



Member Feedback on the IACC Strategic Plan

Third Survey

Full Responses

January 18, 2023

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Name/Agency	Health Resources and Services Administration (HRSA)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>No</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>p.6 - A primary barrier to ASD early diagnosis is the limited availability of diagnostic clinics with providers trained in ASD diagnosis, leading to long waiting lists and poor reimbursement for comprehensive diagnosis - if not included elsewhere, can we add suggestions to expand recruitment and training for those who can diagnose? p 6 - This limited availability is especially pronounced in underprivileged and rural areas, with many children not diagnosed until they have entered the school system - suggest changing under privileged to under resourced. p. 11 - just noting that this bullet needs editing: Develop a culturally competent and more culturally diverse services? workforce.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>I noted that in one of the earlier chapters ASD is used heavily, though through the plan autism spectrum is more commonly used as a more inclusive term. Overall this was very nicely done!</p>

Name/Agency	Paul Wang
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>The gap between a failed screen (i.e., positive screen results) and diagnosis needs greater emphasis. Many who fail screening are not referred; many who are referred never go for full evaluation; some who are diagnosed after full evaluation do not receive services. This issue should be addressed in the Recommendations.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>"...the known functions of these genes converge on biological processes..." - The known points of convergence include chromatin regulation, which is not mentioned in the sentence. "...validating the relevance of genetic mutations to autism." Here and some other places, the word "variants" might be preferable to "mutations."</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>The bullet on developing Outcome Measures is currently the last bullet in Recommendation #2 (psychosocial/devel/other). In fact, this is equally relevant to Recommendation #1 (pharmacologic/medical). I feel that this bullet could stand alone as a full Recommendation itself.</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>ABLE accounts (ABLE savings plans): consider mentioning this in the text. The ABLE Act was signed into law in December 2014, but they ABLE plans were just coming into being in 2016. Consider a goal of promoting awareness and use of ABLE accounts.</p>

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Major issue: NIMH Data Archive is not used nearly widely enough. Need to promote its usage. Suggest revising Recommendation #1 to say "Promote growth, linkage, coordination, security, AND USAGE..." Updated paragraph on SPARK: In 2016, the Simons Foundation launched SPARK (Simons Foundation Powering Autism Research for Knowledge) to recruit, engage and retain a large cohort of individuals with ASD. SPARK has enrolled 123,000 individuals with autism and over 175,000 of their family members, to participate in autism research. To participate in SPARK, families enroll online, provide saliva samples for genetic analysis, and agree to be re-contacted for future research opportunities. SPARK participants are being sequenced and genotyped to identify new genes associated with autism risk, and individual clinically confirmed genetic causes of autism are returned by a genetic counselor provided by the study. Clinical, behavioral, and genetic data on the SPARK cohort are available to all qualified investigators. Research Match has approved 226 studies to recruit SPARK participants to other ASD research studies including 12 treatment/clinical trials. Over 50,000 participants have participated in at least one Research Match study. SPARK partners with 32 U.S. medical schools and autism research centers to help recruit autistic individuals and their family members. There are 74 peer reviewed publications using SPARK.</p>
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Dena Gassner
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>Overall Suggestion: Change all ASD to Autism. Having a master page number in addition to the section page numbers would be extremely helpful. ¶ one page 2 no mention of the implications of massive office closures and personnel losses from SSA and similar agencies due to cover, or the loss of direct support personnel due to withdrawal from the workforce, illness, or death. ¶ 2 "There is still much more to be done, however, to understand..." is an incomplete sentence. Pg. 5 ¶ 2 should there not be a mention or at least a recommendation to ascertain the ROI for the research? In other words, what positive outcomes are we getting for \$X for a study?</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Pg 1 ¶ 2 "...special populations such as women, adults...." Should include gender minorities as well. Pg 2 ADOS references... are less effective for minorities and females. Also subjectively measured and too dependent on provider expertise rather than standardized tools. Last ¶- caution related to early signs as many with less externalizing features of autism will NOT be caught with many of the current "early signs" tools as they are not lacking in capacity but in quality and age related norms. Pg 5 ¶ 5 should include gender minorities. P. 6 ¶ 4 hyphens look strange. And according to CDC numbers females fall far behind all males (including BIPOC males) for diagnosis. Females remain the most marginalized. P. 7 ¶ 3 Burrows, C. A., Gradzinski, R. L., Donovan, K., Stallworthy, I. C., Rutsohn, J., John, T. S., ... & IBIS Network. (2022). A data-driven approach in an unbiased sample reveals equivalent sex ratio of autism spectrum disorder-associated impairment in early childhood. <i>Biological psychiatry</i>, 92(8), 654-662. this study rejects prior sex ratio findings of male/female incidence rates. This is further supported in adult studies based out of Europe (). Females are commonly diagnosed at later ages as confirmed by Van Wijngaarden-Cremes et al, via a meta-analytic review of 22 peer reviewed studies (2014) and in other studies (Begeer et al., 2013; Bargiela, et al., 2016; Rutherford et al., 2016; Shattuck et al., 2009; Trubanova, et. al, 2014) due to social camouflaging and social construction of female behavior that influences and modifies true autistic behavior, and other factors.diagnostic overshadowing, wherein a more overtly presenting condition such as depression or anxiety can overshadow the underlying developmental disability, often results in the underlying autism diagnosis being delayed, and in turn, creates a delay or a lack of intensity in supports and services for autistic females (Lai et al., 2015, p. 2), According to Lai et al. (2015), some of the barriers to diagnosis for autistic females include the inadequacies of the DSM criteria. For one, the DSM criteria reflects a male-centric standard (Beeger et al, 2013; Estrin et al., 2020; Green et al., 2019; Kirkovski et al. 2013; Kreiser & White, 2014; Lai et al., 2017; Strang et al., 2018). P. 8 ¶ 1 "...depression or bipolar disorder [sometimes resulting in medical maltreatment such as forced psych admission and/or overmedication".</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>This section needs a call for legitimate, collaborative examination of the ethics (p. 11 ¶ 2?) Also, doesn't biological study require subjects whose features are notable? In mouse, zebra fish etc? As such, are less observably autistic subjects less likely to be included in such studies? Also, ¶ 4 only references the ND movement when in fact, the disability rights movement was the initial civil rights efforts for acceptance. Can we broaden these statements to remember, this isn't an autism only thing...it's part of a much broader civil rights effort. P. 5 Epigenetics section has no mention of the multigenerational implications of trauma. Under other physiological issues, I might include the erratic and sometimes unexpected responses to pharmaceuticals that is common in autism. Also, a lack of long-term consistency (IE they begin with a low and effective dose, but over time, it's no longer helpful and can in fact, increase negative side effects). P. 7 Last para- the under dx of women is the issue-not less of us. See prior citation re: Gender ratio study and adult studies. And the inability of the research</p>

	<p>committee to identify and interact with community gatekeepers who can provide access to multiple female subjects providing the ethical standards are acceptable. P. 8 Summary "...research can be conducted without causing unintentional harms" should include medical maltreatment including misdiagnosis, and diagnostically misdirected use of medication and therapy (IE prescribed meds for Bi Polar for someone needing autism supports; ineffective Eating Disorders care that is not culturally competent for autism care and selective eating).</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Please see Chapter 3 comments; some are out of place and should have been addressed here.</p>
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>P. 1 ¶ 4. "and social training tools" may be overstating given the incidence rates of suicide and the relationship to masking. P. 2 ¶ 2 while other studies do not reflect improvement and in fact, find harm done with behavioral interventions. Let me know if you need citations. ¶ 3 and makes parents who cannot afford ABA feel less than and inadequate. P. 3 ¶ 2 "...rooted in the needs and sensory...." and can serve as a form of communication and as a tool for self-regulation. p. 10 ¶ 3? No mention of interoception or the Mahler studies therein. p. 14 ¶ 3 Many autistics who are on diploma track are denied any self-help supports in public schools. P. 15 on girls and women I would suggest we use the new definition that includes both identified as female at birth and those who self-identify as such. p. 16 I would include specific instruction for the expansion of assistive tech usage training by classroom and special education providers.</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>p. 3 and throughout the doc, we do not mention the millions of autistic students underserved under 504 and the fact that the public school systems are not including them in the autism headcount; only autistic students who have IEPs are included. Also, a good place to reinforce the need for independent living skills development either through extended school year, within the IEPs or as part of a 504 plan. Lastly, these sections focus considerably on employment; not all can be or should be attempting to be full-time or even part-time employees due to the nature of the stress such efforts can cost. As such, a high-quality option for day programming is key to reducing isolation and imbed individuals into the community as a means to reduce co-occurring conditions that can result. However, these options should all be individually created and implemented; not done in large groups. Healthcare focus does not at all discuss Medicare which many autistic adults are eligible for. No discussion of systems navigation with medicare and Medicaid eligibility co-occur. No mention of adult access to these systems. Dental should include discussion of the high cost of sedation dentistry (in office care, out of pocket for clients requiring IV sedation and/or Nitrous) versus the comparatively low cost that provides compared to in-patient hospital-based care. P. 8 no mention of the abuses of guardianships or state-forced guardianships.P. 9 Navigation services are desperately needed for adults and the employees need to be competent on the intersections of ALL support systems from SSA, VR, SNAP, Healthcare systems, school advocacy transportation, post-secondary options and for autistic parents, these supports need to be more intensive. Pg. 10 no mention of support for neurodiverse marriages. P. 11 waitlists should include the 2 year Medicare waiting period with SSA. Many autistic adults dx'd after age 21 are denied access to state services thus leaving out the entire "lost generation" of autistic adults for whom</p>

	<p>a diagnosis was not available (Baron-Cohen & Lai, 2015). p. 12 ¶ 1 another reference to IDEA without a mention of 504. Independent living section has no mention of Medicare or the administrative burden associated with seeking benefits through SSA; the inaccessibility of the system and the punitive nature of any engagement (citations available). P. 14 ¶ 1. There is an illusion that the needs of low support individuals are episodic in nature; we do not have evidence of that. In reality, most autistic individuals would and could benefit from an ongoing and consistent level of outside support but the intensity and frequency could be less than that required of someone with moderate to HSN. p. 15 coordination of care. Inconsistencies in requirements for eligibility, reporting, income variations, are fraught with Administrative Burden that impacts timely access and can result in unintentional errors with extreme results as well as untenable delays in service access. P. 17 recommendation 2; reduce administrative burden within and in collaboration between agencies. Expedite access to healthcare. Reduce extreme punitive reactivity resulting from a clerical error by clients. Insure that the data from SSA related to autistic applicants and clients are publicly available at no cost to students, researchers and the public at large.</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>See last item. Again, without a master numbering system, my page numbers crossed over between 5 and 6. If the stated page numbers are not aligned, it's likely the other section. So sorry for the glitches.</p>
<p>Chapter 7: Infrastructure and Prevalence Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>P. 5 ¶ 2 "...apprehension about the methods and ETHICS". Another space where the discussion of who genetic and bio research benefits would fit. ¶ 4 "... dissemination of research AND GOVERNMENT DATA ". P. 6. ¶3 we need data from 504 which does not assign a disability or diagnostic status. p. 8 ¶4 data from VR and SSA should be included in Medicaid administrative data linkages.</p>
<p>Cross-Cutting Topic: Sex and Gender Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>New study rejects the ratio. Further, as the CDC is using children for their studies, they are missing students under 504 as well as the later dx of girls.</p>
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>A reminder that the CDC finds girls/women face the greatest disparities (even below BIPOC persons).</p>

<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Loss of services from SSA due to health issues, death or people leaving forward facing positions. Lots of office closures and massive, system wide delays (can cite if you would like).</p>
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
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<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>I believe a statement regarding providing parents options for their frameworks is key. The fact that parents have to wait to meet autistic adults or wind their way through toxic pages on the internet to discover a ND framework for parenting and care is unacceptable. This should be a part of the early intervention protocols, along with transgender care and support.</p>

Name/Agency	Indian Health Service (IHS)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>xxxx</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>On p. 10, I would recommend adding "historical trauma" in addition to individual trauma and intergenerational trauma. As historical trauma relates to American Indian/Alaska Natives and other groups of people who may have experienced massive group trauma across the lifespan.</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
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<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Aisha Dickerson
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>I really like the disclaimer about the use of different terms/phrases to describe people with autism and respect for all phrases. Regarding Figure 1, I have two people in my research group are color blind, so the differing colors would not assist them with seeing the different lines. I am not colorblind, but I cannot see the difference between the lines or Questions 1 and 5.</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I do not like the use of the term "minority children." They may be part of minoritized populations, but that phrase can be "othering."</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
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<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>This is very well stated. It might be my favorite chapter.</p>
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
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<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>Thank you for incorporating the thoughts and concerns of all of the committee members as well as those voiced by the public. I have greatly appreciate the opportunity to work with this group.</p>

Name/Agency	Craig Johnson
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>This is a strong introduction.</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>No, the main points are covered.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>For me this is such a crucial area. I do feel overall this is representative of what needs to be presented.</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
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<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>Excited to see this get finished. Looking forward to future conversations in seeing this become a reality.</p>

Name/Agency	Helen Tager-Flusberg
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>p. 4 - physical and mental conditions are mentioned but the critical importance of language/communication is absent. The introduction reads eloquently for the self-advocate perspective in some ways at the expense of the majority of ASD people from children to adults have more extensive needs. The introduction should be used as an opportunity to reflect on the full range of the ASD community, not just the self advocates. More balance is needed in my view.</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>There seems to be somewhat of a disconnect between early screening and the ensuing chapters on biology and genetics. How should early genetic screening be incorporated (including both screening for specific mutations as well as PRS)? Eventually as new biological treatments emerge from the biology/genetics, these will be considered for very young children. This issue should be included at least at some level.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>At times the use of the term "difference" - to avoid more direct language was not only disconcerting but also inaccurate. In some sections 'delay in development' needs to replace the more euphemistic difference term. On p. 32 there is reference to autistic people needing interventions to "perform essential movements and physical activities". This doesn't reflect the reality of motor functioning in ASD. More emphasis on sensory-motor integration (e.g., visual-motor; auditory motor) is needed here. A far greater emphasis on the need for future research on the severe aggression/self-injury and related 'challenging' behaviors is needed here --learn more about the underlying biology, the behavioral topography etc. in order to advance therapeutics. Chapter 4 should also have this as an important highlight. In places there is reference to the importance of community participation in research in this area - please expand to explicitly include not only self-advocates but also family members.</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>The introduction focuses on one side of the broader ASD community. Many people including family members and affected individuals want to know the causes because they hope that this will lead directly to treatments that will eliminate many/most symptoms. In sections where the overlap between causes of autism and other conditions are mentioned it is striking that intellectual disability is completely absent. All the genetic conditions that are linked to ASD/GI/Sleep/epilepsy are also linked to ID. Please correct this omission not only here but throughout the plan - we should not avoid discussion of ID in the context of ASD. In the section on the microbiome - some mentioned should be made of the recent study and discussion of how differences in the microbiome in ASD may be a consequence of differences in diet and not a contributing cause. Overall this chapter is weak in providing a rationale for spending ~\$80,000,000/year on this area of research. By highlighting the concerns of the self-advocates into the study of causes and not providing any alternatives it isn't clear what this investment is about.</p>
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Again this chapter omits any discussion of intellectual disability and the need to place interventions in that context as well as in ASD. Research on behavioral interventions suffers on many methodological levels and perhaps moving forward addressing this should be a goal/recommendation. One key concern voiced by so many in the community (all wings) is the lack of trained therapists to deliver behavioral interventions. In no other areas of medicine/society would we tolerate handing over young children for treatment to people who have received minimal training and may have at most a high school education. Most behavior therapists do not know about NDBIs because we don't even require that they have a grounding in developmental science, broadly and deeply defined. I would argue that this should be the #1</p>

	<p>recommendation ---placing this above biological treatments for people with rare genetic syndromes.</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I don't have the background to evaluate this chapter with great expertise but I was impressed with the wide range of topics and the more inclusive approach than in some other chapters.</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>In the section on health/heathcare I recommend that we add something on the emerging evidence on increased risk of certain neurodegenerative or other health conditions in aging autistic people. We certainly need more research on this.</p>
<p>Chapter 7: Infrastructure and Prevalence Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Nothing to add</p>
<p>Cross-Cutting Topic: Sex and Gender Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Nothing to add</p>
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Nothing to add</p>

<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Nothing to add</p>
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>None to add</p>
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Nothing to add</p>
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	<p>Perhaps a more explicit mention of the urgent needs of children and adults with very severe ASD/co-occurring conditions, especially in self-injury/aggression which impact all aspects of their lives</p>
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Jenny Phan
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>The introduction was so well written, organized, and even thoughtful of all parties involved. A job well done! My only suggestion for edit is under the editorial note on references to autism, perhaps a secondary note for the full strategic plan document is to include: " When using terms "male" or "female" or "girl" or "boy" or "man" or "woman" and the plural forms of these terms, it is referencing individuals who were designated that gender/sex in cited references. Any reference that refer to individuals who identify as a gender different (e.g., transgender) than their assigned sex at birth (e.g, male, female, intersex) are used in this document as references state. "</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>On page 5 "Disparities in ASD Screening", waitlists for screening was briefly mentioned. It might be a good opportunity to reference the "Workforce" section in the Strategic Plan that address the issue of long waitlists for diagnosis of ASD across the nation. On page 7 "Diagnosis of Individuals from Underserved Populations" and in the paragraph about non-native English speakers, I suggest adding a sentence at the end of the paragraph of the IACC recommendation for future work. Something like: " While ADI-R and ADOS-2 validation studies are needed on cultural sensitivity across the vast numbers of cultures represented in the United States, it is also important that language translations are done so or administered with cultural considerations. " On page 8 "Workforce", it is a good opportunity to highlight more than stated in the document about diversifying the workforce of professionals who screen/diagnose for ASD. Increasing the number of diverse professionals who are grounded in communities historically marginalized is a way to address a recurring problem of underserved populations. Training up these community members as professionals is important for language translations of screening and diagnostic evaluations that is culturally responsive.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>This chapter was a good brief synopsis of the current state of research. I only have one minor suggestion. On page 8 "Longitudinal Studies" and the line "organized longitudinal studies across the lifespan are needed to better understand the biology, developmental trajectories, and natural history of autism, from prenatal development to early childhood and through adulthood", is missing to adolescence. The omission of adolescence can be implied as less important than childhood and adulthood.</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>On page 5 "Peer-Mediated Interventions", we might want to include a sentence about peer-mediated interventions in which neurotypical peers interact with autistic peers through mirrored behaviors (i.e., "you flap and smile, I flap and smile") and shared interests. On page 6 "Technology-Based Interventions and Communication Tools" the paragraph on AAC, we need a sentence about text or typing communication. AAC tools can extend beyond PECS and SGDs. It can include texting apps that generate speech. Furthermore, AAC tools can improve development in different languages and is culturally responsive. On page 9 "Complementary and Alternative Approaches", I would add to the list of interventions "physical or physio therapy for managing and reducing chronic pain."</p>

<p>Chapter 5: Services and Supports</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>On page 2, "Education System", education curriculum such as the Unstuck and On Target program can help educators, parents and caregivers, and autistic students a means to overcome learning challenges related with executive functioning impairments. https://www.unstuckandontarget.com/ On page 5-6 "Dental Care", at an IACC meeting, Shannon Des Roches Rosa raised the issue of those who need IV sedation for oral surgery/dental procedures and the medical cost burden on families due to anesthesia related to dental work not covered by insurance. There isn't any research on this subject, however, this issue may be worth considering to be included in this section. On page 6 "Appropriate Services to Address Health and Safety Concerns", I would add in comprehensive sex and reproductive rights education is critical as a preventative intervention. On page 8 "Law Enforcement and Safety", can we add a sentence about family training and education about safety and interactions with law enforcement? For example, I made an appointment with our local police and fire stations to introduce our family. My child regularly says he will call 911. In the case he accesses a phone and calls 911 for non-emergencies, there can be awareness of why they might be receiving a call from our child. Relatedly, if he is found wandering, our local law enforcement should be able to recognize our child as autistic. On page 10 "Caregiver Supports", we can include Circle of Vietnamese Parents to the list of private/non-profit organizations of parent support. https://vongtaychameviet.com/</p>
<p>Chapter 6: Lifespan</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	JaLynn R.Prince
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	<p>This has a good structure and it reflects most of the major points that we discussed. Thank you for the work you all have done in compiling this array of topics.</p>
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>No.</p>

Name/Agency	Social Security Administration (SSA)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>Looks good. Maybe a summary pie chart with the Question and % of funding for 2020?</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Might want to rephrase: While recent prevalence data from the CDC ADDM Network has demonstrated that universal screening can reduce disparities in prevalence⁴⁶, it is still important to demonstrate that universal screening can subsequently reduce disparities in long-term outcomes for individuals with ASD. We aren't really going to "reduce disparities in prevalence" -- it is really getting more accurate prevalence estimates across race/ethnicity/SES, etc.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>"male to female autism diagnosis ratio" should be "male-to-female autism diagnosis ratio". Need to make sure that this is corrected across the document.</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Maybe mention heritability vs. non-heritability?</p>
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK.</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK.</p>

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK.</p>
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I sent this paper over for the inclusion in the 2022 IACC Summary of Advances: Exclusion of females in autism research: Empirical evidence for a "leaky" recruitment-to-research pipeline - PubMed (nih.gov) D'Mello, A. M., Frosch, I. R., Li, C. E., Cardinaux, A. L., & Gabrieli, J. D. E. (2022). Exclusion of females in autism research: Empirical evidence for a "leaky" recruitment-to-research pipeline. Autism research : official journal of the International Society for Autism Research, 15(10), 1929–1940. https://doi.org/10.1002/aur.2795 According to the research findings, a screening test commonly used to determine eligibility for studies of autism consistently winnows out a much higher percentage of women than men. This creates a “leaky pipeline” that results in severe underrepresentation of women in studies of autism. Because of this lack of representation, it makes it more difficult to develop useful interventions or provide accurate diagnoses for girls and women.</p>
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK.</p>
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK.</p>
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK</p>
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>OK</p>

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	<p>OK</p>
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>Looking good! Thank you to everybody for all their hard work.</p>

Name/Agency	Department of Education (ED)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Recommend that the recommendation for pharmacological interventions be last recommendation</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Department of Labor (DOL)
<p>Introduction</p> <p>Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Recent research to cite (add) on workforce needs:</p> <p>McBain, R. K., Kareddy, V., Cantor, J. H., Stein, B. D., & Yu, H. (2020). Systematic review: United States workforce for autism-related child healthcare services. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i>, 59(1), 113-139 https://www.sciencedirect.com/science/article/pii/S089085671930351X</p> <p>Mazurek, M. O., Harkins, C., Menezes, M., Chan, J., Parker, R. A., Kuhlthau, K., & Sohl, K. (2020). Primary care providers' perceived barriers and needs for support in caring for children with autism. <i>The Journal of Pediatrics</i>, 221, 240-245 https://www.sciencedirect.com/science/article/pii/S0022347620300275</p> <p>Aylward, B. S., Gal-Szabo, D. E., & Taraman, S. (2021). Racial, ethnic, and sociodemographic disparities in diagnosis of children with autism spectrum disorder. <i>Journal of Developmental and Behavioral Pediatrics</i>, 42(8), 682 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8500365/</p> <p>I think it would help to add a brief mention of greater emphasis on new tech tools and scaling up best practices re: diagnosis of children and adolescents. Depending on where autistic children and their families live, some providers can make the diagnosis at or before age two and some much later than that. This reflects differences in best and promising practices; tools, technology, and instruments; and knowledge and training. Also, family navigation should consider efforts to involve autistic adults more proactively in helping support families of autistic children and adolescents. For instance, some efforts have examined how autistic adults can receive training to help support autistic adolescents and their families, including for mentoring and systems navigation:</p> <p>Tomfohrde, O., Hudock, R. L., Kremer, K. B., Fatiha, N., & Weiler, L. (2022). Fostering social connectedness among adolescents and adults with autism: A qualitative analysis. <i>Psychology in the Schools</i>. https://onlinelibrary.wiley.com/doi/full/10.1002/pits.22759</p>
<p>Chapter 2: Biology</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Research literature to cite for the Cognition sub-section:</p> <p>Demetriou, E. A., DeMayo, M. M., & Guastella, A. J. (2019). Executive function in autism spectrum disorder: history, theoretical models, empirical findings, and potential as an endophenotype. <i>Frontiers in Psychiatry</i>, 10, 753.</p>

	<p>Desideri, L., Di Santantonio, A., Varruciu, N., Bonsi, I., & Di Sarro, R. (2020). Assistive technology for cognition to support executive functions in autism: A scoping review. <i>Advances in Neurodevelopmental Disorders</i>, 4(4), 330-343</p> <p>Additions: Consider adding a brief mention of the need for greater research on biology and neurology regarding vision and hearing. Recent research suggests differences in the eyes and vision of autistic people, although it is limited thus far:</p> <p>Khanna, R. K., Kovarski, K., Arsene, S., Siwiaszczyk, M., Pisella, P. J., Bonnet-Brilhault, F., ... & Malvy, J. (2020). Ophthalmological findings in children with autism spectrum disorder. <i>Graefe's Archive for Clinical and Experimental Ophthalmology</i>, 258(4), 909-916.</p> <p>(https://link.springer.com/article/10.1007/s00417-019-04594-7)</p> <p>Little, J. A. (2018). Vision in children with autism spectrum disorder: a critical review. <i>Clinical and Experimental Optometry</i>, 101(4), 504-513.</p> <p>(https://www.tandfonline.com/doi/abs/10.1111/cxo.12651)</p> <p>Lindly, O. J., Chan, J., Fenning, R. M., Farmer, J. G., Neumeyer, A. M., Wang, P., ... & Kuhlthau, K. A. (2021). Vision care among school-aged children with autism spectrum disorder in North America: Findings from the Autism Treatment Network Registry Call-Back Study. <i>Autism</i>, 25(3), 840-853.</p> <p>(https://journals.sagepub.com/doi/abs/10.1177/1362361320942091)</p> <p>Lau, C. S. L., Tong, J. M. K., Tang, E. W. H., & Li, K. K. W. (2022). Ocular Features and Autism Spectrum Disorder: A 10-Year Retrospective Review. <i>Indian pediatrics</i>, 59(7), 581-582.</p> <p>(https://www.indianpediatrics.net/july2022/581.pdf)</p> <p>Beers, A. N., McBoyle, M., Kakande, E., Santos, R. C. D., & Kozak, F. K. (2014). Autism and peripheral hearing loss: a systematic review. <i>International Journal of Pediatric Otorhinolaryngology</i>, 78(1), 96-101.</p> <p>(https://www.sciencedirect.com/science/article/abs/pii/S0165587613005533)</p> <p>Ludwig, N. N., Jashar, D. T., Sheperd, K., Pineda, J. L., Previ, D., Reesman, J., ... & Gerner, G. J. (2021). Considerations for the identification of autism spectrum disorder in children with vision or hearing impairment: A critical review of the literature and recommendations for practice. <i>The Clinical Neuropsychologist</i>, 1-20.</p> <p>(https://www.tandfonline.com/doi/abs/10.1080/13854046.2021.2002933)</p>
<p>Chapter 3: Genetic and Environmental Factors</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>No feedback for this chapter</p>

Chapter 4: Interventions
Do you feel that there are any items that were missed in this section? If so, please identify them below.

It would benefit from a brief mention of the need for greater exploration of innovation of technology (high-tech and low-tech) to help address challenges in executive functioning, sensory needs, mental health, etc. Research cited in the box for Chapter 1 might also be helpful here re: workforce needs for interventions:

McBain, R. K., Karedy, V., Cantor, J. H., Stein, B. D., & Yu, H. (2020). Systematic review: United States workforce for autism-related child healthcare services. *Journal of the American Academy of Child & Adolescent Psychiatry*, 59(1), 113-139

(<https://www.sciencedirect.com/science/article/pii/S089085671930351X>)

Mazurek, M. O., Harkins, C., Menezes, M., Chan, J., Parker, R. A., Kuhlthau, K., & Sohl, K. (2020). Primary care providers' perceived barriers and needs for support in caring for children with autism. *The Journal of Pediatrics*, 221, 240-245

(<https://www.sciencedirect.com/science/article/pii/S0022347620300275>)

Also, these articles would be helpful to cite re: the services cliff (for OT, speech and language therapy, etc.) as autistic children age (from elementary school to adult life) and racial disparities in services access:

Benevides, T. W., Tao, S., Becker, A., Verstrete, K., & Shea, L. (2022). Occupational therapy service delivery among Medicaid-enrolled children and adults on the autism spectrum and with other intellectual disabilities. *The American Journal of Occupational Therapy*, 76(1).

(<https://research.aota.org/ajot/article-abstract/76/1/7601180100/23165/Occupational-Therapy-Service-Delivery-Among>)

Dallman, A. R., Artis, J., Watson, L., & Wright, S. (2021). Systematic review of disparities and differences in the access and use of allied health services amongst children with autism spectrum disorders. *Journal of autism and developmental disorders*, 51(4), 1316-1330.

(<https://link.springer.com/article/10.1007/s10803-020-04608-y>)

I also provide some literature below re: reviews on technology use for interventions and gaps in research:

Desideri, L., Di Santantonio, A., Varruciu, N., Bonsi, I., & Di Sarro, R. (2020). Assistive technology for cognition to support executive functions in autism: A scoping review. *Advances in Neurodevelopmental Disorders*, 4(4), 330-343.

(<https://link.springer.com/article/10.1007/s41252-020-00163-w>)

Lorah, E. R., Holyfield, C., Miller, J., Griffen, B., & Lindbloom, C. (2022). A systematic review of research comparing mobile technology speech-generating devices to other AAC modes with individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 34(2), 187-210.

(<https://link.springer.com/article/10.1007/s10882-021-09803-y>)

	<p>Syriopoulou-Delli, C. K., & Gkiolnta, E. (2022). Review of assistive technology in the training of children with autism spectrum disorders. <i>International Journal of Developmental Disabilities</i>, 68(2), 73-85.</p> <p>(https://www.tandfonline.com/doi/abs/10.1080/20473869.2019.1706333)</p> <p>Koumpouros, Y., & Kafazis, T. (2019). Wearables and mobile technologies in Autism Spectrum Disorder interventions: A systematic literature review. <i>Research in Autism Spectrum Disorders</i>, 66, 101405.</p> <p>(https://www.sciencedirect.com/science/article/abs/pii/S175094671930087X)</p>
<p>Chapter 5: Services and Supports</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Note that ODEP's Partnership on Inclusive Apprenticeship (PIA) is a project that supports the Registered Apprenticeship system under the National Apprenticeship Act. However, it is not funded through this law. PIA fosters policies and practices to help advance inclusive apprenticeships, particularly in high-growth, high-demand sectors (e.g., IT, healthcare, clean energy, etc.). The Employment and Training Administration (ETA), which is a sister agency of ODEP, implements the National Apprenticeship through targeted grant funding and other initiatives. ETA sets the regulations and rules for the national Registered Apprenticeship system under the National Apprenticeship Act.</p> <p>Either this chapter or another chapter should consider briefly noting the gap in lack of a focus on positive psychology facets (e.g., resilience, courage, self-optimism) for autistic youth and adults.</p> <p>Research to cite mentioning apprenticeships and educational preparation for gainful employment:</p> <p>Raymaker, D. M., Sharer, M., Maslak, J., Powers, L. E., McDonald, K. E., Kapp, S. K., ... & Nicolaidis, C. (2022). "[I] don't wanna just be like a cog in the machine": Narratives of autism and skilled employment. <i>Autism</i>, 13623613221080813.</p> <p>(https://journals.sagepub.com/doi/abs/10.1177/13623613221080813)</p> <p>Baker-Ericzén, M. J., ElShamy, R., & Kammes, R. R. (2022). Current Status of Evidence-Based Practices to Enhance Employment Outcomes for Transition Age Youth and Adults on the Autism Spectrum. <i>Current Psychiatry Reports</i>, 1-10.</p> <p>(https://link.springer.com/article/10.1007/s11920-022-01327-2)</p> <p>Eilenberg, J. S., Paff, M., Harrison, A. J., & Long, K. A. (2019). Disparities based on race, ethnicity, and socioeconomic status over the transition to adulthood among adolescents and young adults on the autism spectrum: A systematic review. <i>Current Psychiatry Reports</i>, 21(5), 1-16.</p> <p>(https://link.springer.com/article/10.1007/s11920-019-1016-1)</p> <p>Wong, J., Coster, W. J., Cohn, E. S., & Orsmond, G. I. (2021). Identifying school-based factors that predict employment outcomes for transition-age youth with autism spectrum disorder. <i>Journal of autism and developmental disorders</i>, 51(1), 60-74.</p> <p>(https://link.springer.com/article/10.1007/s10803-020-04515-2)</p>

	<p>Whittenburg, H. N., Cimera, R. E., & Thoma, C. A. (2019). Comparing Employment Outcomes of Young Adults with Autism: Does Postsecondary Educational Experience Matter?. <i>Journal of Postsecondary Education and Disability</i>, 32(2), 159-172.</p> <p>(https://eric.ed.gov/?id=EJ1228971)</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>The narrative should note that small size of study samples and other factors have meant that we cannot definitively state the precise unemployment and underemployment stats for autistic adults and rates stratified by support and service needs, etc. (We know that autistic adults experience major unemployment and underemployment, but cannot quantify this precisely for all autistic adults in the U.S.) A brief mention of the gaps re: economic status and income for autistic adults would be helpful. Research in this area remains limited because most studies on employment and autism have not collected data on income and economic status. Where economic status is known from studies, it is often limited to the economic status of families of autistic youth and adults.</p> <p>However, many autistic people live alone and have income independent from their parents and families. Likewise, the literature tends to prioritize jobs but not often career paths for autistic adults for the long-term. Retention of jobs remains an issue even though most autism literature on employment only focuses on attaining jobs rather than retaining jobs and advancing in careers. Likewise, research gaps regarding intersectionality (e.g., race and ethnicity, LGBTQIA+, etc.) and autistic adults' employment access and income remain. Other gaps include lack of sufficient research data and promising practices on supporting autistic people in transitioning from benefit systems to gainful employment. (We barely have any data on autistic adults who are beneficiaries of the Social Security and Medicaid and Medicare systems.)</p> <p>Additionally, it would be helpful to cite here or in Chapter 5 transportation access gaps. Most autistic adults face major barriers in accessing supports needed to use public transportation, and most autistic adults lack driver's licenses.</p> <p>Also, research remains limited regarding navigation of the healthcare system and health insurance for autistic adults to support employment and community living. Allied service providers for occupational therapy and speech-language therapy frequently lack training on the needs of autistic adults regarding executive functioning, communication and social supports, etc.</p> <p>Research to cite:</p> <p>Wissel, S., Shenk, M., & Rice, M. (2022). Programs, Models, and Strategies to Support Employment Outcomes of Young Adults on the Autism Spectrum. Mathematica report prepared for the U.S. Department of Labor's Office of Disability Employment Policy. https://www.mathematica.org/publications/programs-models-and-strategies-to-support-employment-outcomes-of-young-adults-on-the-autism-spectrum</p> <p>Shenk, M., Krantz, A., & Shattuck, P. (2022). Evidence on the Effectiveness of Programs, Models, and Strategies to Support Employment Outcomes of Young Adults on the Autism Spectrum. Mathematica report prepared for the U.S. Department of Labor's</p>

Office of Disability Employment Policy.

<https://www.mathematica.org/publications/evidence-on-the-effectiveness-of-programs-models-and-strategies-to-support-employment-outcomes>

Shenk, M., & Aguiard, K. (2022). Barriers and Facilitators to Employment and Careers for Young Adults on the Autism Spectrum. Mathematica report prepared for the U.S. Department of Labor's Office of Disability Employment Policy.

<https://www.mathematica.org/publications/barriers-and-facilitators-to-employment-and-careers-for-young-adults-on-the-autism-spectrum>

Wilson, N. J., Stevens, A., Srasuebkul, P., Kersten, M., Lin, Z., Trollor, J. N., & Arnold, S. R. (2021). Exploring the relationship between community mobility and quality of life, employment and completing further education for autistic adults. *Journal of Transport & Health*, 22, 101117.

Kim, S. Y., Crowley, S., & Lee, Y. (2022). A Scoping Review of Technology-Based Vocational Interventions for Individuals with Autism. *Career Development and Transition for Exceptional Individuals*, 45(1), 44-56.

(<https://journals.sagepub.com/doi/full/10.1177/21651434211041608>)

(<https://www.sciencedirect.com/science/article/abs/pii/S221414052100147X>)

Feeley, C., Deka, D., Lubin, A., & McGackin, M. (2015). Detour to the right place: A study with recommendations for addressing the transportation needs and barriers of adults on the autism spectrum in New Jersey. Rutgers The State University of New Jersey.

(https://vtc.rutgers.edu/wp-content/uploads/2015/10/Detour_to_the_Right_Place_Technical_Report_2015.pdf)

Lindsay, S. (2017). Systematic review of factors affecting driving and motor vehicle transportation among people with autism spectrum disorder. *Disability and rehabilitation*, 39(9), 837-846.

(<https://www.tandfonline.com/doi/abs/10.3109/09638288.2016.1161849>)

Saez-Suanes, G. P., & Alvarez-Couto, M. (2022). Factors associated with quality of life in adults with autism spectrum disorder: A systematic review. *Review journal of autism and developmental disorders*, 9(3), 307-319.

(<https://link.springer.com/article/10.1007/s40489-021-00254-x>)

Shattuck, P. T., Garfield, T., Roux, A. M., Rast, J. E., Anderson, K., Hassrick, E. M., & Kuo, A. (2020). Services for adults with autism spectrum disorder: A systems perspective. *Current psychiatry reports*, 22(3), 1-12.

(<https://link.springer.com/article/10.1007/s11920-020-1136-7>)

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>The narrative could be strengthened regarding its emphasis on the need for prevalence and needs assessments, including through monitoring projects, to improve access and opportunity for autistic adults and help bolster quality of life. We have this work occurring at the state level (e.g., Pennsylvania) but not nationally. Example articles from Pennsylvania's work in assessing needs of autistic adults appear below:</p> <p>Miller, K. H. K., Cooper, D. S., Song, W., & Shea, L. L. (2022). Self-reported service needs and barriers reported by autistic adults: Differences by gender identity. <i>Research in Autism Spectrum Disorders</i>, 92, 101916.</p> <p>(https://www.sciencedirect.com/science/article/pii/S1750946722000034)</p> <p>Shea, L. L., Verstrete, K., Nonnemacher, S., Song, W., & Salzer, M. S. (2021). Self-reported community participation experiences and preferences of autistic adults. <i>Autism</i>, 25(5), 1295-1306.</p> <p>(https://journals.sagepub.com/doi/abs/10.1177/1362361320987682)</p>
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>No feedback</p>
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Research to cite:</p> <p>Steinbrenner, J. R., McIntyre, N., Rentschler, L. F., Pearson, J. N., Luelmo, P., Jaramillo, M. E., ... & Hume, K. A. (2022). Patterns in reporting and participant inclusion related to race and ethnicity in autism intervention literature: Data from a large-scale systematic review of evidence-based practices. <i>Autism</i>, 13623613211072593.</p> <p>(https://journals.sagepub.com/doi/abs/10.1177/13623613211072593)</p> <p>Yingling, M. E., Bell, B. A., & Hock, R. M. (2019). Comparing neighborhoods of children with autism spectrum disorder in a Medicaid waiver program and a state population, 2007–2015. <i>Psychiatric Services</i>, 70(11), 1034-1039.</p> <p>(https://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.201800479)</p> <p>Steinbrenner, J. R., McIntyre, N., Rentschler, L. F., Pearson, J. N., Luelmo, P., Jaramillo, M. E., ... & Hume, K. A. (2022). Patterns in reporting and participant inclusion related to race and ethnicity in autism intervention literature: Data from a large-scale systematic review of evidence-based practices. <i>Autism</i>, 13623613211072593.</p> <p>(https://journals.sagepub.com/doi/full/10.1177/13623613211072593)</p> <p>Yingling, M. E., Bell, B. A., & Hock, R. M. (2019). Treatment utilization trajectories among children with autism spectrum disorder: Differences by race-ethnicity and neighborhood. <i>Journal of Autism and Developmental Disorders</i>, 49(5), 2173-2183.</p> <p>(https://link.springer.com/article/10.1007/s10803-019-03896-3)</p>

<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Research to cite:</p> <p>Maljaars, J., Gijbels, E., Evers, K., Spain, D., Rumball, F., Happé, F., & Noens, I. (2022). Impact of the COVID-19 pandemic on daily life: Diverse experiences for autistic adults. <i>Journal of autism and developmental disorders</i>, 1-13.</p> <p>(https://link.springer.com/article/10.1007/s10803-022-05437-x)</p> <p>Goldfarb, Y., Gal, E., & Golan, O. (2022). Implications of employment changes caused by COVID-19 on mental health and work-related psychological need satisfaction of autistic employees: A mixed-methods longitudinal study. <i>Journal of autism and developmental disorders</i>, 52(1), 89-102.</p> <p>(https://link.springer.com/article/10.1007/s10803-021-04902-3)</p> <p>Bundy, R., Mandy, W., Crane, L., Belcher, H., Bourne, L., Brede, J., ... & Cook, J. (2022). The impact of early stages of COVID-19 on the mental health of autistic adults in the United Kingdom: A longitudinal mixed-methods study. <i>Autism</i>, 13623613211065543.</p> <p>(https://journals.sagepub.com/doi/abs/10.1177/13623613211065543)</p>
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Department of Housing and Urban Development (HUD)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I appreciate that there were several places that acknowledged difficulty in making interventions accessible to underserved (you might also add low-income communities). In the final paragraph under Policy Issues and Research on pg. 83, you might consider acknowledging that broadband and general internet access remain a barrier for accessing many of the technology-based interventions, and limitations in transportation and community resources limits the ability of find and get to other interventions.</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Pg. 102 and 103 do an excellent job of discussing how accessible services and supports for caregivers are lacking for underserved minority groups and also parents of older adults. You might consider including low-income individuals and communities in this section.</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Yetta Myrick
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>In the last paragraph on page one that starts as follows: "The COVID-19 pandemic has had a profound impact on the autism community" I think it would also be important to note the lack of supports initially in hospitals for autistic individuals. Communication First has a toolkit on patient accommodations: https://communicationfirst.org/covid-19/ I am also thinking about the impact of caregiver death on the autism community, although I am not sure where we can find specific data on this. Additionally, in the National Council on Disabilities report, (https://ncd.gov/sites/default/files/NCD_COVID-19_Progress_Report_508.pdf), they talk about the shortage of direct care workers. Would it be worth adding a sentence or two about these issues? Lastly, on page 6, it states "there are still many areas of research that lack sufficient support" could speak to why this is the case?</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>While I recognize this section is screening and diagnosis, the first step of early identification is parent-engaged developmental monitoring. I truly believe that making the statement that all families need to monitoring their child's development up front will be key in shifting mindsets around screen and diagnosis. Developmental monitoring complements screening, and needs to happen on an ongoing basis. Recommending to "Improve family engagement and help build an awareness of appropriate developmental milestones" is not enough. We need to include developmental monitoring. I would change to: "Improve family engagement and help build an awareness of appropriate developmental milestones and monitoring of child development" On Page 9, first full paragraph, I think adding ECHO Autism as an example of training is a must! Learn more here: https://echoautism.org/about-us/ On page 10, second paragraph, I think "family systems" need to added to the following sentence: "In addition, systems do not take into account families' concerns about stigma, the reluctance of professionals to make a diagnosis or share concerns about traits of ASD in very young children, missed or false positive diagnoses, and the need for earlier evaluations and re-evaluations of very early assessments as symptoms are unfolding" Many providers operate under this one size fits all model where the parents are the only caregivers they need to talk to about autism, but this does not take into account various cultures that included multi-generations in care. Remember, we all exist with the context of our families.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 7: Infrastructure and Prevalence Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Lindsey Nebeker
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>- There are a few inconsistencies in single-spacing and double-spacing sentences that need to be checked (it might also be a good idea to check the additional chapters as well). - Last sentence on Page 3 (Editorial Note): I suggest specifying the most recent publication (DSM-5) instead of just "DSM".</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Include a mention of recommended federal/state financial support options (if not mentioned in the other sections): - ABLE accounts - MFP (Money Follows the Person) - SSD / Medicaid</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>INTRODUCTION, Paragraph #1: Do we need to update the CDC data to reflect the most recent statistics (1 in 44; 2018)? Reference Link: https://www.cdc.gov/ncbddd/autism/data.html</p>

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Suggestion: Insert hyperlink for "NIMH Data Archive (NDA)" (on Page 2).</p>
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>PAGE 3, "Sex- and Gender-Specific Services and Supports" - We also need to consider including acknowledgement of LGBTQIA+ individuals and access to reproductive healthcare (not just mention women). New research: https://doi.org/10.1542/peds.2020-049437</p>
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>- I am not sure where to mention it in this chapter, but it would be beneficial to also include acknowledgement concerning the vulnerability of autistic adults in residential programs / group homes and a far higher risk of COVID-19. (Reference example: https://www.spectrumnews.org/news/coronavirus-threatens-autistic-people-living-in-group-homes/) In addition to mentioning funding challenges for researchers, we also need to include a mention about how the pandemic has affected the access and amount of SSDI funding for individuals who are trying to apply or already have it.</p>
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>- This may already be planned, but one recommendation I have is to include the sub-sections of each chapter in the Table of Contents. - While not necessary for this year's publication, I would strongly suggest in future publications that each chapter can also include an "Easy Read" summary to make it more accessible for readers with comprehension challenges.</p>

Name/Agency	Center for Medicare & Medicaid Services (CMS)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>No. It is quite thorough.</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>On page 20 just before the reference to CHIP (which includes a link to the CHIP site on Medicaid.gov) to add a hyperlink when it references "Medicaid" to Medicaid.gov. Also, the paragraph following that paragraph starts with the number 4 which appears to be a typo.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>On page 29, there is a paragraph that starts with "iPSCs" and it seems as though the I should be capitalized.</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Suggest adding a hyperlink to Medicaid.gov the first time "Medicaid" is referenced under Healthcare System. Also provided a few edits to the paragraphs included referencing Medicaid. I'm not able to include the tracked changes here but see the language below which is inclusive of the suggested changes. Three paragraphs needed significant updates: 1) ON PAGE 95 - One important funding stream for reimbursement of health services provided to individuals with autism is the Medicaid program. Jointly operated between the states and the Federal government, Medicaid provides healthcare coverage for individuals below certain income thresholds. Income and eligibility requirements can vary by state. Among a menu of both mandatory and optional services, a variety of services and supports may be covered by Medicaid, such as case management, rehabilitative services, and physical, occupational, and speech therapies. The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit mandates the provision of medically necessary services found at section 1905(a) of the Social Security Act, including screening, diagnostic, and treatment services, for Medicaid beneficiaries under the age of 21. 2) ON PAGE 96 - Waiver programs are</p>

	<p>used to deliver certain kinds of services for people with disabilities. A Home and Community-Based Services (HCBS) waiver program approved by the federal Centers on Medicare & Medicaid Services (CMS) allows states to offer a broad range of long-term services and supports to individuals in their homes and communities, instead of institutional settings. Nearly all states and DC offer (HCBS) Medicaid Waivers, States can offer a variety of autism services under an HCBS Waiver program, such as intensive individual support services, respite care, and adult life planning.²² HCBS Waivers can help to meet the service needs of people with autism and decrease their unmet healthcare needs.²³⁻²⁵ 3) ON PAGE 105 - For both those who may live independently and those who may live with a family caregiver, home and community-based services provide an important source of support for many people with disabilities who need assistance to live in the community (not in institutional or congregate care settings). Medicaid Home and Community-Based Services (HCBS) programs allow states to help provide different services that allow those who need care to receive services in their homes or communities.¹⁶³ Medicaid 1915(c) waivers in particular are a policy mechanism that states across the United States frequently use to provide health care insurance to specific populations for targeted services, including autistic individuals, although further research is needed to compare access, service use, and outcomes among autistic individuals across different U.S. states.¹⁶⁴ You might also consider whether to weave anything in about the new optional health home state plan benefit for Medicaid-eligible children with medically complex conditions included as part of the Medicaid Services Investment and Accountability Act of 2019 (P. L. 116-16). Enacted under section 1945A of the Social Security Act, beginning October 1, 2022, states have the option to cover health home services for Medicaid-eligible children with medically complex conditions as defined in section 1945A(i) of the Act up to age 21. Severe Autism is listed as a condition in 1945A(i)(2)(H) specifically, but any form of Autism technically could be targeted under any health home (1945 & 1945A).</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Edits needed on page 125 - Community Based Services paragraph. Please remove this sentence "By 2023, the Centers for Medicare & Medicaid Services will require states to be in compliance with requirements published in Jan 2014 for individuals receiving Medicaid services to spend more time participating in communities, rather than in isolated settings. 45. This is not what the rule says and there would need to be more explanation about the rule included here if you want to reference it which I'm not sure is what you want to focus the reader's attention on. In future versions of the strategic plan, we may need to do a thorough review of the background language to help incorporate updates to dated language.</p>
<p>Chapter 7: Infrastructure and Prevalence Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	No
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	No
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	No

Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?

I couldn't access what was provided through the link and had to get a hard copy of the entire draft strategic plan and realize upon reviewing it in its entirety that there are areas that included dated language and it could likely benefit from a scrubbing to bring all related background language up-to-date.

Name/Agency	Substance Abuse and Mental Health Services Administration (SAMHSA)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>p. 8, add Interdepartmental Substance Use Disorders Coordinating Committee (ISUDCC) along with other committees noted. See https://www.samhsa.gov/about-us/advisory-councils/isudcc</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>p. 7 note substance use disorder along with mental health Helverschou SB, Brunvold AR, Arnevik EA. Treating Patients With Co-occurring Autism Spectrum Disorder and Substance Use Disorder: A Clinical Explorative Study. <i>Subst Abuse</i>. 2019 Apr 17;13:1178221819843291. doi: 10.1177/1178221819843291. PMID: 31024216; PMCID: PMC6472168; Anderson SAR, Catalozzi M. Autism Spectrum Disorder and the Risk of Substance Use Disorder: A Call for Targeted Screening and Prevention in Adolescents. <i>JAMA Pediatr</i>. 2021 Feb 1;175(2):e205376. doi: 10.1001/jamapediatrics.2020.5376</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>"p. 5 mental health services and supports. Note Pinals et. al articles discussing developmental disabilities in the mental health system. Pinals DA, Hovermale L, Mauch D, Anacker L. Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 1. Clinical Considerations. <i>Psychiatr Serv</i>. 2022 Mar 1;73(3):313-320</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Maybe note somewhere here or in services chapter importance of including persons with autism and developmental disabilities in emergency preparedness programs and planning. See e.g., Wolf-Fordham S, Curtin C, Maslin M, Bandini L, Hamad CD. Emergency preparedness of families of children with developmental disabilities: what public health and safety emergency planners need to know. J Emerg Manag. 2015 Jan-Feb;13(1):7-18. doi: 10.5055/jem.2015.0213; Baweja R, Brown SL, Edwards EM, Murray MJ. COVID-19 Pandemic and Impact on Patients with Autism Spectrum Disorder. J Autism Dev Disord. 2022 Jan;52(1):473-482. Note importance of access to HCBS and adequate health coverage here (https://jamanetwork.com/journals/jama/article-abstract/2797393).</p>
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Add Interdepartmental Substance Use Disorders Coordinating Committee (ISUDCC) to list with other committees/councils. https://www.samhsa.gov/about-us/advisory-councils/isudcc</p>

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	National Institute on Deafness and Other Communication Disorders (NIDCD)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I thought the discussion about AAC was appropriate and balance. I agree that it could be expanded and my understanding is that Dr. Tager-Flusberg will provide some input to enhance this section.</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>Monumental effort/task. Great job to all who contributed.</p>

Name/Agency	Alycia Halladay
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>The disclaimer in the introduction says: Editorial Note on References to Autism The terms “autistic person,” “person with autism.” and "person on the autism spectrum" are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The Committee respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the term "autism" is generally used in this document, and “autism spectrum disorder (ASD)” is used when referring specifically to the DSM-defined diagnosis. But this is not the case. "Person with autism" is not used at all. If we want to just say that we use "autistic" (even in the case of an "autistic infant" which is not correct) then we should say that. But the disclaimer should be accurate. Otherwise, looks GREAT!!!</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>First, thank you for linking these questions with "draft chapter link". that makes this so much easier!!! We never really addressed the issue of intervention or supports before a diagnosis can be formally made. While I think lowering the age of diagnosis is incredibly important, we need to address the needs while waiting lists are still long.</p>
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>There needs to be a link to behavior or communication or cognition in the title. I'm not sure "differences" is always appropriate here. Some of these comorbid conditions like GI and epilepsy are not differences, they are pathologies. We should not shy away from that.</p>
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I would change the first three words to "Discover and Understand". Also, we need to include something about their interaction, or we are just going to keep going in circles that they work independently. We also need to explore new statistical models to understand g x e and bring in experts from outside autism who have addressed g x e. Also, it should be emphasized that g x e studies requires A LOT of samples, and it's possible that we may have to stratify groups (simplex vs. multiplex, profound, etc.) to better understand the nature of g x e.</p>
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Please delete this under "stem cell therapies": Additionally, more research is needed to determine the proper dosage and cell source to be used in stem cell therapies and if they are effective. This will be an important area of investigation to monitor as researchers work to answer these questions and replicate and expand initial findings. The GI area is one that I'm becoming more familiar with, although I am not a GI specialist, but my understanding is that microbiome is just one area of focus. There is a desperate need for better diagnostics to rule out conditions and treatments to alleviate constipation which may or may not be focused in the gut microbiome. Therefore, this sentence should be changed to reflect the diversity of issues as well as therapeutics needed: "For co-occurring gastrointestinal (GI) problems, treatment generally involve changes to the gut microbiota.¹²⁵"</p>

<p>Chapter 5: Services and Supports</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>In the section about QOL, there are basically NO measures that can be used to assess QOL across the spectrum. There needs to be individualized QOL measurements - because positive outcomes are not the same for each person. For one person, just having a bowel movement every day is a good outcome. For others, being in a romantic relationship. They should include both person centered as well as family centered perspectives. I especially appreciate the role of the sibling section and think that there should be it's own section, not stuck in the middle of "caregiver supports". Thanks!</p>
<p>Chapter 6: Lifespan</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>For this section, we say "lifespan" but actually childhood is lifespan as well. Maybe it's me, but I've found the wording confusing. "Aging" can be aging through life, or becoming a senior citizen. We should probably have some words at the very beginning that define what we mean by "lifespan" as opposed to other chapters. We can even call this "Adolescence and Adulthood" but "lifespan" seems like it is excluding children. Also, sentences like this are not true, this should be changed (this is about adult diagnosis): "Such research will need to consider that adult psychiatric assessment traditionally relies on self- report, whereas autism formal diagnostic practices rely more on direct observation in structured clinical settings and/or caregiver report." You can change it to "Research will need to expand how they gather information beyond caregiver report for a formal diagnosis". You can talk to other people besides a caregiver and in addition to a self-report.</p>
<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>There is a crisis about keeping researchers in academia. It's gotten worse after the pandemic. I would say we need to add a bullet point under recommendation 2 that says "Improve the recruitment and retention of early career researchers who will lead the future discoveries or provide clinical services for those on the spectrum"</p>
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>While the FPE may not fully account for all of the differences in M:F diagnosis, it does account for some of it and I think the first paragraph is somewhat dismissive of the hypothesis altogether, when it in fact, has been proven to be a contributing factor. We need longitudinal studies to understand when differences between M:F emerge and how they play out across the life.</p>
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Do we have cross cutting recommendations? I think lessons learned about hybrid interventions and even supports should be mentioned, that they are promising and we should ensure that they remain an option if needed. Need support for longitudinal studies on this topic.</p>
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>Longitudinal studies should be emphasized in multiple sections!</p>

Name/Agency	National Institute of Environmental Health Sciences (NIEHS)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Administration for Children and Families (ACF)
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>This is a great report and I see my initial comments/suggestions implemented in this version. Thank you for a wonderful collaborative report.</p>

Name/Agency	Matthew Siegel
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>On page 8, there are 2 significant issues: 1. The figure displayed, here in the front matter, gives an overly positive impression of the arc of funding for autism research. the figure is not adjusted for inflation, which =31% during same time period. This figure should be expressed in inflation adjusted dollars. also, divide between public and private funding.. should use figure from page 174, fig.2 2. there is a major drop off in funding for intervention studies - from a stable amount of about \$60 million a year to less than \$40 million, which is a drop by more than 33%. this is marked, and thus the sentence "a slight downward trend" is not an accurate interpretation. this is a significant downward trend.</p>
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Edit needed on page 74: "So far, wearable technology has mostly been used to gather information on different physiological processes.48, 49 This information can be useful in predicting episodes of aggression or increased stress and anxiety.50-55" The second sentence greatly overstates the status of this literature, which is in its infancy. the sentence should be rewritten to say: This information, though preliminary, could prove to be useful in predicting episodes of aggression or increased stress or anxiety."</p>
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 7: Infrastructure and Prevalence Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Conclusion</p> <p>Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Hari Srinivasan
<p>Introduction Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	
<p>Chapter 1: Screening and Diagnosis Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 2: Biology Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 4: Interventions Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 5: Services and Supports Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Chapter 7: Infrastructure and Prevalence</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	

Name/Agency	Administration for Community Living (ACL)
<p>Introduction</p> <p>Do you feel that there are any major issues that were missed in the Introduction? If so, please identify them below.</p>	<p>Couple of thoughts: - make sure the intro references the aspects of living with autism throughout. This is done well, but I noticed a few points where the language was a bit too medical. For example, the part on co-occurring was a bit medicalized. The sentence "There is still much more to be done, however, to understand the mechanisms behind these conditions and develop more effective treatments" would benefit from including a reference to supports for living well with autism and co-occurring mental health conditions. By including supports - it makes it about other types of support and not just treatment. - ACL recommends including in the core values a reference to consistent with federal policy. The IACC's work should contribute to federal policies and priorities and there is no mention of that in the intro. - ACL recommends that the DEI section includes references to individuals with ASD who use alternative means for communication - this is an important group that often times gets overlooked and should be called out specifically.</p>
<p>Chapter 1: Screening and Diagnosis</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>While I know this chapter is focused on autism diagnosis, I wonder if there is benefit to including information / references to the importance of a differential diagnosis and identifying any co-occurring conditions. I think this notion is in there but could be amplified as an important step in the diagnosis of autism and any other co-occurring conditions.</p>
<p>Chapter 2: Biology</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Chapter 3: Genetic and Environmental Factors</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I appreciate the discussion in this chapter about the evolved thinking around this goal regarding prevention vs living well. That said, I'm not sure the recommendations fully make that change. the second one: "Understand the influence of environmental factors on the development and progression of autism and its co-occurring conditions, enabling the development of strategies to maximize positive outcomes" does that, I think. It is recommended that the other recommendations include similar language to promote living well vs prevention.</p>
<p>Chapter 4: Interventions</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I struggled with this chapter because the overall tone still seems to put the burden on the autistic individual to fix oneself / be fixed. In addition, I am very concerned with the way in which people who use alternative means to communicate are described (e.g., Many individuals on the autism spectrum have difficulties with spoken and verbal communication). This is a good example of the overall tone being medicalized / needing to fix to be normal than taking a more socio-cultural approach to living well. I recommend much more editing to this chapter and am happy to discuss in more detail my concerns, that will be noted by ACL.</p>
<p>Chapter 5: Services and Supports</p> <p>Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>Recommend adding / using more of the following key terms: person-centered, culturally competent, self-directed and consumer directed. Person-centered choice is used, but I'm not sure that is a widely accepted / used term. The health care system section makes no mention of health disparities / medical discrimination. This is a significant oversight and should be included. There is research on medical professionals attitudes about people with disabilities and on QALYS. It is very unclear why the law enforcement section is in the health system section. I suggest making this</p>

	<p>a separate section. It is surprising how much time is spent on wandering / elopement in this section. I think that part should come under a different title and the section on law enforcement should focus more on issues in the criminal justice system where there are many more issues than what is suggested in the chapter. The opening to the section on individualization has the following: "People with autism may have a wide range of support needs that evolve over the course of their lifespan. Due to the wide range of needs within the autism community, corresponding supports and services should optimally be tailored to the needs of each autistic individual." "tailored to the needs of each autistic individual" should be revised to "tailored to the choices of each autistic individual" - the section is about self direction / choices, not needs. It is unclear why there is information about legal guardians in this section - it should focus instead on supported decision making. This whole paragraph needs to be revised. "networks of support (i.e., family caregivers, providers, healthcare workers, etc.)" should also include peers, friends, and direct care workers. It seems that many important aspects to living fall under the category of "Independent Living, HCBS, Transportation, and Self-Determination". The topics in this section are very important yet seem to get much less attention than the health care system section. Suggest revising this section and making it similar to the health system section. Equal attention must be paid to all aspects of living. Also, this section makes no reference to Centers for Independent Living, which can provide local supports. There is very little discussion on the DCW crisis / emergency. Recommend adding more here. Finally the recommendations are very targeted at services / interventions - making it feel medicalized. It would be stronger if the statements were more person and outcome oriented.</p>
<p>Chapter 6: Lifespan Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	<p>I'm very confused by this chapter - it references lifespan but focuses on adults and much of it seems repetitive of chapter 5 or what should be a part of chapter 5.</p>
<p>Chapter 7: Infrastructure and Prevalence Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Cross-Cutting Topic: Sex and Gender Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	

<p>Cross-Cutting Topic: Promoting Equity and Reducing Disparities Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>COVID-19 and the Autism Community: Impact and Lessons Learned Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Budget Recommendation Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Statement on Duplication of Effort Do you feel that there are any items that were missed in this section? If so, please identify them below.</p>	
<p>Conclusion Do you feel that there are any items that were missed in the Conclusion? If so, please identify them below.</p>	
<p>Do you have any additional feedback on the current draft of the 2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy that you have not already shared?</p>	<p>I didn't have as much time as I would have liked to review all aspects of the plan in detail. I am happy to talk about the ACL comments if it would be helpful.</p>