

CHOOSING A PROVIDER:

A Guide for Parents and Families of Children, Teens and Adults with Intellectual and Developmental Disabilities (IDD)

The good news is: Your child or loved one with IDD soon will be receiving some much-needed services and supports.

Like many families, you may have waited a long time for this to happen. After you put a name on the **interest lists** for the Medicaid waiver programs that serve people with IDD in Texas:

http://www.dads.state.tx.us/providers/waiver_comparisons/LTSS-Waivers.pdf. (Home and Community-Based Services, HCS; Community Living Assistance and Support Services, CLASS; Texas Home Living, TxHmL; and others), the wait time often is more than 10 years.

You're happy — but also confused.

You've signed papers. You've listened to lots of information.

And now, you are given a **list of service providers** in your area.

You and your child/loved one must **choose one** of these providers — an agency or organization whose job it will be to provide hands-on, direct services.

The list gives each provider's name and contact information, and tells you how many clients they serve, both locally and statewide.

Of course, you ask: "Who's good? Who's the best?" But by law, the local agency (MHMR of Tarrant County) that watches over services to people with IDD **is not allowed to recommend or choose a provider for you**. So...what's a parent, family member or other caretaker to do?

Choosing the "right" service provider — an agency or company that will be a good fit, both for your child/loved one and your family — probably will take time. You might get lucky, and find that your first provider is "The One." But chances are you will need to **try more than one provider** before you find one that works for you.

The kind of provider you need — and the questions you should ask — will depend on your situation, and on the plans your family is making together.

For instance, a person with IDD enrolled in the HCS program may receive services:

- in the family home
- in a home he/she owns
- in a foster/companion care home
- in a 3-4 person residence operated by an HCS provider

So, the first questions you ask probably will be about where he/she is going to live:

Will you and your family continue to provide the majority of your child/loved one's care? Some programs let you **foster** your own child or loved one — continuing to do things you've always done, but being paid (through a provider) for your time and work. In some cases, a **consumer-directed** option puts you in charge: You have funding that lets you hire people to provide services (including friends and family who don't live with you). But if you don't have the ability or time for these options, a provider can help with many of the caretaking tasks for you.

Will your child/loved one live in a group residence, or in someone else's foster/companion care home? Your questions and concerns will be different if he/she is going to live away from home, possibly for the very first time.

Is your adult child/loved one changing from one kind of residence to another—from a nursing home to a group home in the community, for instance? Moving from a very sheltered living situation to a home in the community is a big step. Parents and family need to do a lot of looking and asking — and **involve the person with IDD in the planning** as much as possible — to make sure the “new place” is a good fit.

You can choose a different provider at any time. Don't get discouraged or upset if you need to switch providers in the first months/years. It happens—and it is part of a process that will get you to the provider you're looking for.

We know it's confusing — so we've put together ideas and questions from parents who've been there before you. In the end, you will have to come up your own question list — but these could help you get an idea of the kind of questions you should ask.

When Choosing a Provider: Things to Think About, Questions to Ask...

For starters:

- Start building a parent-to-parent network! Attend support groups. Talk to families you meet in the community, at church, at the doctor's office. Many local groups (The Arc of Greater Tarrant County's Our Special Children/Las Familias groups, the Down Syndrome Partnership of North Texas, etc.) can connect you to parents willing to talk about their experiences, including how they chose a provider.
- Ask other families for reviews and recommendations. What kind of services do they receive? Would they recommend their current service provider? Do they sound enthusiastic about this provider, or just "so-so"?
- Ask for details: Does their provider return family calls right away or soon?
- Does the staff volunteer "news" and information about your child/loved one and their care? Or do you have to chase after staff to find out things you need to know?
- Is staff turnover low or high? Do caregivers and case managers stay around long enough for your child/loved one to become comfortable with them?
- Ask families about other providers they have used in the past. What did they like/dislike? What made them decide to change? What is different/better about the provider they use now?
- If your child/loved one has many medical/physical care needs, look for families in a similar situation. Ask them for referrals to providers who have the staff and skills to give quality care in complex cases.
- Ask professionals who work with your child/loved one for recommendations. Teachers, doctors, therapists and others often have informed opinions about different providers.
- MHMR has a Parent & Family Representative who is happy to talk with families about the process of choosing a service provider. Contact:

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Talking to providers:

- Make a list of questions, and ask as many of them as you want!
- Is the provider able to answer quickly, clearly, and with plenty of details?
- Does he/she seem open and patient with your questioning? Do the staff members treat you with respect?
- Do you feel this provider sees you as future member of the caregiving “team”—someone with valuable information and opinions to offer?
- Different providers have different strengths. Decide what you and your child need most: Caregiving staff skilled in handling complex medical/physical/behavior needs? A provider and staff enthusiastic about teaching independent living skills and getting residents involved in community activities? A staff (on-site and on call) that is experienced at working with challenging behaviors? Does this provider have the “focus” you want?
- Do the services offered match what you were told about the program you’re in? Do they include the services you **want** for this person? You can always go back to your local “oversight” agency (MHMR) to ask if a provider could do more.
- Online information is sometimes just a “commercial” for providers, but there is information out there. In Tarrant County, some of the 200-plus HCS providers answered a questionnaire from MHMR. You can find the results at: <http://www.mhmrtarrant.org/Services/Intellectual-and-Developmental-Disabilities/HCS-Virtual-Provider-Fair> Provider responses can give you a “feel” for the company or group’s caregiving philosophy and style.
- Check past complaints made against providers at: <http://facilityquality.dads.state.tx.us/grs/public/grs.do%3Fpage%3Dsearch> or go to: <http://facilityquality.dads.state.tx.us/grs/public/grs.do?page=grsHCBP1&serviceType=HCBP&lang=en&mode=P&dataSet=2&ctx=16089113> Here you can look at “quality reports” for different waiver programs. Click on the name of a provider to get more detailed information.

If you are thinking about a group home or Intermediate Care Facility (ICF/IDD):

- Look for yourself! Don’t just talk to the “front office” of a provider. Make time to visit facilities the provider runs, including their “day hab” program and group homes. Do a walk-through of one or more of the provider’s group homes. Talk directly to the staff who work there, not just the “rep” who brought you. If possible, briefly meet some/all of the residents.
- Is the residence clean and comfortable? How do people spend their time? What activities are scheduled during a typical week or month? How much **choice** do residents have about their activities, daily schedules, etc.?
- How involved are other parents in the lives of the residents? Do residents go home with their families on the weekends? In some group homes, parents take a hand in choosing and hiring staff.
- If you are looking for a “right now” home for your child/loved one, talk to staff about the people who live there. Does this sound like a social group your child/loved one would enjoy being with? A provider may have openings in other group homes with a different mix of residents.

- Request a **weekend stay** at a group home that appeals to all of you. You can try different homes run by different providers. After one such weekend, a young woman said she wasn't leaving—she had found her place!
- Remember to do **person-centered** thinking and planning as you think about a “home away from home.” That means you focus on what your child/loved one needs and wants. **Keep him/her involved all through the process, talking and communicating about what they like, want, need and hope for.**
- Always ask yourself: Will this home help our son/daughter/loved one grow and learn? Will this home offer **opportunities** for choices, and friendships, and connections to the wider community (church, recreation, movies, events, etc.)? These are things all of us want from our lives.
- Are there any red flags—routines or requirements that would make him/her uncomfortable or unhappy?
- If your child/loved one has complex care needs, ask very specific questions about how these will be handled. Who is at the home or “on call” to meet those needs?

And remember: You can always circle back and talk again with other parents and professionals who work with your child. Tell them what information and experiences you've gathered as you met with providers. **Get their feedback and advice.** All these informal conversations add up to a kind of “Yelp” for parents of kids and adults with disabilities. Together, we can help each other get the information we need to know.

Questions...and More Questions!

The Texas Department of Aging and Disability Services (DADS) is in charge of many services for people with disabilities in Texas. The in-depth list of questions below is adapted from DADS material. Some of what's on the list may not apply to your situation—but these questions can help you think about what questions need to be on **your** list as you talk to providers!

How long have you been in operation?

How many people do you serve?

What percentage of them live at home with their families? What percentage live in community-based group residences or foster homes? (This can tell you where this provider's focus and experience are—and if it matches what you want.)

Who are the owners?

What is their background?

Why are they in this business?

Is there a care philosophy?

What are your (the provider's) hopes and expectations for the people with IDD you serve?

Have any complaints of abuse or neglect been made about your organization—ever?

What was the outcome?

Who is on staff?

What education/training is required?

Do you pre-screen all employees?

What kind of ongoing training does direct-care staff receive?

Are they trained specifically to care for people with (fill in your needs: IDD, autism spectrum, etc.)?

May I see some records that show their training?

Does on-call or on-site staff include professionals your child/loved one will need: a behavior specialist, for example, or staff with the training and experience needed to handle complex needs (medical or physical)?

What is the ratio of staff to clients/patients/residents?

What happens when there is an emergency?

What kinds of emergencies are staff trained to handle?

How much choice and control do residents have: over visitors, daily routines, job programs, participation in group activities, etc.?

What specific activities are scheduled? Are any activities or "outings" mandatory?

What sort of choice/control do residents have over their daily schedules?

If English is not this person's first language, is there one/more than one staff member who speaks his/her language?

How connected are your facilities/homes to the community?

Will the staff help this person get to church, recreation, sports and music events?

Is transportation available—and what kind?

How does the staff—be specific—work with residents to promote independent living skills?

We Have a Voice!

How to Involve Your Child/Loved One...

Sometimes it's easier to believe we know "what's best" for our son, daughter or loved one with IDD. But it's good to remind ourselves, on a regular basis, that while we are an important part of all the planning and choosing...it's *his* life, *her* dreams, *their* likes and dislikes we're talking about.

- Do whatever you can to make sure your child/adult child/loved one is a real and **respected** part of the decision-making process. This will benefit your relationship, and encourage others (including providers) to see him/her as someone who "counts."
- Encourage him/her to express opinions and preferences in whatever way is possible.
- Offer clear choices. After discussing all the options, you might narrow things down to two (equally acceptable) choices: "We can either do this...or that. Which one do you like better?"
- Be a patient listener.
- Don't ignore negative behavior or reactions — to a service option, a staff member, a situation, or a living arrangement — as "just" part of the person's cognitive disability. These all can be clues that something isn't right, or needs to change.
- Write down things you learn from talking with your child/loved one. What do they enjoy doing? What activities would they like to add? Do they think about living away from home? If so, what would that place be like? Would they prefer a few people living in the house, or a larger group?
- As the list grows, try to see how the services you're being offered can help this person get the life they want. Sometimes it's hard to see the connection—but you, your provider, and your MHMR service coordinator can work together to make things happen.