



FINDING COMMON GROUND

**What PARENTS Want
Providers to Know**

Developmental Disabilities Services in Dane County

Finding Common Ground

Parent

Provider

1. Respect our role in the person's life

We love them. We know what we're doing. <ul style="list-style-type: none">• Advocacy• Family culture	We're professionals. We know what we're doing. <ul style="list-style-type: none">• Advocacy• Agency Culture
We know them. <ul style="list-style-type: none">• Knowledge of what has worked• Likes and dislikes	We're trained to work with them. <ul style="list-style-type: none">• Knowledge of what works with others• We learn about people

2. Defining the family or guardian role

We've felt misled by providers in the past. <ul style="list-style-type: none">• Keep us informed	We need as much information as possible. <ul style="list-style-type: none">• Keep us informed
We may be resistant to changing. <ul style="list-style-type: none">• Expectations• Parenthood	We may want to change the way things were done in the past. <ul style="list-style-type: none">• Expectations• Adulthood
It hurts to hear your kid's home called a program. <ul style="list-style-type: none">• Keeping a house a home• We want to feel confident in staff	We work within a system. <ul style="list-style-type: none">• Ensuring a house meets all the regulations• We work hard to have skilled staff
We want to choose our level of involvement. <ul style="list-style-type: none">• We need knowledge and help in defining our role• We want to feel useful	We may have preconceived ideas about parental involvement. <ul style="list-style-type: none">• We need your help in defining your role• We want you to be useful

3. Wanting what's best

We want what is best for our sons and daughters. <ul style="list-style-type: none">• We want to know what works	We want what is best for the people we support. <ul style="list-style-type: none">• We want to know what works
---	--

Introduction to 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 building 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

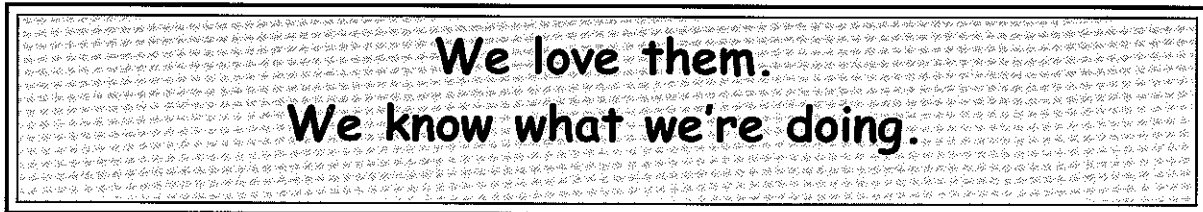
April 9, 2004

Workgroup Members:

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

Finding Common Ground: What PARENTS Want Providers to Know

1. RESPECT OUR ROLE IN THE PERSON'S LIFE



- **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.

2. 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

Finding Common Ground
What Parents Want Providers to Know

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

Finding Common Ground
What Parents Want Providers to Know

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.

3. 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. 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.



FINDING COMMON GROUND

**What PARENTS Want
Providers to Know**

Developmental Disabilities Services in Dane County

Finding Common Ground

Parent

Provider

1. Respect our role in the person's life

We love them. We know what we're doing. <ul style="list-style-type: none"> • Advocacy • Family culture 	We're professionals. We know what we're doing. <ul style="list-style-type: none"> • Advocacy • Agency Culture
We know them. <ul style="list-style-type: none"> • Knowledge of what has worked • Likes and dislikes 	We're trained to work with them. <ul style="list-style-type: none"> • Knowledge of what works with others • We learn about people

2. Defining the family or guardian role

We've felt misled by providers in the past. <ul style="list-style-type: none"> • Keep us informed 	We need as much information as possible. <ul style="list-style-type: none"> • Keep us informed
We may be resistant to changing. <ul style="list-style-type: none"> • Expectations • Parenthood 	We may want to change the way things were done in the past. <ul style="list-style-type: none"> • Expectations • Adulthood
It hurts to hear your kid's home called a program. <ul style="list-style-type: none"> • Keeping a house a home • We want to feel confident in staff 	We work within a system. <ul style="list-style-type: none"> • Ensuring a house meets all the regulations • We work hard to have skilled staff
We want to choose our level of involvement. <ul style="list-style-type: none"> • We need knowledge and help in defining our role • We want to feel useful 	We may have preconceived ideas about parental involvement. <ul style="list-style-type: none"> • We need your help in defining your role • We want you to be useful

3. Wanting what's best

We want what is best for our sons and daughters. <ul style="list-style-type: none"> • We want to know what works 	We want what is best for the people we support. <ul style="list-style-type: none"> • We want to know what works
---	--

Introduction to 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 building 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

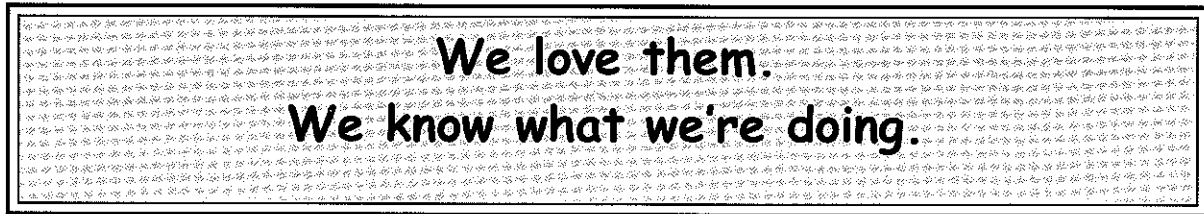
April 9, 2004

Workgroup Members:

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

Finding Common Ground: What PARENTS Want Providers to Know

1. RESPECT OUR ROLE IN THE PERSON'S LIFE



- **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.

2. 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

Finding Common Ground
What Parents Want Providers to Know

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

Finding Common Ground
What Parents Want Providers to Know

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.

3. 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. 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.

Finding Common Ground
What Parents Want Providers to Know

- 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.