

QUESTION 5: WHERE CAN I TURN FOR SERVICES?

IACC Strategic Plan Objectives

Conclusions

Funding 2008-2012

5S.A Support two studies that assess how variations in and access to services affect family functioning in diverse populations, including underserved populations, by 2012.

Funding: The recommended budget was met.
Progress: The initial target of two studies has been met, but more work needs to be done in this area.
Remaining gaps, needs and opportunities: The projects under this objective cover several topics related to family functioning and health disparities, but not the full breadth of the gaps mentioned in the objective. This objective, as written, may be too broad. Work is still needed to understand why underserved populations have poorer outcomes and what can be done to close the gaps. We need to understand what portfolio of services will result in the best outcomes for different populations. To address these questions, a qualitative approach (i.e., needs assessment or survey) may be needed to understand the context of barriers different groups face. Research on disparities needs to move beyond observational studies to experimental designs to see what works.

\$5,277,713

IACC Recommended Budget: \$1,000,000 over 3 years

5S.B Conduct one study to examine how self-directed community-based services and supports impact children, youth, and adults with ASD across the spectrum by 2014.

Funding: The recommended budget was partially met.
Progress: More work is needed in this area to achieve the goals set forth by the objective. While more than the number of studies called for have been supported, the area is underfunded (the projects have been small) and the projects do not examine all areas targeted in the objective.
Remaining gaps, needs and opportunities: Several of the funded projects relate to recreational activities, but more projects that focus on issues such as housing, employment, and quality of life (self-direction) are needed. Issues such as housing and employment may not be reflected in the portfolio data because the agencies and organizations included in the analysis may not have these topics as a primary focus, and many housing and employment-related efforts may not be specific to ASD. This area may benefit from a “practice to research” approach where already-operating programs can be evaluated for efficacy and this may help to develop more easily implementable services. Work is also needed to determine what outcome measures are informative and useful. Another issue is the scalability, as many vocational projects are very small and intensive and this is not an effective model for broad implementation. Potential funding mechanisms for these evaluations include the Dept. of Education Institute of Educational Science program for partnering researchers and educators and the NIMH Research Initiative for Scientific Enhancement (RISE) R25 program.

\$737,975

IACC Recommended Budget: \$6,000,000 over 3 years

5S.C Implement and evaluate five models of policy and practice-level coordination among State and local agencies to provide integrated and comprehensive community-based supports and services that enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with ASD across the spectrum and their families, (which may include access to augmentative and alternative communication [AAC] technology), with at least one project aimed at the needs of transitioning youth and at least one study to evaluate a model of policy and practice-level coordination among State and local mental health agencies serving people with ASD, by 2015.

Funding: The recommended budget has been partially met.
Progress: Progress has been made but the objective is not fully achieved as it is underfunded and the projects do not cover all of the issues mentioned in the objective.
Remaining gaps, needs and opportunities: Studying services coordination is very difficult and it is hard to define outcomes. State to state dissemination is very limited and fragmented. State policies also often are translated to practice very differently in different areas and counties. State and local services programs also suffer from a lack of knowledge in how to engage and sustain community and partnerships. A pairing of existing state and local services programs, including those that may be participating in federally-funded state demonstration programs, with research funding for evaluation would be the most cost-effective way to collect and analyze data about the implementation of models of coordination. For example, building research projects onto existing state demonstration programs and supporting the development of partnerships between academic researchers and state agencies to study models of policy implementation would be ways to advance this type of research.

\$5,425,315

IACC Recommended Budget: \$25,000,000 over 5 years (revised in 2011)

5S.D Support two studies to examine health, safety, and mortality issues for people with ASD by 2012.

Funding: The recommended budget was partially met.
Progress: More work is needed on this objective; studies have been funded in this area (e.g. wandering, victimization), but they are small and they do not address all issues within this objective.

\$164,135

Remaining gaps, needs and opportunities: There may be some projects in other Strategic Plan Questions that are related to this objective (i.e., Question 7 Utah epidemiological study that examines health risks and causes of mortality). There is ongoing data mining of existing data sets to identify risks, new methods of prevention, methods of recovery, and best practices. Best practices need to be developed to respond to wandering (prevention, response, and search). A “practice to research” model, where data are collected in the process of delivering services, would also be appropriate. One issue that is underrepresented in the portfolio is sexual/reproductive health communication for adolescents and adults with ASD. In general, adult needs are not well-represented in the current research.

IACC Recommended Budget: \$4,500,000 over 3 years

5L.A Test four methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings by 2013.

Funding: The recommended budget has been met.

\$26,386,050

Progress: This is a very broad objective, but a lot of research is being supported in this area. More work is needed, however, to cover the range of topics addressed in the objective.

Remaining gaps, needs and opportunities: Specifically, the requirement of projects looking at diverse community settings has not been met. Most of the projects listed are not focused on dissemination or may be using a model that is not well-translated to autism. Dissemination should be part of a grant application and this should be rigorously enforced. An opportunity in this area would be to create and support training institutes within existing networks that are focused on implementation and dissemination.

IACC Recommended Budget: \$7,000,000 over 5 years

5L.B Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for people with ASD across the spectrum and of all ages living in community settings by 2015.

Funding: The recommended budget was partially met.

\$603,717

Progress: There are ongoing projects under this objective with regard to efficacy but not cost-effectiveness. More work is needed and in general, the intention of this objective has not been achieved.

Remaining gaps, needs and opportunities: Cost-effectiveness evaluations have to be paired with randomized controlled trials. Efforts should be made to build onto existing efforts by adding cost-effectiveness evaluation to existing RCTs. Administrative supplements may help to achieve those additions. There are not well established autism-specific measures of cost-effectiveness. Some barriers to achieving this objective include the need for a long follow up period, which often is not possible due to the cost of running longer term trials, and these projects are not well reviewed during grant review proceedings because review favors tightly controlled experimental designs rather than experimentation in real-world conditions.

IACC Recommended Budget: \$16,700,000 over 5 years

5L.C Evaluate new and existing pre-service and in-service training to increase skill levels in service providers, including direct support workers, parents and legal guardians, education staff, and public service workers, to benefit the spectrum of people with ASD and to promote interdisciplinary practice by 2015.

Funding: The recommended budget has been met,

\$46,338,747

Progress: there have been several projects in this area. However, there is a need to continue to support efforts in this area.

Remaining gaps, needs and opportunities: Significant workforce needs remain, especially with regard to paraprofessionals. With all studies in this objective, there remains an issue of scale. Most training programs are designed for small groups. In order for training to be effective at the community level, it has to be able to scale up for broad dissemination, so training programs need to be evaluated for potential to be scaled up. We also need to better understand whether or not providers need more training, and if so, what types of training, and what methods are most effective? Also, who needs which type of training? We need comparative effectiveness studies of training models.

IACC Recommended Budget: \$8,000,000 over 5 years

5L.D Evaluate at least two strategies or programs to increase the health and safety of people with ASD that simultaneously consider principles of self-determination and personal autonomy by 2015.

Funding: This is a broad objective with a small recommended budget, and both the recommended budget and the intent of the objective have only been partially met.

\$631,838

Progress: More work is needed in this area. This objective overlaps significantly with 5SD and also with 4SH. In the future, perhaps these objectives should be collapsed and combined.

Remaining gaps, needs and opportunities: Obesity is an important issue related to this objective that is not in the portfolio, but should also be a focus.

IACC Recommended Budget: \$2,000,000 over 2 years

5L.E Support three studies of dental health issues for people with ASD by 2015. This should include:

- One study on the cost-benefit of providing comprehensive dental services, including routine, non-emergency medical and surgical dental services, denture coverage, and sedation dentistry to adults with ASD as compared to emergency and/or no treatment.
- One study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to people with ASD.
- One study evaluating pre-service and in-service training program to increase skill levels in oral health professionals to benefit people with ASD and promote interdisciplinary practice.

IACC Recommended Budget: \$900,000 over 3 years for each sub-objective (\$2,700,000 total)

Funding: The recommended budget has been partially met.

Progress: While funding is on track there is a gap in projects that focus on dental services for adults and training for dentists working with autistic adults.

Remaining gaps, needs and opportunities: While the funded studies focus on behavior management, a more comprehensive health focus is needed to address the dental needs of children and adults with ASD. This objective is very specific, but there are other important primary health care needs for people with ASD that need to be addressed. In the future, perhaps this topic could be collapsed under a broader general objective that addresses primary health care needs (combined with 5SD, 5LD). If a new objective were to be written, other important primary care issues such as mental health services should be included.

\$948,101

Not specific to any objective (Core Activities)

\$37,303,139

Total funding for Question 5

\$123,816,730