

# Effective Health Care Program

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Future Research Needs Paper  
Number 20

## **Future Research Needs: Interventions for Adolescents and Young Adults With Autism Spectrum Disorders**



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## **Future Research Needs: Interventions for Adolescents and Young Adults With Autism Spectrum Disorders**

**Identification of Future Research Needs From Comparative Effectiveness Review  
No. 65**

**Prepared for:**

Agency for Healthcare Research and Quality  
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This report is based on research conducted by the Vanderbilt Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. 290-2007-10065-I). The findings and conclusions in this document are those of the author(s), who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

The information in this report is intended to help health care researchers and funders of research make well-informed decisions in designing and funding research and thereby improve the quality of health care services. This report is not intended to be a substitute for the application of scientific judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical research and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances.

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## Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

An important part of evidence reports is to not only synthesize the evidence, but also to identify the gaps in evidence that limited the ability to answer the systematic review questions. AHRQ supports EPCs to work with various stakeholders to identify and prioritize the future research that is needed by decisionmakers. This information is provided for researchers and funders of research in these Future Research Needs papers. These papers are made available for public comment and use and may be revised.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality. The evidence reports undergo public comment prior to their release as a final report.

We welcome comments on this Future Research Needs document. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to [epc@ahrq.hhs.gov](mailto:epc@ahrq.hhs.gov).

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# Executive Summary

## Background

This Future Research Needs (FRN) report is based on the Agency for Healthcare Research and Quality (AHRQ) comparative effectiveness review, Interventions for Adolescents and Young Adults With Autism Spectrum Disorders.

The Key Questions (KQs) from this review were:

- KQ1: Among adolescents and young adults with Autism Spectrum Disorders (ASD), what are the effects of available interventions on the core symptoms of ASD?
- KQ2: Among adolescents and young adults with ASD, what are the effects of available interventions on common medical and mental health comorbidities (e.g., epilepsy, sleep disorders, motor impairments, obesity, depression, anxiety, acute and episodic aggression, attention deficit hyperactivity disorder, etc.)?
- KQ3: Among adolescents and young adults with ASD, what are the effects of available interventions on functional behavior, attainment of goals toward independence, educational attainment, occupational/vocational attainment, life satisfaction, access to health and other services, legal outcomes, and social outcomes?
- KQ4: Among adolescents and young adults with ASD, what is the effectiveness of interventions *designed to support the transitioning process*, specifically to affect attainment of goals toward independence, educational attainment, occupational/vocational attainment, life satisfaction, access to health and other services, legal outcomes, and social outcomes?
- KQ5: Among adolescents and young adults with ASD, what harms are associated with available interventions? (Harms are defined by the Effective Health Care Program as all possible adverse consequences of an intervention, including adverse events.)
- KQ6: What are the effects of interventions on family outcomes?

Findings from the comparative effectiveness review identified 32 studies, of which 10 were randomized controlled trials (RCTs). Most studies were of poor quality; only 5 were fair quality and none were good quality. Strength of evidence was uniformly insufficient for all KQs. Fourteen studies addressed the core symptoms (impairments in communication, social interaction, or behavior) of ASD (KQ1) and the effects of interventions on functional and adaptive behavior (KQ3). Nine studies addressed medical interventions (KQ2).

Harms of interventions (KQ5) were only discussed in studies of medical approaches. One study addressed interventions targeting the transition process (KQ 4), and two assessed effects of an intervention on family outcomes (KQ6).

Across all intervention types, research is needed on which outcomes to use in future studies. No studies provide adequate information on longer term outcomes, and particularly on outcomes related to achieving goals for independence and quality of life. Research is also necessary to understand how individuals' expression of ASD symptoms and the severity of symptoms may affect treatment over the lifespan. Despite a growing population of adolescents and young adults who have diagnoses of an ASD and the need for effective intervention across the lifespan, very little research is available to guide therapy in adolescents and young adults with ASD. Overall, there is a dearth of evidence in all areas of care for adolescents and young adults with ASD, and it is urgent that more rigorous studies be developed and conducted.



## **Methods**

### **Stakeholder Engagement**

Stakeholders were identified from initial lists developed for potential Key Informants and Technical Expert Panel members for autism reviews. We sought representation from experts in treatment for adolescents and young adults, researchers focusing on this age group, advocates, and family members.

### **Identifying Evidence Gaps and Developing PICOTS**

We extracted a preliminary list of future research gaps as identified in our draft review and translated the identified research gaps into researchable questions. During our stakeholder teleconference call, we further refined the initial list of research questions and stakeholders identified additional gaps. We sent a snowball survey by email to solicit any additional comments and questions after the teleconference call. We reviewed stakeholder responses from the teleconference call and snowball survey, and developed a refined list of research questions. We then categorized research needs by PICOTS (participants, interventions, comparator(s), outcomes, timings, and setting) elements. We compiled the research needs/methodological issues that fell outside of our scope of our draft review related to therapies for adolescents and young adults with ASD into Appendix A of the full report. We did not ask stakeholders to prioritize these out of scope needs.

### **Criteria for Prioritizing Evidence Gaps**

Methods for developing future research needs are listed in Table A below. We identified stakeholders from multiple areas of expertise (clinical, psychopharmacological, behavioral, parents/advocates) to help ensure broad representation of viewpoints. Each stakeholder submitted conflict of interest documentation and curriculum vitae that was approved by the AHRQ Task Order Officer. We conducted one conference call with stakeholders and gave stakeholders the opportunity to comment on the initial list of research questions during the snowball survey after the teleconference call. We then refined the comprehensive list of research gaps related to therapies for adolescents and young adults with ASD after reviewing the teleconference responses and snowball survey.

**Table A. Methods for developing future research needs**

Approach to Evidence Gap Identification	1. Generate preliminary list of research gaps related to interventions for adolescents and young adults with ASD based on the gaps noted in the CER 2. Form stakeholder workgroup with representatives from groups including patient/family/advocacy organizations, the provider community, the research community, and funding agencies 3. Locate ongoing trials and other funded research 4. Conduct conference call with stakeholders to refine initial list of evidence gaps 5. Review teleconference responses and refine list of research gaps related to interventions for adolescents and young adults with ASD
Approach to Prioritization and Stakeholder Engagement for Prioritization	6. Request that stakeholders prioritize research gaps 7. Cull list of prioritized gaps to top tier research needs based on stakeholder voting 8. Request that stakeholders assess top priority needs using modified EHC selection criteria
Approach to Research Question Development and Considerations for Potential Research Designs	9. Determine potential study designs to address final list of research needs 10. Develop research needs report 11. Request stakeholder input on the draft research needs report 12. Finalize research needs report

**Abbreviations:** CER = comparative effectiveness review; EHC = Effective Health Care Program; ASD = autism spectrum disorders

## Development of List of Research Questions

We requested that stakeholders prioritize the expanded list of research needs via a Web-based prioritization survey that asked stakeholders to allot a number of votes to each question to indicate priority. We asked stakeholders to consider overall importance of the question for interventions for adolescents and young adults with ASD but did not proscribe specific criteria for prioritizing at this phase. We limited the number of votes available to two-thirds of the number of questions identified to ensure that stakeholders selected high priority issues. We then compiled votes across stakeholders and questions to determine the top tier research needs. We determined that the cutoff for top tier and bottom tier was five or more votes allotted to each individual question. By using these criteria, it allowed us to move forward 12 questions (roughly half) to the next prioritization round for further ranking by Effective Health Care criteria.

We sent a second Web-based survey to stakeholders and asked them to prioritize the top-tier needs using modified EHC program selection criteria (Prioritization Criteria Methods [PiCMe]).

- Potential for significant health impact
- Potential to reduce variation in clinical practices
- Potential for significant economic impact
- Potential risk from inaction
- Potential to address inequities
- Potential to allow assessment of ethical, legal, social issues pertaining to the condition
- Potential for new knowledge

Stakeholders ranked each question on each of the criteria using a 1 (low) to 5 (high) point scale. We tallied scores across each criterion to determine an overall score for each question. We tallied the scores for each question on each criterion to determine an overall score and considered questions by a range of scores into top, middle, and lower tiers.

## Results

In the draft review we identified significant gaps in the research literature addressing adolescents and young adults with ASD. We then developed the list of preliminary evidence gaps into research questions organized by KQs, based on information from the draft review input from our stakeholders. In the first prioritization survey, stakeholders were allowed to distribute a specific number of points across the potential research questions as they saw fit. The total number of points available to be allotted was 18 and they could put as many or as few as they selected on individual questions to indicate how strongly they felt about the particular questions, up to a total of 18. The highest priority questions (questions scoring at least 5 points,  $n = 12/27$  needs) identified via the first prioritization survey were organized by broad area of focus and in no particular order. Twelve research questions received five or more votes, and were considered the top-tier priorities after the first prioritization round. The remaining lower tier questions with four or fewer votes did not advance to the final prioritization round.

We then asked stakeholders to prioritize each of the 12 high-priority research questions using the EHC criteria during the second prioritization survey. Six out of seven stakeholders completed the survey. We tallied the scores for each question on each criterion to determine an overall score and considered questions by a range of scores into top, middle, and lower tiers. The research needs are not listed in order of priority and are all considered of high importance. The details of each top priority future research questions are listed below in Table B with PICOTS and potential study considerations, and Table C lists the top tier methods questions/foundational research identified in the final round.

**Table B. Top-tier treatment-related research questions with detail**

<b>Research Question</b>	<b>Tier</b>	<b>Relevant PICOTS Area(s)</b>	<b>Study Considerations</b>
What is the effectiveness of available interventions for treating behavioral issues (e.g., aggression, self-injury, and other challenging behaviors) during transition years in adolescents and young adults with ASD?	High	Population: Adolescents and young adults with ASD Intervention: Manualized ABA-based interventions Comparators: Drug + ABA Drug + Manualized psychotherapy Manualized psychotherapy Outcomes: Measures of health care utilization, hospitalization, and psychotropic drug use; Family functioning Timing: 16 weeks + followup	Appropriate control groups are essential and interventions should be manualized to allow replication.
What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?	High	Population: Children, adolescents and young adults with ASD Intervention: ABA-based interventions in early childhood Comparators: Community based services Outcomes: Improvement of functional behavior over long periods of time into adolescence and adulthood	Prospective studies are needed, despite the challenge of following children through childhood and adolescence. Randomization may be impossible so ascertainment and control for confounding variables is especially important.
What is the effectiveness of available manualized transition programs (e.g., work readiness programs, vocational programs, person-centered planning, training programs) in ASD?	High	Population: Adolescents and young adults with ASD Intervention: Manualized transition programs(e.g., work readiness programs, vocational programs, person-centered planning, training programs) Comparators: No participation in transition programs or other types of transition programs Outcomes: Hours out of the home (e.g., volunteering, working) to measure behavioral flexibility; Functional engagement; Family hours working/increase in income	Randomization is ideal, or very good characterization of participants for analysis. Investigators need ways to identify the “active ingredient” in these interventions, and should report longer term outcomes and outcomes other than simply having employment.
What is the effectiveness of community-based programs (e.g., private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills programs) to provide care for adolescents and young adults with ASD?	High	Population: Adolescents and young adults with ASD Intervention: Community based programs (e.g., private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills programs) Comparators: No participation in community-based programs or other types of community-based programs Outcomes: Measures of social engagement; participation in external activities Setting: School based, community based	Randomization is ideal, or very good characterization of participants for analysis. Investigators need ways to identify the “active ingredient” in these interventions, and should report participant-centered outcomes.

**Table C. Top-tier methods/foundational research**

Methods/Other Related Research Questions	Tier
What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as affect quality of life metrics?	Top

## Discussion

The purpose of this project was to generate a list of high-priority future research needs for interventions for adolescents and young adult with ASD, soliciting stakeholder input through a multistep process. Throughout the conference call and snowballing survey, stakeholders emphasized several needs that included: (1) strategies for transition and support including predictors for successful transition; (2) quality of life measurements for the individual and family members (life satisfaction, measures on success); (3) interventions implemented in the community; (4) assessment of comorbidities during adolescent and transition years; (5) evaluation of programs (vocational, work-readiness, community, and transitional); and (6) harms related to intervention programs for both the individual and family members. Stakeholders focused on behavioral, evaluation of transitional programs, and quality of life measures for the individual and family members. The stakeholders reiterated the critical need for fundamental studies on adolescent and young adults with ASD in all areas. While there was substantial overlap between what the team had identified as research needs in the original CER, and those identified in this process, the stakeholders were instrumental in providing additional detail and in prioritizing which questions should be of highest priority at this time.

The final list includes research questions and priorities that center on identifying methodologies and evaluating interventions during fairly critical developmental timeframes where specific emergent issues are quite common. More specifically, this list highlights the import of issues related to accurately assessing and ameliorating the impact psychiatric comorbidity for this population, developing and understanding the impact of well-defined treatments for some of the most impairing emergent acute behavioral issues and challenges during this time, and specific programs aimed at moving adolescents and adults from supportive educational environments to meaningful work settings. There was also a specific priority set for understanding the broad swath of common interventions often supplied and supported for this population that as yet do not have sufficient evidence base to understand impact of such programs on individual or population levels. Interestingly, one top-priority research question focused not specifically on interventions for this age range per se, but focused on measuring the effect of earlier interventions on the functioning of adolescents and young adults. This last point highlights the limits of studies and reviews confined to specific age-points as ASD represents a lifespan disorder and interventions and their evaluation must clearly understand individuals over years and decades rather than months to truly understand and evaluate impact.

These research priorities highlight several gaps as well as limits in foundational and methodological knowledge base likely critical for understanding the comparative efficacy of interventions for adolescents and young adults. Primarily, these priorities highlight the fundamental lack of sufficiently rigorous evaluations of the development and course of ASD across the lifespan that would help identify specific lifespan oriented trajectories and elucidate appropriate treatment targets and context. More simply, an enhanced understanding of the course of the disorder is necessary to help guide decisions about what some of the important targets should be and in turn what the most promising interventions might be.

The current identified priorities stress that we do not yet understand the best modalities for treating emergent acute focal impairments much less the complex and dynamic neuropsychiatric and developmental vulnerabilities that emerge over this timeframe. Given the tremendous heterogeneity of the disorder and complex interactions of this heterogeneity with developmental, educational, intervention, familial, and system factors, it is clear that hoping to identify simple, single treatments for the multitude of impairments across and within individuals and environments over time is unlikely. What is more likely is that specific focal issues, relative to individual levels of impairment and developmental status and potentially responsive to interventions, could be identified and evaluated in more rigorous form. Identification of critical interventions at critical points of vulnerability that improve functioning relative to level of impairment would help promote movement toward realistic individualized intervention decisions.

The identified priorities relating to understanding transitional vocational intervention paradigms highlights this fact. At present, there is not yet a sufficient evidence base to guide what programs could be implemented for whom and toward what level of effect. In simpler terms, expanded scope of study in terms of time frame (e.g., from childhood to adolescence to adulthood) across the range of individual abilities associated with ASD is clearly necessary. In this regard, as suggested by our respondents, identifying specific methodologies for appropriately indexing change across these outcomes is also a necessity to help achieve progress toward these priorities.

Challenges presented by this process included scheduling conflicts with stakeholders and incomplete participation from one member. Two of our stakeholders with pharmacological backgrounds were unable to participate in the teleconference call due to scheduling conflicts, which may have contributed to the lack of potential research gaps in harms, or psychopharmacological research. We did, however, allow everyone time to add any additional comments/questions during the snowballing survey. Second, the small sample size of our stakeholder panel limited the generalizability of our findings. Finally, although every attempt was made to engage a balanced group of stakeholders, the group consisted mainly of clinicians with one family member and advocate. One other challenge was identifying an appropriate cutoff point for top tier ranking. We decided on a cutoff of five or more votes to move into the final prioritization round, roughly half of our initial list of research questions. The final results should all be viewed as highest priority needs, and are not ranked in any particular order.

## **Conclusion**

Four intervention studies were identified as highest priority. Interventions that warrant rigorous evaluation include: those intended to treat behavioral issues, including aggression and self-injury; long-term impact of early intervention provided in childhood; manualized transition programs; and community-based programs targeting adolescents. In all cases, prospective studies should be conducted, either in the form of RCTs or cohort studies that include appropriate comparison groups and rigorous assessment and analytic management of confounding variables. In order to best conduct these studies, foundational research should also be conducted to better understand the degree to which psychiatric and medical comorbidities may affect successful transition to adulthood, and to better describe the trajectory faced by maturing adolescents and young adults with autism.

# Background

## Context

This Future Research Needs (FRN) report is based on a draft Agency for Healthcare Research and Quality comparative effectiveness review titled Interventions for Adolescents and Young Adults with autism spectrum disorder. The purpose of the review was to synthesize recent research focused on interventions for adolescents and young adults between the ages of 13 and 30 with autism spectrum disorder (ASD; autistic disorder, Asperger's syndrome, pervasive developmental disorder—not otherwise specified). We addressed questions related to: the effectiveness of therapies targeting core symptoms of ASD (impairments in communication, social interaction, and behavior); common medical or mental health comorbidities, including associated symptoms such as irritability; the process of transitioning to adulthood; and family outcomes. The draft review is based on literature searches that were executed between September 2010 and December 2011. The publication of the final review is expected for August 2012.

The Key Questions (KQs) for the review were:

- KQ1: Among adolescents and young adults with ASD, what are the effects of available interventions on the core symptoms of ASD?
- KQ2: Among adolescents and young adults with ASD, what are the effects of available interventions on common medical and mental health comorbidities (e.g., epilepsy, sleep disorders, motor impairments, obesity, depression, anxiety, acute and episodic aggression, attention deficit hyperactivity disorder, etc.)?
- KQ3: Among adolescents and young adults with ASD, what are the effects of available interventions on functional behavior, attainment of goals toward independence, educational attainment, occupational/vocational attainment, life satisfaction, access to health and other services, legal outcomes, and social outcomes?
- KQ4: Among adolescents and young adults with ASD, what is the effectiveness of interventions *designed to support the transitioning process*, specifically to affect attainment of goals toward independence, educational attainment, occupational/vocational attainment, life satisfaction, access to health and other services, legal outcomes, and social outcomes?
- KQ5: Among adolescents and young adults with ASD, what harms are associated with available interventions? (Harms are defined by the Effective Health Care Program as all possible adverse consequences of an intervention, including adverse events.)
- KQ6: What are the effects of interventions on family outcomes?

## Importance of the Subject

ASD (autistic disorder, Asperger syndrome, or pervasive developmental disorder—not otherwise specified) has an estimated prevalence of one in 88 children.<sup>1</sup> More than 55,000 individuals between the ages of 15 and 17 in the United States likely have ASD.<sup>2</sup> The diagnosis for ASD is behaviorally based, relying on documented core impairments in social interaction and communication, as well as restricted and repetitive behavior. For some individuals, core symptoms of ASD (impairments in communication, social interaction, and behavior) may improve to some degree with intervention and over time.<sup>3-6</sup>

As children transition to adolescence and young adulthood, developmentally appropriate interventions targeting core deficits may continue, but the focus of treatment often shifts toward promoting adaptive behaviors that can facilitate and enhance independent functioning.<sup>7</sup> Investigators have noted that less research on therapies for adolescents and young adults exists than for younger children<sup>8</sup> and that such research is increasingly critical as the prevalence of ASD continues to grow and as children with ASD diagnoses reach adolescence.

The AHRQ review grew out of a recognition that care for adolescents and young adults with ASD varies greatly across care providers and that clinicians and families must make important health care decisions with little guidance or knowledge. Similarly, lawmakers struggle with making the best decisions about policy and funding due to lack of an adequate knowledge base regarding the most effective treatments. The lack of services available to help young adults with ASD transition to greater independence has been noted by researchers for a number of years and is increasingly a topic in the lay media.<sup>9</sup>

There is also evidence to suggest that improvements in symptoms and in problem behaviors may diminish after youth with ASD leave high school.<sup>10</sup> This change in improvement is likely due, at least in part, to the termination of services received through the secondary school system upon high school exit, as well as the lack of adult services and long waiting lists for many services.<sup>10,11</sup> Despite a growing population of adolescents and young adults who have diagnoses of an ASD and the need for effective intervention across the lifespan, very little research is available to guide treatment of adolescents and young adults with ASD.

## **Findings of the Comparative Effectiveness Review**

The authors of the draft review examined the effectiveness of therapies intended to improve the core symptoms of ASD, promote independent functioning, facilitate transitions, and assist families of individuals with ASD. The draft review identified 32 studies meeting prespecified inclusion/exclusion criteria. Most were poor quality, five were fair quality, and none was good quality.

For KQ1, 14 studies targeted core symptoms (impairments in communication, social interaction, or behavior) of ASD. Ten studies addressed functional behavior/independent living skills (KQ3). Nine studies addressed medical interventions (KQ2), and only medical studies addressed harms (KQ5). One study addressed the transition process (KQ4) and two studies addressed family outcomes (KQ6).

The studies in KQ2 examined the effects of interventions on comorbid medical or mental health conditions (e.g., epilepsy, sleep disorders, motor impairments, obesity, depression, anxiety, acute and episodic aggression, attention deficit hyperactivity disorder, etc.). Most studies assessed the use of medications to address challenging behaviors (i.e., defiance, aggression, or self-injury) in adolescents and young adults. Evidence remains insufficient regarding what works for managing challenging behaviors in adolescents and young adults.

One study addressed interventions targeting the transition process (KQ4). In vocational research, studies are needed that illuminate which aspects of multifaceted supported employment programs have the greatest impact. Individual studies also suggested that vocational programs may increase employment success, but the studies were small. Given the number of individuals affected by ASD, there is a dramatic lack of evidence on best approaches to therapies for adolescents and young adults with these conditions.

Harms of interventions (KQ5) were only discussed in studies of medical approaches. Two studies addressing KQ6 assessed effects of an intervention on family outcomes. More research



over a broader time frame with more clearly defined populations is critical for helping individuals with ASD transition to greater independence. Foundational research is necessary to understand the goals of individuals with autism and their families as future research studies are planned. Similarly, little research addresses the effects of family and caregiver interactions and characteristics on the responses of individuals' with ASD to interventions.

Better outcome measures are needed to allow assessment of a broader range of symptoms, particularly in individuals who may be higher functioning. Despite increasing numbers of adolescents transitioning into adulthood, no area of research provides sufficient strength of evidence for the impact of specific intervention strategies in terms of improving important outcomes for specific groups of individuals with ASD. Overall, there is a dearth of evidence in all areas of care for adolescents and young adults with ASD, and it is urgent that more rigorous studies be developed and conducted.

## **Objectives**

The purpose of this FRN project was to identify research gaps and prioritize the identified research needs related to interventions for adolescents and young adult with ASD to help inform ongoing research and assist individuals, families, and clinicians in making health care decisions.

## **Evidence Gaps**

The Vanderbilt Evidence-based Practice Center (EPC) identified significant gaps in the research literature addressing adolescents and young adults with ASD including:

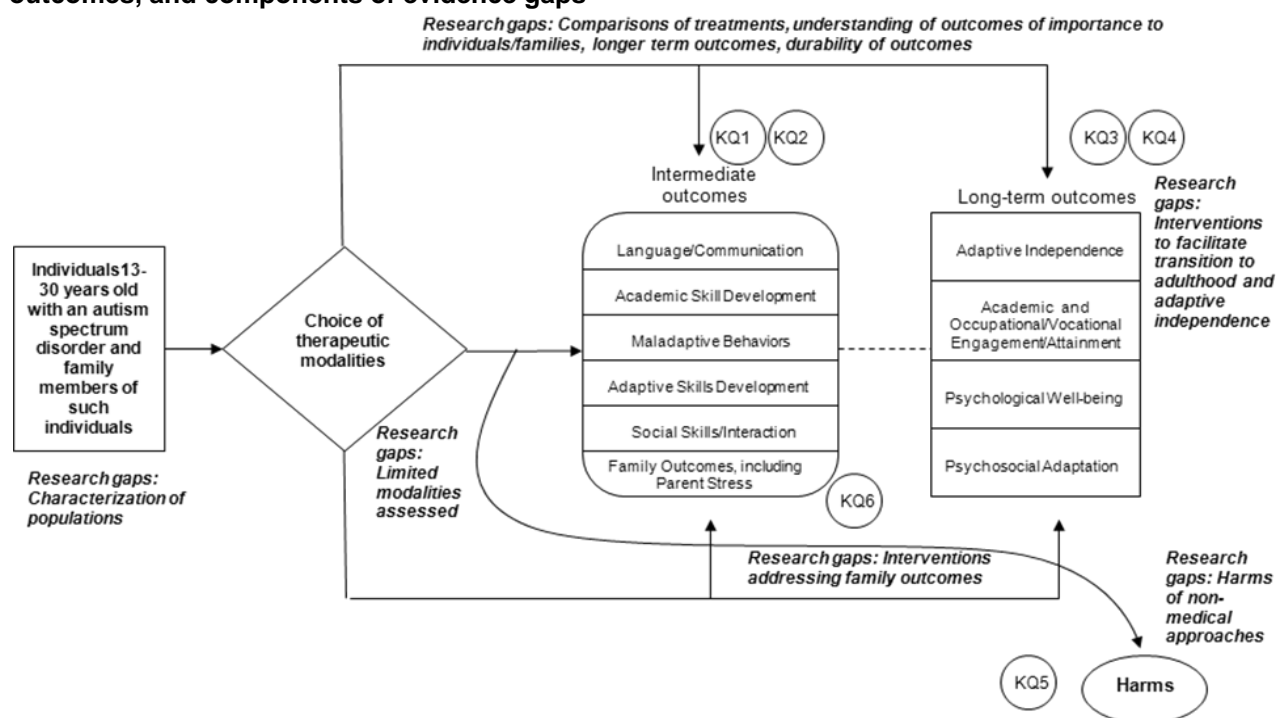
- An overall paucity of research, especially addressing questions related to transitioning to independence (total studies included in the review = 32, with none of good quality)
- Small sample sizes, with studies typically including fewer than 50 individuals, many with co-occurring intellectual disability
- Very little long-term followup with only three studies reporting outcomes past 12 months
- Lack of randomized controlled trials in all categories of intervention, but especially so in medical interventions, where substantial adverse events may be associated with medication use in adolescence.
- Multiple interventions and outcomes studies, with little replication of studies using the same interventions or outcomes
- Gaps in reporting characteristics of the study populations
- Inconsistent reporting of methodology
- Inconsistent or absent reporting of harms

Specifically, in KQ1, further research is needed to understand the impact of behavioral interventions and how these interventions generalize to real-world impact and outcome for individuals with ASD. Allied health studies are also needed to understand best approaches to fostering independent living skills, as well as evaluate how improvements in motor skills may affect communication and other domains. In KQ2, additional data are needed on medical comorbidities in adolescents with ASD. Population studies and increased use of standardized age groupings would facilitate comparisons of effectiveness within medical intervention categories as well as with nonmedical therapies. We found in KQ4 that no studies provided adequate information on longer term outcomes, and particularly on outcomes related to achieving goals for independence and quality of life. Foundational research is needed to identify and validate outcome measures in the adolescent and young adult population with ASD. Future research is

also necessary to understand how individuals' expression of ASD symptoms and the severity of symptoms may affect treatment over the lifespan. For KQ5, data about harms were only available from medical studies.

We added indications for these preliminary gaps to the analytic framework from the full report. The analytic framework illustrates the KQs, population, interventions, comparators, outcomes, timeframes, and settings (PICOTS), and identified research gaps below in Figure 1.

**Figure 1. Analytic framework depicting relationships between KQs, populations, interventions, outcomes, and components of evidence gaps**



# Methods

## Identification of Evidence Gaps

We developed the preliminary evidence gaps identified in the report into research questions, with input from our EPC team content experts, and stakeholder contribution during a teleconference call and online snowballing survey. The snowball survey allowed us to solicit additional comments and questions after the teleconference call. We reviewed stakeholder responses from the teleconference call and snowball survey, and developed a refined list of research questions. We compiled the gaps that fell outside of our scope of research gaps/methods related to therapies for adolescents and young adults with ASD into Appendix A. We did not ask stakeholders to prioritize these out-of-scope needs. Methods for developing future research needs are listed in Table 1 and expand on the table's brief description in each of the following sections.

**Table 1. Methods for developing future research needs**

Approach to Evidence Gap Identification	<ol style="list-style-type: none"> <li>1. Generate preliminary list of research gaps related to interventions for adolescents and young adults with ASD based on the gaps noted in the CER</li> <li>2. Form stakeholder workgroup with representatives from groups including patient/family/advocacy organizations, the provider community, the research community, and funding agencies</li> <li>3. Locate ongoing trials and other funded research</li> <li>4. Conduct conference call with stakeholders to refine initial list of evidence gaps</li> <li>5. Review teleconference responses and refine list of research gaps related to interventions for adolescents and young adults with ASD</li> </ol>
Approach to Prioritization and Stakeholder Engagement for Prioritization	<ol style="list-style-type: none"> <li>6. Request that stakeholders prioritize research gaps</li> <li>7. Cull list of prioritized gaps to top tier research needs based on stakeholder voting</li> <li>8. Request that stakeholders assess top priority needs using modified EHC selection criteria</li> </ol>
Approach to Research Question Development and Considerations for Potential Research Designs	<ol style="list-style-type: none"> <li>9. Determine potential study designs to address final list of research needs</li> <li>10. Develop research needs report</li> <li>11. Request stakeholder input on the draft research needs report</li> <li>12. Finalize research needs report</li> </ol>

**Abbreviations:** CER = comparative effectiveness review; EHC = Effective Health Care Program; ASD = autism spectrum disorders

## Criteria for Prioritization

We identified stakeholders from multiple areas of expertise (clinical, behavioral, psychopharmacological, parents/advocates) to help ensure broad representation of viewpoints. Each stakeholder submitted conflict of interest documentation and curriculum vitae that were approved by the Agency for Healthcare Research and Quality (AHRQ) Task Order Officer (TOO). We conducted one conference call with stakeholders to refine the preliminary list of research questions by KQ. We sent out a snowball survey by email to solicit additional comments after the teleconference call. We reviewed the stakeholder responses and developed a comprehensive list of research questions related to therapies for adolescents and young adults with ASD after reviewing the teleconference responses and snowball survey.

We then developed two self-administered, Web-based research prioritization questionnaires. The first round prioritization allowed the stakeholders to identify an initial set of priority questions by allotting 18 votes across the 27 questions.

We asked stakeholders to consider overall importance of the question for interventions for adolescents and young adults with ASD but did not proscribe specific criteria for prioritizing at

this phase. We limited the number of votes available to roughly two-thirds of the number of questions identified to ensure that stakeholders selected high priority issues. We then compiled votes across stakeholders and questions to determine the top tier research needs. We determined that the cutoff for top tier and bottom tier was five or more votes allotted to each individual question. By using this criterion, we were able to move forward 12 questions to the next prioritization round for further ranking by Effective Health Care criteria. The second and final prioritization survey allowed the stakeholders to further prioritize the questions using the criteria developed in the Prioritization Criteria Methods (PiCMe; Appendix B) approach to prioritization:

- Potential for significant health impact
- Potential to reduce variation in clinical practices
- Potential for significant economic impact
- Potential risk from inaction
- Potential to address inequities
- Potential to allow assessment of ethical, legal, social issues pertaining to the condition
- Potential for new knowledge

Stakeholders ranked each question on each of the criteria using a 1 (low) to 5 (high) point scale.

## **Identification of Ongoing Research**

We reviewed ongoing or recently completed studies related to adolescents and young adults with ASD since the draft of the evidence review in 2012, through a search of clinical trial registries, grant databases, and individual funders' Web sites (Appendix C). All current and ongoing research was searched between March 13 and March 21, 2012. We found 111 current or recent studies on ClinicalTrials.gov, of which 72 were drug therapy studies, 14 were behavioral studies, 9 were on dietary or supplement-based studies, and 3 were studies in complementary and alternative medicine. Most of the ongoing studies included children and/or adults and were not specific to adolescents and young adults (ages 13 to 30).

We found six unique trials through Center Watch, a Web-based resource that catalogues clinical trials. Three were drug therapy studies, two were assessment related, and one did not list any intervention specifics. We search the National Institute of Health Reporter and located four therapy trials addressing language learning skills, cognitive enhancement therapy, school/community-based intervention for social skills, and an employment skills program. We also searched Autism Speaks Clinical Trials Network and found trials on memantine and fluoxetine drug therapies. We searched Autism Speaks Grant Database and retrieved 156 grants from 2006 to present. We were not able to parse out age groups for this database.

## **Engagement of Stakeholders, Researchers, and Funders**

Stakeholders were emailed an invitation with followup reminder emails as needed. The email invitation included an overview of our project, what their participation would entail, and contact information should they have any questions. Once they indicated willingness to participate, a member of our research team responded with potential times for the teleconference call. Stakeholders were informed that the project would involve participation in an initial 60-minute

teleconference call, followed by a snowball survey to gather additional research questions, and two rounds of prioritization to vote on the selected future research questions.

We initially invited 19 potential stakeholders to participate in our multistep process for identifying and prioritizing future research needs for interventions for adolescents and young adults with ASD. Of the 19 invited, 7 stakeholders agreed to participate, and none declared significant conflicts of financial or professional/business interests. Stakeholders unable to participate did not provide reasons for not participating. We identified stakeholders from multiple areas of expertise (clinical, psychopharmacological, behavioral, parents/advocates) to help ensure broad representation of viewpoints. The AHRQ TOO reviewed all disclosures and identified no conflicts of interest that precluded participation in the project. Stakeholders were informed that they were not required to participate in all components of the multistep process.

To increase our understanding of the most critical research gaps, we conducted a teleconference call with five out of the seven stakeholders (two had time conflicts). The teleconference call was open-ended and elicited stakeholder perspectives on priority areas related to future research on interventions for adolescents and young adults with ASD. We emailed each stakeholder an electronic copy of the executive summary of the draft review and a list of identified potential research questions prior to the teleconference call. At the beginning of the call, the lead investigator reiterated the overall findings of the draft evidence review and the scope of the future research needs project. The teleconference format was intentionally open ended to allow stakeholders time to ask clarifying questions and to influence the direction of the conversations. We were mindful throughout to emphasize our goal of identifying areas of research that were relevant within the scope of the KQs from the evidence review. At the end of the teleconference call, we described the next steps that included snowballing and two prioritization surveys.

During the teleconference call, we elicited stakeholder opinions on where uncertainties in care decisions existed as well as what fundamental questions remained unanswered regarding transition of adolescents with ASD to adulthood. The research questions identified focused on topics such as strategies for transition and support programs for adolescents; predictors of successful transition; quality of life measurements for the individual and family members; interventions implemented in the community; assessment of comorbidities during adolescent and transition years; evaluation of programs (e.g., vocational, work readiness, community, transitional); and harms related to intervention programs (nonmedical).

Prior to the prioritization rounds, we sent out a snowball survey through email to elicit any additional feedback/comments and additional questions to add to the initial list of research gaps. The snowball survey was sent in the form of an email and attachment (Appendix D) and was available for comment from May 17 to May 23, 2011. The purpose of the snowball survey was to allow stakeholders an additional chance to comment and make contributions to the existing list of research gaps.

We developed two Web-based research prioritization surveys: one to identify an initial set of top priorities (Appendix E), and a final prioritization survey to rank the top-tier highest priority research areas. The first prioritization survey included the 27 identified research needs from the draft review, stakeholder teleconference call and snowball round. We tested the initial questionnaire to assess comprehensiveness and usability of the instrument.

The first round of prioritization was conducted using self-administered Web-based prioritization software developed by the University of North Carolina Sheps Center. Up to two reminders were sent by email to remind participants to complete the survey. The first

prioritization round survey consisted of 27 research gaps in the form of a research question related to the KQs from the draft evidence review, to identify priority research topics. The first prioritization survey was open from May 25 to June 5, 2012. For each of the identified research questions, stakeholders were asked to rank the question from 1 to 5; low to high priority for future research, and to provide any additional comments on the existing list of questions. Stakeholders were not asked to rank the research questions by EHC criteria during the first prioritization round. The votes for each research question were totaled and are listed in Appendix F. The items with four or fewer votes were removed from the second round as lower priority needs.

The final prioritization round was conducted using a self-administered Web-based prioritization software REDCap™, developed by Vanderbilt Institute for Clinical and Translational Research. Up to two reminders were sent by email. We asked the stakeholders to rank each of the top-tier research questions using a modified version of the Effective Health Care (EHC) selection criteria called PiCMe. We asked stakeholders to rank each of the seven modified EHC selection criteria from 1 to 5 for each of the research questions, with 1 being the lowest priority and 5 being the highest priority for each of the criteria. The survey was sent electronically to participants on June 7 to June 15, 2012 (Appendix G).

# Results

## Research Needs

In the draft review we identified significant gaps in the research literature addressing adolescents and young adults with ASD. We then developed the list of preliminary evidence gaps into research questions (Table 2) and methodologic recommendations (Table 3), based on information from the draft review and input from our stakeholders.

**Table 2. Snowballed list of research questions**

Number	Research Questions
1	What is the validity of best available quality of life measurements across adolescents and young adults with ASD? Examination of measures in comparison to objective metrics (educational, occupational, developmental milestone), self-determined outcomes, and family based outcomes.
2	What is the impact of common social and behavioral interventions in combination/comparison with pharmacological paradigms aimed at enhanced social learning on core symptoms?
3	What is the impact of augmentative communication and novel technological paradigms for individuals with severe communication impairments at specific developmental target ranges (e.g., nonverbal, comorbid intellectual disability, adolescents)?
4	What is the effectiveness of comprehensive and intensive treatment approaches (specific educational, residential, intensive work programs) in adolescents with ASD for ameliorating core symptoms?
5	What is the effectiveness of interventions implemented in the community compared to the research setting among adolescents and young adults with ASD?
6	What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?
7	What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities.
8	What is the effectiveness of available interventions for treating behavioral issues including sudden aggression and catatonia during transition years in adolescents and young adults with ASD?
9	What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, CBT programs, social skills training and programs, person-centered planning) in ASD?
10	What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?
11	What is the impact on the most common transition programs across individual, familial, and more broadly defined outcomes?
12	What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?
13	What is the impact of interventions on stress levels for family members and adolescents and young adults with ASD?
14	What is the effectiveness of systems level interventions specific to the legal system in managing adolescents and young adults with ASD?
15	To what extent does participation in services and potential dependency on services lead to declining ability to function independently in adolescents and young adults with ASD?
16	What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?

**Abbreviations:** ASD = autism spectrum disorders; CBT = cognitive behavior therapy; ABA = applied behavioral analysis

**Table 3. Snowballed list of methodologic recommendations**

Number	Methodologic Recommendations
1	What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?
2	What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?
3	What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics?
4	What is the validity of standard measurements for assessing mental health in adolescents and young adults with ASD?
5	What is the utility of measures developed for nonautistic individuals with mental health disorders in adolescents and young adults with ASD with mental health comorbidities?
6	How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?
7	What is the impact of comorbidities on family life over the lifespan?
8	What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?
9	What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?
10	Explicit inclusion markers of broadly defined harm, adverse event, distress/impact across defined intervention studies above.
11	Explicit inclusion markers of broadly defined measures of family impact in studies above.

**Abbreviation:** ASD = autism spectrum disorders

We also identified a number of nonresearch issues/recommendations from the full report and stakeholder feedback (Table 4) that are fundamental study designs and outcome measurement issues, which fell outside the scope of the future research needs project's focus. These questions were not included in the prioritization surveys but are important to address in additional research.

**Table 4. Nonresearch recommendations/needs identified in CER and by stakeholders**

1	Need for pragmatic trials that look at interventions as they actually occur.
2	Need to develop studies that are adequately powered and designed to capture the moderator information.
3	Need measures to define quality of life beyond good or poor outcomes, work status, relationship status, and how to measure quality of life across the research base.
4	Need tools/measurements to assess harms throughout the intervention regarding patient satisfaction (e.g. happiness, quality of life measures) and stress.
5	Need to develop studies that look at prevention of wandering and elopement during transitional years in adolescent and young adults with ASD
6	Systems-level measures need to be developed to measure outcomes of adolescents and young adults with ASD, including family outcomes. Outcomes need to include the family as a usual element of studies of adolescents and young adults with ASD.
7	Need to compare caretaker burden in other disease conditions (i.e., Alzheimer's) and the effect it has on family members, spouse and children, and other relatives.

**Abbreviation:** ASD = autism spectrum disorders

## Round One Prioritization

In the first prioritization (round one) survey, stakeholders prioritized needs by allotting a limited number of points (18 points for 27 questions/needs) to the questions. Six out of seven stakeholders completed the survey. The highest priority questions (questions scoring at least 5 points,  $n = 12/27$ ) identified via the round one survey are organized below by broad area of focus. Twelve research questions received five or more votes, and were considered the top tier after the first prioritization round. Of these, seven were treatment questions and five were methodologic questions. The remaining lower tier questions with four or fewer votes did not



advance to the final prioritization round, listed in Appendix F. The top seven treatment questions were the following:

1. What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills training and programs, person-centered planning) in ASD?
2. What is the impact on the most common transition programs across individual, familial, and more broadly defined outcomes?
3. What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?
4. What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?
5. What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities?
6. What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?
7. What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?

The top five methodologic questions were:

8. What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?
9. What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?
10. What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics?
11. What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?
12. How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?

## Round Two Prioritization

We asked stakeholders to prioritize each of the 12 high priority research questions using the modified Effective Health Care Program selection criteria (PiCMe) using a 1(low) to 5 (high) point scale:

- Potential for significant health impact
- Potential to reduce variation in clinical practices
- Potential for significant economic impact
- Potential risk from inaction
- Potential to address inequities
- Potential to allow assessment of ethical, legal, social issues pertaining to the condition
- Potential for new knowledge

Six out of seven stakeholders completed the survey. We tallied the scores for each question on each criterion to determine an overall score (Appendix H) and considered questions by a range of scores into top, middle, and lower tiers (Table 5). The top priority future research needs are listed below with PICOTS elements and study design considerations that were identified by the EPC team. Each question in the top tier is considered to be of equal importance; the order is not an indication of ranking.

**Table 5. Top-tier treatment-related research questions with detail**

Research Question	Tier	Relevant PICOTS Area(s)	Study Design Comments/Suggestions
What is the effectiveness of available interventions for treating behavioral issues (e.g., aggression, self-injury, and other challenging behaviors) during transition years in adolescents and young adults with ASD?	Top	<b>Population:</b> Adolescents and young adults with ASD <b>Intervention:</b> Manualized ABA-based interventions <b>Comparators:</b> Drug + ABA Drug + Manualized psychotherapy Manualized psychotherapy <b>Outcomes:</b> Measures of health care utilization, hospitalization, and psychotropic drug use; Family functioning <b>Timing:</b> 16 weeks + followup	Appropriate control groups are essential and interventions should be manualized to allow replication.
What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?	Top	<b>Population:</b> Children, adolescents and young adults with ASD <b>Intervention:</b> ABA-based interventions in early childhood <b>Comparators:</b> Community based services <b>Outcomes:</b> Improvement of functional behavior over long periods of time into adolescence and adulthood	Prospective studies are needed, despite the challenge of following children through childhood and adolescence. Randomization may be impossible so ascertainment and control for confounding variables is especially important.
What is the effectiveness of available manualized transition programs (e.g., work readiness programs, vocational programs, person-centered planning, training programs) in ASD?	Top	<b>Population:</b> Adolescents and young adults with ASD <b>Intervention:</b> Manualized transition programs(e.g., work readiness programs, vocational programs, person-centered planning, training programs) <b>Comparators:</b> No participation in transition programs or other types of transition programs <b>Outcomes:</b> Hours out of the home (e.g., volunteering, working) to measure behavioral flexibility; Functional engagement; Family hours working/increase in income	Randomization is ideal, or very good characterization of participants for analysis. Investigators need ways to identify the “active ingredient” in these interventions, and should report longer term outcomes and outcomes other than simply having employment.
What is the effectiveness of community based programs (e.g., private ABA schools, CBT programs, social skills programs) to provide care for adolescents and young adults with ASD?	Top	<b>Population:</b> Adolescents and young adults with ASD <b>Intervention:</b> Community based programs (e.g., private ABA schools, CBT programs, social skills programs) <b>Comparators:</b> No participation in community-based programs or other types of community-based programs <b>Outcomes:</b> Measures of social engagement; participation in external activities <b>Setting:</b> School based, community based	Randomization is ideal, or very good characterization of participants for analysis. Investigators need ways to identify the “active ingredient” in these interventions, and should report participant-centered outcomes.

**Abbreviations:** ASD = autism spectrum disorders; ABA = applied behavioral analysis; CBT = cognitive behavior therapy

## **Study Design Considerations for Top-Tier Research Needs**

**What is the effectiveness of available interventions for treating behavioral issues (e.g., aggression, self-injury, and other challenging behaviors) during transition years in adolescents and young adults with ASD?**

Challenging behaviors are relatively common among adolescents and young adults with ASD, and the presence of severe behavior problems limits the ability of these individuals to find employment (supported or otherwise) in the community.<sup>12</sup> Thus, interventions aimed at reducing behavioral issues might increase transition success for young adults with ASD.

Research is needed to examine the effectiveness of interventions for treating behavioral issues in adolescents and young adults with ASD. Some of these interventions have been tested with school-age children, and their effects may or may not generalize to this older age range. Researchers interested in addressing this question will want to pay attention to the feasibility of the behavioral interventions for young adults, in particular. If the intervention is delivered to younger children in a school setting, finding an appropriate out-of-home setting to deliver the intervention to young adults might prove to be a challenge. This is because young adults with ASD participate in a vast array of educational and vocational activities, from segregated vocational placements to independent jobs in the community. Further, many young adults with ASD have no educational or vocational activities after leaving high school.<sup>12,13</sup> Similarly, interventions that are delivered in home to children with ASD might need to be adapted for young adults with ASD who no longer live in the parental home.

Investigators will also want to be sure to include an appropriate comparison group to test this question, ideally with random assignment to treatment and control. This is particularly important because autism symptoms and problem behaviors improve over adolescence and adulthood for many individuals with ASD.<sup>3,10</sup> Without a control group, it will be impossible to determine whether improvements in problem behaviors are a result of intervention or maturation. Finally, it is important that studied interventions are manualized, which will allow for replication and implementation in other samples.

**What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?**

With intensive early intervention becoming a relatively common treatment approach for children with ASD and their families, research should address whether these programs have long-lasting effects. That is, do early intervention programs improve functional behavior and transition outcomes for adolescents and young adults with ASD?

Although this is an important research question, there are three major challenges that would be faced by researchers. First, it would be best to follow children from the time of diagnosis and early intervention through adolescence and young adulthood. Asking parents of young adults to retrospectively recall detailed information about early intervention programs would likely lead to inaccuracies. Second, random assignment to different types of early intervention programs will be difficult, as the types of programs available differ by region and withholding potentially beneficial intervention might be seen as unethical. Thus, researchers will likely have to contend with demographic or other differences between families who do and do not have access to early intervention, making it difficult to determine whether the intervention itself is the “active ingredient” in differences observed in young adult outcomes. For example, families with more economic resources may be more likely to get more intensive early intervention, but these same

economic resources may provide additional opportunities for a young adult with ASD.<sup>14, 15</sup> Thus, economic resources would be the “active ingredient” and not the intervention per se. Even with random assignment, given the heterogeneity in early intervention programs (type of program, number of hours administered, etc.), as well as the many other possible services and therapies accessed by families of children with ASD (e.g., speech therapy; special diets, varying amounts of additional supports in schools, etc.), it may be difficult to isolate the long-term impact of the early intervention itself.

**What is the effectiveness of available manualized transition programs (e.g., work readiness programs, vocational programs, person-centered planning, and training programs) in ASD?**

Perhaps the key consideration for researchers who are interested in testing the effectiveness of manualized transition programs is the inclusion of an appropriate control or comparison group, ideally with random assignment. As revealed in our draft report, no studies of vocational programs utilized random assignment. In many cases, there were characteristics of adults with ASD that were conducive to employment, which were used to assign them to the intervention (vs. comparison) group. Thus, there were differences between the intervention and comparison groups to start out with, making it difficult to determine whether observed effects of the program were a result of the program itself.

Researchers should also consider the long-term effects of the transition programs. Do any observed gains continue after the program is terminated? The most effective interventions will result in gains that are maintained even after the intervention is completed. Perhaps the most significant challenge facing researchers interested in this question is discovering which aspect of the transition program is the “active ingredient.” Manualized transition programs are often multifaceted, recognizing the many different skills that need to be taught or the many different pieces that need to come together for youth with ASD to successfully transition.<sup>11</sup> Determining the most effective aspect of the program will be difficult, but is necessary to design maximally effective programs with little waste.

**What is the effectiveness of paradigms and combinations of paradigms currently used in community-based programs (e.g., private ABA schools, CBT programs, social skills programs) to provide care for adolescents and young adults with ASD?**

As described above, a key consideration for this research question will be the identification of an appropriate comparison group. Equivalence in terms of presentation of ASD, as well as clinical and psychiatric comorbidities will either need to be achieved in the design or managed in the analysis of these types of interventions. It will also be challenging to isolate the effects of the interventions themselves beyond other care and supports that are being provided to the adolescent. It would be further helpful to characterize the families and communities in which the adolescents reside to identify potential modifiers of effectiveness in terms of family dynamics or community characteristics. The intervention programs themselves will need to be fully described, and ideally, manualized. As we have noted in previous work, detail is often lacking on treatment programs to allow investigators to understand the outcomes they are observing. A range of outcomes will be important, including measures of individual and community engagement, and it would be helpful to understand the impact of these interventions on educational and vocational attainment.

## Remaining Study Design Questions

The remaining study design considerations identified by the stakeholders listed in Table 6 were not considered highest priority. The low priority intervention studies center around the issues of common behavioral interventions treating psychiatric comorbidities and interventions to support goals toward life satisfaction for individuals with ASD and family members.

**Table 6. Lower priority intervention studies**

Question/Need	Tier
What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities?	Low
What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?	Low

**Abbreviations:** CBT = cognitive behavior therapy; ASD = autism spectrum disorders

## Study Design Considerations for Methods Questions and Foundational Research

The lack of evidence for the effectiveness of treatments for adolescents and young adults with ASD identified in our draft report is indicative of a more general paucity of research focused on individuals with ASD in this age range. That is, there are also very few studies of the natural history of individuals with ASD as they transition to adulthood. This foundational research is necessary as it would provide an understanding of the range of transition outcomes experienced by youth with ASD, as well as the factors that might promote successful outcomes. Without this work, it becomes nearly impossible to conceptualize and design maximally effect treatments and interventions. Below, we summarize some of the key methodological and foundational research needs identified by our stakeholders and necessary to inform treatments for adolescents and young adults with ASD. One foundational question was ranked in the highest priority tier (Table 7).

**Table 7. Top-tier methods questions/foundational research**

Methods/Other Related Research Questions	Tier
What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as affect quality of life metrics?	Top

### What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as affect quality of life metrics?

Psychiatric and medical comorbidities are extremely common in adolescents and young adults with ASD, and likely affect their ability to successfully transition out of high school and into the adult world. In order to understand which comorbidities should be the target of intervention (e.g., anxiety; seizures; gastrointestinal issues), descriptive foundational research is necessary to determine which comorbidities seem to be most associated with transition problems.

In order to best answer this question, youth with ASD will need to be followed prospectively, starting during adolescence and continuing through the transition years and beyond. Retrospective research should be avoided, as it would be difficult to determine whether medical and psychiatric comorbidities predicted transition difficulties or whether they emerged concomitantly with or after the youth with ASD had transitioned. This is especially important because some mental health comorbidities often do not emerge until early adulthood. Finally,

because any given comorbidity is relatively rare (although comorbidities as a group are common among youth with ASD), examining the differential effects of individual comorbidities will necessitate a relatively large sample size.

## Remaining Methods/Foundational Questions

The remaining methods questions and foundational research needs (Table 8) identified by the stakeholders, but not considered the highest priority, center around the issue of measurement.

**Table 8. Middle- and low-tier methods/foundational research**

Question/Need	Tier
What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?	Middle
What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?	Middle
How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?	Middle
What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?	Low
What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?	Low

**Abbreviation:** ASD = autism spectrum disorders

First, research is needed to understand how best to conceptualize and measure psychiatric comorbidities among adolescents and young adults with ASD. Although there are many different, well-validated ways to measure psychiatric disorders in adolescents and adults who do *not* have ASD—including both questionnaires and clinical interviews it is unclear how well these existing measures capture psychiatric comorbidities among individuals with ASD. Thus, our ability to measure the emergence of comorbidities in these adolescents and young adults, as well as whether treatments can impact comorbidities, are constrained by the lack of well-validated outcome measures.

Second, research on treatments for adolescents and adults with ASD are constrained by the lack of agreement on what should be considered a “good” outcome and thus the target of intervention. Although many natural history studies focus on competitive employment and independent living as key indicators of good transition outcomes, these measures clearly disadvantage those individuals with greater impairments and greater support needs. Given the vast heterogeneity in characteristics of young adults with ASD, sensitive metrics should be developed and tested that can capture aspects of a positive transition other than just objective living and working arrangements. Examples might be the development of quality of life measures or measurement of the goodness of fit between the environment of the young adult with ASD and his/her needs and interests.<sup>16</sup> Another possible metric might be reduction in challenging behaviors or the addition of functional skills during the transition time.

## Discussion

The purpose of this project was to generate high-priority future research needs for study of interventions for adolescents and young adult with ASD soliciting stakeholder input through a multistep process. We engaged stakeholders in the first part of this future research needs project to explore potential research needs for each of the KQs from the draft review, and further developed the list of identified research gaps. During the prioritization round and the final prioritization, we asked the stakeholders to allot votes in order of importance/high-priority and then again using a modified version of EHC criteria (PiCMe). The draft evidence review discussed the small and methodologically flawed evidence base, which is inadequate to inform treatment decisions for a large and growing segment of the population. As little research exists, gaps occur in outcomes reported and interventions assessed. Gaps also occur in the characterization of populations in studies and the duration of studies.

Autism spectrum disorders are lifelong disabilities and are among the most common neurodevelopmental disorders, with an estimated prevalence of one in 88 children in the United States having ASD.<sup>1</sup> Though the Centers for Disease Control and Prevention data do not include analysis by age group, they suggest that there are a significant number of adolescents and young adults currently affected by ASD, as well as a large cohort of children with ASD approaching the adolescent range.

We identified current and ongoing studies using the criteria from the original review. We identified randomized controlled trials (RCTs) that address a range of topics including drug therapy, behavioral interventions, dietary or supplement-based interventions and studies in complementary and alternative medicine. The majority of the RCTs were not exclusive to the age limit of the original review (ages 13 to 30), but overlapped either studies of children up to age 18 or studies of adults 18 years of age and older. There is a dearth of RCTs focused solely on adolescent and young adults (ages 13 to 30) with ASD.

Seven stakeholders accepted our invitation to participate in the future research needs project to identify and prioritize research needs. We attempted to solicit stakeholders from multiple areas of expertise (clinical, psychopharmacology, behavioral, parents/advocates) to help ensure broad representation of viewpoints. We conducted one conference call with stakeholders to refine the initial list of evidence gaps and gave stakeholders the opportunity to comment on the initial list of research questions through email during the snowball survey after the teleconference call.

Throughout the conference call and snowball survey, stakeholders emphasized several needs that included: (1) strategies for transition and support, as well as predictors for successful transition; (2) quality of life measurements for the individual and family members (life satisfaction, measures on success); (3) interventions implemented in the community; (4) assessment of comorbidities during adolescent and transition years; (5) evaluation of programs (vocational, work-readiness, community, and transitional); and (6) harms related to intervention programs for both the individual and family members. Stakeholders focused on behavioral, transitional, and quality of life measures for the individual and family members. The stakeholders reiterated the critical need for fundamental studies on adolescent and young adults with ASD in all areas.

The final list includes research questions and priorities that center on identifying methodologies and evaluating interventions during fairly critical developmental timeframes where specific emergent issues are quite common. More specifically, this list highlights the import of issues related to accurately assessing and ameliorating the impact of psychiatric comorbidity; developing and understanding the impact of well-defined treatments for some of

the most impairing behavioral problems; and studying specific programs aimed at moving adolescents and adults from supportive educational environments to meaningful work settings. There was also a specific priority set for understanding the broad swath of common interventions for this population that as yet do not have a sufficient evidence base to understand their impact. Interestingly, one research question of top priority focused not specifically on interventions for this age range per se but rather on measuring the effect of earlier interventions on the functioning of adolescents and young adults. This last point highlights the limits of studies and reviews confined to specific age-points as ASD truly represents a lifespan disorder, and outcomes must be studied over years and decades to truly understand impact.

These research priorities highlight several gaps as well as limits in the foundational and methodological knowledge base critical for understanding the comparative effectiveness of interventions during adolescence and young adults. Primarily, these priorities highlight the lack of sufficiently rigorous evaluations of ASD across the lifespan. An enhanced understanding of the course of the disorder is necessary to help guide decisions about what some of the important targets should be and, in turn, what the most promising interventions might be.

The current identified priorities stress that we do not yet understand the best modalities for treating impairments, much less the complex and dynamic neuropsychiatric and developmental vulnerabilities that emerge over this timeframe. Given the tremendous heterogeneity of the disorder and complex interactions of this heterogeneity with developmental, educational, intervention, familial, and system factors, it is clear that simple, single treatments are unlikely to address the multitude of impairments across and within individuals and environments. Instead, specific focal issues might be responsive to interventions in some individuals at particular developmental timepoints, when they could be rigorously evaluated. Identification of interventions at critical points of vulnerability would promote more realistic individualized intervention decisions.

The identified priorities related to transitional vocational interventions highlights the need for more data. At present, there is not yet a sufficient evidence base to guide what programs could be implemented for whom toward what level of effect. In simpler terms, the current scope of ASD research needs to expand in terms of time frame (e.g., from childhood to adolescence to adulthood) and across the range of individual abilities associated with ASD. As suggested by our respondents, the field needs to identify specific tools for indexing transitional outcomes.

Our research methodology had some limitations that deserve discussion. First, although the survey included a broad range of topics, it did not emphasize psychopharmacological questions. Challenges presented by this process included scheduling conflicts with stakeholders, and led to incomplete participation from one member. Two of our stakeholders with pharmacological backgrounds were unable to participate in the teleconference call due to schedule conflicts, and might have missed potential research gaps in harms or psychopharmacological research. Second, the small sample size of our stakeholder panel limits the generalizability of our findings.

Finally, although every attempt was made to engage a balanced group of stakeholders, the group consisted mainly of clinicians with one family member and advocate. Challenges presented by this process included scheduling conflicts and led to incomplete participation from one member. One other challenge was identifying an appropriate cutoff point for top-tier ranking. We decided our cutoff would be five or more points to move into the final prioritization round; roughly half of our initial list of research questions. The final results should all be viewed as highest priority needs, and are not ranked in any particular order.



## Conclusions

Four intervention studies were identified as highest priority. Interventions that warrant rigorous evaluation include those intended to treat behavioral issues, including aggression and self-injury, long-term impact of early intervention provided in childhood, manualized transition programs, and community-based programs targeting adolescents. In all cases, prospective studies should be conducted, either in the form of RCTs or cohort studies that include appropriate comparison groups and rigorous assessment and analytic management of confounding variables. In order to best conduct these studies, foundational research should also be conducted to better understand the degree to which psychiatric and medical comorbidities may affect successful transition to adulthood, and to better describe the trajectory faced by adolescents and young adults with autism as they mature.

## Abbreviations

AHRQ	Agency for Healthcare Research and Quality
ASD	Autism Spectrum Disorders
CBT	Cognitive behavior therapy
CER	Comparative Effectiveness Review
EHC	Effective Health Care
EPCs	Evidence-based Practice Centers
FRN	Future Research Need
KQ	Key Question
PiCMe	Prioritization Criteria Methods
PICOTS	Population, interventions, comparators, outcomes, timeframes, and settings
RCT	Randomized controlled trial
TOO	Task Order Officer

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# Appendix A. Nonresearch Recommendations/Needs Identified During the Snowball Survey

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**Nonresearch recommendations/needs identified in CER and by stakeholders:**

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- 1 Need for pragmatic trials that look at interventions as they actually occur.
  - 2 Need to develop studies that are adequately powered and designed to capture the moderator information.
  - 3 Need measures to define quality of life beyond good or poor outcomes, work status, relationship status, and how to measure quality of life across the research base.
  - 4 Need tools/measurements to assess harms throughout the intervention regarding patient satisfaction (e.g. happiness, quality of life measures) and stress.
  - 5 Need to develop studies that look at prevention of wandering and elopement during transitional years in adolescent and young adults with ASD
  - 6 Systems level measures need to be developed to measure outcomes of adolescents and young adults with ASD, including family outcomes. Outcomes need to include the family as a usual element of studies of adolescents and young adults with ASD.
  - 7 Need to compare caretaker burden in other disease conditions (i.e., Alzheimer's) and the effect it has on family members, spouse and children, and other relatives.
- 

**Abbreviation:** ASD = Autism Spectrum Disorders

## Appendix B. Prioritization Criteria Methods (PiCMe)

**Table B-1. Modified EHC Criteria based on Prioritization Criteria Methods (PiCMe)**

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Potential for significant health impact on the current and future health status of people with respect to burden of the disease and health outcomes: mortality, morbidity, and quality of life.
Potential to reduce important inappropriate (or unexplained) variation in clinical practices known to relate to quality of care. Potential to resolve controversy or dilemmas in what constitutes appropriate health care. Potential to improve decision-making for patient or provider, by decreasing uncertainty.
Potential for significant (nontrivial) economic impact related to the costs of health service, to reduce unnecessary or excessive costs; to reduce high costs due to high volume use, to reduce high costs due to high unit cost or aggregate cost. Costs may impact consumers, patients, health care systems, or payers.
Potential risk from inaction: Unintended harms from lack of prioritization of proposed research, opportunity cost of inaction.
Potential to address health inequities, vulnerable, diverse populations (including issues for patient subgroups), potential to reduce health inequities.
Potential for new knowledge: Research would not be redundant, question not sufficiently researched, including completed and in-process research, utility of available evidence limited by changes in practice, e.g., disease detection or evolution in technology.

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## **Appendix C. Current and Ongoing Research**

### **I. ClinicalTrials.gov – 3/13/2012**

autism OR autistic OR asperger\* OR pervasive development\* OR PDD-NOS | Interventional Studies

272 results

Omitted 161 due to being exclusively outside the 13-30 year age range, not having a therapeutic component, or not being a study of autism, Asperger syndrome, or PDD-NOS.

Retained 72 drug therapy studies, 14 behavioral studies, 9 studies on dietary or supplement-based interventions, 3 studies in complementary and alternative medicine (all on acupuncture), and 13 miscellaneous studies. The drug therapy studies included: atomoxetine for ADHD symptoms, antipsychotics including aripiprazole, risperidone, and ziprasidone, along with guanfacine, galantamine, oxytocin, fluoxetine, valproate, divalproex sodium, oxcarbazepine, arbaclofen, baclofen, methylphenidate, metformin, riluzole, buspirone, paliperidone, memantine, citalopram, and other drugs (including investigational drugs). Behavioral and educational interventions include cognitive behavioral therapy, social skills training, parent education, and other approaches. Dietary/supplement approaches included gluten-free diets, broccoli sprout extract, omega-3 fatty acids, and other interventions. There were also several other interventions under investigation, including neurofeedback, hyperbaric oxygen therapy, hippotherapy, and other approaches.

### **II. CenterWatch – 3/15/2012**

Browsed to Clinical Trials: Autism - <http://www.centerwatch.com/clinical-trials/listings/condition/612/autism>

10 unique trials were identified; 4 of these are omitted due to be duplicates of clinicaltrials.gov results and/or being the inappropriate age group. Of the 6 retained results, drug therapy approaches (3) included arbaclofen for social withdrawal, an unnamed drug for behavioral problems, and an unnamed investigational medicine. Two additional studies should likely be omitted as assessment only (IQ tests, sensory integration). The final retained study did not provide details of the intervention.

### **III. NIH RePORTER – 3/20/2012**

Searched Advanced Text for (autism OR autistic OR asperger OR PDD-NOS) AND (teen OR adolescent OR "young adult" OR "young adults") limited to Protect Title, Project Abstracts, and Project Terms.

117 results

Many of these results are observational, researcher training, basic science, genetic, or animal studies or otherwise not therapy trials in desired population. Only 4 of the results appeared to be therapy trials in the relevant population; these addressed language learning skills, cognitive enhancement therapy, school/community-based intervention for social skills, and an employment skills program.

### **IV. Autism Clinical Trials Network (at Autism Speaks) – 3/20/2012**

<http://www.autismspeaks.org/science/resources-programs/autism-clinical-trials-network>

Lists trials on memantine (not enrolling, age groups not described) and on fluoxetine (completed enrollment, ages 5-17 years)

V. Autism Speaks (autismspeaks.org) – 3/20/2012

RFA, Treatment Research Grants: Full and Pilot Level, 2012 Cycle

Includes the following treatment related research priorities (along with environmental risk factors, biomarkers, and dissemination/implementation): “improve quality of life through more effective medicines, behavioral interventions, and technologies;” treatment of underserved/understudied populations, specifically including nonverbal persons with AS< ethnically-diverse and/or low resource communities; adults; those with medical comorbidities.

VI. Autism Speaks Grant Search – 3/20/2012 - <http://www.autismspeaks.org/about-us/grant-search/results/taxonomy%3A10006>

156 grants, 2006-present (18 from 2006, 28 from 2007, 20 from 2008, 6 from 2009, 23 from 2010, 60 from 2011, 1 from 2012)

Interventions include or address pivotal response treatment, bilingual language exposure, virtual reality, melatonin, memantine, social skills interventions, play, joint attention, sensory integration, mecamylamine, complementary and alternative medicine approaches including acupuncture and acupressure, verbal skills, risperidone, cholesterol, robotics, cognitive-behavioral group treatment, parent training, noise cancelation, and other approaches. However, it is not readily apparent whether the appropriate age group is addressed from the basic records here, and many studies included among the 156 results may be basic science, animal studies, or other approaches that are not of interest.

VII. AHRQ – Grants On-Line Database - [http://gold.ahrq.gov/projectsearch/grant\\_search.jsp](http://gold.ahrq.gov/projectsearch/grant_search.jsp) - 3/21/2012

Search Criteria - Abstract Text contains: autism, autistic, asperger, PDD-NOS

Retrieved 4 results. Three of these apply to a computer-based decision support system for providers of autism care and effects on patient care; the fourth is related to dissemination of relevant AHRQ CER products.

# **Appendix D. Snowball Survey**

## **Future Research Needs**

### **Interventions for Adolescents and Young Adults with Autism Spectrum Disorders Project**

#### **Round #1: Snowball Survey**

Thank you for your participation in the Future Research Needs for Interventions for Adolescents and Young Adults with Autism Spectrum Disorders Project. The Vanderbilt EPC team has compiled a list of research questions which include questions added from our May 9, 2012 stakeholder call.

The purpose of this project is to generate an exhaustive list of potential research questions. We would like your input in the following areas:

- Addition of new research questions
- Specific edits and/or refinements to the proposed research questions
- Exclusion of questions for which ongoing research is likely to provide appropriate answers to fill current evidence gaps
- Any additional general feedback on the research questions

We ask that you send your edits/comments on the list of research questions as well as any new research questions by ***Wednesday, May 23, 2012*** to Katie Worley at Katherine.j.worley@vanderbilt.edu.

#### **Research Questions**

(To later be ranked by clinical importance, feasibility, contribution to knowledge gaps, and overall importance)



### Key Question 1

No.	Among adolescents and young adults with ASD, what are the effects of available interventions on the core symptoms of ASD?
1	What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?
2	What is the validity of best available quality of life measurements across adolescents and young adults with ASD? Examination of measures in comparison to objective metrics (educational, occupational, developmental milestone), self-determined outcomes, and family based outcomes. <ul style="list-style-type: none"> <li>• How do families define transition?</li> <li>• How do individuals affected by ASD define transition (individualistic constructs of meaningful engagement and productivity)?</li> <li>• Efficacy studies aimed at promoting novel and relative definitions of meaningful social engagement (i.e., community engagement, social networks, peer-mediated, adult mentored, club/activity).</li> </ul>
3	What is the impact of common social and behavioral interventions in combination/comparison with pharmacological paradigms aimed at enhanced social learning on core symptoms? <ul style="list-style-type: none"> <li>• Social skills / learning paradigms</li> <li>• Explicit markers and timeframe related to assessment of generalization of skills</li> </ul>
4	What is the impact of augmentative communication and novel technological paradigms for individuals with severe communication impairments at specific developmental target ranges (e.g., nonverbal, co-morbid intellectual disability, adolescents)?
5	What is the effectiveness of comprehensive and intensive treatment approaches (specific educational, residential, intensive work programs) in adolescents with ASD for ameliorating core symptoms?
6	What is the effectiveness of interventions implemented in the community compared to the research setting among adolescents and young adults with ASD?
7	What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?

### Key Question 2

No.	Among adolescents and young adults with ASD, what are the effects of available interventions on common medical and mental health comorbidities (e.g., epilepsy, sleep disorders, motor impairments, obesity, depression, anxiety, acute and episodic aggression, attention deficit hyperactivity disorder, etc.)?
8	What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?
9	What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics (see KQ1)?
10	What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities.
11	What is the validity of standard measurements for assessing mental health in adolescents and young adults with ASD?
12	What is the utility of measures developed for nonautistic individuals with mental health disorders in adolescents and young adults with ASD with mental health comorbidities?
13	How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?
14	What is the impact of comorbidities on family life over the lifespan?
15	What is the effectiveness of available interventions for treating behavioral issues including sudden aggression and catatonia during transition years in adolescents and young adults with ASD?

### Key Question 3

No.	Among adolescents and young adults with ASD, what are the effects of available interventions on functional behavior, attainment of goals toward independence, educational attainment, occupational/vocational attainment, life satisfaction, access to health and other services, legal outcomes, and social outcomes?
16	What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?
17	What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills training and programs, person-centered planning) in ASD?
18	What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?
19	What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?

### Key Question 4

No.	Among adolescents and young adults with ASD, what is the effectiveness of interventions designed to support the transition process, specifically to affect attainment of goals toward independence, educational attainment, occupational/ vocational attainment, life satisfaction, access to health and other services, legal outcomes, and social outcomes?
20	What is the impact on the most common transition programs across individual, familial, and more broadly defined outcomes?
21	What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?

### Key Question 5

No.	Among adolescents and young adults with ASD, what harms are associated with available interventions? Harms are defined by the Effective Health Care Program as all possible adverse consequences of an intervention, including adverse events.
22	Explicit inclusion markers of broadly defined harm, adverse event, distress/impact across defined intervention studies above.
23	What is the impact of interventions on stress levels for family members and adolescents and young adults with ASD?
24	What is the effectiveness of systems level interventions specific to the legal system in managing adolescents and young adults with ASD?
25	To what extent does participation in services and potential dependency on services lead to declining ability to function independently in adolescents and young adults with ASD?

### Key Question 6

No.	What are the effects of interventions on family outcomes?
26	Explicit inclusion markers of broadly defined measures of family impact in studies above.

## Comments:

**Additional (nonresearch) recommendations/needs:**

1	Need for pragmatic trials that look at interventions as they actually occur.
2	Need to develop studies that are adequately powered and designed to capture the moderator information.
3	Need measures to define quality of life beyond good or poor outcomes, work status, relationship status, and how to measure quality of life across the research base.
4	Need tools/measurements to assess harms throughout the intervention regarding patient satisfaction (e.g. happiness, quality of life measures) and stress.
5	Need to develop studies that look at prevention of wandering and elopement during transitional years in adolescent and young adults with ASD
6	Systems level measures need to be developed to measure outcomes of adolescents and young adults with ASD, including family outcomes. Outcomes need to include the family as a usual element of studies of adolescents and young adults with ASD.
7	Need to compare caretaker burden in other disease conditions (i.e., Alzheimer's) and the effect it has on family members, spouse and children, and other relatives.

**Comments:**

If you have any questions or concerns regarding in the interim, please feel free to contact Katie Worley at Katherine.j.worley@vanderbilt.edu.

# Appendix E. First Web-Based Prioritization Survey

## Future Research Needs: Interventions for Adolescents and Young Adults with Autism Spectrum Disorders Prioritization Round 1

Your Name

**Save and Continue**

**The prioritization survey will close on June 4, 2012. If you have any questions , please contact Katie Worley by email at [katherine.j.worley@vanderbilt.edu](mailto:katherine.j.worley@vanderbilt.edu)**

## Future Research Needs: Interventions for Adolescents and Young Adults with Autism Spectrum Disorders Prioritization Round 1

Thank you for participating in the Future Research Needs: Interventions for Adolescents and Young Adults with Autism Spectrum Disorders Project.

For this first round of prioritization, please allot stars to each research question listed below. The more stars you add by any question, the higher you rank that item in comparison with the other items in the list.

You are given a total of 18 stars which you may allocate to any of the 27 items listed below.

You may use up to 5 stars per item.


To add stars to a selection, position your mouse over the dots in the right hand column.

To remove all stars from the row, please click on the outlined, transparent star in the far left of the right-hand column.

To remove just one star, click on the star to the left of the star to be removed.

**The prioritization survey will close on June 4, 2012. If you have any questions , please contact Katie Worley by email at [katherine.j.worley@vanderbilt.edu](mailto:katherine.j.worley@vanderbilt.edu)**

Remaining stars: (18 of 18)  


What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?	 . . . . .
What is the validity of best available quality of life measurements across adolescents and young adults with ASD? • How do families define transition? • How do individuals affected by ASD define transition (individualistic constructs of meaningful engagement and productivity)? • Efficacy studies aimed at promoting novel and relative definitions of meaningful social engagement (i.e., community engagement, social networks, peer-mediated, adult mentored, club/activity)	 . . . . .
What is the impact of common social and behavioral interventions in combination/comparison with pharmacological paradigms aimed at enhanced social learning on core symptoms?	 . . . . .
What is the impact of augmentative communication and novel technological paradigms for individuals with severe communication impairments at specific developmental target ranges (e.g., non-verbal, co-morbid intellectual disability, adolescents)?	 . . . . .
What is the effectiveness of comprehensive and intensive treatment approaches (specific educational, residential, intensive work programs) in adolescents with ASD for ameliorating core symptoms?	 . . . . .
What is the effectiveness of interventions implemented in the community compared to the research setting among adolescents and young adults with ASD?	 . . . . .
What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?	 . . . . .
What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?	 . . . . .
What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics?	 . . . . .

What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities?	☆ . . . . .
What is the validity of standard measurements for assessing mental health in adolescents and young adults with ASD?	☆ . . . . .
What is the utility of measures developed for non-autistic individuals with mental health disorders in adolescents and young adults with ASD with mental health comorbidities?	☆ . . . . .
How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?	☆ . . . . .
What is the impact of comorbidities on family life over the lifespan?	☆ . . . . .
What is the effectiveness of available interventions for treating behavioral issues including sudden aggression and catatonia during transition years in adolescents and young adults with ASD?	☆ . . . . .
What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?	☆ . . . . .
What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, Cognitive Behavior Therapy programs, social skills training and programs, person-centered planning) in ASD?	☆ . . . . .
What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?	☆ . . . . .
What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?	☆ . . . . .
What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?	☆ . . . . .
What is the impact on the most common transition programs across individual, familial, and more broadly defined outcomes?	☆ . . . . .
What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?	☆ . . . . .
Explicit inclusion markers of broadly defined harm, adverse event, distress/impact across defined intervention studies above.	☆ . . . . .
What is the impact of interventions on stress levels for family members and adolescents and young adults with ASD?	☆ . . . . .
What is the effectiveness of systems level interventions specific to the legal system in managing adolescents and young adults with ASD?	☆ . . . . .
To what extent does participation in services and potential dependency on services lead to declining ability to function independently in adolescents and young adults with ASD?	☆ . . . . .
Explicit inclusion markers of broadly defined measures of family impact in studies above.	☆ . . . . .

Remaining stars: (18 of 18)  
 ★★★★★★★★★★★★★★★★★★

[Save and Continue](#)

### Future Research Needs: Interventions for Adolescents and Young Adults with Autism Spectrum Disorders Prioritization Round 1

Please add any comments you would like to make:

[If you would like to return to the prioritization survey, please click here.](#)

[To submit your response please click here](#)

The prioritization survey will close on June 4, 2012. If you have any questions , please contact Katie Worley by email at [katherine.j.worley@vanderbilt.edu](mailto:katherine.j.worley@vanderbilt.edu)

# Appendix F. First-Round Prioritization Survey Results

## Prioritization Survey Round 1: List of Research Questions with Total Votes Allotted

### Upper tier research questions (receiving 5 or more stars)

No.	Research Question	Total # of stars	# of stakeholders contributed
17	What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills training and programs, person-centered planning) in ASD?	10	5
21	What is the impact on the most common transition programs across individual, familial, and more broadly defined outcomes?	8	5
22	What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?	7	5
1 & 16	What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?	3* & 4*	4
8	What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?	6	3
9	What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics?	6	4
10	What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities?	6	4
15	What is the effectiveness of available interventions for treating behavioral issues including sudden aggression and catatonia during transition years in adolescents and young adults with ASD?	6	4
19	What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?	6	4
7	What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?	5	3
13	How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?	5	3
18	What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?	5	4
20	What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?	5	4

\*KQ1\_1 and KQ3\_1 were the same question. There was no overlap on stakeholder votes, combined total from both questions

**Lower tier research questions (receiving 4 or fewer stars)**

No.	Research question	Total # of stars	# of stakeholders contributed
2	What is the validity of best available quality of life measurements across adolescents and young adults with ASD? • How do families define transition? • How do individuals affected by ASD define transition (individualistic constructs of meaningful engagement and productivity)? • Efficacy studies aimed at promoting novel and relative definitions of meaningful social engagement (i.e., community engagement, social networks, peer-mediated, adult mentored, club/activity).	4	3
4	What is the impact of augmentative communication and novel technological paradigms for individuals with severe communication impairments at specific developmental target ranges (e.g., nonverbal, co-morbid intellectual disability, adolescents)?	4	3
14	What is the impact of comorbidities on family life over the lifespan?	4	3
24	What is the impact of interventions on stress levels for family members and adolescents and young adults with ASD?	3	3
3	What is the impact of common social and behavioral interventions in combination/comparison with pharmacological paradigms aimed at enhanced social learning on core symptoms?	2	2
6	What is the effectiveness of interventions implemented in the community compared to the research setting among adolescents and young adults with ASD?	2	2
11	What is the validity of standard measurements for assessing mental health in adolescents and young adults with ASD?	2	2
12	What is the utility of measures developed for nonautistic individuals with mental health disorders in adolescents and young adults with ASD with mental health comorbidities?	2	2
5	What is the effectiveness of comprehensive and intensive treatment approaches (specific educational, residential, intensive work programs) in adolescents with ASD for ameliorating core symptoms?	1	1
23	Explicit inclusion markers of broadly defined harm, adverse event, distress/impact across defined intervention studies above.	1	1
26	To what extent does participation in services and potential dependency on services lead to declining ability to function independently in adolescents and young adults with ASD?	1	1
25	What is the effectiveness of systems level interventions specific to the legal system in managing adolescents and young adults with ASD?	0	0
27	Explicit inclusion markers of broadly defined measures of family impact in studies above.	0	0

# Appendix G. Second Web-Based Prioritization Survey

## Exploring Future Research Related to Interventions for Adolescents and Young Adults with Autism Spectrum Disorders --Prioritization Survey #2

Resize font:



[Returning?](#)

Thank you for participating in this project. Below are the highest ranking research questions resulting from the first round prioritization.

**In this final survey, we ask that you rank each potential area of research (1 [lowest] to 5 [highest]) on six AHRO Effective Health Care Program Topics prioritization criteria listed below:**

1. Potential for significant health impact on the current and future health status of people with respect to burden of the disease and health outcomes: mortality, morbidity, and quality of life.
2. Potential to reduce important inappropriate (or unexplained) variation in clinical practices known to relate to quality of care. Potential to resolve controversy or dilemmas in what constitutes appropriate health care. Potential to improve decision-making for patient or provider, by decreasing uncertainty.
3. Potential for significant (nontrivial) economic impact related to the costs of health service, to reduce unnecessary or excessive costs; to reduce high costs due to high volume use, to reduce high costs due to high unit cost or aggregate cost. Costs may impact consumers, patients, health care systems, or payers.
4. Potential risk from inaction: Unintended harms from lack of prioritization of proposed research, opportunity cost of inaction.
5. Potential to address inequities, vulnerable, diverse populations (including issues for patient subgroups), potential to reduce health inequities.
6. Potential for new knowledge: Research would not be redundant, question not sufficiently researched, including completed and in-process research, utility of available evidence limited by changes in practice, e.g., disease detection or evolution in technology.

When all surveys are returned we will total the number of points each research question received and report the questions with the highest scores for each criteria.

**The survey will close on June 13, 2012.** If you have any questions regarding this survey or this project, please contact [katherine.j.worley@vanderbilt.edu](mailto:katherine.j.worley@vanderbilt.edu).

Thank you!

Please enter your email address:

### Research Questions for Interventions for Adolescents and Young Adults with Autism Spectrum Disorders

Please rank each item, from 1 (low) to 5 (high), on each of the following criteria:

- Potential for significant health impact.
- Potential to reduce variation in clinical practices.
- Potential for significant economic impact.
- Potential risk from inaction.
- Potential to address inequities.
- Potential for new knowledge.



**1. What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills training and programs, person-centered planning) in ASD?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

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**2. What is the impact of common transition programs across individual, familial, and more broadly defined outcomes?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

**3. What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

**4. What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

**5. What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

**6. What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

**7. What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

**8. What is the effectiveness of available interventions for treating behavioral issues including sudden aggression and catatonia during transition years in adolescents and young adults with ASD?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

**9. What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

**10. What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

reset value

**11. How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

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Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

**12. What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

**13. What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?**

Please rank, from 1 (low) to 5 (high), on each of the following criteria:

Potential for significant health impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to reduce variation in clinical practices.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for significant economic impact.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential risk from inaction.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential to address inequities.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

[reset value](#)

Potential for new knowledge.

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

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**Submit**

Save & Return Later

# Appendix H. Second-Round Prioritization Survey Results

## Final prioritization results over all modified EHC criteria

Research Question	Total points combining all criteria	Total overall ranking
Q8 What is the effectiveness of available interventions for treating behavioral issues including sudden aggression and catatonia during transition years in adolescents and young adults with ASD?	148	High
Q13 What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?	147	High
Q1 What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills training and programs, person-centered planning) in ASD?	146	High
Q10 What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?	138	High
Q2 What is the impact of common transition programs across individual, familial, and more broadly defined outcomes?	138	High
Q6 What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics?	137	High
Q4 What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?	135	Middle
Q9 What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?	133	Middle
Q11 How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?	132	Middle
Q7 What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities?	128	Low
Q5 What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?	124	Low
Q12 What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?	121	Low
Q3 What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?	120	Low



### Final prioritization results for each modified EHC criteria and stakeholder votes

<b>Q8 What is the effectiveness of available interventions for treating behavioral issues including sudden aggression and catatonia during transition years in adolescents and young adults with ASD?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q8
5	5	5	5	5	5	30
5	4	4	5	4	5	27
5	5	5	5	5	5	30
3	3	3	3	3	4	19
4	3	4	3	4	4	22
4	4	3	3	3	3	20
26	24	24	24	24	26	148
<b>Q13 What is the effectiveness of early intervention programs to improve functional behavior in adolescents and young adults with ASD?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q13
4	4	4	3	4	4	23
5	4	5	4	4	5	27
5	5	5	5	5	5	30
3	3	3	3	3	3	18
4	4	4	4	4	4	24
5	4	4	4	3	5	25
26	24	25	23	23	26	147
<b>Q1 What is the effectiveness of available transition programs (e.g., work readiness programs, community programs, vocational programs, private ABA schools, Cognitive Behavior Therapy (CBT) programs, social skills training and programs, person-centered planning) in ASD?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q1
4	4	4	4	4	5	25
5	3	5	5	4	5	27
5	5	4		3	3	20
4	3	5	4	4	4	24
5	4	4	5	4	5	27
4	3	5	4	3	4	23
27	22	27	22	22	26	146
<b>Q10 What is the effectiveness of paradigms and combinations of paradigms currently used in community based programs for adolescents and young adults with ASD?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q10
3	3	3	3	3	3	18
5	4	4	4	5	5	27
5	5	5	5	5	5	30
4	4	4	3	3	3	21
4	3	4	4	3	4	22
4	3	4	3	3	3	20
25	22	24	22	22	23	138

<b>Q2 What is the impact of common transition programs across individual, familial, and more broadly defined outcomes?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q2
4	4	4	4	4	5	25
3	3	4	4	3	3	20
5	4	2	2	4	5	22
4	3	5		4	4	20
5	4	5	4	4	3	25
5	4	5	4	3	5	26
26	22	25	18	22	25	138
<b>Q6 What measurable psychiatric and medical comorbidities predict less successful transition from supportive educational settings as well as impact quality of life metrics?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q6
5	4	4	5	5	5	28
5	4	4	5	4	5	27
4	4	5	4	3	4	24
3	3	4		3	3	16
5	4	4	3	3	5	24
3	3	3	3	3	3	18
25	22	24	20	21	25	137
<b>Q4 What measurable characteristics (individual, familial, system) predict successful transition from supportive educational settings?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q4
4	4	3	3	4	4	22
4	3	4	2	4	5	22
5	5	5	5	5	5	30
3	3	4	3	3	4	20
4	4	4	3	3	5	23
4	3	3	3	2	3	18
24	22	23	19	21	26	135
<b>Q9 What are the measurable characteristics that determine a satisfying quality of life for adolescents and young adults with ASD?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q9
3	3	3	3	3	3	18
4	3	3	4	3	4	21
5	5	5	5	5	5	30
4	3	4	3	4	4	22
3	3	4	3	4	3	20
4	3	4	4	3	4	22
23	20	23	22	22	23	133

<b>Q11 How can the trajectory of comorbidities in adolescents and young adults with ASD be measured over the lifespan?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q11
3	3	2	2	2	2	14
5	4	4	4	4	5	26
5	4	5	5	5	5	29
4	3	4	3	4	4	22
3	4	4	4	4	5	24
4	2	2	3	2	4	17
24	20	21	21	21	25	132
<b>Q7 What is the impact of common behavioral interventions (manualized CBT and familial treatment paradigms on anxiety/depression) treating psychiatric comorbidities in non-ASD samples in combination/comparison with pharmacological paradigms aimed at treating comorbidities?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q7
4	5	4	4	4	4	25
5	4	4	4	4	5	26
1	1	1	1	1	1	6
4	3	4	3	4	4	22
5	5	4	5	3	4	26
5	4	4	3	3	4	23
24	22	21	20	19	22	128
<b>Q5 What is the validity of best available existing psychiatric comorbidity measurements across adolescents and young adults with ASD?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q5
4	4	4	3	3	4	22
4	4	3	4	4	5	24
2	2	2	1	2	1	10
3	4	4	3	3	4	21
5	4	4	3	3	5	24
4	4	4	4	3	4	23
22	22	21	18	18	23	124
<b>Q12 What are appropriately sensitive metrics of quality of life, functional outcome, and how does that overlay with the heterogeneous range of characteristics of individuals, families, and systems in ASD?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q12
2	2	2	2	2		10
4	3	3	4	4	5	23
4	4	4	4	4	4	24
4	3	4	3	3	4	21
3	3	3	3	3	4	19
5	3	4	4	3	5	24
22	18	20	20	19	22	121

<b>Q3 What is the effectiveness of interventions designed to support goals toward life satisfaction for adolescents and young adults with ASD and family members?</b>						
Potential for significant health impact.	Potential to reduce variation in clinical practices.	Potential for significant economic impact.	Potential risk from inaction.	Potential to address inequities.	Potential for new knowledge.	Total Q3
3	3	3	3	3	3	18
4	3	3	3	3	4	20
3	3	1	1	4	3	15
4	3	4	3	3	4	21
4	3	3	4	3	3	20
5	3	4	5	4	5	26
23	18	18	19	20	22	120