IACC Strategic Plan Question 5

Where can I turn for services? – Volunteer drafter- David Mandell

Introduction

The aspirational goal for question five is that “Communities will access and implement necessary, high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD.”

The 2009 Strategic Plan, which was revised in 2010 and 2011, delineated nine objectives related to Question 5, which include four short-term objectives and five long-term objectives to address gaps in current policy and services research that will benefit the autism community. These objectives call for studies and demonstration projects addressing issues such as: ways to improve access to services in traditionally underserved populations, developing successful models for self-directed care, evaluating how best to coordinate services across multiple state and local agencies, studying and improving health and safety and reducing mortality in individuals with ASD, implementing and disseminating proven-efficacious interventions, and evaluating cost effectiveness of services. The total recommended budget was $71.1M across all nine objectives for this question.

Progress Toward Strategic Plan Objectives

The 2011-2012 Portfolio Analysis reviewed projects funded by both government agencies and private foundations from 2008 – 2012. Based on this analysis, the cumulative investment from 2008 – 2012 was $124M. Approximately 70% of the investments assigned to Question 5 were in gap areas addressed by the Question 5 objectives, while 30% were in areas covered by the core/other category.

Of the nine specific objectives under Question 5, three objectives addressing access to services and implementation of evidence-based interventions in diverse populations, and evaluation of training for service and support providers, met or exceeded the recommended budget and fulfilled the recommended number of projects. The objective on and studies to address dental health issues of people with ASD met the recommended number of projects, but the projects were done with less funding than was projected in the budget recommendation and only covered dental services for children. Four specific objectives, were far below the recommended budget and number of projects. These include objectives regarding evaluation of state and local coordination of community-based services, projects to examine health, safety, and mortality issues, testing evidence based services for community living settings, and evaluation of programs to increase health and safety. Additionally, one objective, on studies to examine how self-directed community-based services impact individuals across the ASD spectrum, did not have any funding or projects in the past two years, though there were some projects in this objective category earlier. The committee felt, however, that even with the earlier projects, they did not adequately cover some of the key community-based services, such as those related to employment and housing.

Overall, considerable progress was made in some areas of the services research field related to these nine Question 5 objectives. A growing body of research examines the best strategies to implement evidence-based autism interventions in diverse community settings, especially schools. Large-scale randomized implementation and effectiveness trials have shown that, with appropriate organizational and individual supports, evidence-based interventions developed in university-based research settings can be implemented with fidelity in community settings and result in more positive outcomes than usual community care[1]. Implementation science is developing within autism, and new developments in implementation science, such as methods for addressing organizational, provider and consumer level factors to improve services and outcomes, can and should be applied to autism intervention.

In a related development, the National Professional Development Center on Autism Spectrum Disorders, supported by the U.S. Department of Education, now provides free information on evidence-based practices for children and adolescents with ASD for these groups. The same center has made great progress on the development of web based training programs for the dissemination of early educational intervention best practices to states. This provides an opportunity for research examining the effects of such resources on implementation in both rural and urban settings. In the medical arena, with support from Autism Speaks and HRSA, a wide range of physician and parent tool kits[2], and the first empirically-supported physician guidelines for the treatment of gastro-intestinal conditions[3-4], sleep conditions[5-6], and ADHD[7-8] are now available, defining standards of care and increasing the ability of practitioners to appropriately treat these conditions in service delivery settings. In the realm of safety issues, the Department of Education issued a resource document[9] for restraint and seclusion in 2012 that provided guidance to schools on limiting restraint and seclusion while promoting positive behavioral supports and interventions as a safe and effective alternative. Additionally, the first research studies of ASD-associated wandering have been done[10-11] and progress has been made by National Autism Association in developing toolkits and information for preventing wandering and by the Department of Justice and the National Center for Missing and Exploited Children on quickly and appropriately responding to ASD wandering incidents to reduce injury and mortality[12-13].

The passage and implementation of the Affordable Care Act (ACA) creates the opportunity for states to include behavioral treatments for individuals with ASD as part of their essential health benefits. This determination was based on the growing body of evidence supporting the efficacy of behavioral interventions and provides an example of how scientific advances can support policy changes that benefit the community. The extent to which states will include behavioral treatment coverage within their plans and the effects of the adoption of these benefits on treatment and outcomes remains unclear. Additionally, more than 30 States have explicitly listed autism as a related condition or explicitly included autism in the definition of people served under the State's Medicaid Home and Community Based Services waiver for people with intellectual disabilities and 10 states offer waivers that specifically cover Applied Behavioral Analysis. Similar policy changes have been taking place in the military. As of July 25, 2013, TRICARE, the medical benefit plan of the military health system, extended coverage of Applied Behavioral Analysis (ABA) to non-active duty family members in addition to active duty family members that previously had coverage for this service.

Since 2010, CMS has undertaken several activities that have provided new information about ASD services being provided in the community. In 2010, CMS issued a report entitled *Autism Spectrum Disorders (ASDs) Services Final Report on Environmental Scan*[14] that describes the results of an extensive literature review of the scientific evidence regarding the efficacy, effectiveness, safety, and availability ASD-related services and supports, including those funded through federal sources, that support daily living for people of all ages with ASD. In 2011, CMS also issued a report on a nine-state study entitled, *Report on State Services to Individuals with Autism Spectrum Disorders (ASD)*[15], which assessed the implementation of evidence-based/promising practices through the lens of state experience, summarizing the current state of ASD-related services covered by Medicaid and other sources in each of the nine states. The report describes the types of services and supports provided by state and local governments, the sources of funding for programs, and the policy, staffing and implementation issues that states and localities encounter in the administration of programs that serve people with ASD. CMS will also be issuing an upcoming report, *Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD*, in 2014. This study assessed existing state programs and supports for families living with ASD in 50 states and the District of Columbia, providing a comprehensive view of services that received support from various federal sources and were made available through state programs across the country.

Internationally, there is also increased focus and resources aimed at monitoring and improving access to services for people with ASD. In 2012, the United Nations (UN) General Assembly unamimously passed a resolution calling on governments to monitor and report as well as improve access to healthcare, education, training, and intervention programs for persons with ASD and other developmental disabilities[16-17]. In 2013, the executive board of the World Health Assembly, governing body of the World Health Organization (WHO), adopted the resolution “Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders”[18-19]. The resolution was co-sponsored by more than 50 countries and supported by all, including the U.S.

A wealth of descriptive studies over the last five years has quantified the economic and health impact of autism on families. In one recent study, the economic cost of autism in the United States was updated, showing a substantial increase in cost across a variety of domains. The overall cost of ASD in the US is now estimated at $137 billion per year and the cost of providing care for each person with an ASD ranges from $1.4 million to $2.3 million over their lifespan, a number that is impacted by intellectual disability of the person[20]. This is a dramatic increase from the 2007 estimate of $35 billion per year. Drivers of costs for children were special education services and parental productivity loss. These costs were substantially smaller, however, than those related to residential care and individual productivity for individuals with ASD in adulthood.

There is also a much better and sophisticated understanding of disparities in the delivery of care to children and adults with ASD. More recent research has moved beyond examining disparities in age of diagnosis to examine disparities in components of the diagnostic experience and in service use post diagnosis. Recent findings that the mortality of people with ASD is not substantially different from typically-developing peers points to the need to address the issues of geriatric and older adults with ASD.

Progress Toward the Aspirational Goal

Health disparities in the diagnosis and treatment of autism now are well described but poorly addressed. Studies must move from observational to experimental, in which strategies to reduce disparities are developed and tested. One issue of particular importance may be whether improving quality of care in traditionally underserved geographic regions is enough to ameliorate disparities, or instead interventions targeted towards specific cultural and ethnic groups are needed. The Committee highlighted the need for the research portfolio to focus on developing practical, affordable and culturally-competent services and support approaches that can be used in a variety of settings, and for these approaches to be able to be adapted to the required scale to meet community needs.

While considerable strides have been made towards understanding the best ways to implement evidence-based practices in community settings, there is much work left to do in bringing interventions to scale. One barrier to studies that address related issues is the lack of strong, ongoing community-academic partnerships. These partnerships are necessary to conduct field research on effectiveness, implementation and scale-up of evidence-based practices. The Department of Education Institute of Education Science (IES) offered a partnership (request for award) RFA in 2013 and NIMH previously supported a research infrastructure program (RISP) mechanism to develop and maintain this type of infrastructure. On a related note, most implementation or effectiveness studies have examined one intervention at a time and in single service systems. Many, if not most, individuals with ASD receive multiple services concurrently in response to complex needs. Methods are needed to account for, and perhaps coordinate or simplify this complexity.

Progress in this area also has been hampered by some significant measurement issues. Currently there are few instruments that are appropriate use at the population level to measure either availability or quality of services, or outcomes of these services. State agencies already may collect some of these important measures or may have the infrastructure to do so, suggesting the need for a different type of public-academic partnership. This measurement is urgently needed to provide a benchmark for the success of different programs at improving the health of the population and to identify models of excellence.

One important recent development is the investment by the NIH in a series of three initiatives to support research on services implementation across the lifespan, with the goals of addressing the challenges of improving outcomes for children, adolescents and adults. The first initiative targets models for coordination of ASD identification, evaluation, and early intervention services for children with ASD within the first two years of life, including test of the feasibility and effectiveness of the intervention across settings[21]. The second focuses on models to assist adolescents ASD to transition to adult supports and services while preventing lapses in services and supports, enhances functioning across settings, and maintaining or improving ASD symptoms, general health, safety, and quality of life[22]. The third addresses development of adult ASD service strategies that address areas of employment and training, social relationships, physical and mental health, and independent functioning including community housing and safety, alone or in combination, with the ultimate goal of improving behavioral, functional and health outcomes[23]. Awards for all three initiatives are expected in 2014.

In the past several years, while there have been important strides in estimating the economic impact of autism, there is still a need for more information on the cost effectiveness of services that can help support policy decisions. New cost effectiveness research should take a lifespan approach to assess long-term cost benefits. Economic cost is not the only cost however, and should not be examined at the expense of other potential benefits of intervention. The concept of "social return on investment" may be an important one to examine. One possibility to address both types of return on investment is to take advantage of ongoing or recently completed randomized trials to continue to follow both the experimental and control conditions to determine the long-term impacts of these interventions.

In the past 5 years, the IACC and private organizations have helped raise a new level of public awareness of safety issues such as seclusion and restraint and wandering that have had significant impact on the ASD community. Some initial steps toward disseminating information and data gathering activities have begun, but much more progress is needed in order to reduce the number of incidents, injuries and deaths associated with these preventable circumstances.

Overall, there are many opportunities for increased investment in ASD services research to fill important gaps in knowledge about what services are needed, how to best deliver them, which services work for which communities and strategies to increase uptake of best practices across settings. With infusion of additional support, infrastructure such as state demonstration programs that have been established within the past 5 years could provide an important opportunity for new research partnerships that could yield valuable information about services approaches in real-world settings. Such innovative approaches and resulting research data will be needed in the future to support progress toward the IACC Question 5 aspirational goal of creating an environment where "Communities will access and implement necessary, high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD."

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