

22Q and Boo Resources for consideration in NJ/PA

Madeline Chadehumbe, M.D., FAAN Chief Medical Officer October 27, 2024

Autism in 22q11.2 syndrome

- The diagnosis is not always assigned when some individuals do meet criterion
- Significant social challenges in children all the way to adulthood need intervention
- Services are limited when diagnoses not accurate
- Previous estimates of 15-50% are likely underestimates. Recent trial cites 82%.
- What are downsides to getting that "label" if indicated?





https://www.artoffriendshipsocialskills.com/

Haverford, PA

6-8 year old GIRLS group

Thursdays, 4:30pm

6-8 year old BOYS group

Thursdays, 5:30pm

9-11 year old BOYS group

Mondays, 5:30pm

14-16 year old BOYS group

Mondays, 4:30pm

Paoli, PA

4-5 year old Co-Ed group

Tuesdays, 3:30pm

6-8 year old Co-Ed group

Saturdays, 3:00pm

4-5 year old Co-Ed group

Fridays, 3:30pm

9-11 year old BOYS group

Fridays, 4:30pm

9-11 year old Co-ed/GIRLS group

Fridays, 5:30pm

12-15 year old BOYS group

Wednesdays, 4:30pm

16-19 year old BOYS group

Wednesdays, 5:30

Plymouth Meeting, PA

4-5 year old Co-Ed group

Wednesdays, 3:30pm

6-8 year old Co-Ed group

Mondays, 4:30pm

9-11 year old GIRLS group

Thursdays, 5:30pm

9-11 year old BOYS group

Wednesdays, 5:30pm

12-15 year old BOYS group

Fridays, 5:30pm

Center City, Philadelphia

6-8 year old Co-Ed group

Mondays, 4:30pm

9-11 year old BOYS group

Tuesdays, 4:30pm

12-15 year old BOYS group

Wednesdays, 5:30pm



https://www.phillyarttherapy.com/child-adolescent-art-therapy-andsocial-skills-groups

Philadelphia Art Therapy Associates

a division of Child & Family Art Therapy Center, P.C.

Mailing (administrative) address:

600 Haverford Rd.

Suite G-101

Haverford, PA 19041

Phone:

610.649.1080

Fax:

610.649.0503

Email:

connect@childandfamilyarttherapycenter.com





https://elbabehaviorsolutions.com/events/

Social Skills Events

Now Accepting Registrations For:

South Philly: Social Skills Group | TUESDAYS

Fairmount Pediatrics (East Norriton): Social Skills Group | WEDNESDAYS

Fairmount Pediatrics (Philly): Social Skills Group | THURSDAYS

Fairmount Pediatrics (Philly): Social Skills Group | SUNDAYS

Bache-Martin School: Social Skills Group |

THURSDAYS





https://www.elevatedkids.com/services/elev 8-social-skills-groups/





Locations

110 Church St, Philadelphia 1100 N. Delaware Ave., Philadelphia South Jersey, New Jersey Long Island & Brooklyn, NY Austin, Texas





 https://equilibriapcs.com/psychologistsphiladelphia-therapists-philadelphia/



Adult Clients
Therapy



Children & Teens
Therapy



Marriage & Couples
Relationship Counseling



Parents & Co-Parents
Therapy and Coaching



Emergency Responders

Therapy



Biofeedback Therapy

LOCATIONS

Society Hill:

525 S. 4th Street

Suite 471

Philadelphia, PA 19147

Fishtown:

1516 N. 5th St

Suite 401

Philadelphia, PA 19122

Media:

105 W 3rd Street

Media, PA 19063

LOCATIONS

Lafayette Hill:

632 Germantown Pike

2nd Floor

Lafayette Hill, PA 19444

Broomall:

2004 Sproul Road

Suite 206

Broomall, PA 19008

Willow Grove:

630 Fitzwatertown Rd

Suite A1

Willow Grove, PA 19090



By Design Social Skills & Counseling Center

South Jersey

Individualized Therapy for Children, Teens, & Adults

- https://www.socialskillsnj.com/teensocial-skills-group
- Monmouth County
- Aberdeen, Atlantic Highlands, Belmar, Brielle, Colts Neck, Deal, Eatontown, Fair Haven, Farmingdale, Hazlet, Highlands, Holmdel, Howell, Little Silver, Manalapan, Manasquan, Marlboro, Matawan, Middletown, Ocean, Ocean Grove, Red Bank, Rumson, Sea Girt, Shrewsbury, Spring Lake, Tinton Falls, Wall, West Long Branch
- Northern Ocean County
- Bay Head, Brick, Mantoloking, Point Pleasant, Toms River, Island Heights

Lego Social Skills Groups



Lego & Games Club - Ages 5 to 8

Teen & Tween Groups



<u>Teen Thrive Tribe</u>
Open to High School Students



Jersey Shore area



Group Schedules

Tuesday 6-7 PM High School Group
Thursday 5:15-6:15 PM Elementary Group
Thursday 6:30-7:30 PM Middle School Group

We are IN-Network with Blue Cross/ Blue Shield

Groups may be reimbursed by your Out-Of-Network insurance benefits. We will gladly check with your insurance company for you!



Social Skills Group Therapy

520 Main Street Toms River, NJ

Phone:

(732) 600-0971

Email:

ckaspermsw@yahoo.com



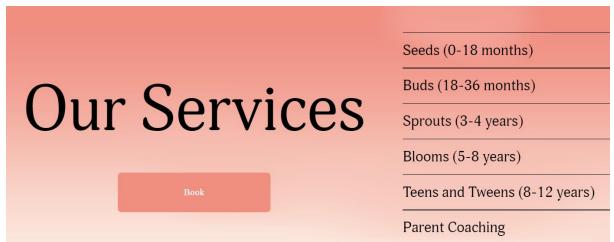
Jersey Shore area

https://www.sproutand playnj.com/

Questions?

Email Us: sproutandplaynj@gmail.com

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New Jersey - SW

Coffee Talk With The Speechies

Chew and Chat

Join our comprehensive caregiver training course designed to equip you with practical tips and strategies to enhance your child's feeding experience.

- Team up with professionals to expand your toddler's diet
- Help your child find enjoyment in mealtimes
- Learn how to safely transition your infant to solid food

SIGN UP TODAY





Meet likeminded parents while learning tips and tricks to enhance mealtimes in your home!

Friday, Nov. 8th

6:00 - 7:00 pm

Nurture & Nourish Maternal Wellness 949 Lacey Rd. Forked River, NJ

We'll bring the coffee 🛡 Little ones always welcome 🛡

\$15 Chew and Chat

\$20 Chew and Chat plus Tiny Talkers Toolkit Course



Contact US

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Co-Founder/Owner

Co-Founder/Owner

Kate Compton, M.S., OTR/L

SLP, PROMPT Trained

Occupational Therapy Supervisor

SLP. PROMPT Certified (732) 910-4074

(732) 996-6532

(908) 902-3276

Co-Owner

Email us at: breakthroughpediatrictherapy@gmail.com

Breakthrough Pediatric Therapy is accepting new clients at our office location: 1806 Route 35, Suite 207 in Oakhurst, NJ.





Young adult resources

- NJ Special Needs Resources for Adults and Young Adults in Transition | Facebook
- https://spectrum360.org/independence360/

Programs Overview

Academy360

Independence360

FilmAcademy360

CulinaryAcademy360

Programs Overview

Academy360

Independence360

FilmAcademy360

CulinaryAcademy360

Find out about our comprehensive day habilitation program that enriches the lives of adults with autism and related disabilities through education, socialization and therapeutic support.







Programs Overview

Academy360

Independence360

FilmAcademy360

CulinaryAcademy360

Explore our film, digital media and graphic arts programs. From classroom studies to instudio experiences, FilmAcademy360 students work on productions which build social, emotional and communication skills.





Young adult resources

- https://rcaas.rutgers.edu/PSC/services/therapy
- Therapy | Rutgers Center for Adult Autism Services

PEERS for Young Adults

PEERS for Young Adults is a social skills intervention for adults with ASD who are interested in learning new skills to make and keep both social and romantic relationships. Over the course of a 16-week period, young adults attend weekly group sessions that cover a variety of social skills.

These skills include, but are not limited to:

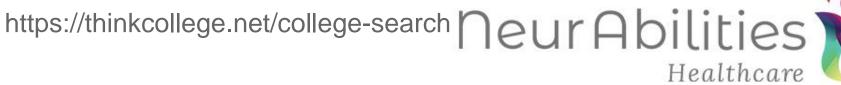
- Conversational skills
- Appropriate sense of humor
- · Handling direct and indirect bullying
- · Electronic communication
- Handling arguments and disagreements
- Organizing get-togethers with friends
- · Dating skills
- Strategies for handling sexual pressure





College experiences

- College Programs for Autism, ADHD, Dyslexia, Disabilities | College **Consultants**
- https://www.topcollegeconsultants.com/autism-in-college/
- https://arc.tcnj.edu/2018/03/14/lion-plus-program/
- https://rcaas.rutgers.edu/
- https://www.neurodiversitynetwork.net/neurodiverse-universitiesinitiatives
- Teach program at Rider University
- https://www.thearcfamilyinstitute.org/spceial-campiangs/collegeprograms/college-programs.html



General

- For all types of counseling:
- www.psychologytoday.com
- They support age 18+, please call us at 855-932-RISN (7476) to schedule an appointment with one of our primary care physicians.
- https://centers.rowanmedicine.co m/risn/
- https://youtu.be/NFoqNV2Sg5Y
- SAIL program: https://jfcssnj.org/socialrecreational-programs/





ABA Therapy

In the state of PA – no need for autism diagnosis

Available in NJ and PA locations: www.neurabilities.com

- Freehold, NJ
- Cherry Hill, NJ
- Allentown, PA
- Bala Cynwyd, PA
- Bethlehem, PA
- Center City, PA
- Harrisburg, PA
- Hatboro, PA
- King of Prussia, PA
- Lancaster, PA
- NE Philadelphia, PA
- Seaport in Chester- Delaware Co, PA
- Wexford, PA
- Wyomissing, Berks Co, PA









School Accommodations List of considerations

- 1. Learning Challenges and Academic Accommodations
- Executive Functioning: Many children with 22q11.2 deletion syndrome struggle with planning, organizing, and completing tasks.
- Accommodations:
- Provide visual schedules and checklists to break down assignments into smaller, manageable steps.
- Use graphic organizers to aid in organizing thoughts and structuring writing assignments.
- Offer extra time for assignments and tests.
- Allow for flexible due dates when possible.
- Memory and Processing: These children may have difficulties with working memory, long-term memory, and processing speed.
- Accommodations:
- Break down information into short segments and check for understanding frequently.
- Use repetition and allow extra time for response during class participation.
- Provide written instructions in addition to verbal instructions.
- Allow note-taking assistance or provide teacher notes for review.
- Math Difficulties: Math learning disabilities, such as dyscalculia, are common.
- Accommodations:
- Use manipulatives and visual aids to reinforce math concepts.
- Provide step-by-step instructions for multi-step problems.
- Allow the use of calculators or math software for complex calculations.
- Reduce the number of math problems required to demonstrate mastery.
- Reading and Language-Based Learning: Children with 22q11.2 deletion often have difficulties with reading comprehension and language processing.
- Accommodations:
- Offer audio books or text-to-speech software to aid reading comprehension.
- Provide reading materials at the child's reading level, even if it's below grade level.
- Allow extra time for reading assignments and tests.
- Use multisensory reading programs and activities.



For children with 22q11.2 deletion syndrome (also known as DiGeorge syndrome or velocardiofacial syndrome), school accommodations must address a range of learning, behavioral, and emotional challenges. The following is a comprehensive guide to accommodations across these domains to help support educational success for children with this condition.

- 2. Speech and Language Challenges and Accommodations
- Expressive and Receptive Language: Challenges in both understanding and expressing language.
- Accommodations:
- Work with a speech-language pathologist (SLP) to develop individualized language supports.
- Encourage the use of visual aids and gestures to support verbal communication.
- Allow extended time for responses during class participation.
- Use assistive communication devices if needed.
- Articulation and Phonological Processing: Physical anomalies and processing difficulties may affect speech clarity.
- Accommodations:
- Provide speech therapy as part of the child's individualized education plan (IEP).
- Implement alternative methods of assessment (e.g., oral assessments).
- Encourage peer understanding and provide education on respectful communication.
- 3. Social, Emotional, and Behavioral Accommodations
- Social Skills: Many children with 22q11.2 deletion syndrome have social skill deficits and can struggle with peer interactions.
- Accommodations:
- Facilitate social skills groups or peer-buddy systems.
- Use role-playing or social stories to help with understanding social cues.
- Assign a "safe person" the child can turn to when overwhelmed socially or emotionally.
- Anxiety and Emotional Regulation: Anxiety, especially in social or academic settings, is common.
- Accommodations:
- Provide a quiet, low-stimulation area where the child can take breaks as needed.
- Collaborate with a counselor or psychologist to incorporate coping strategies for managing anxiety.
- Offer predictable routines and prepare the child in advance for changes in routine.
- Allow access to a calm-down box or sensory materials.



- Behavioral Challenges: Impulsivity, ADHD, and oppositional behaviors can be part of the 22q11.2 deletion profile.
- Accommodations:
- Use positive behavior reinforcement strategies, with rewards for meeting behavioral goals.
- Provide a structured environment with clear rules and expectations.
- Implement a behavior intervention plan (BIP) if needed, created in collaboration with the child's support team.
- Allow movement breaks and offer tasks that allow the child to expend physical energy constructively.
- 4. Fine and Gross Motor Challenges and Physical Accommodations
- Motor Skills: Delays in fine and gross motor skills can impact writing, gym, and other activities.
- Accommodations:
- Provide occupational therapy for fine motor skill development.
- Allow the use of a keyboard or speech-to-text software for assignments if handwriting is a struggle.
- Modify physical education requirements to focus on participation and effort rather than competition or skill.
- Allow extra time for tasks that require motor coordination.

5. Additional General Accommodations

- Homework and Assignments:
- Limit homework quantity, focusing on mastery of critical concepts.
- Allow extensions or adjustments to homework based on fatigue and daily functioning.
- Testing Accommodations:
- Use alternative assessments (oral, multiple-choice, project-based) to gauge understanding.
- Provide a distraction-free testing environment.
- Allow open-book tests or formula sheets as necessary.
- Parental Communication:
- Implement a daily communication log between home and school to ensure continuity of support.
- Schedule regular check-ins between parents, teachers, and the child's care team to adjust accommodations as needed.



More community resources...

- 1. Elwyn www.elwyn.org
- 2. **ASERT Autism Resource Center** www.paautism.org
- 3. Vision for Equality www.visionforequality.org
- 4. The Arc of Philadelphia www.arcpddc.org
- 5. Philly Autism Project www.phillyautismproject.org
- 6. Community Integrated Services (CIS) www.cisworks.org
- 7. Kinney Center kinneyautism.sju.edu
- 8. NJ Division of Vocational Rehabilitation Services (DVRS) www.nj.gov/labor
- 9. Easterseals New Jersey www.easterseals.com/nj
- 10. **JEVS Human Services** www.jevshumanservices.org



- 11. Jewish Family and Children's Services (JFCS) www.jfcsphilly.org
- 12. Special Olympics New Jersey <u>www.sonj.org</u>
- 13. Bancroft NeuroRehab www.bancroft.org
- 14. Disability Rights Pennsylvania www.disabilityrightspa.org
- 15. **Temple Institute on Disabilities** disabilities.temple.edu
- 16. **Supportive Behavioral Resources** www.supportivebehavior.com
- 17. **Goodwill of Southern NJ & Philadelphia** www.goodwillnj.org
- 18. Camden County College <u>www.camdencc.edu</u>
- 19. Bucks County Community College www.bucks.edu
- 20. Montgomery County Community College <u>www.mc3.edu</u>



- 21. **Next Step Programs** <u>www.nextstepprograms.org</u>
- 22. **Abilities Solutions** <u>www.abilities4work.com</u>
- 23. Eden Autism Services <u>www.edenautism.org</u>
- 24. PA Assistive Technology Foundation www.patf.us
- 25. Disability Rights NJ www.disabilityrightsnj.org
- 26. Arc of New Jersey www.arcnj.org
- 27. Parents of Autistic Children (POAC) www.poac.net
- 28. **NJ Transit Access Link www.njtransit.com**
- 29. Friendship Circle of Philadelphia www.phillyfriendship.com
- 30. Alliance for Full Participation www.allianceforfullparticipation.org



Thank you!!!

