

Skirboll Family Autism Conference Panel: Navigating Next Steps Following an Autism Spectrum Disorder Diagnosis

November 4th, 2021

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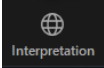
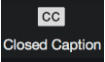

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MEDICINE *of* THE HIGHEST ORDER



Housekeeping Announcements

- ❖ Spanish live interpretation is available by clicking “Interpretation” at the bottom of your screen. 
- ❖ English captioning is available by clicking “Closed Caption” at the bottom of your screen. 
- ❖ Presentation materials and recordings will be available after the event on the DBP website at <http://event.urmc.edu/Skirboll>.
- ❖ Attendees’ video and audio is automatically turned off.
- ❖ Use the Q & A to ask presenters questions. They will be answered at the end of each session. 
- ❖ Attendees will receive an email with a link to an evaluation survey and certificate of attendance. We value your feedback!

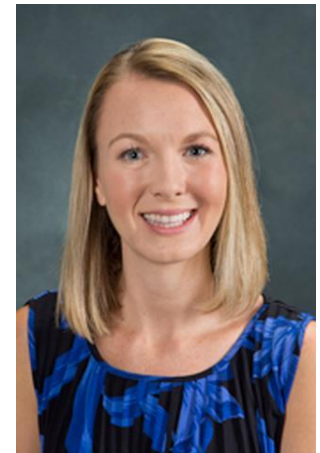
Navigating Next Steps Following an Autism Spectrum Disorder Diagnosis



Lisa R Luxemberg, LMSW



Kelly Manigault



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Disclaimer

Information shared during this panel is intended to provide **general** tips and resources to families, providers, and individuals with autism, that may or may not be helpful or available to you specifically.

Information shared does not constitute medical or other professional advice or services. Tips shared do not constitute a formal therapeutic-patient or consultant-consultee relationship.

Please remember that information shared is not specific to you or your child. Discuss these resources and recommendations with your or your child's therapists, doctors, and educators to determine what will be most beneficial for you.

How do I best prepare for my child's evaluation/visits/meetings?

- ❖ Write down questions you have/things you want to cover before the visit
- ❖ Write down observations of your child to share
- ❖ Take videos of your child to show providers
- ❖ Bring someone with you
- ❖ You or someone else can take notes



What does an autism evaluation consist of? What information is needed /what is used?

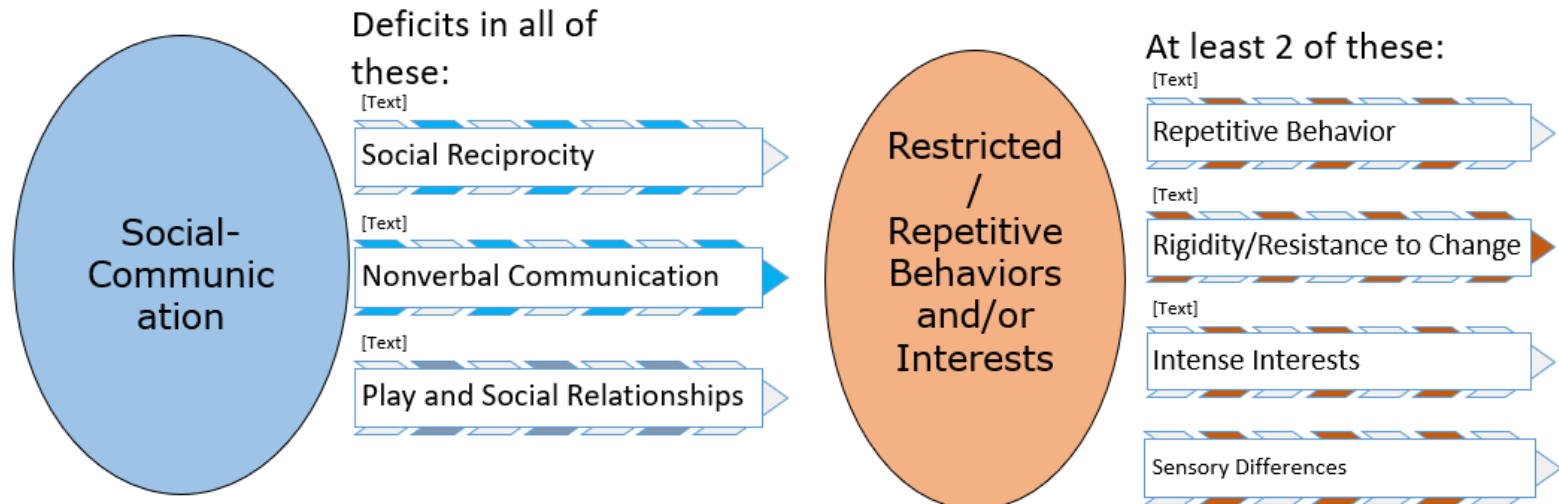
Often consists of:

- Collecting background information from parents, school, providers
- Obtaining information on child's cognitive and adaptive skills
- Completion of standardized screening measures (M-CHAT, SCQ)
- Directly observing the child (or adult)
- Administration of a standardized autism assessment by a provider
 - CARS-2 (Childhood Autism Rating Scale)
 - ADOS-2 (Autism Diagnostic Observation Schedule)***

What does an autism evaluation consist of? What evaluations are used?

Clinician is figuring out whether your child meets DSM-5 diagnostic criteria for ASD, that symptoms are long-standing, and that they are not better accounted for by something else.

Autism Spectrum Disorder



What are the first signs of autism?

Very hard to identify/diagnose before 18 months

Some parents recall noticing:

- Few social smiles
- Limited eye contact
- Little back-and-forth sharing of sounds, smiles, and facial expressions
- Little babbling
- Lack of gestures (pointing, waving)
- Little response to name

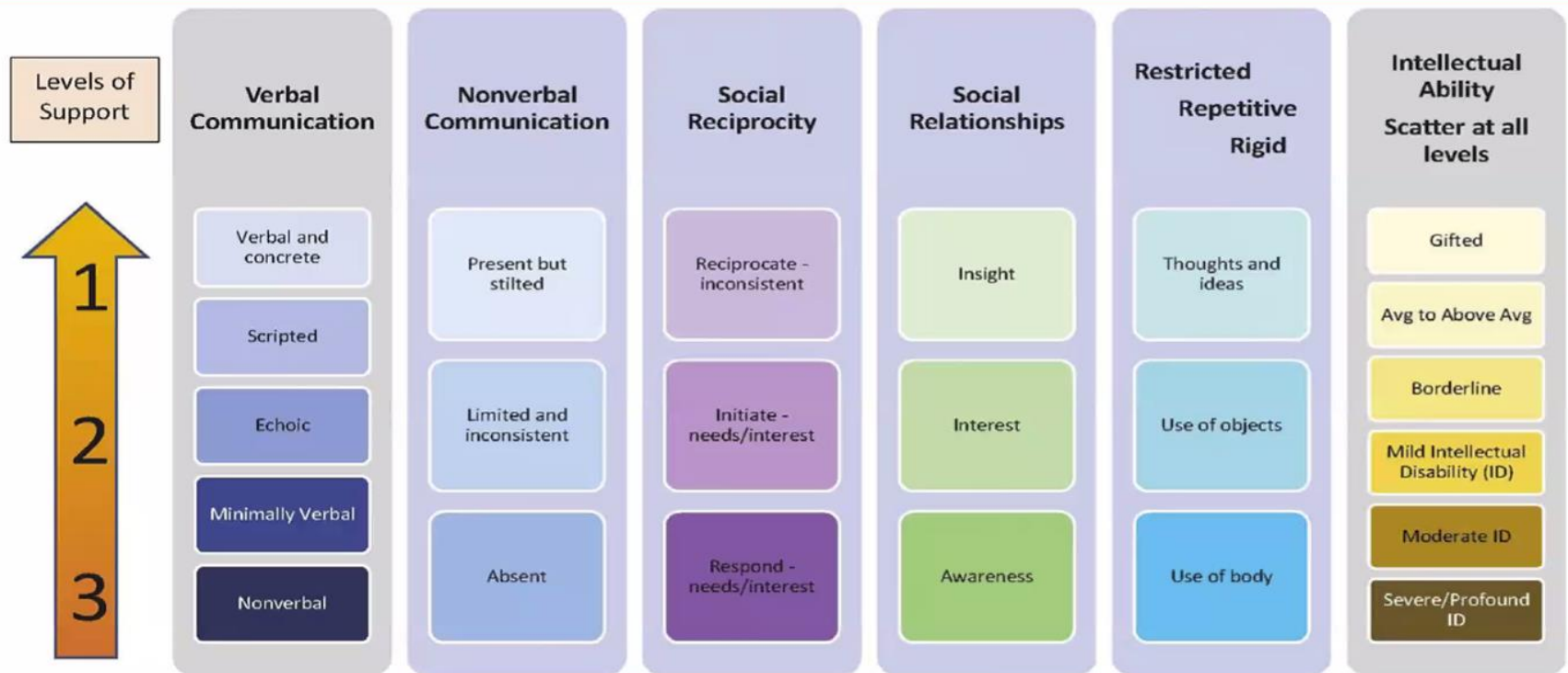


Online Screening Tool (16-30 months): <https://www.autismspeaks.org/screen-your-child>

Common Questions

Where is my child on the spectrum?

So hard to answer!



Core Domains: Social Communication and Interaction
Restricted, Repetitive Behavior, Interests, Activities

Common Questions

What will their “symptoms”/autistic traits look like when they are older?

Again, so hard to answer! We are very bad at predicting.

Things we do know can help:

- A child being in a loving, supportive family
- Development of some language in early years
- Average to above-average cognitive skills
- Early intervention, and your child responding to intervention



10

Common Questions

Can my child “grow out” of their autism?

Typically, no.

Traits can vary throughout the lifetime.

~10% of individuals diagnosed with ASD will “drop” the diagnosis in their lifetime.

What is the difference between a medical diagnosis and educational classification?

Medical diagnosis is a formal diagnosis obtained through an outside, licensed provider

Educational classification is a classification on a child's IEP for special education services

[Deeper Dive 13 Classifications Starbridge Updated3.6 \(starbridgeinc.org\)](#)

They are not dependent on one-another, and one does not necessitate the other



How can schools/clinicians support a family in getting a diagnosis? What if there is resistance?

Pursuing a diagnosis is a personal decision for the individual and/or family

In some cases, a diagnosis has little-to-no practical implications

Always ask “how will this help?”

Are there other ways to get this help?

Explore feelings and perceptions in a non-judgmental way

Weigh the pros and cons

Empathize with concerns

Educate on the benefits, if there are clear ones

What information should I share with my child's school?

- ❖ Pursue a school classification- your child may be eligible for other therapies.
- ❖ Let the teacher know how they communicate .
- ❖ Discuss with the teacher your child's sensitivities
 - ❖ Example: If they have food texture issues ask for the lunch menu so you know what the school will be serving
- ❖ Very important to let the teacher know if your child is at risk of elopement and develop an elopement plan.
- ❖ Keep the teacher informed if your child is having a bad morning or has not gotten a lot of sleep.
- ❖ Be available if your child's teacher needs to talk to you.

CREATING A POSITIVE HOME/SCHOOL RELATIONSHIP

Get to know your child's school team (who is involved in your children's day- Specialist teachers, OT, PT, Speech, Music, Art, etc)

Set up an agreement about the best way to communicate with each other (email, notebook, text)

Tell the teachers about your child - examples from <https://www.busykidshappymom.org/writing-to-your-childs-teacher/>

Questions To Get You Started – Can be used for any age:

- ✓ **How does your child approach school or learning? (apprehension or excitement)**
- ✓ **How would you describe your child's learning style? (hands-on, visual, etc)**
- ✓ **What kind of environment do you think your child learns best in?**
- ✓ **Child's strengths and weaknesses academically and socially**
- ✓ **Hobbies your child enjoys, special interests**
- ✓ **Your home situation (pets, divorce, death, new baby)**
- ✓ **Social skills**



TIPS ON WORKING EFFECTIVELY WITH YOUR CHILD'S SCHOOL TEAM

Begin by communicating clearly and being a good advocate for your child while working with the school district. Keep in mind they have regulations that they have to follow as well.

How can I learn to be a good advocate?

- Starbridge inc (www.starbridgeinc.org) has a lot of good information and tools. One is a Guide to Prepare for School meetings-
www.starbridgeinc.org/images/files/Starter_Set_Family_Student_Meeting_Prep_Starbridge.pdf
- It helps families to think about what is working and what are the areas of concern and how to discuss them at a CSE/CPSE meeting.
- There is a system for requesting more services or new evaluations at every district. We recommend putting your request in an email to the chair of the CPSE/CSE and include the child's teacher. You can request a meeting anytime.
- REMEMBER- Keep calm, use examples of what is NOT working and share potential solutions. Put timeframes on how long it might take.
- Bring an advocate or other therapist with you to meetings

How can clinicians support a family when receiving the diagnosis and starting next steps?

Every family (and person within the family) will have a unique and personal reaction to the diagnosis (or not receiving a diagnosis). Assess expectations, hopes, fears, and feelings.

Always use **EMPATHY** and **COMPASSION**.

Some families will be eager and ready to get started with next steps

Others will feel overwhelmed and need time/space to process first

For families who are ready for next steps:

What is most important to them?

Help them break it down, and come up with concrete next steps (max of 3)

Write it down

Use “teach-back”

What is the most critical step after receiving a diagnosis?

It depends on the values and needs of the family and individual. We don't know what is most important to them.

Some common first steps:

- For children over 3: Share the diagnosis with the school and schedule a CSE/CPSE meeting. Determine if they would benefit from an IEP or additional support.
- For children under 3: Share the diagnosis with their PCP to access early intervention, if your child doesn't have this. If they do receive EI, talk to your care coordinator to see if they would qualify for more services.



What Types of services are immediately available to families upon initial diagnosis?

There are no services that you get immediately upon diagnosis and the needs of families vary. Here is a list of services you may want to think about: **An autism diagnosis doesn't automatically qualify your child(ren) for OPWDD.**

1. **OPWDD** :They provide your family a Care Coordinator that can assist you in accessing services/ programs that support your child with a disability, including funding to cover them. You have to be approved for OPWDD.
2. **SCHOOL** : IEP/ 504 plan, counseling, speech, OT, PT, Music therapy, Adaptive PE, Special Ed or smaller classroom.
3. **Local agencies and programs that support children with a disability.**
 - Parent to Parent (national organization)- NY (www.parenttoparentny.org)
 - Challenger Sports (national organization) - <https://www.challengersports.org>
 - Autism Speaks- Local NYS resources, clinics, toolkits and webinars- <https://www.autismspeaks.org/>
 - Golisano Autism Center, Auitism UP, Camp Puzzle Piece and others.
 - Internet searches, Facebook groups

What therapies are available for my child with an autism diagnosis?

Most of these therapies can be accessed with or without a diagnosis

Early intervention therapies

- Speech therapy
- Occupational therapy
- Physical therapy
- SEIT

School therapies

- Speech therapy
- Occupational therapy
- Physical therapy
- Autism or behavior consultation
- Social skills support
- Behavior support (for any challenging behaviors)
- Safety supports (such as for elopement or other dangerous behavior)
- A supportive classroom setting



What therapies are available for my child with an autism diagnosis?

ABA Therapy

Social Skills Groups

Parent-Mediated Behavior Therapy

Feeding Therapy

Individual therapy for other concerns

What is ABA and how do I access it?

ABA stands for Applied Behavior Analysis.



ABA is a therapy approach often used for individuals with autism. Currently, it is our most evidence-based intervention for children with autism.

The goal of ABA is to teach your child appropriate behavior and new skills, and decrease inappropriate behavior.

In ABA, skills are broken down for your child and taught in small steps. The idea is that your child learns through consequences, such as rewards and reinforcement for their behavior.

What is ABA and how do I access it?

Currently, your child needs an autism diagnosis to get ABA (although this is changing!).

You have to check with your insurance provider to see if it is covered. ABA is not currently covered by Medicaid (also, something we are working on changing).

A few local organizations who offer ABA therapy:

- Proud Moments ABA: <https://www.proudmomentsaba.com/rochester-ny-aba-therapy>
- Center for Autism and Related Disorders (CARD): <https://www.centerforautism.com/services/aba/>
- Autism Learning Partners: <https://www.autismlearningpartners.com/>

How to get Mental Health Services without waiting 6 months or more?

Finding Mental Health Services can be challenging, especially with COVID. Here are some ways to try and find services...

1. **County Mental Health Office-** They usually take all insurances and have all different types of providers (LCSW, LMHC, Psychologists and Psychiatrists)
2. **Talk to your Pediatrician-** More and More offices are having Mental Health services as part of their offices.
3. **Talk to the school counselor, Social Worker or CSE team** to see if your child can meet with them in school or if they know of any community providers taking new patients.
4. **Use www.psychologytoday.com to find a MH provider.** When you go on the site, you will see “find a therapist”, when you push enter it will take you to a second page. There are a lot of filters on that page.

Keep in mind that Mental Health Services vary in availability due to – insurance, ages they can serve, location and if it is a good match for your child.

Is there an organization or agency that we can go to for financial assistance?

Children with a disability can get Medicaid or Medicaid Waiver through one of two programs-

1. **SSI**- Children with a qualifying diagnosis and the families income are factors in getting SSI. To see if your child qualifies you can apply at : www.ssa.gov/ssi

2 **OPWDD**- Office for People with a Developmental Disability (every county in NY has an office)

Region 1 Finger Lakes: **1-855-679-3335** (Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Wyoming or Yates County)

Region 1 Western NY: **1-800-487-6310** (Alleghany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara or Orleans County)

Region 2 Broome: **607-771-7784** (Broome, Chenango, Delaware, Otsego, Tioga or Tompkins County)

Region 2 CNY: **315-793-9600 x603** (Cayuga, Cortland, Herkimer, Lewis, Madison, Oneida, Onondaga or Oswego County)

Region 2 Sunmount: **518-561-8190** (Clinton, Essex, Franklin, Hamilton, Jefferson or St. Lawrence County)

Region 3 Capital: **518-388-0398** (Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren or Washington County)

https://www.opwdd.ny.gov/welcome-front-door/Front_Door_Contact_Numbers

Families with private insurance can get "Medicaid Waiver" (Medicaid is based on a diagnosis and the finances of the family are waived, for qualification). Children on OPWDD can have a primary and secondary insurance.

How do I explain the diagnosis to my child?

Generally, we do recommend sharing the diagnosis with your child. This gives them an opportunity to understand, process, and accept who they are and their uniqueness.

Many children/individuals will find relief in their diagnosis. They often already know they are different, and may already ask questions (e.g., Why do I have to go to so many appointments? Why do I ride the small bus?).

Most adults take pride in their identity as an autistic individual.

Meeting and interacting with others with autism can have positive impacts.

How do I explain the diagnosis to my child?

Talk to your child's providers- they may be able to help!

Explanation should be individualized and appropriate for their understanding

- Keep it simple at first. Can get more in-depth as the child understands and grows. This is going to be an ongoing, and perhaps lifelong process.

Can start by talking about differences and diversity in general

Stay positive! Point out more strengths than challenges.

Example: Talk about you child's super powers (like their hearing!)

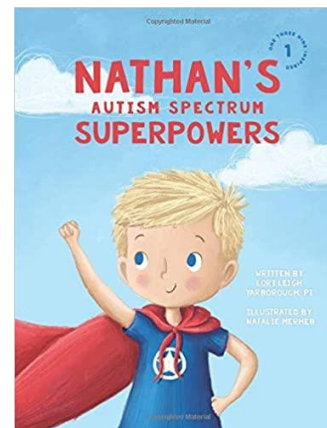
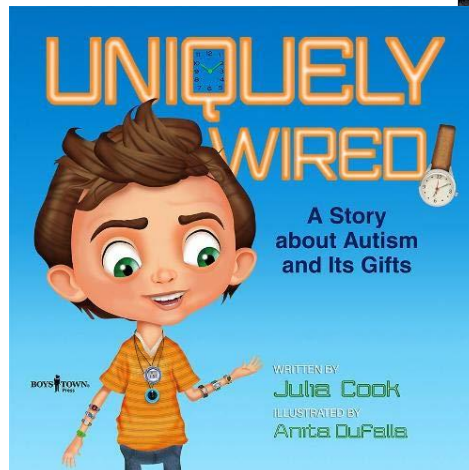
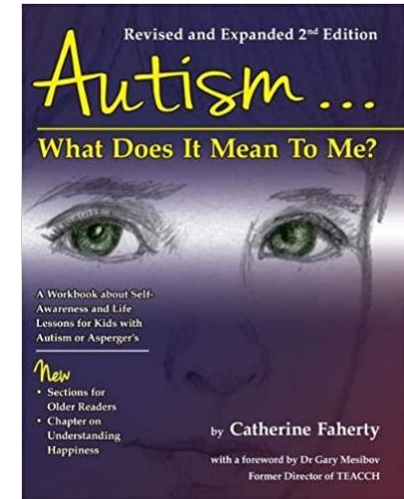
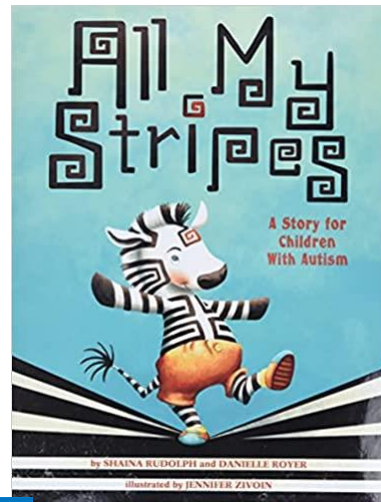
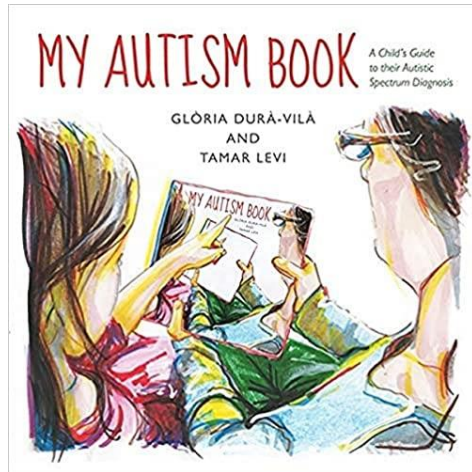
Use books, workbooks, and videos to help.

Example: Watch videos of others talking about having autism



27

How do I explain the diagnosis to my child?



How do I involve my child's siblings?

- ❖ Use books and television shows to explain and discuss the diagnosis (example: "Atypical")
- ❖ "Certain things you are born knowing . For example, you are born knowing smiling means being happy. Your brother is not born knowing that so we have to teach him."
- ❖ Have siblings join therapy sessions:
 - ❖ They can join parent training sessions
 - ❖ They can "help" in direct therapies, like ABA (e.g., teaching how to throw a ball back). They then may feel like they can help in other situations

How do I explain my child's differences to my family?

Involve :

- ❖ Invite family members to autism support groups
- ❖ Ask family members to attend school meetings



Educate:

- ❖ Explain what and why your child might have a meltdown, as family members may not understand and can be very judgmental giving unwanted advice .
- ❖ Explain routines and sensitivities your child may have
- ❖ Try Youtube "autism TMI virtual reality experience" which allows you to see the world through the eyes of an autistic person.

Prepare:

- ❖ Family events could be harder for a child with ASD, due to sensory issues, social interactions and expectations.
- ❖ Plan ahead - Find a quiet spot for your child to go to, if needed. Pack foods they prefer. Educate the people at the event about your child best that you can.
- ❖ For family dinners google the restaurant menu and bring quiet toys, tablet with headphones.

How can I continue to best support my child ?

- Pursue for both school evaluations/ assessment (psychoeducational, OT, Speech, PT) and medical assessment /diagnosis, request specialists referral, if needed.
- Teach your child to communicate when they need a break. Use Visuals, timers, or set up a break corner for your child.
- Allow them to have a tough day or moment. Give them tools and space to calm down and regroup.
- **For providers:** please keep in mind for families members might be in different places, as far as accepting the diagnosis and be patient. Support families where they are, but encourage them to seek supports and services, as a way to help their child grow.
- **For parents:** Take time for yourself and do self-care.

Have a non-kid outing with friends, sit quietly with your favorite beverage, go for a walk or talk a class. Find what works for you and give yourself permission to take the time to do that thing. ***You will be a better parent if you take time to take care of yourself.***

How do I find my "Village" connecting with other families?

Every family has different needs and the services available vary by county, so what can you do to find your "village" support network?

- ❖ Parent to Parent – Sign up for their emails. They will post on what other local agencies are doing, webinars and activities.
- ❖ School class - reach out and talk about a meet up or play date.
- ❖ Outings through local organization - Parent to Parent can help you find these.
- ❖ Facebook groups
- ❖ Use your work place as more and more kids are being diagnose you may have a coworker who has child is on the spectrum.
- ❖ Autism UP - family meet ups (currently virtual)
- ❖ Autism Speaks
- ❖ Developmental and Behavioral Pediatrics Family Navigators can look for activities in your area, if you email with specifics of what you are looking for- familynavigator@urmc.rochester.edu



Connect With Us!

Developmental and Behavioral Pediatrics (585-275-2986)

- <https://www.urmc.rochester.edu/childrens-hospital/developmental-disabilities.aspx>
- <https://www.facebook.com/DBPeds.GCH/>

DBP Family Navigators (585-273-4513)

- familynavigator@urmc.rochester.edu