

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.

The recommended budget was met. The initial target of two studies has been met, but more work needs to be done in this area. 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 the outcomes they have and what can be done to close the gaps. Different races are seeing different outcomes. We still don't know what the best portfolio of services includes. To address these questions, a qualitative approach may be needed to understand the context of barriers different groups face. We also need to move beyond observational studies to experimental designs to start 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.

The recommended budget was partially met. 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. For example, 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 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 in determining what outcomes measurements 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 Institute of Educational Science program for partnering researchers and educators and the NIMH RISK 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.

The recommended budget has been partially met. Good work has been done 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. Studying coordination is very difficult and it is hard to define outcomes. State to State dissemination is very limited and piecemeal. State policies also often trickle down very differently in different areas and counties. These programs also suffer from a lack of knowledge in how to engage and sustain community and partnerships. A pairing of existing programs with research funding for evaluation would be the most cost-effective solution. 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.

The recommended budget was partially met. 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. 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 causes of mortality). There is ongoing data mining of existing data sets examining new issues to prevent, new methods of prevention, recovery, and helping to determine best practices. Best practices need to be developed to respond to wandering (prevention, response, and search). A "practice to research" model would also be appropriate here. Another issue that is underrepresented is sexual/reproductive health communication for adolescents and adults. Adult

\$164,135

needs across the board are suffering from a lack of research focus.

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.

The recommended budget has been met. This is a very broad objective but a lot of research is being supported in this area, though, more work is needed to cover the range of topics addressed in the objective. Specifically, the requirement of projects looking at diverse community settings has not been met. Most of the projects listed aren't looking into 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 support training institutes on implementation of dissemination, creating institutes of training and research – providing these opportunities through networks.

\$26,386,050

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.

The recommended budget was partially met. 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. Cost-effectiveness evaluations have to be paired with a randomized control trial. Efforts should be made to add 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 this objective include the need for a long follow up period and these projects are not well reviewed during grant review proceedings because review favors tightly controlled experimental designs.

\$603,717

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.

The recommended budget has been met, and there have been several projects in this area. However, there is a need to continue to support efforts in this area. 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- how do we scale up to be able to effectively train the large numbers needed in the workforce? There are many questions remaining here: Do providers need more training? What types of training? Have we properly determined which trainings are most effective? Who needs which type of training? We need comparative effectiveness studies of training models.

\$46,338,747

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.

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. More work is needed in this area. This objective appears to overlap heavily with 5SD and also with 4SH. Obesity is an important issue related to this objective and should also be a focus.

\$631,838

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.

The recommended budget has been met. 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. 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 particular aspect of primary health care could be combined into the objectives focused on primary health care concerns (5SD, 5LD). Other primary care issues such as mental health services are equally important.

\$948,101

IACC Recommended Budget: \$900,000 over 3 years for each

Not specific to any objective

\$36,306,742

Total funding for Question 5

\$122,820,333