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Resources for High Support Needs Autism

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What are “high support needs”?

When people use the term “high support needs” regarding autism, they are usually talking about individuals who need consistent, ongoing support across many areas of daily life.

In formal diagnostic terms, this generally aligns with Autism Spectrum Disorder, Level 3, as defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), which is described as “requiring very substantial support.”

What does that actually mean?

Every autistic person is different. That said, individuals with high support needs often share some common support patterns:

- **Have limited or no spoken language.** Some individuals may not use spoken words at all. Others may use a few words, scripts, or echolalia (repeating words or phrases they’ve heard). Many communicate in other ways such as gestures, pictures, or communication devices (AAC). In most cases, they need support from others to reliably express needs, make choices, or be understood.
- **Need help with daily living skills.** This can include eating, dressing, toileting, bathing, and managing daily routines. Even when someone can do parts of these tasks, they may still need prompting, supervision, or hands-on help to complete them safely and consistently.
- **Experience significant sensory sensitivities.** Sounds, lights, textures, and crowded environments can be overwhelming or even physically painful. This is not a preference.

It is a real neurological response. Sensory differences often shape where someone can go, how long they can stay, and what environments feel manageable.

- **Show repetitive behaviors or rely on strong routines.** This might include repeated movements, use of objects, or needing things to happen in a certain way. These behaviors are not random. They often support regulation, predictability, or communication. When routines are disrupted, it can be genuinely distressing and may lead to shutdowns or escalation.
- **Need close supervision across settings.** Many individuals require ongoing support at home, in school, and in the community to stay safe and engaged. This can include help with transitions, recognizing danger, and navigating everyday expectations.

Important things to understand

- “High support needs” describes the level of support, not the person’s value or potential.
- Support needs can change over time with the right supports in place.
- Communication and understanding may look different, but they are always there.
- The goal is not to “fix” the person. It is to increase quality of life, access, and well-being.

Why this term matters

Using “high support needs” shifts the conversation away from labels and toward a more useful question:

What does this person need to be safe, understood, and able to participate in daily life?

For families and caregivers, that question helps guide real-world decisions:

- **Services and supports** -This framing helps families advocate for the right level of support, not just any support. That may include therapy (behavioral, speech, occupational), in-home services, respite, or specialized medical and behavioral care. The focus becomes what daily life actually requires for this person.
- **Communication approaches** - For many individuals, spoken language is not the most reliable form of communication. This is where AAC, visual supports, and structured systems become essential. The goal is that the person has a dependable way to express needs, preferences, and feelings.

- **School and adult programming** - Supports should match the person, not just their age or diagnosis. This may include specialized classrooms, individualized supports, life skills instruction, or structured adult programs. The focus is on meaningful participation, safety, and engagement.
- **Long-term planning** - Planning often needs to start earlier and be more intentional. This can include decision-making supports or guardianship, housing options, financial planning, and continuity of care. Clear understanding of support needs helps families plan for a future that is stable, supported, and respectful across the lifespan.

High Support Needs and Safety

Individuals with Autism Spectrum Disorder (ASD) who require high levels of support often experience unique and complex safety challenges related to communication differences and societal barriers. They may experience increased vulnerability during emergencies due to limited verbal communication/difficulty communicating needs, reduced awareness of danger, heightened sensory sensitivities and challenges with self-regulation, and/or interpreting social cues.

Wandering/Elopement

One of the most prevalent and serious concerns is wandering or elopement. These behaviors can occur at any age and in any setting and may result in exposure to life-threatening situations such as traffic accidents, accidental falls, or drowning. Research shows that drowning is one of the leading causes of death among individuals with ASD, particularly children, with many incidents occurring after a person wanders toward nearby bodies of water.

Water Safety

Water safety is therefore a critical area of focus. Building swimming and floating skills can significantly reduce risk, especially for individuals who are naturally drawn to water. Families are encouraged to explore swim lessons within their local communities, as low-cost or free options are often available for individuals with disabilities. In some cases, insurance plans including certain Medicaid programs may offer coverage or reimbursement for swim instruction. Families are advised to contact their insurance provider directly to learn about available benefits, eligibility requirements, and approved programs.

In addition to skill development, consistent safety practices are essential. These include close and continuous supervision near water, swimming with a partner, and reinforcing simple, repeatable safety rules. Educational tools such as child-friendly books, songs, and community-based safety campaigns can also support learning and increase awareness in engaging and accessible ways.

Other Safety Concerns

Safety risks for individuals with high support needs may also include challenges related to medication and poison safety, as well as increased vulnerability during emergencies such as severe weather events. Because of these factors, individuals may have difficulty understanding or responding appropriately to dangerous situations in their environment.

Proactive planning, individualized supports, and targeted strategies such as safety education, environmental modifications (e.g., door alarms or locks), and connections to local organizations are vital to reducing risk and promoting well-being. Community programs, such as CARD, can further support families by offering safety materials, resources, and opportunities to build practical skills.

[Jump to Safety Resources](#)

Community, Opportunity, and Acceptance

For individuals with high support needs, being part of the community is not just about access. It is about meaningful inclusion, safety, and respect.

And the reality is this: opportunities may not look like what is often highlighted in media or even in broader autism conversations. But they are no less valid or important.

Social opportunities

Engaging in social opportunities affords your loved one space to interact with others with or without disabilities, engage in social skill development, and gain peers. Social connection is possible for everyone. It just may not look the way people expect. Some individuals may not seek out traditional friendships or group activities. Others may prefer being around people in quieter, more structured, or more predictable ways.

Social opportunities might include:

- Spending time with familiar, trusted people (family, support staff, small groups)
- Being near others while engaging in preferred activities
- Participating in community outings with the right supports in place (for example, sensory friendly events)

The goal is not to push or force interaction. The goal is to create opportunities for connection that feel safe, comfortable, and meaningful to the person.

Employment opportunities

Employment is often part of the conversation, but for individuals with high support needs, it requires honesty, flexibility, and the right level of support.

Some individuals may participate in:

- Supported or customized employment
- Volunteer roles
- Structured day programs with purposeful, engaging activities

For others, traditional employment may not be a realistic or appropriate goal, and that is okay. What matters is not checking a box labeled “employment.” What matters is access to meaningful daily activity, a sense of contribution, and engagement in the world around them.

Gaps in representation

This is an area that families often feel, even if it is not always named.

Many public conversations about autism focus on individuals with fewer support needs. As a result:

- People with high support needs are often left out of the conversation
- Their experiences may be misunderstood or minimized
- Families may feel isolated, unseen, or even dismissed
- Policies and services may not reflect the true level of support required

All autistic individuals deserve visibility, respect, and appropriate resources, including those with the highest support needs.

What is true acceptance?

True acceptance goes beyond awareness campaigns or statements about inclusion.

- It means recognizing autistic individuals as whole, valuable people whose ways of communicating, interacting, learning, and experiencing the world are valid.
- It means providing the level of support a person actually needs, even when that support is intensive, while still respecting autonomy.
- It means designing environments that adapt to the person, rather than expecting the person to adapt to everything around them.
- It means valuing quality of life, comfort, and dignity.

Acceptance is about meeting people where they are and ensuring they are supported to live a life that is meaningful to them.

Resources and Tools

CARD-USF has compiled the following resources and tools with input directly from families with loved ones who have high support needs, autistic self-advocates, and other caring professionals in our community. The inclusion of a provider should not be considered an endorsement. Please contact CARD-USF for personalized assistance with finding service providers.

- [Register Online](#)
- **Phone:** (813) 974-2532
- **Email:** card-usf@usf.edu

Not in our catchment area? [Find your local CARD.](#)

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Florida Statewide Systems and Agencies

Ages served	Agency/Resource	Services Description
Birth to 24 months	<u>Baby Navigator</u>	Offers free resources, tools, and self-screeners for families to track and support early learning and social development.
18 to 24 months	<u>Autism Navigator</u>	Offers free resources, tools, and self-screeners for families of children diagnosed with or at risk of autism.
Birth to 36 months	<u>Early steps</u> Phone: 1-800-218-0001 Email: <u>EarlyStepsDirectory@flhealth.gov</u> Search for your local office <u>here</u>	Early Steps is Florida's early intervention system. Infants and toddlers are assessed in the following developmental domains to determine eligibility: physical, cognitive, communication, social-emotional and adaptive.
Under 5 years	<u>Child Find</u>	Child Find coordinates with school districts to locate children who are potentially eligible for services under the Individuals with Disabilities Education Act (IDEA) and links them with needed services. They provide diagnostic screening, placement, training and support services.
Ages 3+	<u>Agency for Persons with Disabilities (APD)</u> Phone: (850) 488-4257 Toll-Free: 1-866-APD-CARES (1-866-273-2273) Email: <u>APD.info@apdcares.org</u>	APD offers a wide range of social, medical, residential, and behavioral services. There is a lengthy waitlist for services, so parents are encouraged to apply early. APD Also administers the <u>Medicaid iBudget Waiver</u> program, which includes support coordination and case management services.

Birth to 18 years	<p><u>Florida KidCare</u> Phone: 1-888-540-KIDS (5437)</p>	<p>Florida KidCare includes free, subsidized and full-pay options for health insurance based on family income and household size. Florida KidCare has year-round enrollment, so you do not need to wait for an open enrollment period to apply.</p>
School Age	<p><u>Florida Inclusion Network (FIN)</u></p>	<p>The Florida Inclusion Network (FIN) provides services to schools and districts to increase and improve inclusive practices for students with disabilities in general education classrooms and other natural settings. When contacted for support and assistance, FIN can provide families with a variety of information and resources and may, upon request, contact the district's exceptional student education (ESE) office or school to discuss concerns on behalf of the family.</p>
School Age	<p><u>Family Network on Disabilities (FND)</u> Phone: (727) 523-1130 or (800) 825-5736 Online form: https://fndusa.org/contact-us/</p>	<p>FND provides assistance and support to parents, educators, community organizations, and faith-based groups to increase the kinds and types of parental involvement and engagement to increase student academic achievement across Florida.</p>
School Age	<p><u>Florida Diagnostic & Learning Resources System (FDLRS)</u></p>	<p>FDLRS Parent & Family Services provides information, training, and support to districts and families to promote effective parent participation in the education of children with disabilities or exceptionalities.</p>
Ages 14+	<p><u>Florida Division of Vocational Rehabilitation (DVR)</u> Phone: 850-245-3399 and 800-451-4327 Find local offices here</p>	<p>Vocational Rehabilitation (VR) is a federal-state program that helps people who have disabilities get or keep a job. VR has programs that help students with disabilities begin the transition process starting at age 14 as well as programs for adults of all ages.</p>

Ages 14-22	<u>The Able Trust</u>	A foundation dedicated to supporting employment and independence for Floridians with disabilities. The Able Trust provides youth programs that give high school students opportunities to explore career and post-secondary options and develop skills for the workforce.
All Ages	2-1-1 Dial 211 on your phone to connect to your local hotline or visit the 211 locator website .	A free, confidential referral hotline that can help connect you to numerous local services including financial assistance, food assistance, housing benefits, mental health/crisis resources, and more.
All Ages	<u>Autism Society of Florida</u> Email: info@autismfl.org Phone: 407-207-3388	A community advocacy group. Offers support groups, social skills groups, and community events.
All Ages	<u>Disability Rights Florida</u> Phone: 800-342-0823 Toll Free: 850-488-9071	A legal advocacy group dedicated to protecting the rights of individuals with disabilities. Their services are free and confidential.
All Ages	<u>Child Care Resource & Referral</u> (provided by local Early Learning Coalitions) Phone: 1-866-357-3239 (Toll free) or 866-357-3239. Find your local coalition here	Whether you need information, help finding child care or other family assistance, you can turn to Child Care Resource and Referral Services at your local early learning coalition . They can help you find quality childcare and connect you with other community resources such as food, medical care, workforce support, housing assistance, creative financial assistance options and more.
All Ages	<u>Supplemental Security Income (SSI)</u> Phone: 1-800-772-1213 Apply Online: https://www.ssa.gov/benefits/ssi/	The Supplemental Security Income (SSI) program provides monthly payments to adults and children with a disability or blindness who have income and resources below specific financial limits

All Ages	<u>Florida Center for Independent Living</u>	<p>CILs are consumer-driven, non-profit organizations who support community living and independence for people with disabilities based on the belief that all people can live with dignity, make their own choices and participate fully in society.</p> <p>CILs provide tools and support for integrating people with disabilities fully into their communities.</p> <p>CILs serve all disabilities and all ages in every county in Florida.</p>
All Ages	<u>Florida Alliance for Assistive Services & Technology (FAAST)</u> Phone: +1 844-FL-FAAST TTY: 1-877-506-2723 Email: Info@FAAST.org	<p>FAAST is a nonprofit dedicated to increasing access to assistive technology. Their services include short term device loans, training, and financial assistance.</p>
All Ages	<u>Wrightslaw</u>	<p>Parents, advocates, teachers, and attorneys come to Wrightslaw for reliable, up-to-date information about special education law and advocacy for children with disabilities.</p>
All Ages	<u>Florida Developmental Disabilities Council</u>	<p>Florida Developmental Disabilities Council focuses on advocacy and policymaking for individuals with developmental disabilities all across Florida. They offer an advocacy training program called Partners in Policymaking</p>
All Ages	<u>Family Care Councils (FCCs)</u> Find your local Council here .	<p>Family Care Councils (FCCs) advise the Agency for Persons with Disabilities (APD) on local needs, gaps in services, and advocate for people with developmental disabilities and their families.</p>

Safety Resources

If you have safety concerns, please contact CARD for assistance with personalized resources and strategies!

- [Register Online](#)
- **Phone:** (813) 974-2532
- **Email:** card-usf@usf.edu

Not in our catchment area? [Find your local CARD.](#)

General Safety

- Contact CARD-USF to see if you qualify for a FREE [CARD Safety Kit!](#)
 - Para español: [Consejos de seguridad](#)
- [CARD Emergency Communication Board](#)
 - Para español: [Tarjeta de comunicación en caso de emergencia](#)
- [Medipal Seatbelt ID Insert](#)

Water Safety

Swim lessons are essential! Please check out options in your local community for free or low cost lessons. CARD's Resource Office can assist you in finding lessons near you.

- Find Swim Lessons: [CARD Swim Lessons Directory](#)
- [CARD Autism Spectrum Disorder & Water Safety](#)
 - Para español: [Trastorno del Espectro Autista & la seguridad en el agua](#)
- [Being Safe with Elena – Swim Safety for Kids!](#) (VIDEO)
- [Being Safe with Elena – Swim Safety for Adults](#) (VIDEO)
- [Autism Society of Florida drowning prevention resources](#)
- **Josh the Otter wants all kids to know:**
 1. Learn to float!
 2. Always swim with a buddy.
 3. Always be with an adult when in or around water.

[Water Safety Bookmark](#)

- Para español: [Seguridad en el agua: Marcador de libro](#)

[Water Guardian Postcard](#)

➤ Para español: [Tarjeta seguridad en el agua](#)

[Visit his website](#) to learn more, sing songs with Josh and read the book together. Josh the Otter loves to give high fives when he's out in the community. Follow our social media to see where he might be spotted near you!

Swim lesson scholarships & vouchers:

- [WaterSmartFL](#) – Check frequently to see when the application window opens!
- [Every Child A Swimmer](#)
- [Florida Drowning Prevention Foundation](#)
- [Just Against Children Drowning](#)
- [Step Up for Students](#)
- Some Medicaid plans may cover swim lessons! Yes, some Florida Medicaid plans cover swim lessons as an expanded benefit, but coverage varies by plan and requires verification with your specific insurance provider.

How to find out if your plan covers swim lessons

- 1. Check your insurance card:** Look for the Member Services or Customer Service phone number on your insurance card.
- 2. Call your provider:** Contact the Member Services number on your card to inquire about swim lesson coverage and benefits.
- 3. Ask about eligibility and the application process:** Inquire about any age restrictions, the application process, and whether a voucher or direct reimbursement is provided.

Examples of possible plan benefits*:

- **Sunshine Health:** Offers a Care Grant that can cover up to \$150 annually for swim lessons for children up to 18 years old, as well as a swim lesson benefit for Child Welfare plan members under 21.
- **Humana Healthy Horizons:** Provides an expanded benefit of up to \$200 per year for swim lessons, with a focus on preventing water-related accidents.
- **Simply Healthcare (Florida Healthy Kids):** May provide benefits for swim lessons, but specific amounts and limits (such as \$160 for the first 1,250 members) can vary.

[Go to: Resources](#)

**This information is subject to change and should be verified for your specific plan. Each program has its own eligibility criteria and requirements. Check with your insurance provider for full details.*

County Resources

Hillsborough

- [Water Smart Tots Foundation](#)
- [BayCare Kids Wellness and Safety Center](#): Door alarms, pool alarms, CPR classes and Swim Lesson Vouchers
- YMCA vouchers funded through the Children's Board of Hillsborough County; contact Lacey.Boldman@tampaymca.org or visit www.tampaymca.org for more information
- [Watermelon Swim](#)

Pasco

- [Pasco County Aquatics Program](#): Scholarship opportunities available for Pasco County residents aged 3 to 8 years. Check eligibility based on Florida Income Guidelines. Please contact 727-861-3033 for more information on registering.
- [Watermelon Swim](#)

Wandering Prevention

- Find local wandering prevention programs in your area: [CARD Safety Programs Information Page](#)

Fire Safety

- [CARD Autism Spectrum Disorder & Fire Alarm Safety](#)
 - Para español: [Alarma contra incendios](#)

Poison Prevention

- [CARD Poison Prevention Tips](#)
- Poison Emergency Helpline: **1-800-222-1222**
- www.PoisonCenterTampa.org

CARD will be in your local community, and you can pick up door alarms, Josh the Otter water safety bookmarks, and cabinet locks. Visit our [Calendar](#) and follow our social media to see where our team will be this month!

Health & Wellness

- [CARD Autism & The Hospital Emergency Room](#)
 - Para español: [Trastorno del Espectro Autista & La Sala de Emergencia del Hospital](#)
- [CARD Taking My Medications Social Narrative](#)
- [CARD Going to the Dentist Social Experience Booklet](#)
- [CARD Practical Strategies to Support Feeding Aversions](#)
 - Para español: [Estrategias prácticas para lidiar con aversiones alimenticias en personas con autismo](#)
- [Visual Cookbooks for Children and Adults with ASD](#)
- [CARD Getting a Haircut Visual Story](#)

Therapies & Support Services

- [Florida Developmental Disabilities Resources Provider Search](#)
- [PBIS Family Plan for Positive Behavior at Home](#)
 - See [additional resources for families here](#)
- [National Center for Pyramid Model Innovations](#)
- [OCALI Autism Center](#)
 - Check out their [Grab and Go Resource Gallery of Interventions](#) as well as the [Autism Internet Modules](#)
- [Florida Elks Children's Therapy Services](#)
- [Small Steps in Speech](#) (Grant program)
- [PrAACtical AAC](#)
- Communication Apps: [Proloquo2Go](#), [Coughdrop](#), [TD Snap Core First](#)

Respite & Crisis Support

If you are in immediate danger, always call 911 first!

- **988 Lifeline:** Call or text 9-8-8, or use the [online chat](#), for 24/7 free, confidential mental health support
- **Crisis Textline:** Text HOME or HOLA to 741741 to reach a live volunteer Crisis Counselor
- **211:** Dial 2-1-1 for local Florida services including respite, housing, and food support
- [ARCH National Respite Network](#)
- [Children's Home Network Caregiver Support Services \(CSS\)](#)
- [Florida Easterseals](#)
- [Parc Center for Disabilities Caregiver Relief](#)
- [Nathaniel's Hope Buddy Break](#) (*Locations in Seffner, Lakeland, Brandon, and Venice*)
- [We Rock the Spectrum Tampa](#)
- [Always Promoting Independence](#) (Pinellas)

Caregiver & Family Support Resources

- Find local support groups: [CARD Support Group Directory](#)
- [Support4Caregivers](#)
- [Kinship Support Groups](#)
- [Parent to Parent of Florida](#)
- [Sibling Support Project](#)
- [Florida Developmental Disabilities Council Resources](#)
 - [Easing Your Stress](#) (Para español: [Aliviando su Estrés](#))
 - [Stress and What You Can Do About It](#) (Para español: [EL ESTRÉS y Qué Puede Hacer al Respetto](#))

Legal & Financial Planning Resources

- [Disability Rights Florida](#) is a nonprofit organization that provides legal advocacy and rights protection for adults and children with a wide range of disabilities.
- [Office of Civil Rights Florida](#)
- [Florida Rural Legal Services](#)
- [Southern Poverty Law Center](#)
- [Wrightslaw](#): Information about IEP and special education rights
- [Special Needs Alliance](#): A national alliance of attorneys for special needs planning
- [ABLE National Resource Center](#): ABLE Accounts are tax-advantaged savings accounts for disability-related expenses

Community & Recreation

- Find summer camps and childcare: [CARD Out-of-School Time Directory](#)
- [CARD Autism Friendly Business Directory](#)
- [Special Olympics Florida](#)
- [TOPSoccer](#)
- [Buddy Baseball](#)
- [Tennis for Fun Florida](#)
- [Spectrum Sailing](#)
- [Surfers for Autism](#)
- [Do The Beach Jump Park](#)
- [Arts4All Florida](#)
- [Shyama's Art](#)
- [Pyramid](#)

Additional Resources

- [Profound Autism Alliance](#)
- [National Council on Severe Autism](#)
- National Autism Center - [*Profound Autism: A Parent's Guide*](#)

Books

Most of these books, and more, are available in our [eLibrary](#)! Registered constituents and professionals that serve our catchment area can join the eLibrary for FREE by [requesting access here](#).

- Uniquely Human — Barry Prizant
- The Reason I Jump — Naoki Higashida
- The Autistic Brain — Temple Grandin
- Emergent — Amy Sequenzia