Supporting Autistic Youth

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Prevalence of Autism Spectrum Disorder (ASD)

1 in 36 children meet criteria for a diagnosis of ASD by age 8

More than are affected by diabetes, cancer, cerebral palsy, cystic fibrosis, AIDS, Down syndrome, and muscular dystrophy combined (CDC 2023)

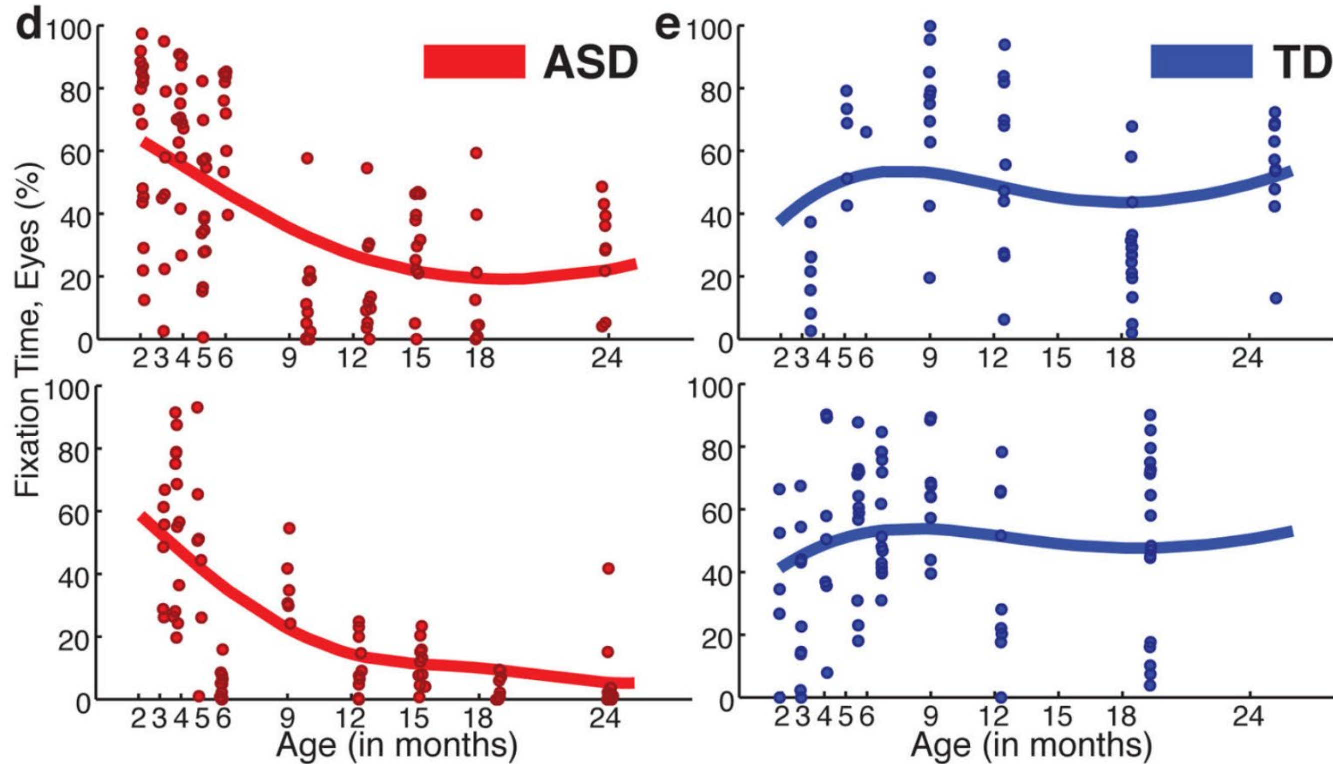
Factors Contributing to Increased Prevalence

- Diagnostic substitution
- Increased awareness
- Better diagnostic measures (including for those with typical IQ and younger children)

Autism Spectrum Disorder: Core Symptoms

1. Deficits in social communication and social interaction:
   - Diminished social-emotional reciprocity, nonverbal communicative behaviors, developing and maintaining relationships
2. Restricted, repetitive patterns of behavior/interests:
   - Stereotyped or repetitive speech (echolalia), motor movements, or use of objects
   - Strict adherence to routines, ritualized patterns of verbal or nonverbal behavior, or resistance to change
   - Highly restricted, fixated interests that are abnormal in intensity or focus
3. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment

ASD: A Social Disorder Driven by Early Experience



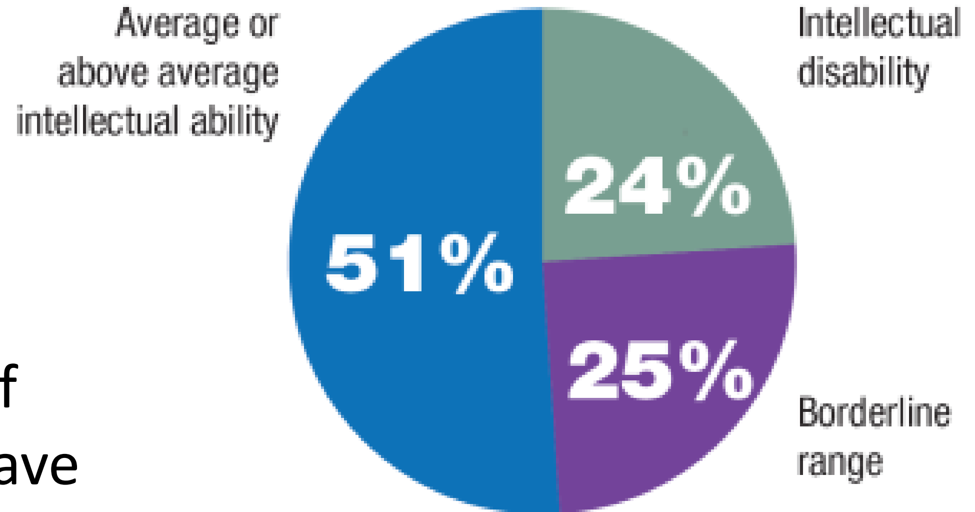
Jones & Klin (2013)

Age (in months)

The Heterogeneity of ASD

- Children may not present as people expect
  - Intellectual disability
  - Presence of splinter/savant skills

- Increasingly, <u>the majority</u> of children with ASD do not have an intellectual disability[1]



Children's Healthcare of Atlanta

[1]Centers for Disease Control & Prevention (2016)

The Heterogeneity of ASD

- Heterogeneity of ASD extends beyond cognitive level
  - Significant variability in
    - Number and type of restricted interests/repetitive behaviors
    - Comorbidities
    - Emotional dysregulation
    - Social affect
    - Number and types of sensory sensitivities
    - Preferences
- This means that although many of the strategies used to help typical children may work, one shouldn't assume that they will
- **Individualization is KEY**

Supporting those with Sensory Sensitivities

- Certain settings may be particularly problematic
  - Although some may have unique sensitivities that can’t be planned for, there are some stimuli/situations that are more commonly aversive
    - Loud or unexpected noises
    - Bright lights
    - Lots of commotion
    - Disruption to routines
    - Requirement to engage with people/make eye contact
  - Limiting these stimuli can be helpful, but again, individualization will be needed
- Example: Coping Plans, social stories

The Autism Spectrum

- Severe intellectual disability
- Little or no functional communication
- Few social relationships outside immediate family
- Requiring constant lifetime care

- Average or above average intelligence & language
- University-educated
- In a professional job
- In a marriage or partnership with children

The Neurodiversity Movement

- Considers autism as a neurological difference rather than a disorder
- Many view autism as part of their identity
  - Sometimes associated with opposition to efforts to find a cause or treatment
- There is controversy about how those with high support needs are represented by a non-medical model

Supporting Youth with ASD without ID

- Recognize that social engagement/interaction may be desired but difficult
- Attachments to caregivers may be qualitatively different, but that doesn’t mean it isn’t there
- Mental health comorbidities are common

Dually Diagnosed (ASD +)

- High prevalence of psychiatric comorbidities in youth with ASD

Table 2.1.2b: Selected psychiatric comorbidities and psychotropic medications by age strata in Medicaid ASD participants

	All	3-4	5-11	Age (years) 12-17	18-24	25-49	50+
N=	46,696	3,440	19,527	12,954	6,716	3,807	252
Psychiatric comorbidities (% in age group)							
ADHD	40.49	14.19	47.67	51.08	30.75	11.03	2.38
Anxiety disorder	13.98	2.59	11.50	17.73	17.67	17.02	23.81
Bipolar disorder	7.96	0.26	3.93	10.97	14.82	12.84	14.68
Conduct disorder	19.34	11.80	19.67	23.81	16.57	14.53	13.89
Depression	9.19	3.28	5.08	12.31	14.74	14.16	24.21
Epilepsy	10.76	5.41	7.40	10.38	16.62	23.09	20.63
Intellectual disability	23.36	16.66	15.19	20.58	34.86	57.81	64.68
Schizophrenia	2.29	0.00	0.30	1.64	5.72	9.77	17.06
Sleep disturbances	9.42	12.79	10.22	8.85	7.88	6.99	9.52
None	28.70	53.31	32.21	23.34	23.48	17.15	9.92
≥2 psychiatric comorbidities	39.22	15.00	34.42	46.19	45.64	49.44	57.54

Houghton, R., Ong, R. C., & Bolognani, F. (2017)

Important Skills and Plans

Self-determination and self-advocacy skills

- Help the child learn how to talk about autism and to ask for any support or accommodations that they need.

Social relationships and opportunities for recreation

- Connecting with the community where they live can provide a wider support network. If appropriate neurodiversity groups may serve as a source of socialization and support.

Plan to address healthcare needs

- Understanding their medical conditions, medications, and finding adult providers.

Skills for employment or educational settings

- Include asking for help, accepting directions and feedback from others, dealing with conflict, being on time, the importance of good hygiene, and dressing appropriately for different settings such as work and social events.

Co-Occurring Autism and Intellectual Disability

Several terms have been used:

- “Low functioning” (Problematic)
- Research literature has used the term **Minimally Verbal** (≥20 functional words)
- DSM-V considers autism a spectrum, with **Level 3** representing those “Requiring very substantial support”

Lancet Commission on Autism

Profound Autism*

Have (or are likely to have as adults):

- Requirement for 24 hr access to an adult
- Inability to be left completely alone in a residence
- Inability to take care of basic daily adaptive needs

*Not appropriate for young children (can't predict their needs as an adult).

Neurodiversity advocates dislike this term too though.

The *Lancet* Commission on the future of care and clinical research in autism

Catherine Lord*, Tony Charman*, Alexandra Havdahl, Paul Carbone, Evdokia Anagnostou, Brian Boyd, Themba Carr, Petrus J de Vries, Cheryl Dissanayake, Gauri Divan, Christine M Freitag, Marina M Gotelli, Connie Kasari, Martin Knapp, Peter Mundy, Alex Plank, Lawrence Scahill, Chiara Servili, Paul Shattuck, Emily Simonoff, Alison Tepper Singer, Vicky Slonims, Paul P Wang, Maria Celica Ysraelit, Rachel Jellett, Andrew Pickles, James Cusack, Patricia Howlin, Peter Szatmari, Alison Holbrook, Christina Toolan, James B McCauley

Executive summary

Affecting about 78 million people worldwide, autism is a condition of global importance because of its prevalence and the degree to which it can affect individuals and families. Autism awareness has grown monumentally in the past 20 years, yet most striking is that much more could be done to improve life outcomes for the highly heterogeneous group of people with autism. Such change will depend on investments in science focused on practical clinical issues, and on social and service systems that acknowledge the potential for change and growth as well as the varied, complex needs of the autistic individuals and their families whose lives could be changed with such an effort.

The *Lancet* Commission on the future of care and clinical research in autism aims to answer the question of what can be done in the next 5 years to address the current needs of autistic individuals and families worldwide. Autism is a neurodevelopmental disorder that typically begins to manifest in early childhood and affects social communication and behaviours throughout the life span. Autism and other neurodevelopmental disorders have seen a tremendous influx of interest from the scientific community in the past 60 years. Substantial progress has been made in many areas of basic and applied science, but the limits of the knowledge and understanding of autism are also very clear. For clinical purposes, reviews and guidelines have proliferated, although the data on which many recommendations are based are typically from short-term interventions that address acquisition of specific skills that are hoped—but not yet known with confidence—to contribute to long-term gains across development. However, large gaps around key questions remain, such as what interventions and support strategies are effective for whom and when, and which interventions lead to changes beyond their proximal outcomes. Underlying these outstanding questions is a deep scarcity of information about what are the active elements or mechanisms, behavioural or neurobiological, for change. These issues are particularly important because autism affects from toddlers to elders and is almost always accompanied by other developmental, behavioural, and mental health difficulties or conditions that have major implications for lifelong outcomes.

On top of these issues is the fact that autism affects individuals and families worldwide, most of whom are receiving no support outside of their own resources. If evidence-based approaches to support the lives of autistic children, adolescents, and adults who are living now are to be developed (in contrast to the fervent hopes for neurobiological approaches in the future), knowing what works for whom, when, and at what intensity is imperative, and will allow the design of systems that are cost-effective, affordable, and scalable across the globe. Such approaches are not possible on the basis of the currently existing data, but might become possible in the future.

In response to this challenge, our Commission proposes a novel, modified stepped care and personalised health model of intervention and assessment for individuals with autism and their families. One important necessity (but not always considered in such models) is that treatment and support takes into account the preferences, needs, and costs (financial and otherwise) to individuals and families at each step. These individual differences across autistic children, adolescents, adults, and their families are nested within communities, cultures, and social systems that must also be considered.

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See Comment pages 215 and 217
See Perspectives pages 228 and 229

*Commission chairs
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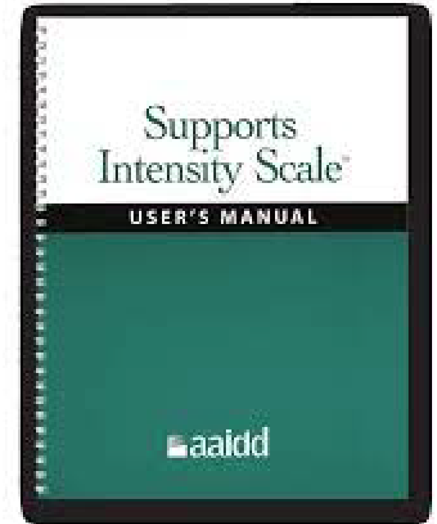
Key messages

- At least 78 million people worldwide have autism; the majority do not receive support from, or have access to, adequate health-care, education, and social care services
- Children and adults with autism can have happy and healthy lives, but urgent action is required to promote these outcomes
- Autism is heterogeneous and requires personalised, evidence-based assessments and interventions, accessible and affordable to every person, that can improve the lives of individuals and their families
- People with autism have complex needs; meeting these needs requires government coordination between health-care, education, finance, and social sectors across the life span, and active inclusion and participation of autistic people and their families
- A stepped care and personalised health approach to delivering services and monitoring effectiveness across time provides a framework for efficient and equitable distribution of resources to improve outcomes
- More information about the economic and personal consequences of autism is urgently needed to inform the case for government and societal investment, action, and support worldwide
- People with autism and those with other neurodevelopmental conditions have many similar needs; developing appropriate systems of care for people with autism will also improve outcomes for individuals with other neurodevelopmental conditions
- Valuing autism and neurodiversity benefits society as a whole
- Research that will result in immediate improvements in the lives of people with autism and their families should be prioritised

Supports Intensity Scale

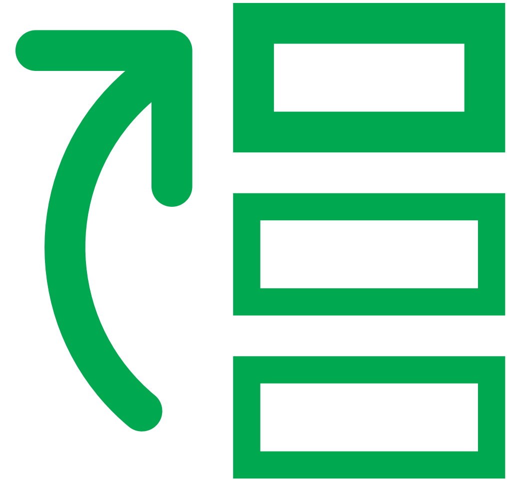
A standardized measure of the intensity of support required by a person with an intellectual or developmental disability

- Domains include:
  - Home
  - Community
  - Employment
  - Lifelong learning
  - Health and safety
  - Social activities
  - Protection and advocacy
  - Exceptional medical and behavioral support need



Challenging Behavior is the Biggest Issue

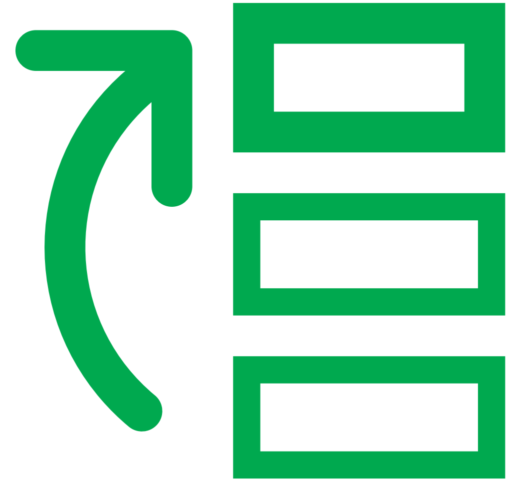
- Aggression
- Unsafe behavior
  - Elopement
  - Pica
  - Self-injury
- Other behavior that may impact access to services or placement
  - Toileting
  - Sleep



Challenging Behavior is the Biggest Issue

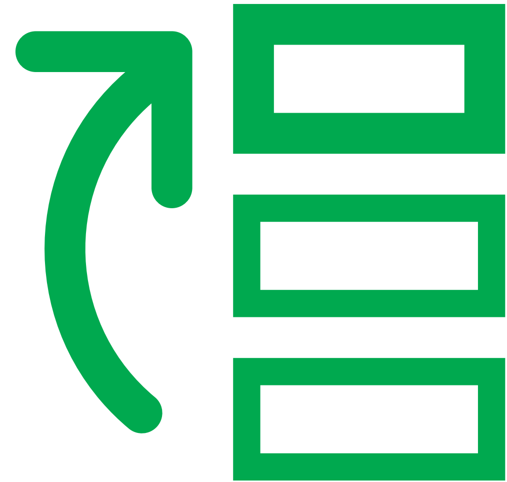
The function of challenging behavior is key

- Socially mediated
  - Best addressed by conceptualizing it as a form of communication
- Automatically maintained
  - Address any contributing underlying medical issues
- Behavioral psychopharmacology



Other Priorities with Lifelong Impact

- Language and adaptive skills
  - Prevent challenging behavior later
- Barriers to acquiring new skills
  - Limited preferences
  - Interfering stereotypy
  - Challenging behavior



Referring for Behavioral Intervention

- **School** (IEP targets challenging behavior and skill gaps)
- **Community providers**
  - Psychologists; although few have specific training in ID/ASD
  - BCBAs; most have training in treating skill deficits in young children with ASD
    - Variable quality and few have expertise in focused treatment
      - New accrediting bodies for BCBAs (BHCOE; ACQ)

ABA as a New Profession

- Certification/Licensure
  - Board Certified Behavior Analysts (BCBA)
  - Registered Behavior Technician (RBT)
- Quality measures and best practice guidelines are still being developed
- Not all providers are equally skilled at all facets of treatment (e.g., addressing problem behavior)

What ABA for ASD Often Looks Like

Comprehensive Treatments

- Targets all the core symptoms of autism spectrum disorder (i.e., social communication deficits, restricted interests/repetitive behavior, etc.)

Focused Treatments

- Targets a subset of behavior or challenges that may include core symptoms, but also often co-occur (e.g., aggression/self-injury; ARFID; anxiety)

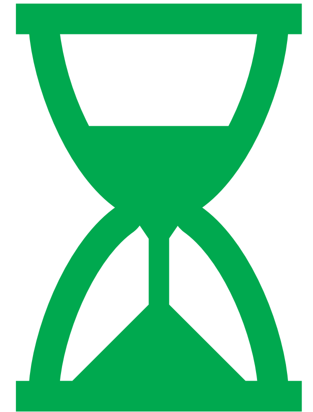
Referring for Behavioral Intervention

- Severe Behavior Program
- Toileting Service
- School Consultation
- Language and Learning Clinic
- Medical Compliance Clinic
- Feeding Program

Transition Planning: Timing

- Eligibility for some services or rights (e.g., medical release) end at 18
- Eligibility for some services last until 21 (e.g., special education)
- When should transition planning should start?

<u>**The earlier the better**</u>

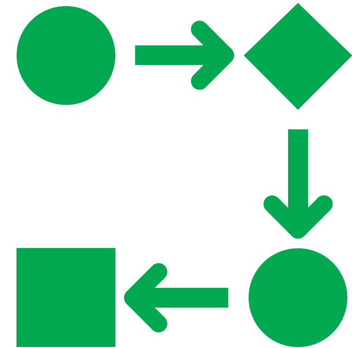


Administrative Steps

Respite Funding

- Covers up to +5 hours/week for respite

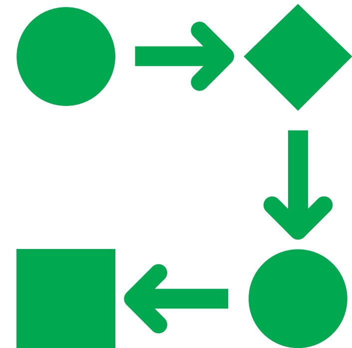
- Families of individuals with significant challenging behavior struggle to find a provider



Administrative Steps

Family Supports Services

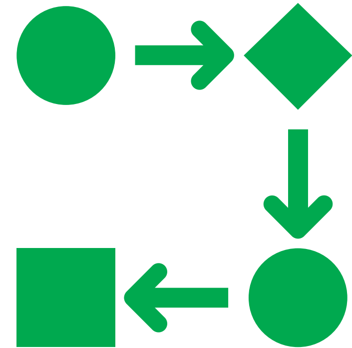
- Provides funding and case management
- Family selects provider in their region
- Not all providers offer the same constellation of services
- Requires annual reapproval



Administrative Steps

Waiver Programs

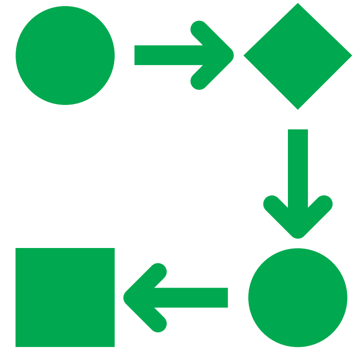
- New Options Waiver (NOW) & Comprehensive Supports (COMP)
- Covers services not covered by Medicaid
  - adult ST/OT
  - ABA
  - supported employment
  - residential services
  - specialized medical equipment and supplies
  - vehicle adaptation
  - behavior support services



Administrative Steps

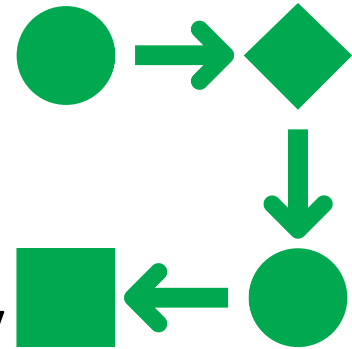
Waiver Programs

- Requires Medicaid eligibility (SSI at 18 yr for disability)
- Waiver funding makes you ineligible for Family Support or Respite



Waiver Programs (Process)

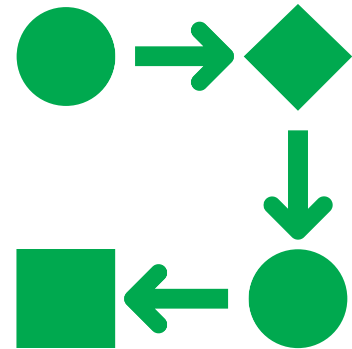
1. Family submits application and documentation to regional field office
2. Qualifying ≠ Eligibility (underfunded)
   - Most families apply more than once
3. Regional field office works with the family develop an individual service plan and connect with providers in their area



Administrative Steps

Delegation of authority

- Guardianship; lengthy and expensive process
- Parents can start applying up to six months before the adolescent turns 18
- More limited arrangements include
  - Joint financial accounts, financial power of attorney, or full conservatorship



Recommended Timeline

Transition Planning at School

14-15

Apply for Benefits

- Adult Medicaid or SSI
- NOW & COMP

14-18

Access Medical Records

15-18

Guardianship or Conservatorship (if applicable)

17

Contact Adult Providers

- Day Programs
- Medical Care

18+

Legal & Advocacy Resources

- Health Law Partnership for Children's patients who qualify
  - 404-705-2005
- Parent to Parent of Georgia
  - 800-229-2038
- Probate Court in your county
  - Search your county's probate court information online
- Guardianship petition form:
  - https://www.gasupreme.us/wp-content/uploads/2017/06/GPCSF12_0717.pdf
- Georgia Guardianship Project
  - https://www.legalaidprobono.org/projects/project.679990-Special_Needs_Adult_Guardianship_Project

Community Resources

- Parent to Parent of Georgia
  - www.p2pga.org
  - (800) 229-2038
- Health Law Partnership
  - 404-785-2005
- Georgia Council on Developmental Disabilities
  - www.gcdd.org
- Georgia Probate Court System
  - www.georgiacourts.gov/probate
- Georgia Family Healthline
  - 1-800-300-9003