



Autism Transition Planning, Community Participation, and Research Partnerships

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Let's start here...

[How can your community be more autism friendly?](#)



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6. Identify **strategies** OTs can use to support all three groups.

Be aware of **preferred** autism terminology

- Language changes
- No consensus over what is preferred right now
- Person-first language has been default
 - Person on the spectrum
 - Person with ASD or autism
- Identity-first language is emerging
 - Autistic
 - Autistic person
 - Autistic individual
- Mixed use of person-first and identity-first is acceptable
- Neurodiverse is in, Asperger's Syndrome is out.
- [Do you prefer person-first or identity-first language?](#)



Excerpts from *Spectrum*

- ...as of 2018 we use person-first and identity-first language interchangeably. As always, if a writer expresses a preference, we will defer to that. Our writers will also start asking sources on the spectrum how they prefer to be identified in a story.
- We believe using person-first and identity-first language interchangeably is the most inclusive choice, as it makes room for both preferences. Our intention underlying both approaches is the same: to write about autism in a way that is accurate, clear and respectful.
- [Citation: Spectrum News - About](#)

Identify participatory research guides for research **on or with** people with autism

- Academic Autism Spectrum Partnership in Research and Education (AASPIRE)
- Cooperative Research Centre for Living with Autism (Autism CRC Knowledge Centre)
- Practice-based guidelines for adults
- Emphasize **practical and adaptable use** of guidelines

AASPIRE guides

Guideline	How We Used Them
Transparent partnership goals	•Define partnership (equals vs. collaborators vs. consultants).
Clear community partner roles	•Define roles and expectations. • Share power with autistic partners.
Effective communication and power-sharing.	•Structure decision process. •Accommodate needs in advance. •Provide clear agendas, time to process, cues for transitioning.
Build and maintain trust.	•Respect all views. •Celebrate success and make space for humor and fun.
Collaboratively disseminate findings.	•Find ways to share projects that advance goals.
Encourage community capacitation.	•Offer opportunities to pursue education and participate in more projects.
Compensate community partners for work.	•Be transparent about project funding.

Cooperative Research Centre for Living with Autism (Autism CRC Knowledge Centre)

- Cooperative Research Centre for Living with Autism (Autism CRC) is **world's first national, cooperative research effort focused on autism.** Taking a whole-life approach focusing on **diagnosis, education and adult life**, Autism CRC researchers are working to provide evidence-based outcomes to be translated into **practical solutions.**
- [Inclusive Practice Guidelines and Checklists for Autism Research](#)

Guides

- 1: Engaging individuals with ASD as **research participants**
- 2: **Facilitating research groups** with individuals with ASD and families
- 3: Partnering with individuals with ASD and their families on **advisory groups or committees**
- 4: **Providing research results** to individuals with ASD and families
- 5: **Co-presenting** research with individuals with ASD and families
- 6: **Co-producing** research with people with ASD and families
- 7: **Recruiting and retaining individuals** with ASD as participants in longitudinal studies
- 8: **Evaluation of research outcomes** and impact
- 9: **Disseminating and utilising** findings

Transition Planning vs. Transitioning

- Transition planning in schools is a formal process
- Transitioning is movement from one task to another – it's different!

[Transition planning for autism](#)



Transition planning

- Focused on improving academic and functional achievement.
- Facilitates movement from school to post-school:
 - vocational - employment
 - education
 - adult services - independent living
 - community participation
- Based on needs, strengths, preferences, and interests.

From Region X Transition in Texas

- In Texas, adulthood is at 18. The student (regardless of the disability) becomes an adult, and rights transfer to them.
- The student is the decision maker in Admission, Review and Dismissal (ARD) meetings, and the one who consents to or refuses services.
- The parent will be notified of ARD meetings, this is not the same as invited. A parent may obtain legal guardianship, if they do not provide paperwork by 18th birthday, the district transfers educational rights to student.

Who participates in transition planning?

- Student
- Family
- Special and general education teachers
- Administrators
- Other staff - counselors, transition specialists, vocational adjustment coordinators, occupational therapists
- Agency representatives - others

Sample college-bound transition plan

Sample IEP transition plan for college-bound students

Supporting IEP goals and services		
Supporting IEP goal	Transition activities/services	Person/agency involved
By December 2020, Noah will fully complete two college applications with 100 percent accuracy.	Prepare a list of what Noah wants in a college. Research colleges and identify three he'd like to apply to that offer training and degree programs in early childhood education.	Noah, his parents, high school counselor
	Noah will obtain applications from each college and will plan a tour of at least one college of his choice.	Noah, his parents, college admissions offices
	Receive proofreading support to help check for errors in the applications.	Noah, his parents, transition specialist (school staff member who helps students transition to life after high school)
By May 2021, Noah will complete a college-skills course offered at a local college or nonprofit organization.	Look into possible programs that will help build organizational skills and prepare him for the demands of college. Apply to program.	Noah, his parents, transition specialist
By May 2021, Noah will identify three careers that involve working with young children.	Noah will find and interview three people in the community who work with young children.	Noah, transition specialist, local community members, possibly a private coach
By June 2021, Noah will apply to volunteer at a local childcare center.	Identify three local childcare centers. Ask about volunteering and complete an interview for each.	Noah, transition specialist, local childcare centers

Sample IEP transition plan for college-bound students

Name: Noah Lee

Grade: 11

Date:

Graduation date:

Student's strengths, preferences, and interests

Noah demonstrates that he's a hardworking student. He reported in an interview that he enjoys spending time with family and going to the gym. Based on transition questionnaires, Noah wants to go to college and is interested in a career working with young kids. However, he isn't sure if he wants to be a classroom teacher.

His most recent evaluation and present level of performance in his current IEP indicate that Noah has a specific learning disability in reading comprehension. He also struggles with time management when completing schoolwork, but he is meeting most of his IEP goals. Noah has acknowledged that his difficulties with organization may be a barrier to his goals after high school.

Measurable postsecondary goals

Postsecondary education/vocational training:

Noah will attend a local four-year college after graduation. He will take courses leading to a major in early childhood education.

Jobs and employment:

The summer after graduation, Noah will work part-time at a local childcare center.

Independent living (if needed):

Noah already has these skills.

Sample career-path transition plan

Sample IEP transition plan for students exploring careers

Supporting IEP goals and services		
Supporting IEP goal	Transition activities/services	Person/agency involved
By December 2020, Tanya will complete a career assessment to identify careers that match her strengths, skills, interests, likes, and dislikes.	Tanya will complete a career assessment and discuss the results with the transition specialist.	Tanya, her parents, transition specialist
By January 2021, Tanya will identify certificate programs for sports-related jobs like lifeguarding or coaching.	Tanya will do online research into certificate programs and discuss her findings with her guidance counselor and transition specialist.	Tanya, her parents, high school counselor, transition specialist
By March 2021, Tanya will identify three types of sports degrees she might be interested in pursuing in the future.	Tanya will meet with her coaches and the high school's athletic director to talk about sports degrees. She will also research degrees online.	Tanya, her coaches, high school athletic director
By April 2021, Tanya will identify five vocational schools, two-year colleges, or four-year colleges with programs she'd like to know more about.	When she has a list of five programs, Tanya will do basic research on their admissions process. Tanya, her parents, and her high school counselor will meet to talk over her list.	Tanya, her parents, high school counselor
By April 2021, Tanya will apply to a sports-related certificate program.	Tanya will obtain application forms, complete them, and submit them.	Tanya, her parents, high school counselor
By June 2021, Tanya will research job opportunities related to sports and begin the application process.	Tanya will obtain application forms for several job opportunities and will complete at least one.	Tanya, her parents, transition specialist

Sample IEP transition plan for students exploring careers

Name: Tanya Brown Grade: 11
Date: Graduation date:

Student's strengths, preferences, and interests

Tanya is a sociable teen who reported in her interview with the transition specialist that she likes to spend time with friends and play sports. She's on the high school varsity softball, swimming, and soccer teams.

In a recent interview with her parents and counselor, Tanya reported that she wants to be involved in a sports-related career. She would like to start working right after graduation, but she also plans to look into vocational or college programs in the field.

Based on her most recent evaluation and present level of performance in her current IEP, Tanya has ADHD and dyscalculia. She has difficulty focusing in class, especially in areas she struggles in, like math. Tanya doesn't drive due to anxiety, which may limit her job opportunities.

Measurable postsecondary goals

Postsecondary education/vocational training:

After graduation, Tanya will research and find vocational or college programs in sports medicine or athletic training.

Jobs and employment:

After high school graduation, she will find employment that is related to sports. After college or vocational training, Tanya will work in a sports-related industry.

Independent living (if needed):

Tanya will practice taking public transportation to allow her to get to work.

What literature reports happens to autistic people after transition and graduation

- Underemployment.
- Limited vocational and rehabilitation services.
- Employment is geared towards adults with specific needs, such as intellectual disability.
- Environmental factors are a factor in maintaining employment.
- Reported stress and challenges finding a job - environmental and interpersonal factors.
- Increased loneliness and isolation.

Our Research: A Case Study of Perceptions of Individuals With and Without Autism Regarding Social Participation

- Background:
- Individuals with autism experience different supports and barriers to social participation than non-autistic counterparts.
- Some may not be accounted for in school or community planning because they are not known or understood.

A Case Study of Perceptions of Individuals With and Without Autism Regarding Social Participation

- Method: We explored autism programs in the DFW metroplex, and interviewed nine individuals with autism, 14 community members, and 10 school employees.
- We queried participants about communication, social, sensory, programming, environmental, and interpersonal/social factors impacting social participation.
- We compared recurrent themes from interviews within and across groups and to DFW area program offerings.

Participant recruitment using pillars of NCLD as guidelines for maximum variation



Learning

The National Consortium on Leadership and Disability - Youth uses the five areas of youth development and leadership to guide their work.



Connecting



Thriving



Working



Leading

NCLD has built a movement of young leaders with learning and attention issues who are armed with the knowledge and skills to break down barriers for themselves and their peers.

A Case Study of Perceptions of Individuals With and Without Autism Regarding Social Participation

Results: We derived six categories and four themes showing similarities between perceptions of participants with and without autism:

- Communication challenges
- Education and exposure normalizing autism
- Needs for easing efforts required for participation
- Value of proactive planning

A Case Study of Perceptions of Individuals With and Without Autism Regarding Social Participation

- Conclusions: Differing perceptions of supports and barriers should be accounted for when programs support social participation of individuals with autism.
- Community and school programs partially meet needs in opportunities for social participation.

Highlights: A Case Study of Perceptions of Individuals With and Without Autism Regarding Social Participation

- Communication and social differences were least manageable barriers.
- Environmental and sensory sensitivities were most manageable barriers.
- Changing culture and increased exposure to autism were supports.
- Participants with ASD had person-specific knowledge but had few solutions.
- Community participants had situational knowledge and context-specific solutions.
- School participants had broad knowledge but limited it to school solutions.

Relevant Comments

- “People like me are kind of sensitive towards anything sensory. If anything happens out of the ordinary, we kind of get confused and try to figure it out. But in the worst cases, we just go crazy.”
- “I often feel if I asked for too much help, then I'll become a burden on other people. I don't think ... people often feel that way about me but ... I just had this sort of thing about it where I'm going to be too much of an imposition personally.”
- “I always had trouble when I was in school --- I had trouble. See --- I have trouble meeting new people and starting a conversation. I could

Relevant Comments

- “Repetitive body movements can be off-putting...but sometimes we're just fidgeting.”
- “People on the spectrum – it's harder for them to convey their ideas and ... and understand what people, other people, are conveying.”
- “It makes the world a lot smaller what you're willing to go do with them... we still try because, it's if you don't try...they'll never learn how to do anything.”
- “I get a little bit tired almost at the end of the day ... my mind really needs to be powered down like after I complete my homework”

Our Grant: Planning for Autism in Communities and Schools

- Create ASD rater teams and protocols to evaluate autism-friendliness of communities.
- For students and schools, outcomes include increased access to venues, understanding of how to provide their own accommodations, increased confidence to self-advocate, and decreased social anxiety and loneliness.
- For communities, outcomes are increased understanding of autism-friendly planning and events and helping other venues in their own self-study.

Our Partners and Plans

- Partners
 - TWU
 - My Possibilities
 - Local schools and agencies
- Plans
 - Create parallel curricula of autism supports for people with autism and communities and schools.
 - Create a website to house our work.
 - Provide links to the State, MP, and TWU for consumer use.

... 8 months to go ...

- We are developing our curriculum – self-aware, self-care, self-advocate.
- Clients with ASD work with TWU students on curriculum, developing visual and Lexile-based supports, and work on the community partner curriculum.
- We will hire TWU students to build a website and format curricula.
- We are recruiting autistic content reviewers and web designers.
- We are presenting at TOTA and have two articles in review, one in press.

One activity – portable sensory spaces

- Conceived as portable evidence-based sensory spaces, new (!) ice fishing houses are retrofitted with enough sensory equipment to be places to regroup but not overstimulate.
- Sensory spaces will be checked out to the community and manned by eOTDs
- Sensory spaces are being piloted at My Possibilities, Frontiers of Flight, Nasher Sculpture, Dallas Museum and people with autism are provided with a picture Likert scale survey to help rate the effectiveness of items.
- A website is in the works for...the Guardian...

INVENTORY

INSTRUCTIONS

CARE

RESEARCH

Sensory Spaces on Wheels

USER MANUAL



STELLAR LIGHTING
www.stellarlighting.co.uk

Meet the Guardian



FROM ONE WORLD INTO ANOTHER...

HOME

THE GUARDIAN

THE WONDER TWINS

THE SENSORY LEAGUE

UNDER THE SHADOWS

GET ON IT

From the Start...

The Guardian:

A Sensory Space for 2-3 Visitors

The Guardian is an Eskimo Quick Fish 2 ice fishing hub. It fits a footprint built from nine 2' foam tiles and has 25 square feet of floor space. It has no floor, allowing for easy insertion of electrical outlets under the shelter edge, and easy clean up of floor tiles. It can be tent staked or the skirt weighted with sand bags for windy settings.

The Guardian weighs 21.5 pounds, is 45" x 8.5" x 8.5" when collapsed for storage and transport, and is 60" x 60" when set-up. It has 2 small vents, four windows, and one door. It is black inside.

Special considerations: Some report the small size of the Guardian is relaxing. At 67" height, many adults will not be able to stand up in the Guardian, and older children will also have to duck to enter it.



Inside the Guardian



What can an OTP do?

- Actively participate in transition planning. Help with school hardening to make transition plans less difficult and unrealistic.
- Involve autistic people in research as participants and researchers. Allocate more time to do this. Be creative.
- Use the voices of a variety of stakeholders to create programs, avoiding pitfalls of creating too many programs for one age or ability level.
- Base program and educational strategies on UDL and UD. Include picture or image-based communication supports. Learn what Lexile measurement is.
- Learn more about post-secondary education opportunities for autistic students.

In conclusion...from one of our autistic participants...

“After high school, what?”

Thank you for being here.

I would like to thank the Texas Higher Education
Coordinating Board for supporting our outlandish ideas.

What are your questions?

