



# Autistic Adolescents and Young Adults: A Research Agenda

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# Autistic Adolescents and Young Adults: A Research Agenda

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# Table of Contents

- 1. INTRODUCTION ..... 3
  - Our Language..... 3
  - Background ..... 3
  - Impact..... 4
  - Guiding Principles ..... 4
  - Purpose and Audience..... 5
- 2. PROCEDURES..... 5
  - Process for setting research priorities and providing recommendations for study methodology and intervention content ..... 5
    - 1. Selected experts for the Advisory Board ..... 5
    - 2. Create a list of priority research topics..... 6
    - 3. Set criteria for priority setting..... 6
    - 4. Establish recommendations for recruitment, intervention design and outcomes measurement ..... 6
- 3. PRIORITY TOPICS IN AUSTISM RESEARCH FOR ADOLESCENTS AND YOUNG ADULTS ..... 7
- 4. INTERVENTION RESEARCH..... 11
- 5. RECRUITMENT, INTERVENTION DESIGN AND OUTCOMES MEASUREMENT ..... 14
- 6. SUMMARY ..... 15

## Our Language

The language used to describe autism can greatly affect people on the spectrum and how society views them. Early in our process, our Advisory Board acknowledged that language is powerful and made choices about which words we would use. The Board, which comprised autistic people and non-autistic people, acknowledged that people who are on the spectrum have different preferences about the words we use to describe autism and autism status. The Board decided that, for our purposes, intention was what mattered the most, and that as long as speakers were coming from a place of respect in communications we would accept whatever language felt right to them. However, the Board also noted that there are strong arguments and passions on both sides of the debate on the use of person-first language (e.g., “person with autism”) and identity-first language (e.g., “autistic person”). Because a growing body of scientific and community literature documents the dislike among many autistic individuals of person-first language and its potential for increasing stigma,<sup>1-3</sup> we have chosen to use identity-first language in this document.

## Background

One in 54 U.S. youth are autistic (1.7%).<sup>4</sup> By 2025, approximately 500,000 autistic children will become adults.<sup>5</sup> As a result, the field is bracing for the increased demand for services, and the U.S. Department of Health and Human Services has specifically called for research and new interventions to help autistic youth make successful transitions to adulthood.<sup>6</sup>

The need for new research and effective interventions to benefit autistic individuals and their families is overwhelmingly clear. Autistic people face five times the odds of suicide attempt compared to the general population,<sup>7</sup> and die 16 years earlier, on average, than

neurotypical counterparts.<sup>8,9</sup> Stigma, discrimination and exclusionary practices in schools, workplaces, and by neurotypical peers can compound experiences of depression, anxiety, loneliness, and the pressure on autistic youth to “camouflage” or hide their authentic selves from others.<sup>10,11</sup> The loss and grief experienced by autistic individuals, their families, friends, and communities is staggering. Moreover, the annual cost burden of autism in the U.S. was as much as \$268 billion in 2015.<sup>12</sup> For this reason, supporting the health of autistic people is a U.S. public health priority.<sup>13,14</sup>

Autism Spectrum Disorder (ASD) was not introduced into the Diagnostic and Statistical Manual (DSM) until 1980.<sup>15</sup> As such, it is still a relatively new diagnosis, and discourse about whether autism should be considered a “disorder” or a “neurological variation” continues.<sup>16</sup> Clinicians recognize ASD as a developmental disability characterized by difficulties in social communication and by restricted, repetitive behavior and interests.<sup>17</sup> Autistic people also experience challenges with receptive and expressive language, atypical social cognition and social perception, executive dysfunction, and atypical information processing.<sup>17,18</sup> Although a substantial percentage of autistic people also have intellectual disabilities, approximately 69% do not.<sup>19</sup>

Research suggests that individuals with acute autism impairments, including delayed speech, motor functioning impairment, and social interactions, can benefit from early intervention treatment services before the age of 3 years old.<sup>20</sup> For autistic individuals with less severe challenges, who may be diagnosed later in life but nevertheless experience adversity related to social communication differences, executive function differences, and sensory processing differences, there is a dearth of services and very few evidence-based interventions. Given that only 65% of autistic young adults (ages 19-23 years old) are employed or receive postgraduate education after high school,<sup>21</sup> services and interventions for autistic young adults are essential for improved health promotion.

## Impact

Previous research agendas to promote health and equity for autistic people have provided important guidance to entities that develop funding priorities for autism research. This research agenda aims to be similarly useful for government organizations, foundations, health care institutions, academic researchers and institutes, and other entities engaged in autism research and health promotion in general.<sup>22,23</sup> This agenda is an important addition to the field because of its focus on adolescents and young adults, which are subpopulations that for too long were overlooked and are still disproportionately less likely to be the beneficiaries of programming or focus of funded research, both in the U.S.<sup>24</sup> and internationally.<sup>25</sup> To this end, with funding from a Eugene Washington Patient-Centered Outcomes Research Institute (PCORI) Engagement Award, we established an Advisory Board of key stakeholders including autistic youth, parents of autistic youth, and service providers/advocates to develop a comprehensive research agenda focused on issues most important for the health of autistic adolescents and young adults. This Advisory Board met approximately monthly from late 2019 through early 2021 to develop this research agenda.

## Guiding Principles

Our commitment to promoting the health and well-being of autistic youth and their families is grounded in four guiding principles. First, consistent with the World Health Organization, our definition of health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”<sup>26</sup> Second, we uphold the dictum “Nothing About Us Without Us,”<sup>27</sup> which is an expression meant to assert that the full and direct participation of autistic individuals in the creation of this research agenda is viewed as essential. Third, we strove for meaningful inclusion of all members of our Advisory Board,<sup>28</sup> acknowledging that the COVID-19 pandemic created an acutely stressful situation for the parents of autistic youth on our Board, as well as the service providers, autistic youth, and the leadership. It is a testament to the commitment of Advisory Board members to autism research and health promotion for autistic youth that they persevered.

Finally, the health and wellbeing of autistic youth and families of color cannot be promoted without centering

anti-racism work simultaneously. Almost every Advisory Board meeting included a discussion of the profound impact of structural racism. The Advisory Board gave voice to the fact that there are more resources, services and options for autistic youth and parents of autistic youth in wealthier and predominantly white communities, and that the marginalization of the needs of Black, Hispanic, Asian, Multiracial and other people of color intersects with the marginalization experienced by autistic youth.<sup>29</sup> The negative synergistic effect of experiencing racism, classism, and disability-based oppression simultaneously challenges thousands of individuals in the U.S. and internationally.<sup>30</sup> Addressing the dual burden of racism and autism is put forward by this group as an overarching priority



that should be addressed at every level of health care, education and service provision. The needs of autistic youth of color, and parents of autistic youth of color, need to be centered going forward.

## Purpose and Audience

The purpose of this research agenda is to promote research on topics that will support health for autistic adolescents and young adults and have relevance to public health. The findings included in this document are organized into three parts including: (1) Priority topics for autism research for adolescents and young adults; (2) Existing intervention research that evaluates the efficacy and effectiveness of programs for the priority topics; and (3) Stakeholders’ perspectives on intervention design, and research study recruitment and outcomes measurement.

## 2. PROCEDURES

### Process for setting research priorities and providing recommendations for study methodology and intervention content

This publication is intended to be used by government organizations, foundations, health care institutions, academic researchers and institutes, and other entities engaged in autism research and health promotion in general. Researchers are encouraged to use this as a guide when prioritizing future studies. Funders are encouraged to align resources to address the priorities in this research agenda, and to align with one another to reduce duplication of effort.

The process for developing the top research priorities is described below.

#### 1. Selected experts for the Advisory Board

The first step in our process was to recruit 15 individuals to our expert Advisory Board. Our goal was to establish an Advisory Board comprising autistic youth, parents of autistic youth, and service providers and advocates for autistic youth and families. Some individuals who were selected to join the Advisory Board identified with more than one of these categories (i.e., a parent of an autistic youth and also an advocate). Advisory Board inclusion criteria included having lived or professional experience on the topic of health promotion for autistic youth, having capacity to contribute time or resources to the project, and living locally to Boston Medical Center, where we planned that monthly in-person meetings would take place.

The project leadership team (Bair-Merritt, Palmucci, and Rothman) generated a list of possible Advisory Board expert participants by asking key stakeholder organizations to nominate youth, parents and service providers. Key stakeholder organizations included the Boston Medical Center Autism Program (BMCAP), the Asperger/Autism Network (AANE), the Federation for Children with Special Needs in Massachusetts, the Brookline High School Special Education Parent Advisory Council, the Metropolitan Council for Educational Opportunity (METCO), the regional Special Education Parent Advisory Council (SEPAC), and the Threshold Program at Lesley University. The Director of BMCAP (Ms. Shari King) also sent a solicitation to parents of autistic youth and providers in her network to help ex-

pand the candidate list. A representative of the leadership team met individually with each candidate to explain the purpose of the Advisory Board and responsibilities of members, and to evaluate each candidate’s fit for the board. Fit was determined, in part, relative to the goal of establishing an Advisory Board that was diverse in terms of participants role (i.e., youth, parent or providers) and race/ethnicity. Of the Advisory Board members, 45% identify as Black, Hispanic, Multiracial, or another race other than white, and 93% identify as female. The service providers represent agencies including BMCAP, AANE, and the Integrated Center for Child Development (ICCD). One Advisory Board member who was a service provider attended one meeting and was subsequently unable to attend, so in effect, the Board comprised 14 members.

#### 2. Create a list of priority research topics

To formulate the research agenda, our Advisory Board divided into three breakout groups (i.e., youth, parents, and service providers/advocates) during our third meeting. Each group met privately with one facilitator from the leadership team and brainstormed adolescent health priority topics for research to benefit autistic youth and young adults. Prompts for the brainstorming were: “What do you see as the most pressing (i.e., most urgent) health issues for autistic individuals ages 11-24 years old?” and “What topics are important for autistic teenagers and young adults’ wellbeing and should be the target of additional research or receive more attention?” They also were asked: “What interventions do you know about that address or solve any of the issues on our list of health issues?” Advisory Board members were encouraged to think of health broadly, as more than just the absence of disease. A total of 21 topics were generated in the breakout groups.

#### 3. Set criteria for priority setting

To prioritize research topics, the 21 topics were listed together on a sheet of newsprint and each Adviso-

ry Board member selected the three topics that they believed to be the most important (i.e., modified nominal group technique). Topics were ranked by the number of high priority votes that they received. Several topics were grouped after the voting process because they were closely related. These included “Diet, body awareness, and body image,” which was grouped with “healthy food choices,” and with “eating disorder,” and “Sex/sexual health” which was grouped with “gender identity.” The top 10 high priority issues were selected as high priority issues for this research agenda, and the remaining 11 issues were retained as priority issues.

Two members of the leadership team (i.e., Ofei and Graham Holmes) undertook 10 separate reviews of the research literature in order to identify randomized controlled trial (RCT)-tested interventions. The goal of the PCORI engagement award was to identify topics where two or more RCT-tested interventions were available for comparative effectiveness research (CER). Not every one of the topics in the top

10 were ones where specific interventions could be identified, and for some, interventions had not been tested through RCTs.

#### 4. Establish recommendations for recruitment, intervention design and outcomes measurement

During subsequent Advisory Board meetings, members provided input about the following topics: intervention design, study recruitment methods and materials, and outcomes measurement. For each topic, members divided into three groups including youth, parents and service providers/advocates. These smaller groups ensured that each participant had space and time to express their opinions. After these breakout groups, the full group discussed the topic together.

The Advisory Board identified the following 10 topics as being of very high importance for health promotion for autistic youth:

### 3. PRIORITY TOPICS IN AUSTISM RESEARCH FOR ADOLESCENTS AND YOUNG ADULTS

#### (1) Sex and Sexual Health (inclusive of gender identity):

Most people on the autism spectrum experience sexual attraction<sup>31</sup> and many are sexually active,<sup>32-37</sup> including teens.<sup>38</sup> Up to 70% of autistic adolescent boys have engaged in partnered sexual behavior,<sup>39,40</sup> and one study found that autistic teen girls had comparable sexual activity to non-autistic girls.<sup>41</sup>

Sexuality brings opportunities for personal and relational fulfillment and introduces some preventable risks, particularly for youth. In the U.S., half of the 19-20 million new sexually transmitted infections (STIs) reported each year affect youth ages 15-24 years old.<sup>42</sup> Left untreated, HIV and other STIs have serious health consequences. Teen pregnancy, with higher risk of complications and opportunity costs, affects more youth in the U.S. than other industrialized nations.<sup>43</sup> Almost 2 million U.S. youth have experienced sexual assault and 9.8% report lifetime sexual abuse,<sup>44,45</sup> which can have lifelong health effects.<sup>46,47</sup> The ubiquity of the Internet and cellular phones brings new opportunities for learn-



ing and connection, yet also presents new avenues for health-risking behaviors<sup>48</sup> and abuse.<sup>49</sup> Autistic youth are particularly vulnerable to these adverse outcomes because they are excluded from both formal sex education<sup>50,51</sup> and the informal learning opportunities that most youth report as beneficial.<sup>52</sup> For these reasons, including autistic youth in existing sexual health pro-

gramming and providing accessible sexual health interventions tailored for autistic youth are both critically important.

Autism may also increase risk of socially inappropriate sexual behavior (SISB) or increase risk that SISB will lead to criminal justice contact. SISB are sexual behaviors that occur in public, without others' consent, or interfere with activities of daily living, and may include criminal sex offending.<sup>53</sup> A recent study (N=298) showed that 1 in 4 autistic adolescents had engaged in a person-oriented or public SISB (e.g., public masturbation, non-consensual touching) that parents knew of,<sup>50</sup> which exceeds rates in general samples of youth.<sup>54</sup> Online offenses (e.g., downloading child pornography, sexual communication with children) are an urgent focus of clinical and research concern in the autism field.<sup>55-58</sup> Despite the public health significance of these issues, services have focused on intervention after the fact rather than prevention.<sup>59</sup> This is a substantial problem because many autistic youth with SISB are adjudicated to the juvenile or adult justice systems where their specific cognitive and emotional needs and limits are unlikely to be recognized or accommodated.<sup>60-63</sup> Furthermore, adjudication for sex offenses can make it almost impossible to live and work in many municipalities subsequently.<sup>64</sup>

In addition to sexuality and relationships, gender is a central determinant of health and well-being across the life course. To highlight gender and sexuality-based marginalization, the National Institutes of Health (NIH) uses the phrase “sexual and gender minorities (SGM)” to refer to those who are lesbian, gay, bisexual, asexual, transgender, queer, intersex, or asexual. A substantial proportion of autistic adolescents and adults are SGM. Up to 22.1% of autistic survey respondents are transgender or gender non-conforming (T/GNC).<sup>65</sup> Moreover, T/GNC have 4-18 times the odds of an ASD diagnosis versus cisgender people.<sup>66-71</sup> Autistic survey respondents also identify as sexual minorities at high rates.<sup>37,72</sup> An ASD registry-based study (n=659) found 18.3% of autistic men and 43.4% of autistic women were lesbian, gay, or bisexual (vs. 4.5% of U.S. adults).<sup>65,73</sup> Thus, autistic SGM are a substantial and increasingly visible population.

The Advisory Board prioritized sexual health and gender identity as key for autistic health promotion. Stakeholders discussed topics like dating, pornography use, and the physical and emotional changes associated with puberty. Participants expressed their frustration that these health issues are not talked about or taught to autistic youth in school. Stakeholders also expressed concern about SISB and the need to find ways to teach

autistic youth about public versus private sexual behavior, and to manage impulsivity when it comes to sexual behaviors, without shaming them, making them feel blamed or judged for being autistic and sexual, and without worsening stigma about autism.

#### (2) Body awareness, body image and making healthy nutritional choices:

Autistic youth often experience sensory functioning that is different from neurotypical peers. Eating behavior can be particularly affected by olfactory and visual sensory processing differences.<sup>74</sup>

Autistic children are also more likely to be obese, and less likely to be physically active, than neurotypical peers.<sup>75-77</sup> Qualitative research suggests that some obese



autistic children experience weight stigma during clinical visits with healthcare providers, and in everyday interactions, and may experience fear, anxiety, anger and frustration about their weight and how people treat them because of their weight.<sup>78</sup> Some overweight autistic youth develop repetitive/restricted interests in weight and body image.<sup>78</sup> The Healthy Weight Research Network, a national research network of pediatric obesity and autism experts, has recently developed recommendations for managing overweight and obesity in autistic children that acknowledge the dietary and physical activity challenges faced by autistic youth and their parents.<sup>77</sup>

Autistic people are more likely to experience eating disorders than non-autistic counterparts.<sup>79</sup> Research suggests that alexithymia, or a difficulty identifying and describing one's emotional states, could contribute to the disparity.<sup>79</sup> Issues related to cognitive flexibility and central coherence may also influence eating behavior and eating disorder in autistic youth.<sup>80</sup> Autistic youth are also less likely than neurotypical peers to accurately perceive their own body size.<sup>81</sup> Several autism-spe-

cific eating disorder services are in development, but there are presently no guidelines or recommendations for providing helping services to autistic people with an eating disorder.<sup>82</sup>

The Advisory Board prioritized diet, body image, eating disorder, and making healthy nutritional choices as a topic because what autistic youth eat and whether they are getting adequate nutrition was viewed as fundamental to all other physical and behavioral health issues. There was widespread agreement that parents receive too little information about how they can encourage healthy eating by their autistic children and help them establish lifelong healthy relationships with food and positive body images.

### (3) Reducing loneliness and social isolation, and increasing social connections

The higher-than-average risk of suicide for autistic people without intellectual disability referenced above (and in Topic 6, below), may be attributable to social disengagement<sup>9</sup>—otherwise known as loneliness or social isolation. The lack of a social support system is suspected to affect psychological well-being and reduce instrumental support.<sup>9</sup> Social anxiety may also inhibit successful socializing for autistic and non-autistic people alike. Recent research suggests that part of the problem that autistic youth and adults may face in attempting to enrich social connections is that neurotypical people tend to form negative first impressions of autistic people based on “thin slices” of their behavior.<sup>83</sup> Within seconds, neurotypical people often reject an autistic person based on how they come across interpersonally—not based on the substance or content of what they are communicating—and neurotypical people do not change their intentions to avoid social interactions with that person with increased exposure.<sup>83</sup>

Advisory Board members were vocal about the need for additional intervention research that uncovers how to increase the social connections of autistic youth. Advisory Board members said that they were worried about isolation causing some autistic youth to not ask for help with psychological stress and other problems when they were facing them, and that it could cause them to wrestle alone with the psychosocial challenges of adolescence—potentially influencing their behavioral health trajectories in the long-term. Advisory Board members were aware of social skills groups and interventions that are designed to improve social skills, but pointed out ways in which social skills classes, groups, and interventions often target an autistic person’s behavior for modification without expanding

their social connections with other people in tangible or meaningful ways. For example, some autistic youth need concrete information about where to go to meet new people and opportunities to practice strategies for making new friends with similar-age peers.

### (4) Reducing vulnerability to violence, bullying, and exploitation

Bullying victimization is a substantial problem for many autistic youth.<sup>84-86</sup> As many as 26% of autistic youth experience bullying in elementary school, 31% in middle school, and 29% in high school.<sup>85</sup> Those who are bullied once face a 13.8-fold increased odds of subsequent bullying victimization as compared to autistic youth who are not bullied.<sup>85</sup> For typically developing and autistic youth alike, bullying victimization is associated with increases in mental health problems including depression, anxiety, and aggressive behavior.<sup>87</sup> Being bullied can also cause autistic youth to refuse to attend or engage in school.<sup>88</sup> Because autistic youth may also have difficulties interpreting complex social situations, they may also perceive themselves as being



persecuted or bullied when they are not.<sup>89</sup> Autistic individuals may also be at increased risk of partner violence victimization, and sexual and financial exploitation.<sup>90,91</sup>

persecuted or bullied when they are not.<sup>89</sup> Autistic individuals may also be at increased risk of partner violence victimization, and sexual and financial exploitation.<sup>90,91</sup>

Advisory Board members voiced the need for classes and programs, school policies, workplace trainings, and other interventions that would reduce autistic youths’ vulnerability to all forms of violence and abuse victimization. While some felt that dating abuse prevention, specifically, was less of a priority because establishing intimate partnerships is challenging for many autistic people, others expressed strong support for developing and providing healthy relationships and violence prevention education to autistic people in as widespread a manner as possible.

### (5) Workforce training for college and university faculty

The effect of education on health has been observed in many countries and time periods and is consistent across a wide range of health measures including life

expectancy and health outcomes.<sup>92</sup> At age 25, remaining life expectancy for people with a college degree is a decade longer than for people who do not have a high school diploma.<sup>93</sup> People with more education also tend to report being in better health and having fewer health conditions and limitations than those with less education.<sup>94,95</sup>

Autistic youth are underserved in the postsecondary education system. Although the existing secondary (K-12) educational system, and practice of inclusion in mainstream classrooms, is imperfect and leaves some autistic students without adequate support—it is also true that many autistic youth are able to access the K-12 general education curriculum, attend class with neurotypical peers, and graduate with their classmates. This doesn’t hold true for college and other post-secondary educational opportunities, and researchers think this could change.<sup>96</sup> Presently only 34.7% of autistic youth attend college in their first six years after high school.<sup>97</sup> Furthermore, supports provided to autistic college students tend not to be individualized or aligned with their needs such that many autistic students who begin college do not finish with a degree.<sup>98</sup> It is important for autistic students to receive proper supports to succeed in academic, social, and independent living skills aspects of postsecondary education.

Notably, there seem to be gender differences in both preparation for college and employment and in the experiences of autistic men and women in postsecondary education and work. In adolescence, autistic boys are more likely to participate in volunteer or work experiences than girls, and parents are less likely to talk with autistic daughters about careers and employment than with sons.<sup>99</sup> In adulthood, autistic women are considerably less likely to maintain postsecondary education or employment,<sup>100</sup> and have vocational trajectories that decline over time, regardless of co-occurring intellectual disability.<sup>101</sup>

Advisory Board members saw establishing training for college and university faculty to better support autistic college students as critical to the health of autistic youth. Although some materials about autism and autistic students are now available to support professional university and college faculty and staff, these are mostly disseminated by advocacy groups, individuals, and nonprofit groups.<sup>96</sup> As a result, what is critically important professional development is not consistently available to many educators who would benefit and typically only provided to faculty and staff who volunteer. To serve the 707,000-1.6M autistic youth reaching adulthood in the U.S. over the next decade, a more systematic approach is needed.<sup>102,103</sup>

## (6) Reducing suicide and self-harm

Autistic children are 28 times more likely than neurotypical peers to think about or attempt suicide.<sup>104</sup> The majority of autistic adults (72%) score significantly above the recommended cut-off for suicide risk in psychiatric populations, which is much higher than the percentage of adults in the general population (33%) who meet that threshold, adjusting for age and gender.<sup>105</sup> Autistic adults who do not have an intellectual disability, but do have attention deficit hyperactivity disorder (ADHD), are nine times more likely to die from suicide than neurotypical peers.<sup>106</sup> One study of adults



diagnosed as autistic in adulthood in the United Kingdom found that approximately 66% reported suicidal ideation, which was 9 times the rate of the general population.<sup>107,108</sup> Within the autistic subpopulation, some factors place autistic individuals at elevated risk for suicidal ideation including having greater unmet support needs, engaging in self-injurious behaviors, having depression or anxiety,<sup>109</sup> and having to “camouflage” or “mask” their autistic identity to fit in with others.<sup>105,108</sup> Some evidence suggests that academic performance and family function do not moderate the association between autistic traits and suicidality,<sup>109</sup> suggesting that interventions to reduce suicide and suicidality should target other factors.

The Advisory Board expressed strong support for additional research that would uncover why autistic youth are at markedly increased risk for suicidality and interventions to reduce that risk. Advisory Board members emphasized that autistic youth often begin to struggle with feelings of depression and thoughts of self-harm as early as middle school. Interventions, therefore, should target younger autistic adolescents as well as older adolescents and adults.

## (7) Supporting autistic youth and families during transition after high school

Transition age youth are those ages 14 to 30 years old who are in the phase of life when they complete schooling and training, plan adult career goals, consider changing their home or living environment to one that is more independent or without parents and guardians, and begin to formulate ideas about their adult lives that may include dating, sex, marriage, and parenting.<sup>110</sup> Transitioning from adolescence to mature adulthood is challenging for all people. For those on the spectrum, it may be particularly challenging, and so support for the development of the skills and capacities that they need to thrive as adults is essential.<sup>110</sup> Unfortunately, less than 20% of all published autism research, and approximately 2% of autism research funding in the U.S., targets the transition age group.<sup>111-113</sup>

The Advisory Board expressed frustration and fear about the fact that autism services often end abruptly when autistic children graduate from high school. One Board member said it felt to her that providers say “goodbye and good luck to you” when autistic children turn 22 years old and families are left to figure out how to address the needs of their autistic young people by themselves. Another Board member said that in her viewpoint, struggles with autism really begin at age 22 years old—because, at least, prior to that age there are opportunities to receive early intervention and school-based services. In Massachusetts, the Department of Developmental Services (DDS) offers an array of services to autistic youth less than 18 years old, but the service options change markedly once youth are older than 18. Furthermore, in Massachusetts autistic youth and adults who develop a comorbidity of depression, anxiety, or another form of mental illness must first go through DDS before applying to the Department of Mental Health (DMH) for support services. This process may deter autistic individuals and their families from seeking support due to the many steps involved.

Advisory Board members suggested that attention to the transition process should begin as early as middle school and receive full attention during the high school years. Autistic youth members of the Advisory Board who now live in dormitories and apartments without family spoke about the need for resources to help them navigate their emotions during the process of gaining independence, and to help them cope with the practicalities of daily life. Importantly, the Advisory Board also talked about the importance of not only educating autistic youth and their families about the transition period or process,

but educating employers and other community institutions to make them more receptive to autistic people. Programs that encourage people to be more accepting of neurodiversity, and equip them to make their workplaces and services friendly to neurodiverse people, were supported as high priority. An autistic youth member of the Advisory Board emphasized that finding a good system of support after high school is particularly difficult, and the Board agreed that attention to system improvement to support youth from middle school through adulthood is important.

## (8) Improving secondary school inclusion and educational options

In recent years the number of autistic youth that have been educated in mainstream schools has increased, but the educational outcomes are worse for these students than for neurotypical students or students with other developmental disabilities.<sup>114,115</sup> Inclusion is not the same as “integration” in the school setting; inclusion refers to the merging of special education and regular education in order to afford all



students full access to the same curriculum while accommodating learning differences, and integration refers to classroom settings in which autistic and neurotypical students learn side-by-side. The benefits of school inclusion may include reducing stigma about autism, social skills development, autistic youths’ engagement in more academic tasks, and experience with class-wide strategies to address behavior and social issues.<sup>114</sup> However, classroom inclusion may not result in better social relationships for autistic youth, and can lead to isolation, teasing, and bullying.<sup>114,116</sup> Teachers sometimes view autistic youth as disruptive and therefore undesirable in the classroom,<sup>117,118</sup> and too often there is insufficient funding for education assistants, reduced noise environments, appropriate equipment or time to provide additional teaching help to autistic youth, inconsistencies in the use of strate-

gies across the school day, between school and home, and between schools (i.e., when youth transition from elementary to middle school), and too little training about teaching autistic youth for teachers.<sup>114</sup> Teachers who educate autistic youth are too rarely provided with specialized support for the extra stressors they face when including autistic youth in their classes.<sup>114</sup>

Advisory Board members brought to the fore their own unsatisfactory experiences with K-12 public school systems. They felt that schools “tend to just move kids on the spectrum along,” without helping them achieve their full potential. One youth reported that finishing high school felt less like an academic achievement and more like “surviving a system,” and that “school felt like a pipeline to failure.” One of the experts on the Advisory Board reported that in her experience when families are able to enroll their autistic children in private school, either by working with the school district to get that as an accommodation or by paying privately, the outcomes for children tend to be better. Other Advisory Board members shared multiple stories about situations in which teachers have been unable to meet the needs of autistic youth in class and resort to sending them to the principal frequently. Although the national organization Asperger/Autism Network (AANE) provides training to 120 public school teachers per year on the topic of educating autistic youth, which is funded by the Massachusetts Department of Education, the Advisory Board felt that this was too little and too limited—teachers nationally need access to training on autism and educating autistic youth. The Advisory Board also suggested that secondary schools that have managed to develop model systems and practices for educating autistic youth should be held up as examples of best practices.

## (9) Understanding learning styles and teaching approaches to improve autistic youths’ academic achievement

Special education enrollment for autistic students has increased markedly over the past two decades, and schools struggle to provide adequate programming for these students.<sup>119</sup> Students with autism are a heterogeneous population, each with a unique set of educational needs. This means that educational approaches that prove successful for some are not successful for others.<sup>120,121</sup> Despite this, national models designed to guide teachers in best practices often prescribe a single teaching method that has demonstrated efficacy for subsets of autistic students (e.g., one-to-one discrete trial training, pivotal response training, incidental



teaching, positive behavior support, and Picture Exchange Communication System).<sup>122</sup> These methods are complex and require training and supervision to implement effectively.<sup>123</sup> For these reasons and others, evidence-based practices for autistic youth that are tested in university settings rarely make it to community settings like schools.<sup>124</sup> Given the lack of consensus about how to effectively engage autistic youth in academic tasks, and that methods teachers are taught to use will fail with a substantial proportion of autistic students, it may not be surprising to learn that surveys show teachers rarely use evidence-based strategies with autistic students in the classroom.<sup>125</sup> Neither general education nor special education teachers are well-prepared via coursework for providing inclusive education.<sup>126,127</sup> In one study, only 15% of teachers reported any training on effective teaching strategies for autistic youth from teacher preparation programs at colleges and universities, while the most common means of training (20%) were full- and half-day workshops.<sup>128</sup> Teachers need training on evidence-based strategies that engage autistic students in academic work and accommodate their learning styles, sensory needs, and executive functioning deficits.

## (10) Educating adolescents on the spectrum about autism and promoting self-advocacy

Understanding, accepting and feeling pride about autism (rather than shame, or exclusively negative feelings) can make a difference in mental health, and possibly other, outcomes. In general, healthy self-pride, also called authentic pride, is associated with better emotional and social health.<sup>129</sup> Research suggests that when youth think of ASD as a difference rather than a disadvantage, they may be more likely to feel pride, positive emotions, and cultivate coping strategies.<sup>130</sup> However, not all parents inform their children that they are on

the autism spectrum, and when they do, the parents typically have had little support for talking with their children about the autism diagnosis or about autism in general.<sup>131</sup> Moreover, research suggests that a sense of connection with the autism community might boost feelings of well-being in autistic individuals.<sup>132</sup>

Taken together, these findings suggest that an important topic for new intervention and research may be whether and how autistic youth are educated about autism, provided with access to the autistic community, and are encouraged to engage in self-advocacy. Advisory Board members talked about the possibility of fostering connecting and community between older and younger autistic youth so that older individuals who have overcome transition challenges or other hardships could provide peer mentoring. Some Board members pointed to the “It Gets Better Project,” which was founded in 2010 to support gay, lesbian, bisexual and transgender teenagers who experience bullying, as an example of a project that could be adapted to support transition-age autistic youth. One youth said that they felt disappointed that they did not really know much about their own autism diagnosis, or autism as a neuro-difference, and there was agreement among autistic youth that it would be helpful if they had opportunities to learn more. Parent members of the Advisory Board wondered if education about autism for youth on the spectrum may prevent bullying victimization.

### Additional topics

Additional topics in the priority list, ranked lower than the top ten priorities, included the following: teaching life skills (i.e., skills for becoming and remaining employed, budgeting money); reducing anxiety and depression, with the note that autistic people do not automatically qualify for services through Departments of Mental Health and that transitions such as from middle to high school might be particularly stressful; alcohol and other drug use; teaching hygiene; promoting exercise; limiting screen time and use of electronics; and addressing every body system when caring for autistic youth including but not limited to gastrointestinal problems, dental health, eyesight, and neurological issues. The Advisory Board wanted to emphasize that these topics were important and should not be viewed as non-prioritized. The reason that many did not make it into the top ten most prioritized may be that they are not as pressing during the transition age period but could become more urgent to address as youth grow older.

The Advisory Board emphasized the dramatic reduction in available services once youth became adults, which depending upon the services is defined at either 18 years of age or 22 years old, despite the desperate need for support during this time in the life course. The Board believed that the paucity of services for emerging adults represented a critical area of need, with preparation for transition needing to start during high school.

## 4. INTERVENTION RESEARCH

The leadership team undertook a scoping review of the peer-reviewed literature in order to identify evidence-based interventions that had already been tested through RCTs and were therefore appropriate for CER which compares head-to-head the effects of two or more interventions.

To be eligible for inclusion in our review, the intervention had to have been tested with youth ages 11-24 years old, and with one or more youth who were autistic. In some cases, we uncovered descriptions of interventions that seemed promising, but had not been RCT-tested. In other cases, we uncovered interventions that were tested with autistic adults, but not with autistic youth ages 11-24 years old. We excluded these studies because our

goal was to identify RCT-tested interventions that are effective for youth ages 11-24 years old and are ready to be compared through a comparative effectiveness research study. We also excluded studies if the target of the intervention did not match our priority health topics. For example, if our topic of interest was suicide, we did not include interventions that targeted depression but did not address suicide and self-harm. In the resulting list of interventions (see Table 1), we present the count of RCT-tested interventions—but not the count of RCT studies. Some interventions, such as the UCLA Peers intervention, KONTAKT, and Social Stories™, for example, have been the subject of multiple RCT studies. We count each of these interventions only once in our table below.

TABLE 1. RCT-TESTED INTERVENTIONS

Topic		Number of unique RCT-tested interventions identified	Names of tested interventions	
1	Sex and Sexual Health (inclusive of gender identity)	2	1. Supporting Teens with Autism on Relationships program	2. Tackling Teenage Training (TTT) program
2	Body awareness, body image and making healthy nutritional choices	0	--	
3	Reducing loneliness and social isolation, and increasing social connections	16	1. The PEERS Curriculum For School-Based Professionals: Social Skills Training For Adolescents With Autism Spectrum Disorder 2. Sociodramatic Affective Relational Intervention (SDARI) 3. SkillsStreaming 4. Social Stories™ 5. Multimodal Anxiety and Social Skills Intervention (MASSI) program	6. Sensory Enrichment Therapy 7. SENSE Theatre Intervention 8. Transitioning Together 9. SOSTA-FRA 10. Reciprocal Imitation Training (RIT) 11. KONTAKT 12. The ACCESS program 13. Alvin model of ‘Free Improvisation’ 14. The Superpower Glass intervention 15. Social Tools And Rules for Teens (START) 16. Mind Reading (Computer Software)
4	Reducing vulnerability to violence, bullying, and exploitation	1	1. Peers engaged in effective relationships decision making (PEER-DM)	
5	Workforce training for college and university faculty	0	--	
6	Reducing suicide and self-harm	0	--	
7	Supporting autistic youth and families during transition after high school	10	1. BOOST-A™ transition planning program 2. COMPASS Project 3. The Interpersonal Problem-Solving for Workplace Adaptation Programme 4. Integrated Employment Success Tool (IEST™)	5. Virtual Reality Job Interview Training (VR-JIT) 6. JobTIPS: 7. Project SEARCH / Project SEARCH plus Autism Spectrum Disorder Supports 8. Interview skills curriculum (ISC) 9. McGill Transition Support Program 10. Transitioning Together
8	Improving secondary school inclusion and educational options	8	1. Accessible Literacy Learning Curriculum 2. Virtual reality driving simulation training (VRDST) 3. PEGASUS 4. TOBY play-pad application 5. Cogmed WMT	6. Autism Spectrum Social Stories In Schools Trial (ASSSIST) 7. Picture Exchange Communication System (PECS) 8. High-tech Speech Generating Device (SGD)
9	Understanding learning styles and teaching approaches to improve autistic youths’ academic achievement	0	--	
10	Educating adolescents on the spectrum about autism and promoting self-advocacy	1	1. Pegasus	



The topics with the most RCT-tested interventions included social skills interventions and interventions to support autistic youth and families during the transition after high school. Interventions to reduce social isolation such as the SENSE Theatre Intervention, and the Multimodal Anxiety and Social Skills Intervention included building social skills and reducing anxiety through different methods such as artistic expression. Interventions to support transitions after high school included two formal transition planning programs and several job readiness and vocation-oriented interventions. There were also numerous interventions designed to improve how autistic youth learn in school and outside of school, including virtual reality driving simulations, phonics and language programs, memory training, and using social stories. Two interventions existed on sex, sexuality and sexual health including the Supporting Teens with Autism on Relationships (STAR) program

and Tackling Teenage Training (TTT) program. STAR is a facilitator-led, 6 session in person intervention that includes a parent curriculum and an interactive computer game for youth. TTT is also delivered by a professional, over the course of 18 sessions.

Notably, the field lacks interventions for autistic transition-age youth on the topics of eating disorders, healthy eating, positive body image and nutrition. Further, the field lacks RCT-tested interventions on reducing bullying victimization, reducing suicide and self-harm, expanding the capacity of college and university faculty to educate autistic youth, understanding the learning styles of autistic youth, and educating autistic youth about autism and promoting self-advocacy. Given that these were topics prioritized by the Advisory Board and are topics for which few RCT-tested interventions exist, they are particularly important topics for new research.

## 5. RECRUITMENT, INTERVENTION DESIGN AND OUTCOMES MEASUREMENT

The Advisory Board made a number of recommendations about optimal ways to recruit autistic youth into research studies as participants. The group suggested advertising through existing autism advocacy groups and networks, schools, and medical centers. Study advertisements should include pictures of people that adequately represent diversity across many different identities including women and Black, Indigenous and other people of color (BIPOC). Basic information about the study should be presented in an easy-to-read format. It should be clear that the study is seeking to recruit autistic youth from recruitment materials. If needed, specifics about whether the study is open to youth with intellectual disability, or those who are verbal and non-verbal, should be provided.

Advisory Board members enumerated multiple ways in which it can be beneficial to participate in research. These include the opportunity to enrich their sense of identity, develop autistic self-advocacy skills, a chance to “see change in the world,” and in some cases such as community-based participatory research, the chance to make new social connections. One participant said that she participated in research because she hoped to help generate information that would be useful to other families of autistic children, so that they had information that would have been helpful to her when her own child was young. Participation in some autism research may include the opportunity to meet peers in a safe space as

well as contribute to science. Advisory Board members both cautioned that remuneration that was too high should be avoided, as it could be coercive, raise concerns about the “invasive” nature of the study, or might also sound “too good to be true” to prospective participants, but that remuneration too low would be unjust. Most Advisory Board members did not feel that recruiting through social media (e.g., Facebook, Instagram, Twitter) would be effective because they personally are not active on social media (though of note the project leadership has done successful recruitment using these methods). With regard to consent, the Advisory Board suggested that study investigators list the requirements of the study several times, and emphasize that people have the option not to participate.

The Advisory Board also discussed a number of considerations related to intervention design including the optimal target age of participants, the degree to which parents should be involved and the best mode of intervention delivery. The Advisory Board emphasized the need for social skills and body image interventions to be introduced earlier in childhood (i.e., elementary school), but emphasized that these interventions should continue throughout adolescence. The Board recommended that sexual health interventions be delivered somewhat later (i.e., middle school or high school); of note, the youth and service providers favored introducing sexual health interventions somewhat earlier than



the parents (i.e., late elementary school/early middle school). In general, the Advisory Board believed that parents should be involved in interventions about key priority topics such as body image. The role of parents was less clear for sexual health interventions, with some Advisory Board members believing that parents were an important source of support, and others feeling less comfortable with active participation in sex and sexuality-related interventions. School was considered an optimal location to deliver interventions, as it allows autistic and neurotypical peers to learn together, and may be more accessible to all youth regardless of socioeconomic status than private-pay interventions at community mental health centers or other agencies. Members of the board did note that intervention providers need to be attuned to the issue of bullying, and ensure that interventions were delivered in a safe and supportive manner for all adolescents and young adults. All interventions should be designed and implemented with cultural humility and a recognition of intersecting identities and their impact on health and well-being.

Advisory Board members discussed the importance of not only measuring the impact of interventions on health outcomes, but also assessing more proximal measures such as establishing friendships, building self-esteem, and developing coping skills. Reporting on mood—including irritability and loneliness—was also considered important for some intervention research. Board members advised that measures should examine positive health outcomes as well as negative ones. Survey-based measures should be brief, specific and concrete to allow them to be more accessible to youth with a range of abilities. One autistic Advisory Board member suggested that breaking down constructs into “smaller pieces” that are assessed via separate survey questions would reduce burden on autistic survey respondents. Inclusion of both closed- and open-ended responses may allow the collection of richer data. However, Advisory Board members also stressed the importance of qualitative research. A high priority should be placed on capturing lived experience, mining wisdom acquired from real-life experiences, and “telling our story.”

## 6. SUMMARY

### RESEARCH AGENDA RECOMMENDATIONS TO BENEFIT AUTISTIC ADOLESCENTS AND YOUNG ADULTS

#### Research on priority topics

Priority	Research question or topic
High	Determine how Black, Indigenous and People of Color (BIPOC) and Latinx autistic youth experience key priority areas (e.g., social isolation; body image; bullying) similarly and differently than White autistic youth. What are the implications for interventions?
High	Test effective strategies to educate first responders about engaging with autistic individuals—particularly autistic men of color—, and deescalating volatile situations..
High	Examine how existing sexual health interventions be adapted to be inclusive of youth with diverse gender identities and of youth who are questioning.
High	Develop studies that incorporate implementation science frameworks that identify barriers and facilitators to implementation of RCT-tested interventions (such as the sexual health interventions) to facilitate more widespread implementation.
High	Identify specific factors, contexts, and situations that make autistic youth more vulnerable to physical, sexual, emotional and dating violence victimization in order to inform prevention efforts.
High	Investigate how knowledge about autism among autistic and neurotypical youth can influence the development trajectory of autistic youth. Assess whether engagement in self-advocacy is beneficial and if so, in what ways.

#### Intervention research

High	Develop and test interventions that promote healthy eating, positive body image, and good nutrition, and reduce eating disorders, among autistic youth. These interventions should engage the youth directly and not only provide parents with information.
High	Develop and test intervention to expand the capacity of autistic youth to recognize warning signs of violence, exploitation and bullying in interpersonal relationships.
High	Develop and test interventions that reduce suicide, suicidal ideation, and self-harm among autistic youth.
High	Compare the relative effectiveness of interventions to promote social connectivity and other social skills development
High	Develop training for college and university faculty and other educators and others in the workforce to promote better inclusion of and accommodations for autistic youth.
Medium	Develop and test interventions that teach autistic youth about autism and encourage self-advocacy.
High	Compare the relative effectiveness of existing sex and sexual health interventions
High	Compare the relative effectiveness of existing middle school, high school and post-high school transition interventions

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