Clinician Guide

Building Connections for Success!

What does it mean to partner with families in treatment?

Clinician-family partnerships are relationships that are built on trust and mutual respect, include two-way open communication and sharing of ideas, and engage each member as equal decision-making partners, and provides opportunities to support one another in achieving goals set (Wisconsin Department of Education). Further, partnerships recognize the unique knowledge, skills, and lived experiences that each person brings to the relationship and creates an atmosphere where cultural values are honored and incorporated into treatment (PACER, 2024).

Related to partnerships, the Maternal and Child Health Bureau (U.S. Department of Health and Human Service, 2023) developed several Leadership Competencies, one being Honoring Lived Experience. They describe the following as key to effective partnerships with people with lived experience:

- Shared decision making, involving self-advocates and/or the family, in planning and implementing activities.
- Addressing the priorities of people with lived experience using a strengths-based approach.
- Recognizing the agency of self-advocates in decision-making as they approach transition age, and across the lifespan.
- Connecting people with lived experience to needed services.

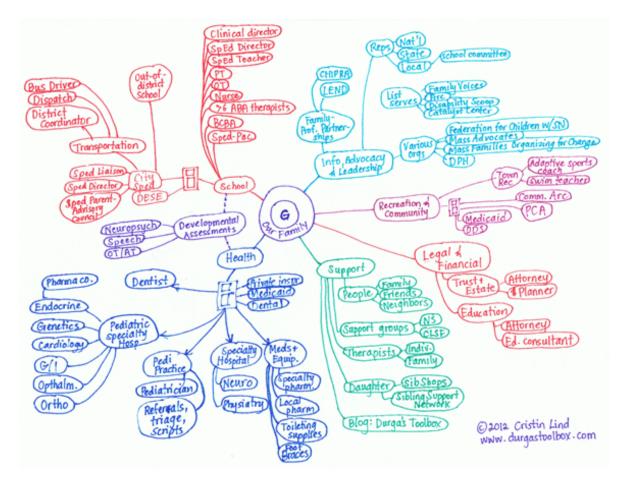
Underlying assumptions or core values can impact the extent to which professionals are able to implement competencies learned. It is valuable for professionals to reflect on their assumptions. The following assumptions have been identified as integral to engaging families as partners (based on lowa's Early ACCESS SCRIPT, 2004; Henderson et al., 2007):

- All families have hopes, dreams, and wishes for their children and want the best for them.
- All people need support and encouragement that recognizes their lived experience and maintains their dignity.
- All people have strengths and different but equally important skills, abilities, and knowledge.

- All families have the capacity to support their child's learning. Families are resourceful, but all families do not have equal access to resources.
- Families should be equal partners in the relationship with service providers.
- The responsibility for cultivating and sustaining partnerships among home and the clinic or school community rests primarily with provider or staff.

Why is partnering with families in treatment beneficial?

Families are often the one constant member of teams as their child grows and transitions between services. They are often the connector for their child's services in and outside of clinic and school. This care map from the <u>Boston Children's Hospital</u> shows the many services families of children with disabilities might navigate.



Families and therapists each bring unique expertise that can enhance outcomes. Families are experts on their child and family. They bring essential knowledge of the child, past challenges and successes, and dreams for what their child's life will be like through adulthood. Families benefit from gaining tools to help their children become active participants in enhancing their quality of life. Similarly, behavior analysts bring knowledge about behavior and evidence-based interventions, and passion to facilitate success. Engaging families as partners can help the members of the team to feel supported and valued. Family engagement is related to improvements for everyone involved:

Benefits for children/youth

- Increased progress with targeted skills
- Strengthened relationship between the parent and the child
- Increased maintenance and generalization of skills to places outside of the clinic or treatment setting

Benefits to Families

- Increased self-confidence and empowerment
- Improved trust in practitioners delivering services
- Improved knowledge and skills that can be used to support their child at home

Benefits to Clinicians/Teachers

- Higher expectations for child/student learning
- Improved communication and problem resolution
- Increased morale and retention
- Reduced tension and barriers between families and clinic or school personnel

How can I build trust and partner with families at the beginning of treatment?

Building trust, involving families in selecting goals, and establishing communication.

- 1. Take time to reflect on your own biases and approach to working with families.
- 2. Invite the family to bring someone (e.g., a family member, friend, advocate, therapist) with them to the meeting for support or to share their expertise about the child.
- 3. Meet with the family at the beginning of treatment to get to know them and the hopes and dreams they have for their child, what has been successful for their family, and areas they would like additional support. You can also learn about their knowledge, assets, practices, and life experience and explore how those can be incorporated into treatment.
- 4. Communicate to the family their expertise and valuable role in treatment. Roles are likely to differ across families since each family's situation is unique.
- 5. Create the treatment plan together, including learning, behavior, and independence goals that are meaningful to the family.
- 6. Invite the family to observe sessions to learn alongside and participate in parent training.

- 7. Find ways to have ongoing, two-way communication. Communication is the key to be able to form a working trust between the therapist and the families. Effective two-way communication involves sharing information and listening actively and using open-ended questions. A few communication tips:
 - Use terminology in clear, everyday words rather than educational jargon. Use individualized examples to communicate what is happening in therapy.
 - Ask parents about their communication preferences. Care should be taken to ensure privacy is protected and Health Insurance Portability and Accountability Act (HIPAA) rules are followed.
 Some parents prefer minimal communication while others require more details and frequent check-ins. They might prefer phone calls, written notes, email, or text messaging. For example:
 - Use a daily journal to have a written copy of what happened at therapy and what happened at home. Topics might include the goals worked on, progress, and successes.
 - Send pictures or videos of accomplishments.
 - Send an email or text message that the family can respond to and share more about the day or what they notice with a skill.



How can I continue to partner with families during treatment?

Maintaining communication, sharing progress and successes, encourage feedback and ideas.

- 1. Share successes, whether they are big or small!
- 2. Maintain effective communication. Check in periodically to see how communication is going and make changes as needed.
- 3. Encourage families to ask questions and offer ideas.
- 4. Be open and honest.
- 5. Meet periodically to discuss treatment progress, establish new goals together, and identify any additional support needs.
- 6. Provide positive feedback to the family for their expertise and ways they support their child.

How can I partner with families as they prepare to transitions from therapy to school or other services?

- 1. Collaborate to make materials the family can share and use
 - a. Create a one-page paper about the child to share with school staff or other providers. This might include:
 - A picture
 - Any medical, allergy, diet, or sensory needs others should be aware of
 - How the child communicates best- word approximations, device, or gestures that the child uses to communicate with you
 - A list of the child's talents and strengths—bragging points
 - Behavioral strategies that motivate the child or help in certain situations
 - List preferences like favorite characters, YouTube videos, favorite foods and drinks
 - List of dislikes, triggers or fears, noises or toys they don't like.
 - Tips from my family
 - b. Create a one-page paper about ABA therapy. This might include:
 - Treatment summary
 - Most recent goals and progress
 - Strengths and areas for support
 - Intervention tips
 - c. Design a binder or way to store documents and a communication logbook. Sections of the binder might include:
 - List of important contacts
 - Evaluation reports like school Multidisciplinary Team Report (MDT)
 - An MDT Report includes the results of the assessments that were done, whether or not the child met criteria for special education services, and the disability/disabilities if the child meets verification criteria.
 - An evaluation is done every three years to see if the child is still eligible for special education (unless the team decides it is not needed).
 - Note: An MDT Report and Individualized Education Program are legal documents. Families have the right to agree, disagree, or decline to sign the document. There are resources to support families as needed. To learn more about due process, visit <u>Family Guide to Special</u> <u>Education</u>
 - Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP)
 - An IFSP or IEP includes information like how the child is currently doing, annual goals, how progress will be monitored, related services provided, accommodations and modifications needed, time in the general education classroom, what special education services look like (when, where, how often, how long), and a transition plan by age 14.
 - The IEP might also include a Behavior Intervention Plan (BIP) that describes intervention strategies to increase targeted behavior(s) and decrease behavior challenges that interfere with education.

- The IEP Team meets at least one time a year to update the plan.
- A family can request to meet with the team at any time.
- Progress Reports on IEP goals. These are given at least as often as it is for other students.
 - Applications for state or federal programs like the Nebraska Disability Waiver, Nebraska Respite Services, Social Security
- Notes for upcoming meetings like questions the family wants to ask, ideas to share, new goals to discuss
- Communication Tracker. Plan to write notes when you speak or communicate (email, text, notes) with someone about your child's needs or services. Include the date, the person's full name and title, and information about the discussion. At times, the family might send a follow up email there is documentation. This tracker can be helpful during team meetings to remember conversations.
- 2. Discuss goals to support a successful transition. Ideas to support transition should match the child's needs. Below are a few ideas:
 - a. Help the child adjust to new routines. Consider an earlier bedtime and wake-up time to prepare as the school year approaches. Work on activities typical in the classroom and moving from one activity to the next.
 - b. Set up a consistent routine. Sometimes having structured environments help kids to know what to expect. Visual schedules or times to signal transitions might help throughout the day.
 - c. Plan a visit to the school playground to become familiar with the place. Most schools allow the public to play on the playground when school isn't in session.
 - d. Arrange playdates with other kids who will also attend the school (e.g., meet at the school playground/park, visit the library). Plan for the playdate to match the child's needs, keep it brief so that it is more likely to be successful.
 - e. Work on school readiness skills and basic academic skills with your child leading up to kindergarten. You can help your child explore numbers, letters, and colors through age-appropriate activities, games, or workbooks. This will help them become familiar with some of the academic topics that they will learn in their kindergarten classroom.
- 3. Encourage the family to meet with the school team. Families can mark the calendar for about a week before school starts to visit school and/or send an email to teachers, the Individualized Education Program (IEP) case manager, and/or your child's counselor. Request a meeting before the first day of school so you can walk around the school and let the child know where they are supposed to go the first day of school, meet the teachers, and let the child get comfortable with the classroom in a quiet time frame. During the meeting, the family might:
 - a. Share the documents you created together.
 - b. Ask school staff how *they* prefer to communicate—email, phone, a notebook sent back and forth between home and school.
 - c. Collaborate to arrange a communication plan that will work for everyone.
 - A communication plan between home and school can be listed as an accommodation on an IEP or 504 Plan; plan to ask for your communication plan to be written into the document at the next formal meeting.
 - d. Review the IEP or 504 Plan, highlighting important accommodations, interventions, and supports. Families might request more information about the teachers or providers working with their child like:
 - Who is providing which services and supports?

- Who is designing the specially designed instruction (SDI)? (SDI helps a child make progress toward IEP goals)
- What training did these staff receive, or are there training needs for the district to consider?
- Ask them how they can share information about their child, such as a one-pager, with school team members. This includes paraprofessionals or aids and other members of the school team.
 Parents have important information that benefits all school team members and can offer support to ensure team members receive information.
- 4. Look ahead to provide encouragement.
 - a. Transitions can be filled with many emotions and that is okay. Families might feel excited, worried, sad, all of which are natural feelings. A few ways to offer encouragement:
 - b. The family might find ways to celebrate the new step in their child's start to school. Be ready to welcome your child home with love and encouragement. You can ask questions and/or read notes from your child's teachers that help your loved one reflect on their day and share about new friends and adventures.
 - c. Send thank you notes to teachers and support staff. Showing someone appreciation for their efforts can strengthen partnerships, encourage communication, and keep them motivated.
 - d. Take time for self-care for yourself and your child.
 - Create an area for the child at home to have a safe and relaxing area for when the child needs downtime they know where to go.
 - Reach out to local parents or advocacy organizations within the area to see what resources are available to help provide support.



Additional Resources to Share with Families to Support Transition to School

• Family Guide to Special Education

- Nebraska Transition to Kindergarten Toolkit and Resource Guide for Families
- Along the Way: A Guide for Parents of Infants, Toddlers, and Children with Disabilities
- Parent Training and Information Center of Nebraska
- Disability Rights Nebraska

References

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This guide was created by Dr. Sara Kupzyk and Francine Armstrong and the Nebraska Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program in collaboration with NEABA.

The information is intended to provide help families in their journey. Content does not imply endorsement by the Nebraska Association for Behavior Analysis or the Nebraska LEND.

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