

—by Katharine Cassens



Beyond The Front Door

How to Assess Which Agency is The Best Fit for Your Child

Who you choose to work with your child is a key decision. But, finding the right service provider can be daunting. Here are some tips to help make it a little easier.

Determine What Services You're Looking For

Do you need a psychological assessment, help finding housing or employment, respite services, or someone to work with your child's school regarding special education programming?

The availability of services will likely depend on the age of your child, as well as his or her specific needs. From early intervention and special education, to respite, housing, job placement, and day programming, there are a lot of options to choose from.

Agencies often provide and specialize in services for specific populations and age groups. For example, if your child has autism, consider Autism Services. If your child has a learning disability, consider an agency with that fo-

cus, such as the the Learning Disabilities Association (LDA) of WNY.

According to Adrienne Kosis, Director of Housing Navigation at the LDA of WNY, some services, such as housing transition and rental subsidies, only require OPWDD (Office for People With Developmental Disability; <https://opwdd.ny.gov/>) eligibility, not Medicaid eligibility. In this case, you want to contact an agency with an ISS (Individual Supports and Services) liaison. The list of ISS liaisons is available from OPWDD, or the local DDRO (Developmental Disabilities Regional Office), which in WNY is located in West Seneca.

Find Providers in Your Area

Once you have an idea of what kinds of services you're looking for, think about where you live, your transportation options, and how far you are willing to travel for services. Then you can begin researching service providers.

There are a number of community resources that offer contact informa-

tion for providers, broken down by geographic area, ages served, and services provided:

- 211 WNY (www.211wny.org)
- DDAWNY Guide (<http://www.ddawny.org/resources/>)
- Family Support Services Region 1 Group, found on Facebook
- LD OnLine (www.ldonline.org)
- Regional Parent Technical Assistance Centers (RPTACs), which in WNY include Parent Network of WNY (www.parentnetworkwny.org) and Starbridge (www.starbridgeinc.org).

Ask Your Service Coordinator

According to Kosis, during the Front Door process, you should have selected a service coordinator, who will help develop an Individualized Service Plan (ISP) or Life Plan that helps identify providers and enroll into services.

The service coordinator's role is to make sure an individual's safety and needs are met, first and foremost, through appropriate services and supports.

Don't Be Afraid to Cold Call An Agency

According to Carol Pearce, Director of Family Support and Intake at the LDA of WNY, agency staff have a wealth of knowledge to guide you in the right direction. They've spent hours on the phone with parents, offering advice, resources, and sometimes just an ear. Whatever concerns or questions you have are probably not new.

If an agency can't help you (for example, if it doesn't offer services in your geographic area), or can't answer a question, they will be able to refer you to an agency that can. Most agencies have contact information through their websites or social media pages.

By contacting disability providers directly, you can find out:

- Specific programs and services provided, and/or ages and populations serviced

- The agency's operating hours
- Where the service will be provided – for example, via video conference, in your home, in the hospital, at a clinic, at a community center, at an early learning center, or at school
- How much services cost, and whether or not the provider accepts your insurance or HMO coverage
- Any programmatic waiting lists
- The agency's policy on cancelling appointments

Although you want to work with someone who makes you and your child feel comfortable, that's not always enough. Know what you want, be clear with your expectations, and don't be afraid to ask questions related to getting support.

Ask Other Parents

Whether it's through face-to-face or online support groups, informal or national, state, or local disability groups, connect with other families like yours, and ask about their experiences and recommendations.

Some groups are organized around one particular disability (e.g., cerebral palsy, Tourette syndrome, Down syndrome), while other groups include parents who, regardless of disabilities, have similar concerns, such as daycare, transportation, or special education.

Ask Your Child's Pediatrician

If you haven't already been referred to a disability service or provider, you can talk about this with your pediatrician or another health professional.

Select a Provider

Consider what's important to you and your child, and see where providers measure up. For example, where does an agency stand on person or family-centered planning, inclusion in school, work, and the community, individualized vs. team approach, staff credentials/qualifications, use of evidence-based practices, communication and

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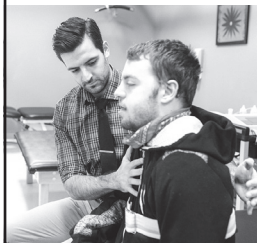
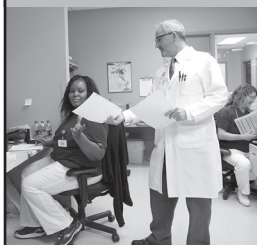
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linkages to other professionals and service providers?

This should help you decide which service provider is right for you. And you're entitled to get further opinions from other service providers if you're not sure about the choice you've made.

Be Prepared to Wait

According to Kosis, the eligibility process can take up to a year, so it's important for parents and caregivers to be patient. Many services, including respite and children's services have waiting lists, as programs only have so many units available, and often only so many staff to deliver these units.

To avoid this, parents may benefit from looking into more than one provider, in case their first choice has a wait list.

Have a Back-Up Plan

You may have selected an agency to provide service coordination during the front door process, but are no longer happy with them. Or you may have found your child on a wait list that seems endless. Whatever the case, it may be helpful to find a different agency to work with, and complete a vendor change form.

The new service coordinator or agency staff will meet with your child and family to determine what services are needed, what life areas in which you are looking to receive help, and whether or not the agency can provide the necessary services. If it can, staff will develop an ISP, which will then guide your child's services and supports.

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Katharine Cassens is the Director of Community Relations at the Learning Disabilities Association of WNY in Kenmore, NY. This article was prepared in cooperation with the Public Relations Committee of the Developmental Disabilities Alliance of WNY (DDAWNY).