



Supporting Caregivers & Maximizing Autonomy & Independence for Autistic People

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Presentation Objectives

- Identify the needs of families and autistic people across the lifespan
- Discover essential elements proven to increase positive outcomes for autistic people and their families
- Explore ways in which families can support their loved ones on the autism spectrum to maximize autonomy
- Explore strategies to help autistic people maximize autonomy and independence



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Parents

Studies from January 1994 - February 2020 indicate that diagnosis is a uniquely stressful and emotionally intense experience for parents

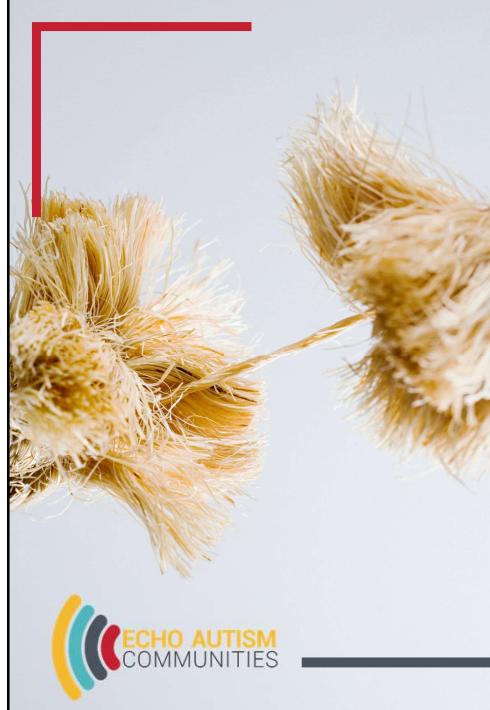


<https://link.springer.com/article/10.1007/s40489-021-00237-y>

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Parental Stress

- Decreased parenting efficacy
- Increased parenting stress and mental and physical health problems
- Poorer psychological well-being and life satisfaction
- Greater prevalence of depression
- Chronic stress
- Less marital relationship satisfaction
- Greater general life stress and daily hassles



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Challenges defined by Autistic Youth

- Social difficulties
- Concerns about the responsibilities of adulthood
- Connect more with others
- Gain more autonomy
- Stress related to school
- Lack of coping strategies



Tesfaye, R., Courchesne, V., Mirenda, P., Mitchell, W., Nicholas, D., Singh, I., Zwaigenbaum, L., & Elsabbagh, M. (2022). Autism voices: Perspectives of the needs, challenges, and hopes for the future of autistic youth. *Autism*, 27(4), 1142-1156. <https://doi.org/10.1177/13623613221132108> (Original work published 2023)

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Impact of Stress

- High stress is a risk factor for physical and mental health, well-being, and low quality of life
- Chronic stress can lead to disease
- Chronic stress or adverse events in young children may increase the likelihood of problematic outcomes later in life



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Hope is in Resilience

The ability to navigate difficult situations and recover from adversity leads to the best outcomes.



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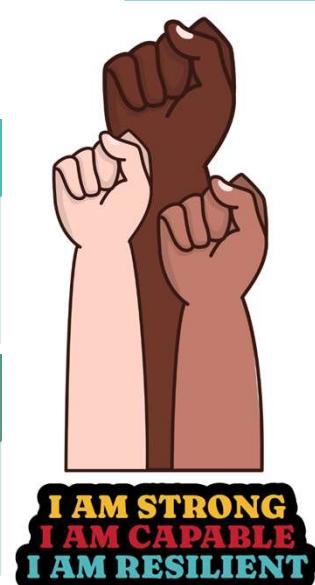
Resilience in Families

Self-efficacy
<ul style="list-style-type: none"> Can positively affect psychological states, motivation, & behavior Associated with better management of parental stress
Optimism
<ul style="list-style-type: none"> Family support is linked to increased optimism Leads to a reduction of maternal stress & depression

Acceptance
<ul style="list-style-type: none"> Promotes ability to adjust and adapt Encourages focusing on what the situation is instead of what it could be or isn't

Sense of Coherence
<ul style="list-style-type: none"> Interventions strengthen parents' ability to develop and maintain a sense of coherence

Enrichment



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Resilience in Autistic People

Societal Expectations & Conformity

- Accepting & have non-judgmental attitudes
- Presume intellect & competence
- Inclusive environments

Adjusting Daily Routines

- Engaging in meaningful recreation & leisure
- Peer support
- Use of technology to interact with others

Learning Over Time

- Identifying strengths & weaknesses
- Be comfortable with diagnosis & understand how to manage autism
- Gaining skills to process traumatic experiences



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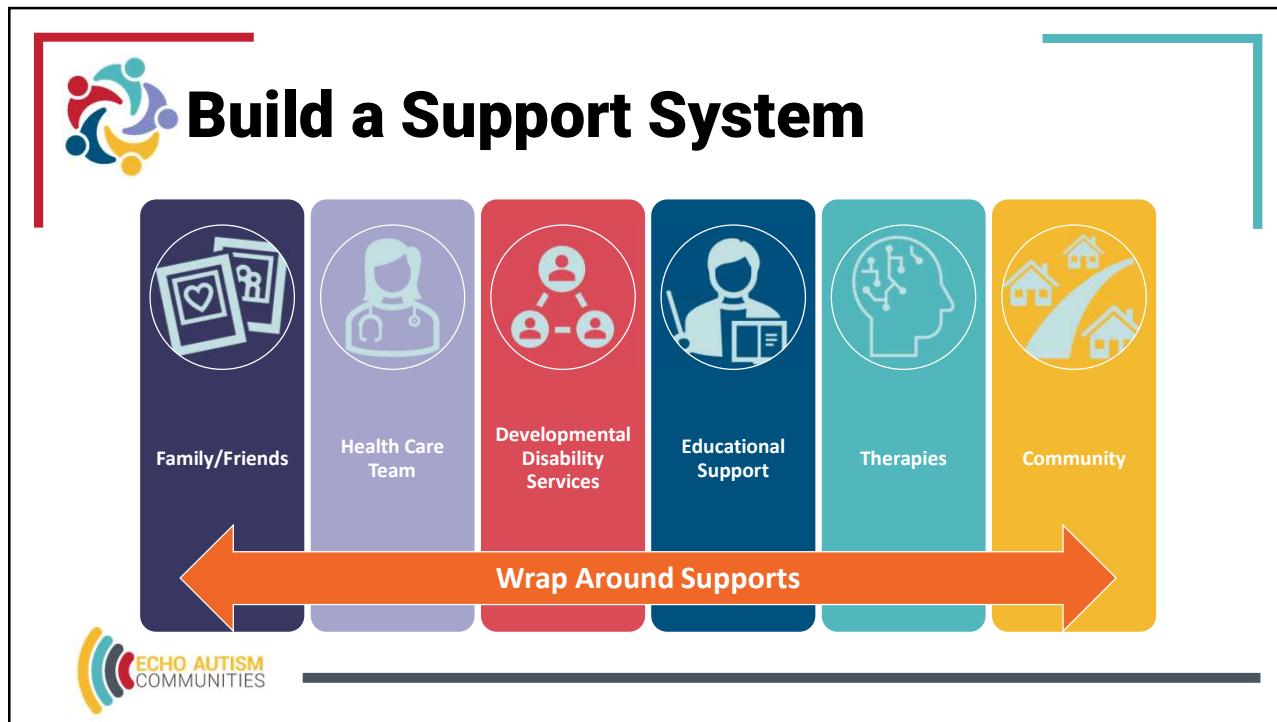
How can families support their loved ones to maximize autonomy?



**BUILD
SKILLS**



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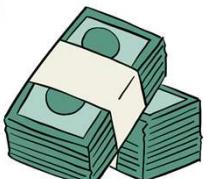


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Plan for the future



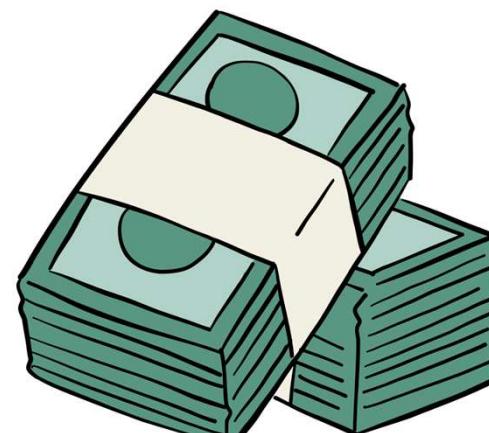



 ECHO AUTISM COMMUNITIES

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Financial Support Programs

- Social Security Income (SSI)
- Social Security Disability Insurance (SSDI)
- Medicaid Benefits
 - Health insurance
 - Long-term services and supports
- Home and Community-Based Waiver Services
- Achieving a Better Life Experience (ABLE) Act



 ECHO AUTISM COMMUNITIES

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Legal Matters

- Supported Decision-Making
- Guardianship
 - Limited
 - General
- Conservatorship
- Power of Attorney
- Special Needs Trust
- Long-term planning



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Community Living

- Living on your own
- Living with family
- Living with roommates
- Supported living
- Supervised living
- Group home living
- Group living/Ownership
- Host home



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Post-Secondary Educational Options

- Four-Year college
- Cooperative education
- Community college
- Technical/Trade schools
- Life skills programs



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Employment

- Competitive employment
- Supported employment
- Customized employment
- Self-employment
- Sheltered-employment
- Day Habilitation programs
- Day Treatment programs



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Health Care Transition

12 Years 16 Years 18 -22 Years

Start the conversation Start the transition process Transfer care to adult physicians

14 Years 18 Years

Discuss expectations & preferences Transition to adult model of care

ECHO AUTISM COMMUNITIES

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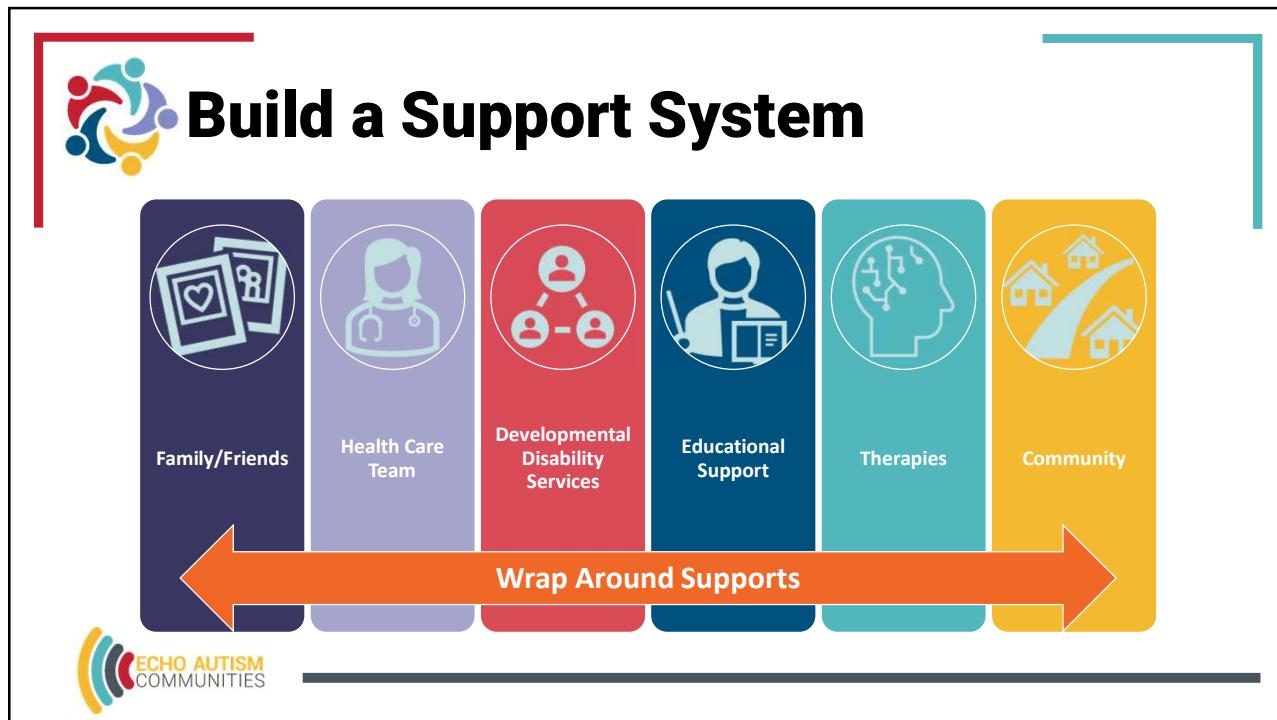
How can autistic people maximize autonomy and independence?

BUILD SKILLS

keep Practicing

ECHO AUTISM COMMUNITIES

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Functional Communication & Social Skills



Work with a speech-language pathologist or an assistive technology specialist to enhance communication through...

- Spoken words
- Visual supports
- Alternative & augmentative communication
- Social skills programs
 - PEERS

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Self-Management

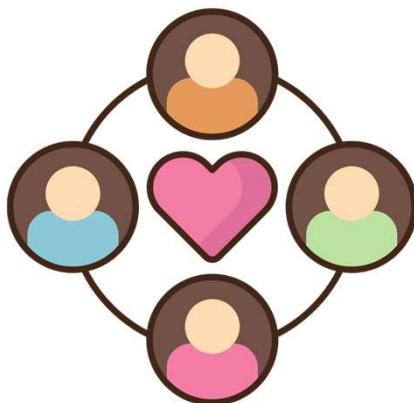


Work with licensed professional counselors, psychologists, or behavior therapists to promote...

- Self-monitoring
 - Being aware of emotions and behavior & how to control them
 - Identify strengths
 - Identify goals and pursue them
 - Identifying needs & knowing when to ask for help
- Coping strategies

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Relationships



Work with family, friends, therapists, and physicians to understand...

- Personal Boundaries
- Relationship Levels
- Circles of Intimacy



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Safety



Work with family members, educators, therapists, and others in the community to...

- Identify strangers vs. familiar people
- Interact appropriately with First Responders
- Know who and when to ask for help
- Navigate the community safely & know what to do when lost
- Communicate emergency contact person's information
- Effectively use technology to communicate
- Utilize internet, social media, and gaming safely & appropriately
- Know how to utilize transportation effectively
- Take swimming lessons



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Self-Care



Work with family, friends, physicians, therapists, and nutritionists to help build skills regarding...

- Hygiene routines
- Toileting
- Exercise
- Eating healthy
- Health: Physical and Mental Health Care
- Relationships – family, friends, romantic
- Sexuality
- Engaging in relaxing techniques
- Hobbies

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Household Chores



Work with family, friends, therapists, and other community agencies to develop skills in...

- Cooking
- Cleaning
- Laundry
- Small repairs
- Know who to call when you need help (i.e., repairs)

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Self-Advocacy



Working with family, friends, therapists, and agencies to learn skills to advocate at all levels....

- Personal Advocacy
- Educational Advocacy
- Advocacy in the workplace
- Local, State, National Advocacy



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Money



Work with family, friends, educators, and therapists to learn about...

- Importance of money management
- Setting up a bank account
- Budgeting
- Using credit – the pros and cons
- Establishing safeguards to avoid being financially exploited



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Vocational



Work with family, friends, educators, therapists, agencies, and employers to...

- Plan the best path for employment
- Learn how to complete an application
- Establish interview skills
- Look for a job
- Match with the right job
- Interact with co-workers
- Ask for a break or help when needed
- Maintain proper hygiene
- Become patient
- Establish self-regulation skills
- Know boundaries

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Time Management



Work with family, friends, educators, and therapists to enhance time management skills by utilizing...

- Calendars
- Checklists
- Alarms
- Pop-up Prompts
- Visual resources to help think about time concretely

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Community & Leisure Activities



Work with family, friends, educators, therapists, community agencies, and other professionals to...

- Determine likes/dislikes
- Develop goals for activities
- Identify strengths & challenges
- Identify how much support is needed
- Secure transportation to and from activities

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Leverage Strengths, Preferences, & Interests



Work with family, friends, educators, therapists, employers, and other community professionals to determine what strengths, preferences, and interests ...

- Drive personal or professional goals
- Identify interests can increase meaningful & successful inclusion
- Identify needs
- Give direction to find meaningful work and participate in enjoyable community activities

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Resources

- <https://echoautism.org/wp-content/uploads/2025/01/Autism-Speaks-Transition-Tool-Kit.pdf>
- <https://centerontransition.org/resources/publications/download.cfm?id=199>
- <https://autismspectrumnews.org/strategies-for-autistic-adults-to-achieve-greater-independence-and-well-being/>
- <https://supporteddecisions.org/about-supported-decision-making/>
- <https://csesa.fpg.unc.edu/sites/csesa.fpg.unc.edu/files/resources/Money%20Management%20for%20Young%20Adults%20with%20Autism.pdf>
- <https://www.autismspeaks.org/expert-opinion/autism-time-management#:~:text=Visual%20supports.&text=This%20can%20involve%20something%20as,your%20appointments%20and%20other%20tasks.>
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- Ghanouni, P., & Quirke, S. (2023). Resilience and Coping Strategies in Adults with Autism Spectrum Disorder. *Journal of autism and developmental disorders*, 53(1), 456–467. <https://doi.org/10.1007/s10803-022-05436-y>



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