

1 **5. Where Can I Turn for Services?**

- 2 • **What types of services and supports should I seek and where can I find them?**
- 3 • **What is my state or local government doing to provide services for ASD?**
- 4 • **What is the cost of services and how will it be paid?**

5 **What do we know?**

6 To fulfill the mission to “profoundly improve the health and well being of every person on the autism
7 spectrum across the lifespan,” scientific discoveries must be implemented in communities and
8 supported by public policy. The gap between knowledge and action can only be overcome by an
9 aggressive focus on engaging families, people with ASD, and the services community in the research
10 process, disseminating research findings into the community, eliminating barriers to services and
11 helping people with ASD and their families identify which services are needed.

12 The communities in which children are diagnosed vary tremendously in their ability to meet the needs
13 of people with ASD (Shattuck & Grosse, 2007). Local school districts vary in their ability to identify and
14 provide appropriate educational and related programs for children with ASD (Mandell & Palmer, 2005;
15 Palmer et al., 2005). States vary in the policies they have developed to organize, finance and deliver
16 care. The professional infrastructure or capacity is often inadequate to provide timely diagnosis,
17 appropriate care, services and supports, and assure health and safety.

18 While remarkable improvements have been made during the last three decades in understanding the
19 best ways to identify, assess, educate and support people with autism and their families, these
20 improvements rarely enter community practice. In fact, some have suggested that the lag between
21 research and practice is close to 20 years. When proven-efficacious services are implemented in
22 community settings, they often do not result in the same positive outcomes (i.e., they are efficacious in
23 research settings, but not effective in community practice). The reasons for this lag and ways to improve
24 services only recently have become an area of research in autism.

25 Another important issue for service delivery is that community needs far outpace the state of research.
26 Most autism services research has focused on behavioral interventions for young children. Behavioral
27 interventions for youth and adults, as well as community supports that address quality of life (as
28 opposed to core symptoms) for people with autism and their families have almost no traditional
29 evidence base to support them. Yet these types of services are some of the most requested and most
30 needed. Providers and policy makers must therefore make decisions in the absence of evidence. Local
31 resources, advocacy, and creativity about existing funding streams all may affect what services get
32 funded, by whom, and for whom.

33 These differences in policies, resources and organization result in marked differences in the prevalence
34 of ASD across geographic areas, the types of services and support that are received, availability of
35 appropriate lifespan transition opportunities, and the associated costs (Fujiura, Roccoforte, & Braddock,

36 1994; Ganz, 2007; Järbrink, Fombonne, & Knapp, 2003; Mandell et al., 2008; Ruble et al, 2005; Stahmer
37 & Mandell, 2007). In general, children with ASD have a much more difficult time accessing appropriate
38 services than children with other special healthcare needs (Krauss et al., 2003). Data are still lacking on
39 how these differences in policy and infrastructure relate to the differences in services used, and in turn
40 how these differences affect outcomes for children and families, and adults with ASD.

41 **What do we need?**

42 People with ASD and their families need assistance navigating complex service systems to find the most
43 appropriate services and supports. Providers and people with ASD and their families need help choosing
44 and implementing evidence-based services that are effective and sustainable. Policy makers and payers
45 for services, including private insurers and school districts, need assistance creating organizational
46 structures and financial incentives so that high-quality interventions are institutionalized. Equally
47 important, services researchers and community organizations must collaborate to quickly and efficiently
48 develop much-needed services and supports for underserved groups among people with ASD, and to
49 test widely-used, safe, and promising services that may not have much evidence to support them.

50 Strategies to educate people with ASD and their families about the best ways to obtain
51 appropriate services and supports should be developed and tested. Methods for simplifying the
52 process by which people access services also are needed, with a focus on improving
53 collaboration across the many agencies that provide services to people with ASD. This is
54 especially important for traditionally underserved groups whose members often are diagnosed
55 late (or not at all), and who are even more likely than other people with ASD to receive
56 inappropriate or inadequate services.

57 An initial part of this process is the assessment of needs and costs. Services for developmental
58 disorders are financed largely by federal, state and local agencies in both the health care and
59 education sectors. Because there are significant regional differences in ASD resources,
60 describing this varied landscape across states and localities in the U.S. will provide important
61 baseline data for those with ASD and policymakers so they can appropriately seek and plan for
62 services respectively. Research can also define the cost-effectiveness of evidence-based
63 practices and thereby provide the data needed by various payers and policymakers.

64 Observational studies of current practice can play an important role in understanding how best to
65 address questions surrounding services and supports. They can identify malleable barriers and
66 appropriate points of intervention, and provide a baseline against which to measure future
67 progress. Because service systems vary greatly from place to place, these types of studies also can take
68 advantage of the natural experiments that occur as systems struggle to respond to the needs of people
69 with ASD.

70 Experimental studies are more difficult to design and conduct in this area of science than they are for
71 traditional intervention trials; yet are key to understanding the best ways to improve community
72 services. Designs such as those used in comparative effectiveness research, where both groups receive
73 intervention (rather than having a “treatment as usual” control), will be critically important to satisfy

74 ethical and practical concerns. Because the unit of analysis for many of these studies is the provider or
75 system, rather than the person with ASD, large-scale network studies and quasi-experimental designs
76 will also yield information.

77 Families, people with ASD, and communities can be empowered to become partners in
78 research that can in turn inform policy. Research must include services that are built upon
79 principles of self-direction and self-determination, and emphasize quality of life across the ASD
80 spectrum. All people with ASD, their families, and support systems should have the services and
81 supports they need and desire throughout the lifespan to lead productive lives in the
82 community, and to reach their fullest potential.

83 **ASPIRATIONAL GOAL: COMMUNITIES WILL ACCESS AND IMPLEMENT NECESSARY HIGH QUALITY,**
84 **EVIDENCE-BASED SERVICES AND SUPPORTS THAT MAXIMIZE QUALITY OF LIFE AND HEALTH ACROSS**
85 **THE LIFESPAN FOR ALL PEOPLE WITH ASD.**

86 **Research Opportunities**

- 87 • Development and effective dissemination of evidence-based community practices for people
88 with ASD across the spectrum and lifespan.
- 89 • Comparative effectiveness studies of services and supports for people with ASD across the
90 spectrum and lifespan.
- 91 • Studies that characterize current ASD diagnostic and service utilization patterns in community
92 settings, examine the relationship between the likelihood of a diagnosis and services availability
93 for ASD, and evaluate services and intervention outcomes across the spectrum and lifespan.
- 94 • Development of a coordinated, integrated, and comprehensive community-based service
95 delivery system for people with ASD.

96 **Short-Term Objectives**

- 97 **A.** Support two studies that assess how variations and access to services affect family functioning
98 in diverse populations, including underserved populations, by 2012. *IACC Recommended Budget:*
99 *\$1,000,000 over 3 years.*

100 **New Objective**

- 101 **B.** Conduct one study to examine how self-directed community-based services and supports
102 impact children, youth, and adults with ASD across the spectrum by 2014. *IACC Recommended*
103 *Budget: \$6,000,000 over 3 years.*

104 **New Objective**

- 105 **C.** Implement and evaluate two models of policy and practice-level coordination among state and
106 local agencies to provide integrated and comprehensive community-based supports and
107 services that enhance access to services and supports, self-determination, economic self-

108 sufficiency, and quality of life for people with ASD across the spectrum and their families, with
109 at least one project aimed at the needs of transitioning youth by 2015. *IACC Recommended*
110 *Budget: \$10,000,000 over 5 years.*

111 **Long-Term Objectives**

112 **A.** Test four methods to improve dissemination, implementation, and sustainability of evidence-
113 based interventions, services, and supports in diverse community settings by 2013. *IACC*
114 *Recommended Budget: \$7,000,000 over 5 years.*

115 **B.** Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for
116 people with ASD across the spectrum and of all ages living in community settings by 2015. *IACC*
117 *Recommended Budget: \$16,700,000 over 5 years.*

118 **New Objective**

119 **C.** Evaluate new and existing pre-service and in-service training to increase skill levels in service
120 providers, including direct support workers, parents and legal guardians, education staff, and
121 public service workers to benefit the spectrum of people with ASD and promote interdisciplinary
122 practice by 2015. *IACC Recommended Budget: \$8,000,000 over 5 years.*

123 **What Progress is Being Made in Fulfilling the Objectives?**

124 (Please provide 1-2 paragraphs to summarize progress.)

125 ***Note:** Objectives labeled “New Objective” are either entirely new additions to the 2010 Strategic Plan or
126 significantly modified objectives from the 2009 Strategic Plan. Objectives from the 2009 Strategic Plan
127 that did not change or that have been slightly modified for clarification purposes are unmarked.