

The International Journal for Direct Support Professionals

Working Effectively with Families

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What is family?

The dictionary definition of 'family' is "a group consisting of parents and children living together in a household." However, we know that family means more than just this. The word family means different things to different people. Family representing different things is also true for the people we support. Family, for some, means mom and dad, or sister and brother. Family, for others, can mean close friends and people who have played a meaningful role in our lives. It does not always have to do with being related by blood or marriage. Family is often a person's primary connection to culture and traditions.

Due to the level of isolation people with intellectual and developmental disabilities (IDD) face each day, this sense of belonging to family, culture, and traditions is even more critical. Family can also create a social connection to other communities, such as religious communities that can decrease a person's sense of isolation. Family can provide an emotional support system in a way that is comfortable, safe, and familiar to a person with IDD. Families can be an excellent support for people with IDD to assist them with reaching their goals and dreams for their future.

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You may hear stories from your co-workers about families that are "hard to support;" you need to put these stories aside and develop your relationship and rapport with the family. Try not to let other people's stories or preconceived ideas affect you and your ability to build a positive professional relationship.



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Respecting diversity

As the Direct Support Professional (DSP), part of your role is to respect and support the different cultures, traditions, and religious beliefs of the individuals you support. Do not be intimidated to show interest and ask the family questions about what they value, and what is important to them. Developing this insight will enable you to understand who they are, what they believe, and why they respond the way they do in certain situations. As the DSP, you are encouraged to help the person you support incorporate what you learn about the family's traditions and culture into their daily routine and lifestyle. This valuable information will also increase



your ability to provide quality opportunities and choices. DSPs are encouraged to share the information they learn with other DSPs on their team, to create a strong circle of support for the individual they support.

Cultural differences can be seen in many ways, for example, in how people respond to food, conflict, and in new situations. DSPs must remember not to impose their values, culture, or traditions upon the people they support. DSPs are not asked to change their personal beliefs; instead, as professionals, it is their job to show compassion, respect, and support for the values, culture, and traditions of the individuals they support. DSPs can consider this when supporting the individual in all activities of daily living, i.e., meal/menu preparation, keeping and maintaining the individual's personal space, how and when they worship, coping with grief or challenging situations.

Establishing clear boundaries

As a professional, it is the DSP's responsibility to establish clear boundaries from the start of the relationship. Be clear from the beginning about your role and the limits that you must follow, based upon your employer and their policies and procedures. It is when those boundaries fade, that it becomes difficult to identify where the line of professionalism is. It is much easier for everyone involved when the boundaries are established at the beginning of the working relationship than to have to backtrack and reestablish appropriate boundaries.

To foster the growth and development of any family relationship, the DSP must provide an open and honest shared space where the family can be involved as much or as little as they choose without judgment.

Some families may be intimidated by the complexity of the system or discouraged by the agency's policies and procedures. This complexity can result in a 'hesitant' family not being as involved because they do not know or do not feel comfortable within the systems. It is suggested that DSPs encourage families to ask questions and engage in information sharing.

The DSP can share ideas on how the family can be involved in their loved one's life in healthy and respectful ways that the individual they support would enjoy and from which they would benefit. Offering to increase interaction by using different forms of communication that are available and accessible could be a possible way to involve families more. Gently and respectfully helping those families who are not as active to appreciate their significance and importance even with a simple telephone call can go a long way to developing the family relationship for the individual that you support.

Some families also have difficulty with allowing their loved ones with IDD to have independence. The family may want constant access to their loved one's home and their life. The family may wish to assume the role of an individual's decision-maker or want to influence decisions in every aspect of daily living, friendships, interests, and goal setting. Sometimes DSPs can become quite judgmental about the family and their overprotectiveness. It is best to leave judgment behind. Files tell you only so much; families are often afraid for the safety of the individual as they move towards independence, and they may be fearful of the quality of support their child may receive. Remember, many other DSPs have come and gone in their child's life before you.

We recommend that the DSPs work collaboratively with the individual being supported, helping them learn to speak up and let their wishes be known, and also with the family to help them listen to and support the individual with whom you work. In these family situations, it is suggested that a person with IDD become involved with self-advocacy groups to help them develop their skills and autonomy.

Five Tips for DSPs to Establish Clear Boundaries with Families:

- 1) Limit disclosing personal details and sharing personal information.
- 2) Do not share your email, phone number, or home address.
- 3) Maintain healthy professional relationships; do not develop close personal relationships outside of work. You must strive for a healthy work/life balance.
- 4) Avoid engaging in gift exchange or accepting personal gifts.
- 5) **Conduct & Professionalism:** You are the professional providing a service. You are representing the agency for whom you work. Carry out your responsibilities with respect and objectivity.

Communication

DSPs need to be kind and compassionate. It is also essential that, as professionals, DSPs are aware of the words that are chosen to be used. As professionals in the field, we have been given opportunities to support individuals in and through different life experiences. We can never assume to know how it "feels" to be in the shoes of the family. Every person's individual experience is unique and their own. Do not assume you have experienced it before with another family or have been through it yourself. To say or think this is to devalue the person you are supporting and their family's individual experiences.

Have the person you support participate in the communication as much as possible and as appropriate for them. This is their information, and they should be involved in providing consent to share information with their family. Having the person you support included in the communication with the family is individualized and based upon many factors; however, when possible, the more involved a person can become the more they can learn to become a self-advocate for themselves.

Respect that the family is an expert on the person you support. They have a history that goes way beyond anything you will read in any file or report. Listen, and listen carefully to the details of what they say; the details they provide will help guide the support and care you give. Document these details, so they are not lost for future care providers.

When connecting with families, the following must be considered to ensure effective communication:

1. Establish Family involvement & Contact: Clear information should be gathered on how the family wants to receive information from the DSP, and how they want to provide information to the DSP. Be clear on what the family wants, i.e., telephone calls, emails, letters, virtual or in-person meetings? How often and when?
2. Be present and stay focused. Give your full and attention to who is in front of you. This is not a time to multitask or be distracted. Try your best not to use professional jargon or abbreviations. If you do, explain what the acronyms mean. Do not wait for the family to ask.
3. Follow up and next steps: If you do not have the answers to the questions they are asking, be truthful and honest. Inform the family you will investigate further and report back promptly (give yourself and them a timeline to when you follow up). Be honest, and do not make false promises that you cannot keep.
4. Documentation: Any family communication should be documented and logged. Telephone conversations or family meetings must include a detailed account of what was discussed, concerns brought forward, and action plans moving forward. Your notes should detail who is responsible for what and a realistic timeline for follow through. Well-documented logs will prevent miscommunication and duplication of information being requested.
5. Information sharing: Share information received with the team to ensure that everyone is aware of what was discussed and the next steps. This will ensure that the team is united in supporting the individual and family.

Families with complex support needs

No one agency can provide all the answers when supporting a family with complex support needs. Having a collaborative approach can provide an opportunity for unique opportunities for families to build their goals and skills together. Collaborations with interdisciplinary teams are essential to support families, especially with complex needs. The idea behind interdisciplinary teamwork is that each member, with different skills and experiences, creates a combined co-operation that enhances and improves overall care. DSPs need to be at this table, along with other professionals. It is crucial that, as a DSP, you do not feel intimidated by others at these interdisciplinary tables. Your feedback from direct observations and support provides an essential lens that, if forgotten, can result in future planning being drastically misguided. A family should be present when the interdisciplinary team meets, if not all the time, then most of the time. During this collaborative approach, it is vital that all voices are heard and respected, and that professionals do not find themselves in a position of needing to be territorial over a family. When professionals become territorial, collaboration breaks down, and the only one that loses is the family.

Working through conflict

Often, when we hear the term conflict, we feel hesitant and even afraid. Our instinct can be to fight back, run, and hide from conflict. This reaction is often why conflict leads to a breakdown of

communication and professional working relationships. It is ok to ask for some time to think about this situation and to come back to it. In order not to react negatively to the conflict, allow yourself some space. Try your best to separate your emotions from the situation and look at the situation objectively. Remember, you are not in competition with the family, and you are the professional. Power struggles are never going to lead to a solution to the conflict.

Working through conflict can build a stronger working relationship with families through a stronger understanding of trust and commitment to support their family members. Keeping the program supervisor updated on family concerns before they become serious conflicts will also help provide you with support and guidance.

Conflict can be positive if given space to be looked at without judgment. It is helpful to come back to the subject that is creating conflict and rethink the situation in a way that can be discussed and supported by the full team; this creates a win-win situation for everyone. Having documented goals, timelines, and follow-up strategies in these meetings is very important to support the progression of conflict to resolution. Conflict brings discussions on new topics and ideas, and when people are open to discuss and listen openly, this can be an opportunity for innovative creativity.

Maintaining the relationship

The value and significance of maintaining a stable and trusting relationship with our families are immeasurable. It is a relationship that will be ongoing for many years. DSPs must have a vested interest in continuing to build and foster its growth and development. DSPs should strive for every interaction to be positive, meaningful, and professional. For every conversation to include transparent information sharing and exchange with the member's best interests in mind... always. We are speaking openly and honestly, with clear takeaways and action plans.

DSPs cannot get too comfortable and overly confident. Your conduct and professionalism are expected, regardless of how much you know about the family and their successes or struggles. You are providing a service. You are the professional and need to represent yourself that way from day one to year 10.

As the individual you are supporting gets older, so do our families. The family relationship you have nurtured and developed may change. The level of support to their family member may alter. In some cases, it increases, in others, it lessens. The role of the DSP is to recognize and respect this. Execute with sensitivity and compassion. Work with the families to determine the best way for them to continue to be involved for as long as they choose.

Summary

Family connects the people we support to their culture, traditions, and communities in ways that paid professionals cannot. The information families provide to us as professionals always needs to be respected and taken seriously; they should be treated as experts when it comes to their child. Setting boundaries and keeping clear boundaries as the professional will set the stage for a healthy, positive working relationship from day one through many years of support. Personal judgment of families and their involvement is not helpful, is not professional, and breaks down

not only your relationship with the family, but your relationship with the individual you are supporting. In all working relationships, there will be moments when people do not always agree, and this will be true of the working relationship between the DSP and the families of the people they support. Managing conflict in a professional manner, with shared goals and outcomes, will help establish ongoing respect and build a stronger working relationship moving forward.

It was vital for us to have the experts on the people we support, - the family – to have the final say in this article. The following are six key strategies that two families at Vita Community Living Services have shared to help DSPs work effectively with families.

Families Provide Six Key Strategies for DSPs to Working with Families:

1. **Compassion:** We want our DSPs to show their care and compassion for our loved ones – any information sharing, discussions, and updates will always have the best interest of our loved ones in mind when dealing with the families.
2. **Mutual Respect & Trust:** We want our DSPs to inspire trust – when speaking with families, they need to be direct (but not too direct!) and to follow up on issues raised promptly. This trust develops over time is what helps us sleep peacefully at night.
3. **Communication:** We want our DSPs to communicate well – to speak calmly and openly about issues, with good interpersonal skills, tact, and a sense of humour. This helps us to understand and feel better about any situation or issue.
4. **Active Listening:** We want our DSPs to be good listeners – we families may feel and show a variety of emotions, so that we may talk too much or not enough, but we need them to be patient and to hear our message and concerns.
5. **Interpersonal Skills:** We want our DSPs to know that families are different and may need to be approached in different ways – some families may be more vocal and demanding, while others may be quieter and passive. But in the end, we all want the same thing – what is best for our loved ones and their best quality of life.
6. **Working Collaboratively:** We both want the best for the people you support. If I know you hear me, I will hear you. And vice versa. If we work together, then you can understand my daughter as I do, and it will be easier to take care of her. I will share what I know, and you can teach me too.

"It must be very difficult and challenging to do and show these things all the time, but I have had the good fortune of witnessing these very qualities in the wonderful DSPs who care for my loved one and, in turn, for our whole family." - Anthony DiMonte

"At times, DSPs are limited in what they can do. They have processes and protocols to follow that I may disagree with. But I know they are working in the best interest of my daughter. It makes me feel good knowing they care and are invested. I walk away from the group home, knowing my daughter is in a good place. It isn't a house. It is a home. It's family." - Cathy Costa

About the authors

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