

1 **6. What Does the Future Hold, Particularly for Adults?**

- 2 • **What will my family member be like when he/she gets older?**
- 3 • **What is known about adults with ASD and how can I plan for the future?**
- 4 • **How does American society support people with ASD?**

5 **What do we know?**

6 An overarching goal of ASD research is to enable people with ASD to lead fulfilling and productive lives
7 in the community. We are in critical need of information about the current landscape of long-term
8 outcomes for all people with ASD across the spectrum. The lack of knowledge about adults with ASD
9 and their lifetime support needs has repeatedly arisen as a critical issue when stakeholders are queried
10 about their most fundamental concerns. Longitudinal studies designed to capture the range of possible
11 outcomes for people with ASD are best suited to inform public policy decision-making, service and
12 support delivery, and funding strategies. It is also important to improve public understanding of ASD in
13 adults, including older adults, so that they may receive support from the communities where they live.
14 Efforts to improve public awareness and community supports help foster acceptance, inclusion, and
15 appreciation of people with ASD.

16 ASD poses economic and social costs for people with ASD, their families, and society at large. Although
17 ASD symptoms vary greatly in character and severity, autism occurs in all ethnic and socioeconomic
18 groups and affects every age group. Some scientists and economists have estimated that the combined
19 direct and indirect costs to provide lifelong supports for all Americans with ASD exceeds \$35 billion, and
20 that each person accrues approximately \$3 million in costs over his or her lifetime (Ganz, 2007). Families
21 often report incurring large debts related to medical and educational services not covered through
22 public programs or medical and dental insurance. Many families find the transition from the education
23 system, where services are mostly obligatory, to the developmental disabilities and vocational systems,
24 where services are optional, difficult to understand and manage. This fragmentation of service systems
25 impedes access to services, especially for youth transitioning to adulthood, as well as during other
26 periods of transition. In addition to financial challenges, ASD can lead to emotional hardships for people
27 with ASD and their families throughout life.

28 **What do we need?**

29 Although considerable research has focused on the earliest phase of ASD, through early screening,
30 improved diagnostics and early intervention, far less effort has addressed the adolescent, adult, and
31 older adult phases of life. Minimal guidance exists for people with ASD across the spectrum and their
32 families about the trajectories of ASD across the lifespan. Although the general assumption is that
33 children who possess expressive and receptive language skills and coping strategies and who do not
34 demonstrate significant challenging behaviors can sometimes excel as adults, while children who do not
35 currently possess typical expressive language skills and who engage in significant challenging behavior

36 will grow up to need long-term, 24/7 supports and services, the evidence base for these ideas is lacking.
37 Scientists have not yet identified key prognostic factors or detailed information about how adults across
38 the spectrum with ASD function, where they are, and how they are best supported.

39 More research is needed to tailor treatments, interventions, and services and supports to the evolving
40 needs of adolescents transitioning to adulthood, and adults across the spectrum with ASD, with an
41 emphasis on principles of self-determination. There is a need to address co-occurring conditions and
42 developmental changes that coincide with transitions such as adolescence to adulthood, to better
43 assess functional outcomes, and to integrate standardized quality-of-life measures for adults across the
44 spectrum with ASD living in community settings. Factors that contribute to improved quality of life and
45 health outcomes in adulthood are virtually unknown.

46 A number of other areas raise serious concerns. There is little information about the number of adults
47 with ASD within the criminal justice system. Some adults with ASD may not be diagnosed, or may have
48 been mis-diagnosed. Although issues surrounding the direct support workforce are well documented,
49 we do not know if they differ respective to adults with ASD. Community integration and access to
50 individualized, quality adult supports and services are problematic across the United States, and long
51 waiting lists for subsidized community-based services persist. Many services are available only to people
52 who meet institutional level of care requirements. Additionally, there is scant research on the use and
53 safety of psychopharmaceutical medications in adults with ASD.

54 **ASPIRATIONAL GOAL: ALL PEOPLE WITH ASD WILL HAVE THE OPPORTUNITY TO LEAD SELF-**
55 **DETERMINED LIVES IN THE COMMUNITY OF THEIR CHOICE THROUGH SCHOOL, WORK, COMMUNITY**
56 **PARTICIPATION, MEANINGFUL RELATIONSHIPS, AND ACCESS TO NECESSARY AND INDIVIDUALIZED**
57 **SERVICES AND SUPPORTS.**

58 **Research Opportunities**

- 59 • Studies of the scope and impact of the spectrum of ASD in adults, including diagnosis of ASD in
60 adulthood, needs during critical life transitions, and quality of life.
- 61 • Longitudinal studies that follow carefully characterized cohorts of the broad spectrum of adults
62 with ASD and their families into adulthood in order to better understand their needs during
63 critical life transitions, and to identify and track risk and protective factors that account for
64 improved quality of life and health outcomes.
- 65 • Projects that increase coordination across State and local delivery systems to improve access to
66 services and supports, particularly those that focus on transitioning youth and adults with ASD.
- 67 • Improved understanding of the challenges associated with accessing community housing for
68 people with ASD.

69 **Short-Term Objectives**

70 **New Objective**

71 **A.** Launch at least two studies to assess and characterize variation in the quality of life for adults on
72 the ASD spectrum as it relates to characteristics of the service delivery system (e.g., safety,
73 integrated employment, post-secondary educational opportunities, community inclusion, self-
74 determination, relationships, and access to health services and community-based services) and
75 determine best practices by 2012. *IACC Recommended Budget: \$5,000,000 over 3 years.*

76 **New Objective**

77 **B.** Evaluate at least one model, at the state and local level, in which existing programs to assist
78 people with disabilities (e.g., Social Security Administration, Rehabilitation Services
79 Administration) meet the needs of transitioning youth and adults with ASD by 2013. *IACC*
80 *Recommended Budget: \$5,000,000 over 3 years.*

81 **New Objective**

82 **C.** Develop one method to identify adults across the ASD spectrum who may not be diagnosed, or
83 are misdiagnosed, to support service linkage, better understand prevalence, track outcomes,
84 with consideration of ethical issues (insurance, employment, stigma) by 2015. *IACC*
85 *Recommended Budget: \$8,400,000 over 5 years.*

86 **New Objective**

87 **D.** Conduct at least one study to measure and improve the quality of life-long supports being
88 delivered in community settings to adults across the spectrum with ASD through provision of
89 specialized training for direct care staff, parents, and legal guardians, including assessment and
90 development of ASD-specific training, if necessary, by 2015. *IACC Recommended Budget:*
91 *\$7,500,000 over 5 years.*

92 **Long-Term Objectives**

93 **New Objective**

94 **A.** Develop at least two individualized community-based interventions that improve quality of life
95 or health outcomes for the spectrum of adults with ASD by 2015. *IACC Recommended Budget:*
96 *\$12,900,000 over 5 years.*

97 **New Objective**

98 **B.** Conduct one study that builds on carefully characterized cohorts of children and youth with ASD
99 to determine how interventions, services, and supports delivered during childhood impact adult
100 health and quality of life outcomes by 2015. *IACC Recommended Budget: \$5,000,000 over 5*
101 *years.*

102 **New Objective**

103 **C.** Conduct comparative effectiveness research that includes a cost-effectiveness component to
104 examine community-based interventions, services and supports to improve health outcomes
105 and quality of life for adults on the ASD spectrum over age 21 by 2018. *IACC Recommended*
106 *Budget: \$6,000,000 over 5 years.*

107 **New Objective**

108 **D.** Conduct implementation research to test the results from comparative effectiveness research in
109 real-world settings including a cost-effectiveness component to improve health outcomes and
110 quality of life for adults on the ASD spectrum over age 21 by 2023. *IACC Recommended Budget:*
111 *\$4,000,000 over 5 years.*

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

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

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