

WEB VERSION

What **PROVIDERS** Want
Parents to Know

FINDING COMMON GROUND

What **PARENTS** Want
Providers to Know

Developmental Disabilities Services in Dane County

Finding Common Ground

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PARENT | PROVIDER

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Respect Our Role in the Person's Life

We love them	We're professionals
We know what we're doing	We know what we're doing
Advocacy	Advocacy
Family culture	Agency culture
We know them	We're trained to work with them
Knowledge of what has worked	Knowledge of what works with others
Likes and Dislikes	We learn about people

Defining the Family or Guardian Role

We've felt misled by providers in the past	We need as much information as possible
Keep us informed	Keep us informed
We may be resistant to changing	We may want to change the way things were done in the past
Expectations	Expectations
Parenthood	Adulthood
It hurts to hear your kid's home called a program	We work within a system
Keeping a house a home	Ensuring a house meets all the regulations
We want to feel confident in staff	We work hard to have skilled staff
We want to choose our level of involvement	We may have preconceived ideas about parental involvement
We need knowledge and help in defining our role	We need your help in defining your role
We want to feel useful	We want you to be useful

Wanting What's Best

We want what is best for our sons and daughters	We want what is best for the people we support.
We want to know what works.	We want to know what works.

Introduction

Finding Common Ground: What **PROVIDERS** Want Parents to Know

This booklet was created to help you -- parents, guardians and friends of people with developmental disabilities -- understand the viewpoint of service providers and agencies. It contains information about the values, beliefs and practices of provider agencies. The main focus is on residential agencies that serve people in their homes and apartments. However, many of these thoughts and ideas pertain to vocational agencies and other providers, such as support brokers.

This booklet reads like a conversation between parents and providers because that is how it was developed. Family members and service providers sat down and talked about these issues. The group that worked on this booklet is hoping that this exchange of viewpoints will lead to greater understanding among all those interested in creating and maintaining good lives for people with developmental disabilities.

Donna Winnick

Program Specialist

Developmental Disabilities Unit
Dane County Department of Human Services
Adult Community Services Division
1202 Northport Drive
Madison WI 53704
608-242-6200
www.co.dane.wi.us

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Workgroup Members:

Carter Ayres, Carrie Bublitz-Cardarella, Maya Fairchild, Rachel Friedman, Beth Fujinuma, Kathy Lukesic, Mary Mezera, Pat Wilson, Donna Winnick

What PROVIDERS *Want Parents to Know*

■ ***RESPECT OUR ROLE IN THE PERSON'S LIFE***

**We're professionals.
We know what we're doing.**

· ***Advocacy***

We are proud of the history we have providing quality services. As an agency, we have advocated for adequate funding from the county and state. We participate in workgroups that work for the betterment of services for people with disabilities.

We do this work because we care. We're not paid as much as workers in other fields, and we are not well compensated for the long hours. We do this work because we choose to. We want to work with your sons and daughters.

· ***Agency Culture***

We want you to know about our agency. We're proud of it. Ask us about our size, mission, and our experience working with people similar to your sons and daughters. We have a structure and hierarchy within our agency. Make sure you understand how this works. We have policies around all issues, including a Grievance Procedure that we implement as fairly as possible.

All agencies have limitations in what they can accomplish due to a variety of barriers. We have to work under rules and regulations from the county, state and federal governments. We have stringent funding limits. As an employer, we work under all the employment laws, including wage and hour, unemployment, discrimination, and fair practices. Our employees have sick days and vacation days. And our staff are people with lives outside of their jobs; some don't drive, and some have children or elderly parents. These employment issues can seem disruptive to services sometimes.

Not all agencies do things the same way. Each of us has our strengths and weaknesses. We are always striving to improve what we do.

Our direct funding comes from Dane County. The county asks for compliance in a variety of areas, including training, service provision, finances and data reporting. The county requires that we access funding through several sources, including CIP (Community Integration Program), MAPC (Medical Assistance Personal Care) and Targeted Case Management. These Medicaid programs have paperwork and other requirements that must be met. You will have forms to sign and jargon to learn. We will try to keep it as easy as possible, but you should know that without these programs we wouldn't have funding for services.

We're trained to work with them.

- ***Knowledge of what works with others***

We have developed expertise in working with a variety of people in a number of different situations. We know quite a bit about resources for people in Dane County and how the system works.

- ***We learn about people***

The staff that works day-to-day with a person gets to know that person quite well. The staff sees the person in different settings, doing different things. They learn what social activities the person likes, and can help develop community connections.

■ DEFINING THE FAMILY OR GUARDIAN ROLE

We need as much information as possible.

- ***Keep us informed***

Families need to share practical details with us. We need to know if people receive Social Security, Medical Assistance (and in what form), Medicare, Food Stamps. We need to know their legal status—is there a guardian or a representative payee. We need to know these things because different programs have different rules, and we have responsibilities to make sure that people receive what they deserve through the programs.

Money can be a contentious topic. Family members or guardians need to understand their role if they're the representative payees. The representative payee must

take care of primary needs, such as health and safety. The payee must work cooperatively with the agency because the county holds the agency responsible for health and safety. If the agency has become the representative payee, there still needs to be a cooperative relationship. Don't expect to be paid back for purchases if it hasn't been discussed beforehand. That is because the money must be used for health and safety needs before all other expenses. Different agencies deal with representative payeeship differently, but good communication about money is essential in all situations. In addition, we need to be kept informed of any financial situation that could impact the person's eligibility for funding.

If you have information that you can share from school or other agencies, please do. That will help us do our job better. We don't want to use a support plan that has already been found to be unsuccessful in another setting.

Keep us informed of pertinent family information. We want the person to have as much family involvement as possible. Also let us know if you change doctors or dentists, or have medical concerns. The person's health is important to us, too.

We may want to change the way things were done in the past.

Expectations

We know you have certain standards that you maintain in your home. Everyone has their own way of cleaning, doing laundry and cooking. We will try to keep the home as you would wish, but remember that we can't always do everything just as you do in your home. If this is a concern of yours, keep the lines of communication open.

Adulthood

Your son or daughter is an adult, in our eyes and the eyes of the law. Confidentiality is important to us, and we take it very seriously. You will need a release of information if you're not the guardian if you want us to discuss issues related to the person with you. Even if you are the guardian, people have basic rights that can't be taken away. Those rights include freedom of association, freedom of speech and personal choice. If you feel that there are health or safety concerns connected with these choices, let us know. We can all work together on the issue.

We want you to be as active a member of the person's support team as possible. When the team does planning, you may think that goals are unrealistic or unneeded. Keep an open mind when planning: If you don't understand why a goal is being set,

ask. It may be related to a larger goal, such as participating in adult activities or expanding choices. You might feel there is a goal or activity that is being overlooked by other team members. Be part of the problem-solving and decision-making process within the person's team. Understand that there are limitations inherent in supported living that relate to issues beyond our control, such as budgets, housemate preferences, and staff abilities.

Know that moving into supported living does not solve all the problems the person had in the family home. In fact, there may be some backsliding. Moving is stressful and both the person and the agency need to get to know each other. Give it a year or two to settle down.

Expect that the person will change—all people do when they move. The agency will treat the person as an adult and an individual. This will likely be different from the family-centered approach of schools or agencies within the children's system.

We work within a system.

Ensuring a house meets all the regulations

We operate under a variety of laws and regulations. There are federal laws like HIPAA (the health information confidentiality law), state rules (like those connected to our funding, such as CIP), and county policies. You may think we sometimes act like a bureaucracy, but that's because we have to work with them. Most of the rules, such as confidentiality, were set up to protect the people we serve. We need to fill out numerous forms. This can take time away from spending time with people we support. If you have questions why we're doing something, ask us about it.

We encourage you to be an active member of the developmental disabilities system in Dane County. We are members of the Developmental Disabilities Coalition of Dane County, an organization that advocates for families and people with disabilities to receive adequate funding. However lawmakers want to hear from families, guardians and people with disabilities about their needs. Join committees and be part of an advocacy system to improve services for people with developmental disabilities.

We can't control some problems in the system. Transportation is one example. It is frustrating for everyone sometimes, but the city and private companies run transportation services. Medical services can be another example. Lack of choice regarding dental services and therapies is disappointing, but is related to Medicaid rules and reimbursements.

We have significant funding limitations. Funding impacts our ability to have one-to-

one staffing which can affect a person's lifestyle and opportunities to individualize. Money also limits people's choices about where they can live and how often they can go out. Unfortunately, people with disabilities almost always have limited funds.

You can help the person financially if you wish to, but discuss it with the agency first so we keep within the rules connected with our funding. Your help can increase the person's quality of life.

- *Housemate issues*

Almost everyone in residential services has a housemate. A housemate shares costs and staff, and provides companionship and socialization. Families and guardians need to remember that housemates have the same rights as their sons and daughters. Remember that it is their home, too.

It is considerate to call before visiting. If you want to make unannounced visits, that should be part of the person's plan. You will be interested in the housemate, but that person has privacy rights that need to be respected. You don't have the right to know about the housemate's medications, behavior plans, and so forth unless it impacts on your son or daughter. You may include the housemate in making decisions. For example, if you want to help decorate, think of the housemate's favorite colors as well as your family member's preferences. Include the housemate in conversations. The housemate is an important person in your son or daughter's life.

- ***We work hard to have skilled staff.***

We try to hire the best support staff we can. Families should be appreciative of good staff and, and say "thank you" occasionally. Recognize their good ideas and appreciate their attention. It's not just who you talk to that can create an impression, but how you talk.

Staff may not have as much experience as you would like, but they wanted the job of caring for someone else. That means they want to do the job well.

Parents can be role models for staff regarding how to interact with the individual, and give them hints as to the person's likes and dislikes. However your choices may not always be the same as the person's, or the person may have changed. Respect staff people who know the person on a day-to-day basis, and therefore get to know the person very well.

- *Staff Issues*

Respect the hierarchy within teams and ask who your contact person is for com-

plaints and questions. It is unfair to expect direct support staff to have all the answers.

We are always training and re-training staff. You can ask us about what kind of training staff has received, and make suggestions if you know of something that could be useful. However, we have complex scheduling that includes many households, staff meetings, and other team meetings. This impacts our ability to find time for training.

We deal with many challenges in providing good staff. Turnover is a constant issue. Poor pay and lack of advancement opportunities are a big part of the problem.

We will try our best to address your concerns.

We may have preconceived ideas about parental involvement.

- ***We need your help in defining your role***

You need to tell us how you perceive your role. Let people know what works for you regarding meeting frequency and communication methods. We can't always get right back to you so we should discuss how quickly you need a response. We want you to be part of the problem solving and decision-making within the person's team.

Those who provide services to the person need to stay in touch with all the team members. The county encourages a team approach, and good communication creates continuity and stability. Therefore, vocational and residential agencies need to be in frequent contact about the person.

- ***We want you to be useful***

We assume that you're interested in the person's progress and activities. It helps people to have others involved in their lives who are not paid providers. You are the eyes and ears of the service system.

■ **WANTING WHAT'S BEST**

We want what is best for the people we support.

· ***We want to know what works—***

TIPS on creating positive working relationships with agencies:

- Let us know what your level of involvement will be.
- Pick your battles. It can be easy to over-react, because the person is so important to you.
- Feel free to express your concerns and complaints, but please do it politely.
- We want to address problems. Report things right away, and don't wait for things to build up. You and your support broker should work together to resolve issues.
- Being a team member means sharing differences of opinion and trying to understand the position of the other team members. Your opinion is vital, as are the opinions of the others at the table. Compromise is part of the process.

**Be patient.
We're trying to do our best.**

Introduction

Finding Common Ground: What **PARENTS** Want Providers to Know

This booklet is intended to provide agencies with a viewpoint they don't usually hear. It's the honest voice of parents, guardians and advocates expressing how they feel about working with agencies as they try to obtain the best life possible for the people they care about. Their voice contains fear, love, and hope. They trust you will listen to their words.

This booklet reads like a conversation between parents and providers because that is how it was developed. Family members and service providers sat down and talked about these issues. The group that worked on this booklet is hoping that this exchange of viewpoints will lead to greater understanding among all those interested in creating and maintaining good lives for people with developmental disabilities.

Donna Winnick
Program Specialist
Developmental Disabilities Unit
Dane County Department of Human Services
Adult Community Services Division
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What *PARENTS* want *Providers to know*

■ ***RESPECT OUR ROLE IN THE PERSON'S LIFE***

We love them.
We know what we're doing.

Advocacy

Before you were the service providers, we were the service providers. Parents work hard when their children live at home. All those years, parents worried, lost sleep, and struggled. Parents worry about the past—what could I have done better? They worry about the present—am I making the right decision? And they worry about the future—what will happen to this person I love?

We love this person. There is a special relationship that is created when a child has a disability. The other children will grow up and leave but this child will always need someone to love him or her. There may be no one else who will. Our greatest fear is that when we're gone, there will be no one left who will love this person. You may think we're intense and unreasonable. We want you to understand where those strong feelings originated.

We have been advocates for many years. We have clashed with schools and doctors and other providers. We have some long-standing hopes and dreams for this person. We have heard the word "unrealistic" many times. But we must advocate for the best quality of life that we can.

Family Culture

The person you know today had many experiences before you were involved. The person has different roles in the family and to others—a sibling, a cousin, a friend. Certain people have been important to the person. There were teachers who knew

just how to handle things.

Every family has its own culture. That includes how we celebrate holidays, what foods are favorites, our funny stories and family tragedies. Some events were very special to the family. You should know that family culture creates continuity and connections for the whole family, including the person you're supporting.

Families have different expectations regarding things like laundry, housecleaning, food, and activities. You may not agree with the way our family does things. Because it has worked for our family, it's just our way.

We have our own ways to rejoice and to grieve. Be sensitive as to how our family deals with disability issues. Families have different ways of handling the complex feelings that develop when there is a child in the family with a disability.

We know them.

- ***Knowledge of what has worked***

We know the person very well. We know what has worked in the past, and what hasn't. We are the keepers of the family history, the medical history, and the education history. We know all the goals that were set in school, and what worked and what didn't. We have learned what methods of support work best with that person's personality traits. And through trial and error, we have learned how to handle various situations.

- ***Likes and Dislikes***

We know what social situations work best, if the person enjoys cooking or sledding. We know the favorite foods, favorite colors, clothes, and weather as well as places to have fun and places to relax. We know who is important to that person, and why. You can learn from us.

■ **DEFINING OUR ROLES**

We've felt misled by providers in the past.

Keep us informed

Trust can be hard to develop. Parents worry about retaliation. If we don't cooperate, perhaps it will be taken out on our children. This is a deep-seated fear that creates anxiety for many families.

Many families do not really believe that providers will listen to them. They may feel distrustful of systems. In the past, we may not have been treated as team members in other experiences, especially the school system. Although adult services are very different, it's hard not to make assumptions based on past experiences.

We want to be kept informed. We will develop trust if we feel people are being honest with us, and listening to what we say. Don't make promises you can't keep. If something can't be done as we thought it would, explain why. We want to trust you, but you may have to earn it.

We may be resistant to changing.

Expectations

You need to ask us about our expectations—our expectations of you, of the person's plan, of the future. We may base our expectations of agencies on the type of home we kept. Or they may be based on our hopes and dreams and fears. We don't always know what's possible. But we think our opinions matter.

Parenthood

It's a fact of life: Parents act parental towards their adult children. We can't help it; we still worry about them and still feel they need our advice. It's truer with an adult child with a disability. The parent has done everything for that person for a long time. We know that the person will always need us, as our other children won't.

The same worries that plagued us when they were young have not disappeared. Instead they reappear in different ways. Sometimes we are called petty, overly protective, obsessive, or unreasonable. Maybe we sometimes are. You should know it's coming from the same place that it comes from with your parents—from caring.

It hurts to hear your kid's home be called a "program."

Keeping a house a home

Our son or daughter has a history. In that history are culture, religion, and family dynamics. It feels good to walk into a home and have a sense of who the person is. We hope to hear music playing that our son or daughter likes, not the music the staff person likes. If you know about the person's background, preferences and interests, you can help the person create a home that feels familiar and natural.

We ask that you remember that you are privileged to receive private information about people. We don't want to hear private things about the housemate or the housemate's family either. Confidentiality is important to us.

Don't make comparisons between one housemate and another. It feels strange to us to hear negative things about a housemate, and even worse to hear it about our sons and daughters. We want to think that people like working with individuals we care about. We know how unique they are, and we trust others want to find that out. We hope you're keeping an open mind about the person.

We want to feel confident in staff

We want well-trained staff. We want staff who enjoy their jobs, which is working with our sons and daughters. We assume that staff reads the materials and reports they get from us, and that they will ask questions as needed. We also assume that information is passed along to the next staff working with the person.

Families and guardians may react to an immediate need. Whether you think it's urgent or not, we think you should be responsive. It shows respect to call us back, to confirm receiving the call, and to say you'll look into the situation. Then, have someone get back to us. Similarly, if we're picking up the person for an outing, help

the person be ready to go on time. It's respectful of our time and the person's time with us. If there's a delay, call.

Problems can be caused by mistrust about money issues. You need to have complete, current records we can understand. If we see you're managing the person's money respectfully, we'll believe you handle other details well too.

It is hard to convey how frightening it is to think of leaving a person with staff who are untrained, indifferent or incompetent. When we get scared, we may seem irrational and fanatic. Really, we're just concerned and afraid.

We want to choose our level of involvement.

We need knowledge and help in defining our role

We're not born knowing how to parent a child with special needs. We learn along the way. Similarly, we don't suddenly know how the adult system works. We need to learn about it.

Everything changes as the child becomes an adult. There are new roles for us. A parent may become a guardian. However we don't always know what that means; we just know we were told to go to court and become a guardian. If guardianship changes, the new guardian needs to know what it means.

The language changes. The words that teachers use are different from those used by adult service providers. The agency says the person is an adult, but we still see the person as our child.

We are told that we are team members. Perhaps we've heard that before, in a school or medical office. We may have become cynical. We may be tired. We may need to pass the responsibility along. Or we may need to be empowered and encouraged to participate in the team. We will likely need help in defining our role. It doesn't come naturally.

It helps to have an identified person at the agency that we can trust, someone who will listen without being judgmental and will communicate our concerns throughout the hierarchy. Help us to identify this person.

Another way for us to learn our role is by attending meetings. Invite us. Have the meeting organized. It feels disrespectful of everyone's time when the meeting is

disorganized and the pertinent issues aren't discussed. Agendas work well. So do rules at meetings, such as listening to each person and not interrupting.

• ***We want to feel useful***

We want to help. When transitions occur, we can help by being the historian. Use the information we have. Information about our involvement should also be passed along. Staff should know we are a good resource. We want to be able to discuss issues and most of us are glad to be called at any time. We don't always feel that we're thought of as useful partners, but we are—really.

■ **WANTING WHAT'S BEST**

We want what's best for our children.

• ***We want to know what works—***

TIPS on creating positive working relationships with families.

- There are ways to infuse a house with who the person is. We are happy to offer photos, items from the previous home, and ideas for how to make a house a home.
- Help us feel useful. Ask us about the person's history, family and friends. We can help new staff feel more comfortable with the person by relating our knowledge.
- You can let us know if something isn't going well. We have empathy for the staff. We know it's hard because we did it all those years!
- Agencies should feel like they can call for help. We are usually happy to be helpers (and we'll let you know if we can't help).
- Don't be afraid to say "I don't know" or "I'll check on that". We'll respect you more if you're honest about it than if you try to excuse something. This builds trust.
- Communication is so important to us. Use the phone, email or whatever works.

Finding Common Ground: What PROVIDERS Want Parents to Know

We want to hear from you regularly and often. A communication log at the house works in a number of situations. Regular communication creates a sense of working together. If it's difficult for you to return calls quickly, let us know the guidelines about when calls will be returned and how other communications will be handled.

- We may feel isolated after our sons and daughters move. Think about offering opportunities for us to meet other parents/guardians.

**Be patient.
We're doing what we think is best.**