

IACC Strategic Plan Question 4 Outline

January 2017

Chapter Title: Which Treatments and Interventions Will Help?

Aspirational Goal: Develop a range of interventions that optimize function and abilities across the life span to achieve meaningful outcomes and maximize quality of life for people on the autism spectrum.

I. Introduction

- Provide a general description of the issues addressed by this question. You can refer to the Question 4 background information in the previous version of the IACC Strategic Plan, but note that the previous plan said little about technology-based and classroom-based interventions. Working group wanted to discuss how advances in cognitive neuroscience have created new opportunities in intervention research.

II. Intervention types:

- Behavioral/social/developmental/cognitive interventions
- Medical/Pharmacological treatments
 - Direct brain stimulation
- Educational/Classroom interventions
 - Development of educational interventions in school settings
- Occupational, physical, and sensory-based treatments
- Complementary, dietary, and alternative treatments
- Technology-based interventions and supports/use of robotics/Alternative Augmentative Communication devices
 - Need increased coordination between federal agencies that fund basic technology development and those that fund trials of technology-based interventions to ensure a developmental path for these interventions
 - Use of technology to collect data
 - Automatic and dense data recording
 - Assessments
 - Data mining
 - Use of technology to deliver interventions and services
- Innovative combinations of therapeutic modalities

Within these intervention types - approaches and target symptoms, target populations

- Evidenced based approaches
- Mechanistically anchored approaches
- Parent- and caregiver-mediated interventions
- Treatments for co-occurring conditions
- Interventions for minimally verbal individuals with autism

- Community-based approaches
- Treatment for different age groups – children, adolescents, adults
- More intervention research needs to be conducted in low-resourced contexts, including the inclusion of more underrepresented groups.

III. Outcome measures and treatment response

- Identifying markers/metrics to measure treatment response
- Studies that address behavioral changes, early indicators of treatment response, moderators, active ingredients, and objective outcome measures
- Sex differences in treatment responses
- Responses to treatment in specific genetic subpopulations and across cultures
- Non-response to treatment
- Stratification of patients/choice of treatments/ tracking treatment response using or based on neural circuitry
- Personalized medicine – ensuring that intervention is tailored to individual needs
- What interventions are most effective in which age groups and/or subtypes?
- Research outcome measures, quality of life outcome measures, long term outcomes
 - Ensure that outcome measures that are meaningful to people on the autism spectrum are incorporated (e.g., interventions resulting in increased social relationships, greater independence, etc.)
- Assessing durability of treatment
- Inclusion of individuals on the autism spectrum, family members, and stakeholders in planning intervention research and determining outcome measures

IV. Accelerating research and increasing uptake of and access to evidence-based interventions

- Ways to accelerate the pace of research
 - Minimum of two efficacy trials to get approval for government reimbursement
 - Successful pilot studies go to later trials
 - Use a modular approach to apply interventions to the individual in combinations
 - Use community settings for research to help generalize findings to a larger population
 - Prepare research protocols with the community based setting in mind to accelerate translation
- Ways to increase interest of private industry in developing interventions
- Endpoint of research is to put treatments in the community through dissemination and training. (Strategies for successful implementation of evidence-based interventions in community-based settings will be covered in Q5, but this working group may also contribute ideas)
 - Prepare research protocols with the community based setting in mind to accelerate translation
 - Use community settings for research to help generalize findings to a larger population

- Strategies for increasing access to evidence-based interventions, including disparity issues; telehealth, parent and peer-mediated, community-based intervention models to make intervention more accessible and cost effective
- Preparing professionals and workforce for implementation of intervention
- Research how to disseminate research effectively in target communities
- Improvement of coordination of interventions across service providers
- Dissemination of information about evidence-based interventions to parents and providers; uptake
- Increase large scale clinical trials
- Discuss opportunity costs – trade-offs of personalized medicine

New Objectives:

- **Objective 1: Develop and improve pharmacological, medical and medical interventions to address both core symptoms and comorbidities in ASD.**
- **Objective 2: Develop and improve cognitive, behavioral, social, developmental, and naturalistic interventions for ASD.**
- **Objective 3: Maximize the potential for technologies and development of technology based interventions to improve the lives of people on the autism spectrum.**

Cross cutting themes applicable to all three objectives:

1. Understand more on the brain basis and mechanisms underlying these therapeutic approaches.
2. Maximize effectiveness for individuals taking advantage of combination therapies.
3. Develop more robust standardized outcome measures, including adaptive measures, predictive measures, measures that address heterogeneity, and measures of practical outcomes that will help better target therapies to individual needs.
4. Ensure support for the entire intervention research pipeline.
5. Support translation of research to community based practice and use of effective dissemination strategies to maximize uptake of evidence based practice.