

SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

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February 15, 2020

DEVELOPMENTAL DISABILITIES (DD)

- ▶ The Centers for Disease Control and Prevention define DD as a *group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.*
- ▶ Approximately 1 in 6 US children have a DD.
- ▶ Common DD include:
 - ▶ Autism Spectrum Disorder
 - ▶ Down syndrome
 - ▶ Cerebral palsy
 - ▶ Intellectual disabilities



AUTISM BASICS

- ▶ Core autism characteristics: social communication and restricted or repetitive behaviors
- ▶ Increasing prevalence (1 in 40 U.S. children; Biao et al., 2018)
- ▶ Common comorbidities: externalizing, internalizing and adaptive behavior challenges; GI issues; food aversions; sleep problems
- ▶ Diagnosis relies entirely on professional observation and parent report of child behaviors.
- ▶ Primary healthcare providers, including pediatricians, nurse practitioners, and other medical professionals, play a critical role in facilitating timely autism diagnoses and access to early intervention.

TYPES OF SERVICES FOR CHILDREN WITH DD: EARLY INTERVENTION

- ▶ Early intervention services
 - ▶ Communication
 - ▶ Gross and fine motor skills
 - ▶ Social and emotional skills
- ▶ All states have an “Infants and Toddlers” Program for children under 3 years old. The programs are FREE for children with developmental delays.
 - ▶ Maryland Infant and Toddlers Program
 - ▶ DC Strong Start Program



BEHAVIOR AND COMMUNICATION SERVICES FOR CHILDREN WITH DD



- ▶ Most common: applied behavior analysis (ABA); some examples:
 - ▶ Discrete Trial Training
 - ▶ Pivotal Response Training
 - ▶ Early Intensive Behavioral Intervention
- ▶ Structured teaching approach (example: TEACCH)
- ▶ Developmental approach (example: Floortime)
- ▶ Other common therapies: sensory integration, occupational therapy, speech and language

OTHER TYPES OF SERVICES FOR CHILDREN WITH AUTISM AND OTHER DD

- ▶ Diets: talk to doctor before using making any dietary changes or use supplements
- ▶ Medication: used only to address other symptoms common among children with DD, such as seizures, hyperactivity, or depression.
- ▶ Complementary and alternative treatments: for example, massage therapy



WHERE TO ACCESS SERVICES?

- ▶ If your child is younger than 3 years old, then contact MD Infants and Toddlers or Strong Start DC.
- ▶ If your child is 3 or older (up to age 21), then your local school district will provide some services.



INDIVIDUALS WITH DISABILITIES EDUCATION ACT (“IDEA”)



- ▶ IDEA is a federal U.S. law that requires schools to provide services for children with disabilities at no cost.
- ▶ Covers 13 categories of diagnoses, including autism, ADHD, and learning disabilities.
- ▶ A diagnosis does not mean the school is required to provide services. The child must also need supports to make progress in school.

WHERE TO ACCESS NON-SCHOOL SERVICES?

- ▶ Add your child to these waitlists:
 - ▶ Medicaid Waiver (in Maryland, through MD Department of Education; in DC, through Department on Disability Services)
 - ▶ MD Developmental Disabilities Administration
- ▶ Use Medicaid or your private health insurer to find a private therapist. DC and MD both have laws to require insurers to cover autism and other DD services, but there are some limitations.



HOW DO YOU KNOW WHAT'S RIGHT FOR YOUR CHILD?

- ▶ Research studies are an important way to understand which therapies work, and for whom.
- ▶ Rely on trusted sources for treatment options (doctors, teachers, etc.). Some reliable online sources for treatment choices are:
 - ▶ Maryland Center for Developmental Disabilities:
<https://www.kennedykrieger.org/community/initiatives/maryland-center-for-developmental-disabilities>
 - ▶ National Autism Center (National Standards Project) Website
<http://www.nationalautismcenter.org/nsp/>



HOW DO YOU KNOW WHAT'S RIGHT FOR YOUR CHILD? (CONTINUED)

- ▶ Professionals working in public schools have the legal obligation to provide evidence-based services (scientific proof they are useful).
- ▶ Your child's provider should share clear, observable, and measurable goals for your child before beginning treatment.
 - ▶ Example: When Marcela goes to the grocery store with her mom, she will sit in the grocery cart and will not scream during the entire trip. This example clearly describes **location** (grocery store), **activity** (shopping), **anticipated behaviors** (sitting/not screaming), and **specific time** (entire trip).
- ▶ Provider should be collecting data throughout therapy to know if the treatment is working.
- ▶ Over time, providers should be able to report an improvement in child's behavior or skills. If not, then *reconsider treatment strategies*.

WHAT CAN YOU DO AT HOME?



1. Play and spend time with your child – even 10 minutes a day can make a difference.
2. Set your child up for success.
3. Provide your child opportunities to interact with peers both with and without DD.
4. Create structure – with some flexibility.
5. Keep in regular contact with your child's teachers and providers.

HELPING YOUR CHILD BY TAKING CARE OF YOURSELF

FAMILIES ARE IMPORTANT IN DD SERVICES!



- ▶ Parents as de facto “case managers”
- ▶ High levels of parenting stress & depression
- ▶ Family financial burden
- ▶ Reduced engagement in early intervention services

PARENTING A CHILD WITH DD

- ▶ Goals:
 - ▶ Ensuring child's health and safety,
 - ▶ Preparing children for life as productive adults
 - ▶ Transmitting cultural values
- ▶ Parenting a child with DD can be very rewarding, however, it also comes with unique challenges.

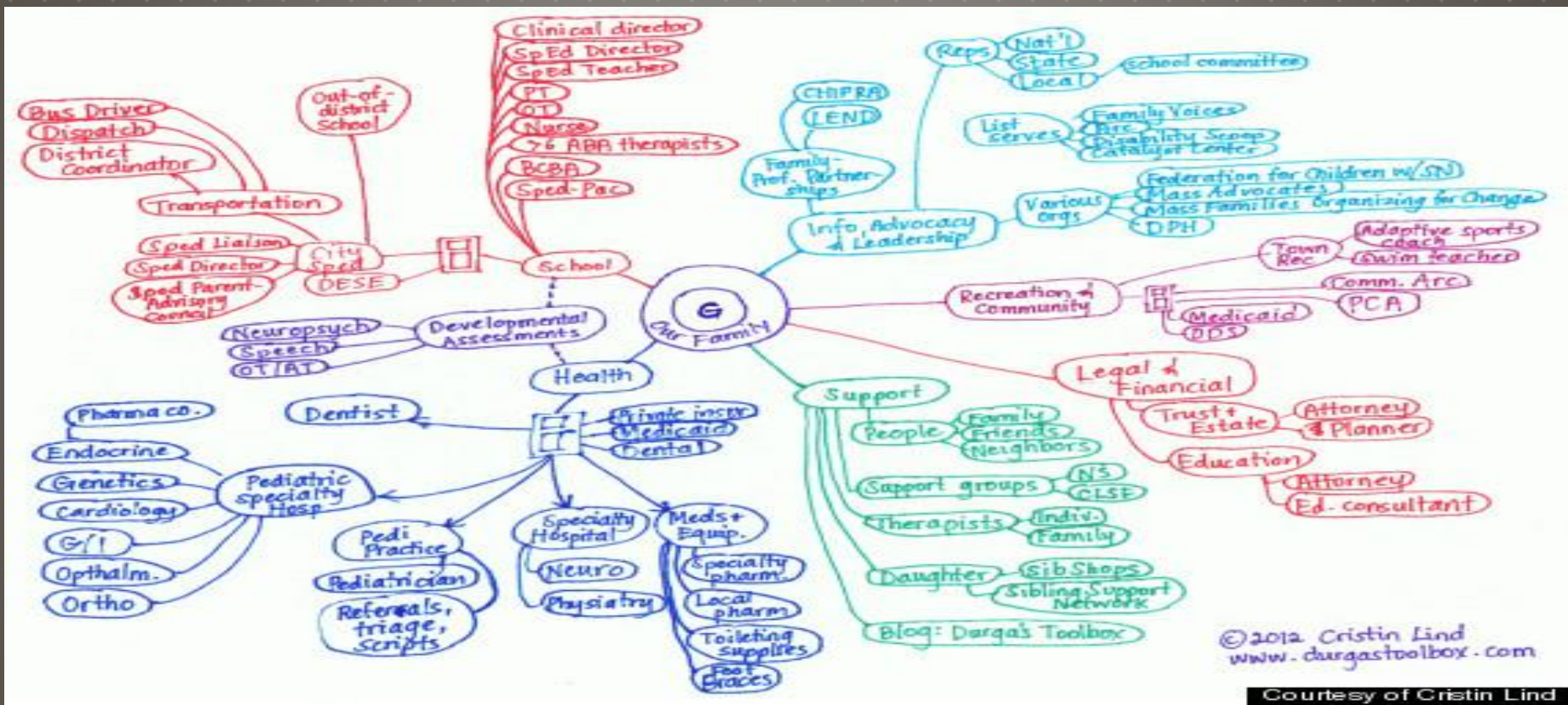


A DAY IN THE LIFE OF A PARENT



- ▶ Driving your child to various appointments;
- ▶ Advocating for the child's educational needs;
- ▶ Helping the child avoid sensory overload; and
- ▶ Dealing with unexpected tantrums in public.

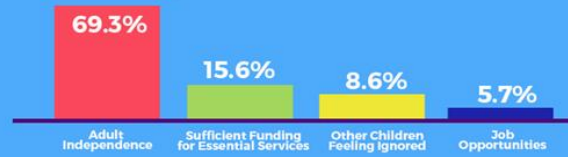
FAMILIES NAVIGATE A COMPLICATED WEB OF SERVICES



WHAT WORRIES PARENTS OF CHILDREN WITH DD?

GREATEST CONCERN:

69.3% cite adult independence as their greatest concern.



EASE OF ACCESS TO CARE:

Nearly **80%** find access to services difficult

14.4%
Somewhat easy

25.4%
Very difficult

5.7% Very easy

54.3%
Somewhat difficult



TRANSITION PLAN:

Only **18.4%** have a transition plan to prepare for life after high school graduation.



64.8% do not include any job skills or vocational training as part of their transition plan.

SOCIAL CONNECTION:

52.6%
do not have many friends or a peer group at school.



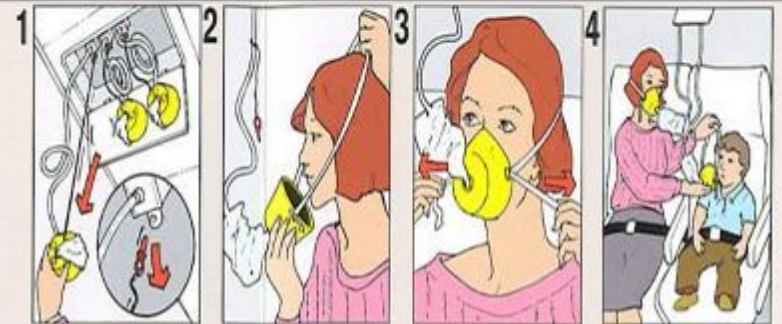
TYPES AND SIGNS OF CAREGIVER STRESS

- ▶ Psychological stress
- ▶ Physical stress
- ▶ Social stress
- ▶ Financial stress
- ▶ Some signs of excessive stress:
 - ▶ Difficulty sleeping (or excessive sleep);
 - ▶ Weight gain or weight loss;
 - ▶ Stomach pain or nausea;
 - ▶ Irritability;
 - ▶ Teeth grinding;
 - ▶ Panic attacks;
 - ▶ Headaches;
 - ▶ Difficulty concentrating;
 - ▶ Heartburn;
 - ▶ Social isolation; or
 - ▶ Feeling overwhelmed.

CONNECTING PARENTING STRESS AND CHILD OUTCOMES

- ▶ Well-established connection between parenting stress and child outcomes, especially behavior and communication
- ▶ Importance of early intervention for both child AND family
- ▶ Few autism and other DD interventions exist that address parent/family outcomes

“...Place the oxygen mask on yourself first before helping small children or others who may need your assistance.”



STRESS MANAGEMENT

- ▶ Caregivers who engage their support systems and actively solve problems experience much less stress than those who disengage or cope in unhealthy ways.
- ▶ A less-stressed caregiver is much more likely to raise a well-adjusted and less anxious child.



OTHER TIPS FOR MANAGING STRESS



- ▶ Start with simple change.
- ▶ Focus on reality and not the “what ifs.”
- ▶ Forget the “should.”
- ▶ Stimulate your brain.
- ▶ Create community.
- ▶ Engage professional help.

EXISTING SERVICES FOR PARENTS

- ▶ Support groups
- ▶ Adapted group-based parenting programs (examples: Stepping Stones Triple P; Incredible Years)
- ▶ One-on-one therapy
- ▶ Peer-to-peer in-home support (example: Parents Taking Action)
- ▶ “Hybrid” programs with mixture of groups and one-on-one; in-home and clinic (example: Caregiver Skills Training Program)



Thank you!

For more information, please
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