



21[•]NEXT COMMUNITIES

5 RESOURCES

NCLD Understood
www.understood.org

Autism Housing Network
autismhousingnetwork.org

CdLS Foundation
<https://www.cdlsusa.org>

Center for Parent Information &
Resources
<https://www.parentcenterhub.org/>

Maryland Developmental Disabilities
Administration
<https://health.maryland.gov/dda/Pages/home.aspx>

INTRODUCTION

I am a mother, author, advocate, and so much more. I began my career in Industrial Management and Engineering but meandered into Elementary Education and eventually into Special Education through a series of unfortunate yet serendipitous events. I have often joked the career prepped me for the kids – one would need degrees in engineering and special education to navigate the labyrinth of bureaucracies that is the world of special education!

Even with credentials and terminal degrees, I have failed often and miserably in securing needed resources, services, and support on behalf of my daughter, who was born with a laundry list of behavioral, medical, and developmental disorders and disabilities. This drives me to stay in the fight for her and for families like mine.

5 TIPS



1. Do not be afraid to ask for help and to accept help! Martyrdom is not a skill requirement for care providers of a loved one with a disability.

2. Identify resources locally, within your state, and nationally.

- Set up an email address for all disability-specific resources – newsletters, events, support groups, medical trials, etc.
- Create a separate contact list of individuals with agencies you are connected to; it helps to develop relationships!
- Learn what services your county and state agencies provide and the processes for accessing those services. Some agencies require medical referrals, while others may require school staff to provide a referral.

3. Develop a timeline (0 -99 years) for your family and your loved one with a disability.

Identify milestones where critical decisions have been made in the following areas :

- Education
- Residential
- Vocational
- Medical/Health
- Leisure/recreational
- Legal
- Financial

-Who will make these decisions?

-When will these decisions need to be made?

-How will you insure these decisions will be carried out in the event you are no longer able to make them?

4. Get everything in writing, making copies, and keep a digital backup! Paperwork, documentation, and bureaucracy are drivers in the disability space and often care providers are the sole source or gatekeepers of information. However, as caregivers age up, they fail to document and pass on this information or verify who they “spoke with.”

- Document calls with a follow-up email, summarizing the conversation, a person(s) relevant to the call, confirmation of any action(s)
- Request additional information, services, or correspondences if necessary
- Print out any document that has original signatures. Save and scan as an additional backup. Many state and federal agencies require documents with “original” or “copies of original” signatures.

5. Create and maintain a respite plan for your loved one with a disability AND yourself/family.

Self-care is healthcare!

- Caregiving is a lifelong journey and requires planning and you have to be as deliberate in planning for breaks or respite as you are for medical appointments.
- Source respite care providers in your area from disability specific- support groups, county agencies, faith-based groups, for-profit providers, volunteers, family members, employee assistance programs, etc.
- Sibling support and respite are essential! It is absolutely critical down the road for healthy relationships as your family matures.



Dr. Thomas, Lisa to family, friends, and colleagues; "Mom-mom-mom" to Dorian, is a career educator, advocate, and by her own admission, a willing saboteur in the "systematic dismantling of the culture of low-to-no expectations" that is pervasive throughout ableist communities.

"Having a loved one with an intellectual disability consistently teaches me about myself, the need to dream bigger, that humanity is flawed but redemptive, and that it really does take a village."

Dr. Lisa Thomas