



**The CORE of a Good Life:
Guided Conversations with Parents on Raising Young Children with Disabilities**

Molly Murphy, Ph.D. & Mark Sweet, Ph.D.

The CORE of a Good Life: Guided Conversations with Parents Raising Young Children with Disabilities

The CORE has been developed by the Natural Supports Project at the Waisman Center, University Center for Excellence in Developmental Disabilities, University of Wisconsin-Madison, with funding from the Wisconsin Department of Health Services by grants from the Centers for Medicare and Medicaid Services, Medicaid Infrastructure Grant (CFDA No. 93.768) and the WI Birth to 3 Program.

Funded by the Centers for Medicare and Medicaid Services, Medicaid Infrastructure Grant, CFDA No. 93.768. Wisconsin Department of Health Services/Pathways to Independence

Waisman Center
University of Wisconsin-Madison
University Center for Excellence in Developmental Disabilities

The mission of the University Center for Excellence in Developmental Disabilities is to support the full inclusion and self-determination of people with developmental disabilities and their families. The Center accomplishes this mission through its preservice training programs, clinical and intervention services, continuing education programs and technical assistance and consultation services.

Natural Supports
Shared Activities
Valued Roles
Real Relationships

The goal of the Natural Supports Project is to discover, support and disseminate creative and promising approaches that support families, children and youth with disabilities to participate more fully and naturally in their family life, in the community, at school and eventually on the job.

Birth to 3
Wisconsin Personnel Development Project

Wisconsin Birth to 3 Personnel Development Project, housed at the Waisman Center, is responsible for providing professional development to Wisconsin's Birth to 3 community through a multifaceted program of training, technical assistance and materials development including Parents as Leaders. WDPD is funded by the Wisconsin Department of Health Services Birth to 3 Program.

Molly Murphy, Ph.D., has supported young children and their families since 1980. Molly is currently working as a resource teacher at Wingra School and autism therapist at Integrated Development Services, Inc. in Madison, Wisconsin. She is also a parent of two children and a facilitator of parent and provider training on the topics of leadership, inclusion, parent/provider collaboration and natural supports throughout Wisconsin.

Mark Sweet, Ph.D., is a trainer and consultant with Disability Rights Wisconsin (DRW). In this role, he works with school districts, supported employment and supported living organizations, consumer and parent groups, long term care programs and others. The emphasis of Mark's work is to help people refine and individualize their support by focusing on learning strengths and by encouraging people to imagine what it's like to be the person receiving support. Prior to joining DRW, Mark worked as a special education teacher and university instructor in teacher education.

© January 2009

Edited by Beth Swedeen, Colleen Kurkowski Moss and Linda Tuchman-Ginsberg.

Desktop publishing by Leah Zimmerman and Colleen Kurkowski Moss.

Table of Contents

The CORE Aspects of a Good Life,	4
Why We Wrote These Materials,	5
Shared Stories from Parents and Providers,	11
Before Conversations Begin,	15
Consider Your Own Perspective,	16
Meaningful Outcomes for Children and Families,	17
How to have Influence: Guided Conversations,	21
Guided Conversations: Teaching and Modeling Ways to Talk to Others About Children,	23
Setting the Stage for CORE Relationships,	24
Figuring Out What is Usable Information,	26
Considering the Child's Perspective,	28
Noticing When Interactions have Influence,	29
Guided Conversations: Supporting Parents in Figuring Out Who They Want as a Part of Their Family's Life,	31
Setting the Stage for CORE Relationships: Relationships Now and Later,	32
Considering Intentional Communication Strategies,	34
Parents' Next Steps in CORE Relationships,	36
Connecting Parents to the Experiences of Parenting,	39
Becoming a Parent,	40
Connecting with Support Systems,	41
Opportunities Now and Later,	41
Opportunities for CORE Conversations,	45
Questions to Embed in Everyday Opportunities,	46
Activities for Guided Conversations,	51
Embedding CORE Conversations into Practice,	54
Translating CORE Conversations into Meaningful Outcomes,	59
Barriers and Challenges,	60
Closing Thoughts,	61

The CORE Aspects of a Good Life

COMMUNITY -connections and participation

OPPORTUNITIES -to explore and pursue our interests

RECIPROCITY -in our relationships

ENJOYMENT - in our lives

Families and their community partners are discovering that it doesn't always require special services and paid supports for children with disabilities to participate and contribute at home, at childcare, in school and in community activities. Extended family members, neighbors, peers, classmates, co-workers and others who can or do come in contact with children can support and welcome babies, children and youth with disabilities and their families. They might need some information, maybe permission and a little guidance to effectively invite and engage parents and children with disabilities into existing community opportunities, childcare, school classes, activities, jobs and other events. Many people in the community who may not know someone with a disability may need strategies that help them feel comfortable, confident and able to relate.

Communities throughout Wisconsin are exploring an array of innovative ideas and strategies that engage children and youth with disabilities in a variety of activities and opportunities. The goal of the Natural Supports Project is to discover, support and disseminate creative and promising approaches that support families, children and youth with disabilities to participate more fully and naturally in the community, at school and on the job, beginning with the early childhood years.

Let's talk about having CORE conversations about CORE relationships with parents raising young children with disabilities.

CORE conversations are aimed at explaining the following ideas through a series of guided conversations:

COMMUNITY: Let's talk about how families will live, work, play and connect with extended family members, neighbors, friends and other community members.

OPPORTUNITY: Let's talk about how children and families will have chances to learn while pursuing interests and interacting and participating in everyday opportunities and activities.

RECIPROCITY: Let's talk about how children will make a contribution in every day interactions and relationships.

ENJOYMENT: Let's talk about how children and families will live as they want to live, finding fun, pleasurable interactions and supportive relationships to balance the challenges life brings.

Why We Wrote These Materials

We begin here, in the early years, to empower parents to create a vision for their child's life and explore opportunities in the community that begin to build that vision. This guide is designed to support anyone who is in a role to assist families as they create a future with the CORE of a good life.

Before we wrote this guide, we met with groups of providers employed by programs that support young children (e.g., Birth to 3 Program, Head Start, childcare) and parents. We wanted to learn about their experiences and what they talked about with one another. We came to the project already thinking that making better use of ordinary or natural support, was a good idea. We wanted to know whether parents and providers thought this might be a good idea, too.

When we talked with parents and providers, they said that many of their conversations focused on finding professional services and resources. They were seeking therapies and interventions to fix the problems their children faced. Both parents and providers spoke of the pressure, stress and frustration this created.

Parents said they often felt that a lack of resources existed and that they had to give up many things that were important to them. The ordinary experiences they wanted for themselves and their families did not seem to be available or possible.

Providers talked about the pressures of mounting paper work and some said they worried about becoming robotic in their conversations with parents. They wanted to have conversations with parents that supported more natural solutions.

The comments we heard revealed that so much energy was being spent on creating service relationships that little or no time remained to consider ordinary or natural relationship, as a way to respond to child and family needs.

We want these materials to support conversations between parents and providers who are involved with programs and services that support young children and their families. This includes, but is not limited to, providers from early intervention, child care, Head Start, schools, home visiting, public health and other community programs. This guide will be most useful to providers who want to support young children and their families by helping them to identify their desired outcomes and the most natural ways of achieving them. These materials are also intended for parents who want to support themselves and other parents in exploring what is important to their families. Throughout this document, the term parent refers to biological and other primary caregivers in a child's life.

For providers and parents, **the goal of guided conversations is to help people find balance between specialized paid support and natural support.** This will probably change over time, given different circumstances in the life of a child or a family. This means that these materials provide support and guidance for ongoing conversations.

Providers already have many conversations with parents about their families and children, both casually and formally through the Individual Family Service Programs (IFSP) process in Birth to 3 Programs and Individual Education Plans (IEP) in the schools. This guide offers content and probing questions that can help balance those conversations to incorporate many of families' long-term concerns and visions while

giving parents new strategies to use. We encourage parents to use these materials to strengthen their roles in their partnerships with providers.

The strategy we offer is called **Guided Conversations**. These are conversations that can be casual or planned. They can also be part of a structured assessment, intervention or educational activity. The questions are intended to invite conversations about the people, places and opportunities that parents want for themselves and their children. Some other questions might be new, others may have already been asked. Some will be questions to remember to ask more often.

Guided Conversations are an invitation to think about;

How to talk about children and influence how others perceive them;

How parents identify the ordinary experiences of being a family; and

How parents sort through the relationships that may be available to them and their child that they have not yet considered.

Conclusions taken from comments and stories heard during conversations with parents and providers:

1. If we consider real life outcomes for children and more balanced relationships and resources that acknowledge whole families... Then we will learn to place less emphasis on service systems that emphasize professional intervention and therapy for a child.
2. If we support parents in becoming more focused on the ordinary experiences common to all parents... Then we may recognize that parents may be living with a sense of never being able to do enough, feeling stressed and confused about parenting a child who is different than they expected.
3. If we focus on outcomes that are meaningful to children and families as members of communities... Then we would better understand that parents do not always feel successful when providers focus most on a child's disability.
4. If we understand that families want natural relationships for their children and themselves and they want to find ways that a child can have the kinds of reciprocal relationships that are important for their quality of life... Then we notice when parents are feeling exhausted by the recommendations to do more and more to address a child's "needs."
5. If we give parents encouragement to think about the possibilities for the future, defined by some parents as next month or by others as 10 years from now... Then parents are more likely to know that what they want and what they deserve are the same options available to all families.

Guided Conversations offer questions to ask that will encourage parents to think more about the CORE aspects of their lives:

**COMMUNITY
OPPORTUNITIES
RECIPROCITY
ENJOYMENT**

What are ordinary places and activities in the COMMUNITY that parents of young children with disabilities use?

“My mother in law’s house is full of tiny fragile breakable knick-knacks. She is the only one of my kids I can take there because she just sits in her stroller smiling at grandma and it keeps them both happy.”

“We get lots of stares when we feed him by his g-tube when we are in restaurants but I’m used to it now. I just smile at them and him and say “bottoms up!!” I will not give up someone else cooking once a week!”

What are ordinary OPPORTUNITIES that are too often overlooked because they are not specially labeled to be educational or therapeutic?

“I figured he was just being his curious two-year-old self when he kept taking his head band off and smiling at me. Then the therapist said he was working on his fine motor and cognitive skills. Was that still good?”

“When she was still small, about six months old, we went to a mom and baby swim class. An instructor leaned into the pool one session and said, ‘You know we do have a special class,’ I said, ‘Thanks, but this is working out fine for us.’ She was just a baby like all the other babies. Why did we need a different class?”

How can young children learn RECIPROCITY in everyday interactions and how can a child’s worth be conveyed to the community?

“I don’t even let myself sit and read the paper with her nearby. I feel guilty if I’m not interacting with her in some way that will help her skills. Maybe now I will, but I will still keep talking to her, she likes that.

“Of all of the kids, he is the best listener. When I come home everybody needs me for something, even the dogs look at me with ‘I need’ in his eyes. He is so happy to just hang out with me in the kitchen. He listens, never interrupts and I tell him all about my day. He even laughs at my jokes.”

How can parents with young children find more ENJOYMENT in their daily routines and interactions?

“Every doctor we saw said not to be too rough with him because his muscles were so tight because of the CP (Cerebral Palsy). You have never heard a kid and a dad laugh so hard as when they are on the trampoline.”

“He is my Dennis the Menace. His uncle gave him a ‘Here comes trouble’ shirt. He is curious, so excited, so joyful and persistent. Even when he is in trouble, he makes both of us laugh.”

Shared Stories from Parents and Providers

What is Important to Parents and Providers?

Parents who we talked with had many different views on how, when and why they depended on natural supports and how and when they depended on specialized relationships. Each told a very different story about their relationships with their child and their interactions with providers and the service system.

Getting The News

Parents told us that they were informed about a child's medical condition or developmental disability in many different ways. Some parents talked about their initial response of grief for the loss of the child they imagined. Rarely is grief an experience that happens once and then is over. Instead, parents talked about revisiting their feelings of loss at different times in their child's life.

For most families, they quickly became busy with the daily tasks of raising their child or children. Many reported being swept up in the ordinary activities of feeding, diapering, playing with their child and getting him or her to sleep. For many children, there were the added logistics and demands of in-home and out-of-home therapies, medical appointments, the opinions and judgment of others, confusing behavior--and for some parents-- learning to use equipment and monitor medications.

Many of the parents had first interactions with providers and the service system while simultaneously learning to navigate all the new demands of parenthood. The more emphasis providers put on the child's disability, the more likely parents were to depend on relationships with providers or paid supports. These parents told us that they wanted to spend time with their child without feeling the demands or expectations that every interaction be therapeutic or that every toy have an educational purpose. They also talked about some people in their lives remaining distant or, based on the specialized information they were receiving, worrying that their child could not be entrusted to ordinary--unpaid, non-specialized-- people.

Moving Forward

Some parents told a different story. They waded through those first months, first year and emerged to find that they were still parents, not of the child they expected, but of a child they were eager to get to know and share with family and friends. They held on to the ordinary experiences of being a parent and held on to giving their child many of the typical experiences of childhood.

For every family, their child's health was in the forefront. When there was a medical crisis, they focused on those needs. Once their child was healthy, they were then able to consider their whole family's needs, not just those related to their child's special needs.

Some parents learned to relax their own expectations about the focus of their daily life. They were learning that ordinary activities and interactions were beneficial to their child and family. This often required different kinds of conversations with providers and others who were emphasizing the child's disability, deficits, medical needs and the recommendation that every interaction be a designed interaction.

Considering the Possibilities for Relationships

Parents talked about their needs for relationships. Some had many friends, others had one or two. Some were closer to their families since the birth of their child, some were more distant and some had always been distant emotionally or geographic distance from their families. Preferences for the kinds of relationships they wanted stayed the same for some parents and for others these changed drastically. Some cultivated relationships because of their child and because of their own increased need for support. Others were angry and resentful that people were not offering themselves as support in ordinary ways.

All families talked about the benefit of hearing and seeing what worked for other families. They wanted to talk to families who had insisted on inclusive preschool for their three year- old; who had their speech therapist come to the library play group with them; who let their niece babysit for the first time. They wanted to hear more stories and make connections with families who were cultivating ordinary relationships as solutions to their family's sometimes complex needs. They relied on one another to remember their often ordinary needs for recreation, adult time, couple time, friendships, sibling activities and family vacations.

Many families struggled with their own need to be protective of their children and their privacy, deciding if the benefit outweighed the risk and questioning what risks were worth taking. What risks were real? Were these the ordinary risks that other children faced? What risks were fueled by their own fear? Some families moved forward even when they did not have answers to their own questions. A big step for many families was allowing their child to have relationships with other people, even when they knew others may not interact in the same way as they did.

Not One Size Fits All

Parents and providers made it clear that every family will consider natural supports from a different starting point. We designed these materials to be responsive to parents while not pushing anyone in a direction they do not want to go. Guided conversations about natural supports are not designed to be another pressure to place on parents. For too many years, the 'support system' has convinced families to accept options that may not have been a good fit for the child or family. Providers can keep the conversation open so that families can find resources that are a good match. Providers also have a unique role and perspective in supporting families. They have met so many children and families over the years that they have a library of stories and successes that can be shared when the time is right.

Before Conversations Begin

- **Consider Your Own Perspective**
- **Meaningful Outcomes for Children and Families**

Consider Your Own Perspective

Before we describe the CORE conversation questions, we offer some ideas for reflection.

The vast majority of parents do not know everything about child development, nor should they have to. Providers cannot know all there is to know about every child. Neither parents nor providers can know how the child will behave and benefit in every environment. External experts cannot know what is best for every family or how helpful their suggestions might be for an individual child or family. Both the “provider as expert” and the “parent as expert” approaches to services have led to interactions that were unbalanced. A more balanced approach requires conversation. Parents need not feel inadequate for not having training in motor development, speech and language development, intellectual development, neurology or early education. Professionals should not assume that they always know best what a child and family needs. Balance and reciprocity require that everyone identify the most usable information and how that information can be shared in ways that are helpful.

Reciprocity in relationships means that people share information. Reciprocity means that people are not just givers or takers but that everyone’s perspective is worth exploring, including the perspective of the child. By inviting others to imagine a child’s point of view, you may create the opportunity for others to consider this child with more interest and compassion. This kind of reciprocity takes genuine curiosity and humility.

What do you think about these approaches to intervention?

There is the “providers are experts and know best about children” belief that guides some approaches of services. Parents reported hearing messages like the following:

You need to hold the child this way.
You need to feed the child this way.
You need to talk to the child this way.
You need to stimulate the child this way.
You need to teach the child this way.
You need to discipline the child this way.
The window of opportunity is closing soon--so hurry.
This child needs therapy, therapy, therapy--more is better.

There is the “parents are the experts about their children” belief that guides some approaches of services. Some providers have encouraged this way of thinking to make up for the mistakes made and relationships damaged by the “provider as expert” way of thinking. This way of thinking can also shut parents off from people and information that might be helpful. The information shared as part of this model or maybe the way it was understood when it was not helpful, has sounded like this:

You have to do it this way or he will get upset.
We worked so hard getting him to do that, don't change it.
He never, ever likes it when...
If you don't do it this way, then it will never work.
Unless he has therapy this often, he will never learn to...
I can always tell when he is going to...when he is feeling...

CORE Conversations would include questions like these.

Ask: What can you tell me about your child that will help me get to know her/him better?

This kind of question allows both parent and provider to offer what they know, with respect for one another's knowledge and experience. Instead of being the expert, both parents and providers have the chance to be the beginner and a resource to one another.

Ask: In your community what kinds of opportunities do you want your child to have at this time in her/his life and in the years to come?

What kinds of opportunities do you want for yourself as a parent at this time in your life and in the years to come?

Why are these opportunities important to you and to your child?

These kinds of questions open the conversation to include possibilities, instead of waiting for the child to develop certain skills before he can have the same opportunities as other children.

Meaningful Outcomes for Children and Families

Many providers have been trained to focus on the steps a child takes to move up the developmental ladder. Early intervention providers have demonstrated how important it is to consider family outcomes, as well as the child's developmental progress in the IFSP. Most children who need additional supports also need many, many opportunities to practice. What providers do with a child once or even a few times each week does not provide enough practice to change the child's developmental course. Practice with parents, brothers and sisters, grandma and even interactions with friendly folks at the grocery store, supports growth and learning for a child.

Consider...

What might be important outcomes for parents as well as children?

How could supporting a parent to learn how to interact playfully with their child become an important outcome?

How might these topics become areas of focus for programs that support families?

When would it be important to include other outcomes in addition to those that focus on the child's development?

What is a family's comfort in discovering opportunities that they want for themselves and a child?

CORE relationships start with the assumption that children and families want:

- To participate in activities in the community.
- To have opportunities that other children and families enjoy.
- To be supported and to support others in a reciprocal manner.
- To enjoy relationships with other children and adults.

Asking about opportunities and why they are important can be an ongoing topic of conversation that can lead to meaningful outcomes for children and parents.

The parent who imagined having an athletic child does not necessarily have an athlete. The parent who imagined having a socially spirited child might have a more solitary and serious one. Children become themselves, changing a parent's imagining of them. Flexibility and accommodation are critical elements of most relationships and that is certainly true for parents in relation to their children. All children should have opportunities to participate in what their families, schools and communities have to offer. Participation, as an option along with independence or mastery, is what makes these conversations reasonable for all children and all families.

For some parents of children who show signs of delay or difference, the adjusting might start sooner and be felt with greater impact. However, there are parents and children who have not let go of their desires for CORE relationships. There are teens and adults with disabilities living and working in the community, pursuing education and job training, owning their own homes, participating in the activities of their communities, engaging in sports and recreation, becoming politically active, enjoying relationships and making their way in the world. Some are following traditional paths and others are creating new ones. Some are participating in ways that are defined by their interests and abilities. Some benefit from technology and accommodations.

It is a life lesson that you can't always have it your way. But it doesn't mean that you can't try. For most people, life is not all-or-nothing. Adaptability and assertiveness are essential characteristics of a successful life.

Conversations are influenced by considering...

Community

What and who are the existing family, friends and connections in the community? How are parents already connected to resources? Does the existing team start with conversations about inclusive opportunities for children and activities that all families with young children use? Is a first response often to suggest an increase in services or another program or waiting list?

Opportunity

What is the decision about family priorities and dreams when a child has a disability? Are opportunities and practice, not just developmental gains, considered? Is there a consistent message from all team members about a range of options, not just therapeutic and structured interactions? How is the importance of considering activities that are also available to other children the same age introduced, even if the child cannot participate in the same ways that his peers might?

Reciprocity

Have parents been exposed to how to talk about their child in a way that emphasizes that the child comes first, as compared to talking mostly about disabilities or medical needs? How are the contributions a child can make considered when deciding outcomes? How are professional and family perspectives about what a child needs discussed and considered?

Enjoyment

Does the team intentionally find ways to provide supports and services in the course of natural interactions (e.g. during play and daily family routines) instead of more structured therapy sessions? Do all parties listen in a way that allows for connections and encourages relationships that are supportive? Is equal attention paid to minimizing relationships that are draining? Are there ways to continuously revisit family priorities and preferences when making new decisions?

How to Have Influence: Guided Conversations

Guided Conversations are different than more casual conversations in that the person initiating the conversation is listening carefully with attention to components of CORE relationships. Throughout these materials, we offer questions to ask during home visits, play times, outings in the community, team meetings, parent to parent connections and more structured meetings, like the IFSP or IEP process. The Guided Conversation questions are intended to invite thought and discussion about how a parent, a therapist, a health care worker, a social worker, a family member – thinks and talks about a child and what is most useful in supporting a child throughout her/his day.

Questions invite people to think about their own capacity in responding to information that evolves through conversations. Too often, people back off when conversations address sensitive topics around children's development. The tendency is to refer to other professionals or service providers rather than finding the solutions within their conversations.

One of the best ways to begin a conversation is to ask an open ended question and listen carefully to the responses. It is also helpful to build on initial responses by asking additional questions. It is important to pick up on key ideas and initial responses to build more meaningful conversations and share information about children in ordinary ways.

Whenever you read Ask in the text, we are offering a question to consider adding to conversations between parents and others in their life.

We have identified three important themes to consider when having CORE conversations. The materials are organized into these three sections:

- 1) We can teach and model ways to talk about children that encourage and support relationships, instead of creating distance and obstacles in those relationships.
- 2) We can sort through the relationships that are working or those we want to cultivate. We can learn ways to manage relationships that may not provide supports or that we may not be able to change. This includes how to use intentional communication and respond to difficult conversations or interactions.
- 3) We can notice the experiences of parenting that are important to families and explore how these can stay the same even though challenges exist in meeting children's need for additional supports. This includes talking about hopes, dreams and fears for a child and listening carefully to what is important.

Guided Conversations: Teaching and Modeling Ways to Talk to Others About Children

Setting the Stage for CORE Relationships
Figuring Out What is Usable Information
Considering the Child's Perspective
Noticing When Interactions Have Influence

Providers and families can support each other by teaching and modeling ways to talk about children that encourages and supports relationships, instead of creating distance and obstacles in those relationships.

In this section we offer strategies for talking about and describing children to others. **The main idea is to describe children and interactions with children using language that can be easily understood by everyone.** This encourages positive descriptions about children and emphasizes usable information. It helps focus on how we talk about children, avoiding jargon and medical terms. Encourage conversations which describe children's needs as more similar than different to other children's needs. Additional information about children's unique characteristics and the supports children need can also be described in every day language.

Setting the Stage for CORE Relationships

Ask: On an ordinary day, how do you think about this child? What words do you usually use to describe her/him?

Words and actions reflect how we think. What is said and how interactions with a child occur can influence how other people think and relate to that child. Some important questions are:

Is this child someone I can or want to have a relationship with?
What would help us build a relationship?

If a child is perceived to be difficult or naughty it might influence how other people think about her/him. When others hear a child described in those terms, they might decide to keep some distance. They might be quicker to judge the child's behavior critically. What people hear can be an opening or an obstacle to a healthy relationship.

If comments are prefaced with diagnostic information, jargon or clinical language like cerebral palsy, autism spectrum disorder, aphasia, crossing midline, meltdowns, sensory overload or use initials, CP, CD, ASD, PT, OT, to talk about this child, what is the message about this child? Words used to describe a child can help someone relate to the whole child or they can convince someone that they are not prepared or qualified to have a relationship with the child.

There may be unintended influence when comments about a child are related to diagnosis, classification (such as mild, severe, profound) or comparative labels (such as high or low functioning). If comments describe what a child cannot do or unwelcome behavior, that can have unintended influence. If there is a lot of talk about how difficult, frustrating and exhausting it is to be with a child, this can influence how others see this child. These statements are not to suggest that parents and others are never supposed to vent their honest feelings.

Representing a child so that others will want to have a relationship is not about lying to or misleading others. This is a fundamental question about what information is most usable to other people and in what form.

What information might help a grandfather relate to a grandchild whose development seems so different than the development of his children or other grandchildren?

What might help an aunt understand that her nephew will not break if she picks him up even though she is not a physical therapist?

What might help a mother's friend better understand the point of view of her friend's daughter who rocks and laughs for extended periods of time?

What comments or questions might bring people into the lives of children and families in natural and supportive ways?

Tommy's mother told a trusted friend that she was sick of hearing members of her church say week after week how special she must be that God chose her to be Tommy's mother. She knew that she loved Tommy and how hard it sometimes felt to be his mother. She knew how hard it was to balance Tommy's needs with those of other members of their family. She told her friend that she wanted to say God should have asked first and I would have said no. But she said that only to her friend. She understood that she was not only representing herself; she was representing Tommy to people who did not always see him as a whole child and a valued member of his family.

What kind of influence do words about a child have on others? Do they convey...
This child is someone I could enjoy getting to know.

Think about words that describe who a child is. The goal is to use words that do not bring thoughts like...
This child needs specially trained people and I'm not qualified.
This child would be too much for me.

Instead, think about language that invites people into a potential relationship with a child.

Ask:

What kinds of relationships might benefit this child and what might she/ he enjoy?

What kinds of relationships might benefit a family and what might a family enjoy?

Think about the words used to characterize this child, like always, never, can't, won't, tantrums, stubborn, inappropriate and noncompliant. Think about the language used to describe a child's activities, like feeding, toileting and sensory diet. Do the words suggest a child who is an active and learning participant in her/his life or a passive and troublesome burden? Do these words suggest a child others might enjoy and be able to relate to?

Think about how words have influence. Consider the differences in possible influence between: Feeding time and time to have lunch; dressing and teaching him to button his shirt; behavioral plan and helping her cope with frustration; PT or physical therapy and stretching; and working on social skills and playing. Which words would more people recognize and be able to relate to?

Use and model language that describes fun, humor, learning, pleasure and other ways in which young children are adorable. Do you use the kind of language that helps people relate to the whole child? Does the language you use suggest the possibility of enjoyable and feasible relationships?

Some words create obstacles to relationships and other words create familiarity. Some questions invite healthy curiosity. Some words unintentionally create barriers. The point is not to gloss over important information or to ignore feelings of frustration. The point is to notice how you think and talk about a child and her/his needs.

Children, even babies, have a point of view. Children would not describe themselves or each other as fussy, naughty, inappropriate or noncompliant. They want to play, eat and rest. They are trying to experience satisfaction. Exploring is their purpose.

An important foundation in all of these conversations is that children are not little adults. They do not and should not be expected to have an adult frame of reference. When an irritated relative says that a child thinks s/he's the center of the world, a reasonable response is to agree - even if the comment was intended negatively. Yes s/he does. Children do think they are the center of the world.

Ask:

What are your most frequent topics of conversations about this child?

What do you want people to think about this child?

How do you want people to interact with this child?

How do you understand this child's perspective? What does s/he like and want to do? What kinds of relationships might s/he enjoy? How does s/he experience her/his surroundings?

Figuring Out What is Usable Information

Ask: What do you think is most important for a person spending time with your child to know?

Usable information can be defined as anything that helps someone relate to a whole child. Some people might want to understand aspects of a diagnosis or classification. When a parent is talking with someone who is interested and wants to understand their child, there are two general practices that can make a difference in what information is relatable.

Use more words that are immediately understandable and fewer words that will have to be explained and then have the explanations remembered.

Talk more about play, interaction and interests and less about diagnosis, therapy and treatment.

Ask:

What does your child value?

What causes her/him to smile?

What is your child's temperament or general energy for life?

How does s/he communicate what s/he wants, does not want or feels? How can you tell when s/he does not feel well?

How does s/he like to play and interact?

How is s/he affected by sound, touch, light, taste and smell? Does s/he prefer or avoid any of these?

What does your child find soothing? What helps her/him to feel at ease?

Are there events or conditions that s/he sometimes finds stressful?

How does s/he prefer to participate in activities? Does s/he prefer to watch, jump right in or talk about them?

When s/he is stuck, is it more helpful to talk, demonstrate or physically guide her/him?

For all of us, it is important to relate to the child as a child first. Here is an example.

The first thing you have heard about a child is that s/he is on the autism spectrum. So far, that is all you know. What else would be helpful to know to spend time with the child? What makes this child laugh? Helps her/him to calm down? What does s/he really love to do? Favorite food? Does s/he need help in the bathroom?

Hearing that the child likes to play with Legos and has special interest in the very smallest pieces tells you more. Hearing that the child thinks the Legos will disappear when it is time to put them away suggests that the child is worried about what will happen to the Legos. Knowing the child's perspective will help to understand her/his resistance when told to clean up. Knowing that the child feels anxious helps to understand why s/he is allowed to keep one Lego piece with her/him when it's time to go out. This is usable information that brings parents and others closer to this child.

Any of the questions in this section could be asked about any child. These questions might help someone better describe a child and relate to this child. When asking these types of questions parents have a chance to discover their own perceptions of their child.

The conversations that emerge from questions like these are qualitatively different than those that focus on naming that the child has Down syndrome or a speech and language disorder or is tactilely defensive. Diagnostic information may not help someone feel that they can interact with a child any better. A parent would want to make someone comfortable and encourage them to have an enjoyable relationship with their child.

Considering the Child's Perspective

Ask: What do you imagine this child is experiencing? What is s/he probably seeing, hearing, feeling, tasting and smelling?

This has been a useful question to ask parents and it is a useful question for parents to ask others in their child's life. Children and adults have experiences that usually involve their senses. For any person who leans toward judgment or criticism, this question can invite them to think in a different way. This question and others like it invite a person to wonder about the child's perspective.

Consider Eli

This is a story that you could share that illustrates the importance of considering the child's perspective, especially when trying to be creative in coming up with strategies and solutions to a difficult situation.

Eli's parents described him as wild and out of control. Most of his relatives agree. Adults want him to behave or they want to send him home. At school his teachers report that he is wild and out of control all the time. Eli is five years old.

When his teachers were asked what Eli might be experiencing, they described a schedule of activities. They mentioned events including arrival, coats, toilet, wash up, free time and calendar. His parents

talked about mealtime, bedtime, playing with his cousins, visiting his grandmother and other events. His parents also said they could not take him anywhere because he would not behave.

A list of activities or events is different than what a child might be experiencing during these activities or events. When asked to speculate about what he might be seeing, hearing, feeling, tasting or smelling, different information began to unfold – from Eli’s perspective. That little shift – from an adult’s perspective to a child’s perspective -- changed the way people talked about Eli and later how they interacted with him.

School staff reported that Eli probably saw adults with outstretched hands moving toward him as he waited to get off the bus. He probably felt pressure around his forearms as they secured him. When he tried to pull away, he probably felt more pressure as the adults’ grip tightened. He might have felt fear or worry as he came down the steep steps of the bus or was led by his teachers. He might have heard people greeting him or telling him what to do without necessarily understanding them. He was trying to pull away. He saw the other children and felt excited, but they were so far away he could not touch them.

When talking about taking him to a store, Eli’s father said he always held him tightly and had to keep telling him what not to do. In addition to physical discomfort, his mother said that he was probably confused because being told to “behave” was not very descriptive to a five year old, who often had difficulty understanding language.

When grownups, school staff or parents let go of his wrists, Eli ran. They said that he was probably running away from them rather than toward anything in particular. Because he was running, it was not uncommon for him to bump into other people and things along the way. He often looked over his shoulder to see where the adults, his handlers, were. He found places for himself under tables, behind book shelves and doors. When it was time to gather as a class or as a family and adults moved toward Eli, he tried to remain hidden or started running again. Based on his facial expression as hands reached for him, Eli was described as looking scared.

Having conversations to imagine a child’s perspective and inviting others into those conversations can influence the way people think. For Eli, when adults started asking each other questions about what he might be experiencing, they came up with more helpful words than wild and out of control all the time. They speculated that if he could communicate more easily he might have been trying to say, “I don’t know what to do. I want to have fun with my friends. I want to do something. It hurts when you squeeze my arm. Let go. I’m scared.”

When people change the way they think and talk, it can lead to changes in interactions with a child. Rather than trying to make Eli behave, to stop running and knocking things over, they decided to teach him what he could do. As soon as he arrived at school, he was given a cloth bag with some of his favorite toys and zoo animal books to carry to the classroom. On family outings, Eli was invited to help with physical activities. He was asked to carry a towel that he was to deliver to his grandmother. He was asked to give it to her when he said hello. She, in turn, invited him to help her get the apples she was going to use to make a pie. Rather than telling Eli what not to do, adults learned to invite him to participate and contribute in ways that made sense to him from his perspective. This shift came because people started asking one another to imagine what it was like to be Eli. He did not immediately become a different child. However he became a child that more people could relate to.

Here are a few other questions that you could use in conversation with a parent to imagine a child's perspective. Parents could then also use these questions with any other people who may have a relationship with their child. This includes other children – potential friends or classmates.

Ask:

- What do you think s/he might be trying to accomplish?
- What do you think s/he might need or want?
- If s/he could talk, what might s/he say in this situation?

Noticing When Interactions Have Influence

One way to support parents is to help them notice how their interactions with their child may be an indirect method of representing their child to others. For example, many parents have had the experience of their child behaving in a loud or disruptive way while others are watching. The parent could respond in very different ways. A judgmental comment or harsh reprimand may lead onlookers to see the child as naughty or willful. A parent's comment that reflects a best guess at understanding what is happening for the child may help the watchers better understand what is hard for the child. A compassionate comment may just be loud enough for someone very close to overhear. It's discrete. The parent's comment creates a triangle of people (parent-child-onlooker) and compassion for the child's experience. The actions that an onlooker might find objectionable are acknowledged in context with respect.

Here are some examples that may be useful in helping a parent understand how powerful his/her own interactions can be in representing her/his child to other people.

Action: A child is on the grocery store floor and kicking her legs.

Response: Her mother says "I know you didn't want to leave the park, you wanted to stay on the swings. You can swing again tomorrow. I would love some help pushing this cart."

Action: A child is blocking his ears and jumping up and down in a hotel lobby.

Response: His father helps the child protect his ears and says "I know that vacuum cleaner is very loud. Let's go someplace quiet until the vacuum stops."

Action: A child is bouncing, tapping and turning around in church.

Response: Her cousin, who has some usable knowledge of the child says, "You need to move, huh? Let's get a drink of water."

Anyone close enough to witness these scenes and overhear the caring people who spoke to the child might find it easier to relate to the ordinariness of the situations and to the child involved. Some might think: "I understand that. I can be compassionate. I can relate to that child (and that adult)."

Guided Conversations: Supporting Parents in Figuring Out Who They Want as a Part of Their Family's Life

Setting the Stage for CORE Relationships: Relationships Now and Later

Considering Intentional Communication Strategies

Parents' Next Steps in CORE Relationships Families often feel more supported when they are able to sort through the relationships in their lives that they want to cultivate and learn how to manage relationships that may not meet their need for support or may not change. This includes knowing how to communicate more intentionally in difficult conversations or interactions with people they meet casually or those who have a more significant role in their family's life.

This section offers strategies for talking about the current relationships in a family's life and other possible relationships they might want to develop. The main idea is to support families in understanding that they have choices in the kinds of relationships they have and they can decide where to invest their time and energy. These strategies consider a family's style and preferences in the kinds of relationships they want to have, as well as those they want for their child.

Setting the Stage for CORE Relationships: Relationships Now and Later

Ask: Are there people who the family would like to have a bigger role in this child's life, including extended family members, friends, other children, neighbors?

Expectations naturally run high when parents think about their own children. They want others to love and enjoy them. They certainly want their family members--a natural source of support and relationships for many children—to be ready, willing and able to relate to their child. Many parents exchange child care responsibilities with family, friends and neighbors. But these natural sources of support are not always easy to arrange when children are perceived as hard to relate to. People, even family and friends, have their own comfort zones. They are not required to think and feel what parents think and feel. That does not mean they cannot love, like, respect, enjoy or in many other ways have a relationship with that child--within their comfort zone. Parents want the world of opportunity to open for their children. However, some people along the way have issues related to comfort zones and biases. A good first step might be to think about people in general, not just those with close existing emotional connections to a child. People may fit into the following categories.

Some people are:

Ready, willing and able to meet a child on her/his own terms and create a relationship.

Open, interested and willing to get to know a child and waiting for a little guidance on how best to approach the child.

Willing to be with a child on a more limited basis, interested in some activities and not others.

Not available. They might have positive feelings but no inclination or capacity to develop a child-focused relationship. Or, their comfort is in the role of critic or advice giver.

Think about people who are already part of this child's life or those who the family would like to have in their lives.

Ask: Which group would you assign to each of the people you talked about? Go through a few examples with people that the parent has talked about.

Here are a few examples with that came up in reflections and conversations during preparation for this guide.

Grandma Mary is ready, willing and able. She sees my child nearly everyday and comes looking for us if I don't call by 10 a.m.! She doesn't hesitate; she even has helped in emergencies.

My neighbor's daughter is open, interested and willing. She spent the day with us last Saturday and now with a little guidance and my cell phone, she is ready to babysit.

My Dad is willing on a more limited basis to spend time with him. He loves to play with him on the nights we have dinner together, but he likes me to be there too. He never changed my diapers, he will never change his grandson's either!

There is a woman at our church who is not available. I would not want to invest the energy to change her mind. She has complained to the pastor about us, but I just stay polite.

To take this conversation further, following are some additional questions to consider:

Ask:

How satisfying are the kinds of relationships this child and family have with others?

Are there any people that fit into the second two categories that this family would like to find out more about?

How much energy is going toward individuals who are essentially not available?

What would happen if the focus shifts to people who are available for CORE relationships?

When new people are identified to get to know this child better, how might they think about this child?

What is disturbing about the reactions of other people to this child? What does this family wish would not happen? What sometimes makes this family want to avoid relationships or quit going out in public?

What happened that was disturbing?

Notice opportunities for conversation. Consider what relationships a family wants to encourage and the ones they want to let go, along with any expectations for change. Expand the conversations with other people that will help develop the relationships that are important to a family. Pay close attention to the difference between actual observations and 'in your head' perceptions of these events.

Consider some of these as possible positive outcomes:

Decrease likelihood of being caught off guard next time it happens. Learn to recognize these events like traffic lights, as signals to stop and consider how time and energy should be spent.

Commitment to letting go of the people who are not going to be available. Everyone has a choice in how to direct attention and the chance to cultivate relationships that hold the most promise for a child.

Increased relaxation and appreciation that there are also people, some known and some yet unknown, who have not yet learned enough to understand this child or family's perspectives. Parents then get to decide if the person will have that opportunity. Everyone benefits from considering and sorting through all of their casual and long term relationships. Over time, everyone can begin to realize there are many accurate and recognizable ways to describe a child without resorting to words that create distraction.

It is invaluable to share real life stories such as the one that follows, to illustrate how families have found the right fit in relationships. These stories show alternative responses to difficult situation and provide encouragement to try the strategies described in this section.

A Real Life Story

Many adults at a gathering of families were commenting on one young girl. She's up and down and up and down. She's been like this all day. She must be hyperactive. She's into everything.

Then, another perspective was heard. She's into everything. She is the most curious little girl I've seen in a long time. Look at the excitement and enthusiasm on her face. She likes to experience everything.

Considering Intentional Communication Strategies

Parents may need support in practicing strategies that will help them to meet their own goals for their child and their family. Communication skills are important in maintaining and expanding the relationships and opportunities that families value for themselves and their child.

The intentional communication strategies described in this section offer parents a way to describe situations that have been difficult or challenging. Opportunities to practice and model these interactions may be very helpful.

Start conversations about the different people in a family's life by considering that some people are more or less willing and able to have a relationship with this family and child. Keep in mind the groups of people described earlier. These strategies will be helpful when taking the next step in developing new relationships and being responsive in the relationships a family may already have. Challenges in communication are a part of every relationship.

COMMUNITY
OPPORTUNITY
RECIPROCITY
ENJOYMENT

In addition to those people in a family's life who are ready for relationships and those who are not available, there are others who might be interested, but are still distracted by perceived differences and need more time or contact. Specific types of information may be useful to these people in helping them relate to a child. Here is an example.

Telling someone that a child is crying due to a diagnosis of sensory integration dysfunction just does not offer the person usable information. Instead, the parent could offer: "It doesn't feel good to him when we tickle or touch him too lightly but he really loves to wrestle with his brother and sister."

One of the most frequently shared and hurtful experiences parents describe is having people stare at their children, often with the assumption that those people are judging the parents harshly. Yet, watching others, even staring, is one of the ways people learn and increase their comfort. Parents often report that they've had a hard time remaining calm and poised at a time when they felt judged, especially when they think their child might have been slighted. It is helpful to focus on a different perspective.

Ask: When the feelings of being slighted or judged are set aside, how would you like to influence those moments? What could be achieved that would benefit this child?

Once familiar with Intentional Communication Strategies, it becomes easier to use them in difficult or challenging situations. Discussing and practicing these strategies beforehand can help a parent be ready and more confident in using them in real life situations. To prepare for the next difficult interaction, consider asking such a question

Ask: What intentional strategies could be used next time something happens that can support the family and move toward achieving this family's goals?

Here is another example of an Intentional Communication Strategy:

A deliberate 'pause' can serve a parent in many situations. In that moment, a parent has the chance to recognize a stressful event (e.g., rolling of eyes or an unwelcome comment), then choose to pause to accept that it is happening and is out of their control. During that pause, there is time for a parent to take an intentional inhale and an even more deliberate exhale. During the pause, there is time to remember that a flare-up of anger or a cave-in to self doubt is not required. Flare-ups and cave-ins are not likely to help achieve the bigger goal of CORE relationships. Instead, a parent has the chance to choose how to respond and whether to invest more of their time and energy in that interaction or relationship.

These strategies are written to model language for a conversation that could take place with a parent and another person. They can be adapted to fit the style of those involved in the conversation.

Intentional Communication Strategy 1: Acknowledge what is true about what the other person said and still try to be influential.

When someone makes an unwelcome comment, consider it anyway. Is there any part of the comment that you accept as a legitimate observation or position. Rather than flaring-up or caving-in, can you acknowledge the bit that was true? Someone might say, "That child is out of control and needs to behave." You could react with anger or you might say, "He is really struggling right now. He just doesn't understand what he can do. He is confused and frustrated." Your attempt at being influential is to plant the seeds of understanding that this child may be confused and frustrated because he wants to be active.

Intentional Communication Strategy 2: Invite people to say more, to think about what they are saying and try to be influential.

The urge to shut someone up and have the last word to tell them they are wrong and leave in a huff is tempting. That is a choice but an opportunity to be influential might be missed. In the spirit of reciprocity, you might consider asking a question to learn more about someone who could become an ally. Someone might say, "That child is out of control and needs to behave." You could ask, "What do you think s/he might be trying to accomplish?" Rather than cutting the person off to stop what you do not want to hear, invite the person to think about the child's perspective. That shift from judgment and blame to considering the child's point of view can open up a relationship because it is changing the way a person thinks.

Asking what someone thinks does not require that you agree. It simply gives you more information about what and how another person is thinking. Extend the conversation to learn more about what might be the obstacle for someone in relating to a child. Ask them to please say more about that.

Intentional Communication Strategy 3: Invite people to think about just one child rather than to talk about what children need.

When someone starts telling a parent what they could, should or need to do--pause. You have nothing to lose by considering a suggestion. Listening does not mean agreeing or making a commitment to do anything more than listen and consider. One way to try to be influential is to invite people to think more about their advice; to focus just on one child. In other words, without being rude, challenge 'one size fits

all' thinking. Maybe the advice will be helpful or maybe there is an opening for a different kind of conversation. Someone might say, "When children act like that, you just need to ... " You might consider saying something like, "That might be helpful for some children. I'm wondering what you have noticed about this child that makes you think what you are suggesting would be helpful for her/ him?" The question should be asked with genuine curiosity. You decide whether you want to disclose anything more about the child that explains why the suggestions might or might not be helpful. It is another opportunity to try to be influential.

Listen to what people say. Allow them to use their own words and descriptions. Selectively encourage people to try to better understand the child's point of view. "What do you think s/he's experiencing? How do you think s/he understands this situation?" This invitation to say more in response to certain questions offers people a way to relate to a child other than by judging, criticizing or giving unsolicited advice. It can be the beginning of an alliance. Some CORE relationships just happen. Others can be cultivated.

Intentional Communication Strategy 4: Work with conflict.

Conflict is an inevitable part of every relationship. Every parent will have their own level of comfort and discomfort in dealing with conflicts big and small. Providers have shared that they also have their own levels of comfort and discomfort and have needed to reflect on that when supporting parents. Having an understanding of these strategies is helpful when facing a conflict. Again, these strategies are written as if a parent were having a conversation with another person. They can be adapted to fit the style of those involved in the conversation.

Ask: How is conflict typically addressed in this family's extended family or among friends and acquaintances?

Working with conflict is not about winning. Working with conflict is about trying to be influential. Consider the person with whom you are experiencing conflict. If you have evidence to suggest that this person is and will continue to be unavailable, forgive them and let them be. As for the rest of the people you know and encounter, notice the moments of possible influence. Sometimes, you may just need a break and may not be able to use every opportunity as an avenue for changing minds and educating others. When you feel more able to engage, more opportunities will always arise.

When working with conflict: Ask: Is this the opportunity to use?. Consider the other person. Is s/he someone who might be available? Keep comments and questions focused on the fact that this child has a point of view.

Ask:

What has been seen or heard that makes this parent think that?
How might this parent be experiencing this situation?
What might this parent be trying to accomplish?
If this child could tell you, what might he/she say in this situation?
From (this child's) perspective, what might be helpful?

The Parents' Next Step in CORE Relationships

When someone begins to have interest and curiosity in this child's point of view, the parent and child have a potential ally.

CORE relationships ask parents to consider paying attention and deciding how they want to pursue relationships in their lives. The daily activities of parenting do not always easily allow for this kind of thinking. Some may struggle emotionally with the balance of risk and benefit in new relationships and experiences. Some questions to ask include:

Ask: Are there ways that a parent could think differently about this child so that others will think differently?

Ask: Are there things a parent could do differently so that others might find it easier and more natural to relate to this child or family?

The next section talks more about the opportunities that parents want for themselves and their children. Many parents have said they welcome conversations that help them connect to their original thoughts about becoming parents. Parents may want to talk about the lives they want for their children, themselves and their families now.

Ask: Where does this family want to go (places)? What do they want to do (activities)?

Remember that there is a big difference between talking with grandma about a child's delayed speech or need for speech therapy and having a conversation to help her notice that, even though her granddaughter is not talking, she is happy to see her and wants her to play hide and seek.

For many parents, some of the joy of parenting comes from seeing their child interact and be happy with other people. This is a universal experience of parenting that happens if a child has special needs or not.

Connecting Parents to the Experiences of Parenting

Becoming a Parent

Connecting with Support Systems

Opportunities Now and Later

Though many parents of children with disabilities face daily challenges in meeting their child's need for additional supports, many also have successful experiences that are shared by all parents. The next step is to explore with families how they can have these important life experiences. This conversation includes listening carefully to the parent's hopes, dreams and fears for their child and helping parents also discover what is important to them and to their child.

The focus of this section is to create awareness of how becoming a parent can have similarities for all parents, whether their child has a disability or not. For some families, the typical experiences of parenthood may have been disrupted when their child received a diagnosis or was identified as needing supports. These conversations are a reminder that parents have:

A say in how other people will interact with and have relationships with their child.

Choices about how they want to spend time as a family and the ways that they would like their child to participate.

Opportunities to have many of the same experiences as other parents raising young children.

These conversations may bring out difficult emotions for some parents. The questions are for people who have developed a trusting relationship. How and when these questions come up depends on the current relationship between the parent and the other person with whom the conversation takes place and the direction in which discussions are going. Often, they can arise naturally within a larger discussion.

Becoming a Parent

These conversations will help a parent connect back to their reasons for becoming a parent. They may remind parents of their connection to their child.

Ask: When did you experience that sense of being a parent? "Oh, now I really am a parent!"

Examples families have shared:

When we found out he was a boy

That first diaper

It took a few days, after some sleep

When we went out as a family

When I figured out the car seat

His nasal tube slipped out and I popped it right back in

I fed him and the food actually stayed down

She was screaming as they examined her and then they handed her to me and she got quiet immediately

Ask: What did you first notice about your child?

Examples families have shared:

Her tiny feet

Very beautiful and very,very LOUD!

He looked familiar

His head was pointed

Those eyes

He had this huge cleft in his lip, but all I could see were his eyes looking right at me

All those tubes, where was the baby in there? But I reached in and touched him and he grabbed my finger.

Here are additional CORE questions to consider that can connect parents with their original intentions as a parent.

Ask:

What did you hope to experience as a parent?

What were the activities of parenting that you looked forward to?

What was the most comfortable experiences for you?

What has been less comfortable? What did you have to work harder at?

How is being a parent now different than you thought it would be?

How has parenting brought you into your community?

Has parenting changed how you think of her/his community?

How has having this child created opportunities to have different relationships and experiences?

(Consider both long and short term relationships that this parent would not have had if s/he were not this child's parent.)

How has this child given back to you?

What parts of parenting have surprised you?

What parts of parenting have been fun, brought enjoyment?

Connecting with Support Systems

An experience very specific to the families of children with disabilities is that once they knew their child needed additional supports, they connected with formal programs. It is important not to assume that the introduction of formal supports was identified as a good experience for all parents. Many families have shared that their own sense of themselves as competent parents was greatly affected when they first had contact with medical professionals, therapists and teachers and other providers.

One parent reflected...

“Now when I look back, I realize how great it was that we had three months with him before the doctors figured out something was different, that he had Down syndrome.”

How can providers and others be responsive when parents share stories of their experiences after their child received a diagnosis or when it was clear that their child would need additional supports?

How providers respond may determine where the story goes and whether a parent's actions reinforce a sense of helplessness and thinking that, "I never have enough or only more services can meet my needs."

These questions may help to begin conversations about what happened when families connected with formal supports.

Ask:

What was this family's experience in their first contacts with providers? How could the experience have been more balanced? More responsive to this child and family's needs?

How has the emphasis on services for this child affected you as a parent?

What might have been the "good intentions" of the people who spent a long time learning about one part of this child; when parents live with the whole child and the interaction of all those parts?

How could this parent find value in all of the different points of view that s/he may have heard from providers who really wanted to help this child and family? How did they help or not?

Opportunities Now and Later

A conversation about opportunities for children is very different than a conversation that begins with "What does this family want their child to be able to do?" Even experienced providers cannot predict the future and know for certain what developmental path a child will follow. No one has enough information to predict what opportunities await a child or young adult based on skill deficits, especially with advancements in science and technology and overall shifts in community attitudes and opportunities. Emphasizing participation and contribution promotes independence in children and youth. This emphasis also may help parents more easily share their ideas.

Parents often can talk about their child's preferences and what is important to them as a family. Parents and providers can use this information to connect a child to opportunities that might be available in the community to meet a family goal. Yet, many parents and providers have shared that they needed support in shifting their thinking about opportunities and participation. Parents may need information about the places other families spend time in their community, what activities are available to other children of the same age, who may have similar interests.

Ask:

What kinds of opportunities does this parent want their child to have?
What will be important in her/his life no matter what her/his abilities are?

These are examples of how parents and providers have created a connection between what is important to a parent and the kinds of opportunities, activities and relationships that they want to cultivate for their family and their child.

What is important for this child? "This is one friendly kid; she makes friends wherever she goes."

What will it take to make this happen? (opportunities, activities and relationships) Have friends by going to a play group, birthday parties and community events. Set up a pen pal and nurture friendships across ages.

What is important for this child? "He has loved music from day one. Music has to be a part of daily life."

What will it take to make this happen? (opportunities, activities and relationships) Play or listen to music by going to concerts, playing in a band, using a MP3 Player, CD player, buying CDs and DVDs.

What is important for this child? "He has so many ideas; he has to have a way to let other people know about them."

What will it take to make this happen? (opportunities, activities and relationships) Have effective ways to communicate ideas and interests through using a computer, drawing pictures and writing letters. Have choices about how to spend her/his time such as outings with family and friends.

What is important for this child? "Any kid of mine has to love baseball and he does!"

What will it take to make this happen? (opportunities, activities and relationships) Share special interests and passions with someone through hobbies, joining clubs, making scrapbooks, community events and keeping team stats.

What is important for this child? "She gets stubborn just like her Dad, so she better have a say in things or you will hear about it."

What will it take to make this happen? (opportunities, activities and relationships) Have effective ways to communicate choices, involvement in decision making, choices in friends and how to spend free time and a sense of personal style and assertive communication.

Notice that there is a relationship between what a parent wants for their child and the opportunities and activities planned for early intervention and education. Asking, "Why is this important?" helps connect a child's unique characteristics and family priorities with potential opportunities, outcomes and relationships. Consider how these examples could be written as outcomes for a child and family.

Possibilities include making choices for independent play and leisure activities and creating opportunities for friendships and participation in community activities for all kids.

This may include activities such as library story hour and neighborhood play groups. Consider the family's interest in and opportunities for their child to have interactions with people outside of the immediate family. Notice how these kinds of outcomes fit with what they have said is important for their child and family.

Opportunities Now and Later for Parents Parents say they feel supported when providers keep the conversation focused on the whole family and include parents in ways that helps them focus on opportunities they want in their own lives. While parenting changes lives significantly, most parents find ways to include their own interests in their families' activities, experiences and relationships.

Many parents have reported that they needed to get past their own perceived obstacles before they could actually consider these questions. A useful strategy is to ask what gets in their way and keeps them from doing the things they want to do, rather than offering advice.

Ask: What would this parent do if they did not have barriers or challenges in the way?

Ask: What kinds of opportunities does this parent want to make sure the family continues to have despite many other responsibilities?

What is important for this parent? "I always knew that once my kids were grown, they would move out, even the one who has autism"

What will it take to make this happen? (opportunities, activities and relationships) Independence, cultivating other important relationships, making choices, self care skills, friendships, effective communication.

What is important for this parent? "She is much more social and interested in friendships than I am, so now she can answer all of those phone calls on her own."

What will it take to make this happen? (opportunities, activities and relationships) Skill in using the phone, effective communication, practice with support, other significant relationships.

As parents are able and willing to consider opportunities for themselves, they can consider a future in which their relationship with their child may change. Parent and child relationships change for all families over time.

These types of conversations give parents a chance to see that even though they face challenges, many families have found ways to work toward making time for the activities and relationships that have always been important to them.

By including unpaid and more ordinary and natural supports in their daily lives, parents can experience the benefits for themselves, their child and the people they invite to be a part of their lives.

Opportunities for CORE Conversations

Questions to Embed in Everyday Opportunities

Activities for Guided Conversations

Embedding CORE Conversations into Practice

Translating CORE Conversations into Meaningful Outcomes

Barriers and Challenges

Questions to Embed in Everyday Opportunities

We have pulled together the following groups of questions from the CORE concepts addressed in this guide. We offer these questions as examples of CORE conversation questions that could be embedded into everyday family experiences. Opportunities for asking these questions may come up at any time, as the context would support. This includes connections between parents and providers, as well as between parents, family members and others in their network. Consider how a child's grandmother or a parent's sibling might ask these questions during daily encounters.

When learning more about how parents view their community...

Where do you like to spend time as a family and on your own?
Who are some of the people you see everyday? Weekly? More or less often?
How long have you lived in this neighborhood? What do you like? What do you find challenging?
Do you ever think about living somewhere else? Why?
Are you and your child going to the places you want to go to in your community?
Are you and your child feeling part of the community to the extent that you want?
What kinds of opportunities do you want for your child and yourself at this time and in the years to come?

When learning more about what kinds of opportunities parents want...

Why are these opportunities important to you and to your child?
What would you like your child to do that has not happened yet?
What would you like your child to have the chance to practice more often?
Are you and your child participating in the activities you want?
Are people in your extended family and others getting to know your child?

When learning more about how children could contribute to their families and have more reciprocal and balanced interactions...

Are there ways that you would like your child to be more independent or to participate more fully in activities?
Do you feel you have a balance of activities in your family's life?
What are the activities your child engages in with your family?

When learning more about what might be enjoyable to a parent and child...

What is something about your child that you like, that makes you happy or gives you energy?
What things about your child do you think other people would enjoy?
Are there things that you like to do that you wish your child could do with you?
What makes you feel the best about your child? What are her/his best qualities?
Has anyone ever complimented you on something about your child?
How can you make your child laugh? What makes you laugh when you are together?
What do you like to do with your child that is enjoyable?
What does your child like to do with other people or the rest of your family that is fun for everyone?

When talking with parents about providing others with usable information about their child...

What do you think is most important for a person spending time with your child to know?

On an ordinary day, how do you think about your child? What words do you usually use to describe her/him?

What kinds of relationships might be enjoyable and beneficial to your child? Your family?

What are your most frequent topics of conversation about your child?

What do you want people to think about your child?

How do you want people to interact with your child?

What does your child value? What causes her/him to smile?

What is your child's temperament?

How does your child communicate what s/he wants, does not want or feels? How can you tell when s/he does not feel well?

How does your child like to play and interact with others? How does your child play on her/his own?

How is your child affected by sound, touch, light, taste and smell? Does s/he prefer or avoid these sensations?

What does your child find soothing? What helps her/him to feel at ease?

Are there events or situations that your child sometimes finds stressful?

How does your child prefer to participate in activities? Does s/he prefer to watch, jump right in or talk about them?

What accommodations are helpful?

When your child gets stuck, is it more helpful to talk, demonstrate or physically guide her/him?

When talking with parents to help them understand their child's perspectives...

What do you imagine your child is experiencing? What is s/he probably seeing, hearing, feeling (sensation and emotions), tasting and smelling?

What do you think your child might be trying to accomplish?

What do you think your child might need or want?

What might your child say in this situation?

When talking with parents to think through the relationships in their lives...

Who are the people you would like to be more a part of your child's life? Consider family members, friends, other children and neighbors.

Which group would you assign to each of these people? Refer to page 32 for descriptions of ready, willing and able; open, interested and willing; willing but limited; and not available.

Are there any people that fit into the open, interested and willing or willing but limited categories that you would like to find out more about?

What kinds of relationships are you and your child happy having with others?

How much of your energy is going toward individuals who are essentially not available? What would happen if you accepted that person's right to her/his point of view and set your focus for CORE relationships on people who are available?

When you find people that you want to know better and they want to know your child better, how do you want them to think about your child?

What do you find disturbing about the reactions of other people to your child? What did you see or hear that was disturbing to you?

What might happen if you decided to stop being angry at people who are not available in the way you would like them to be? What could you do instead?

What do you wish would have happened?

What sometimes makes you just want to keep to yourself?

When talking with families about Intentional Communication Strategies...

What intentional strategies could you use to take care of yourself and move toward achieving your goals the next time you are exposed to another person's reactions to your child?

When you have feelings of being slighted, what influence on others would you like to have in those moments?

What would you like to achieve that might benefit you or your child?

How do you usually respond to conflict in your extended family or among friends and acquaintances?

Are there ways that you could respond differently so that others will respond differently to you and your child?

What might make it easier and more natural for others to relate to your child or to you?

When talking with parents about their experiences of being a parent...

When did you first experience the feeling of being a parent?

What did you first notice about your child?

What did you hope to experience as a parent?

What are the activities of parenting that you look forward to?

What has been the most comfortable experiences for you as a parent?

What has been less comfortable? What do you have to work harder at?

How is being a parent now different than you thought it would be?

How has parenting brought you into your community?

Has parenting changed how you think of your community?

How has having your child created opportunities to have different relationships and experiences?

Consider both long and short term relationships that you would not have had if you were not this child's parent.

How has this child given back to you?

What parts of parenting have surprised you?

What parts of parenting have been fun and brought you enjoyment?

When talking with parents about their first experiences with service systems and providers...

What was your experience in your first contacts with providers?

What aspects of your experiences have been the most valuable for you and your child? How could the experiences have been more responsive to your and your child's needs?

How have the services helped you get to know your child? Have some aspects distracted you from getting to know your child? How?

What might have been the good intentions of the people who spent a long time learning about one part of your child, when parents live with the whole child and the interaction of all of those parts?

How could you find value in all of the different points of view that you may have heard from providers who really wanted to help your child and family?

Activities for Guided Conversations

Guided Conversations are different than more casual conversations because the person asking is listening carefully with attention to CORE relationships (Community, Opportunity, Reciprocity, Enjoyment).

Below are specific questions that can generate conversations between parents and providers, between parents or with anyone else in their lives. They can be included in on-going conversations and integrated into discussions during assessments, service planning and transition planning and parent-to-parent connections.

Guided Conversation: Let's Take Inventory

1. Let's make a list of the places you go with your child; are there other places you want to go?
2. Let's make a list of the activities you like to do with your child; what other activities might this child want to at least try? What other activities would you like to do yourself, with your partner or as a whole family?

Guided Conversation: People in Your Community

1. Think about where you go and what you do. Who do you see and who have you noticed noticing you? Let's make a list of people who are not paid to be in your child's life. It's fine to list people whose names you do not know. For example, the woman with the pony tail whose son is in daycare with your child. Put her down. It's your list. You can always add more later.
2. Find a group that you think is the best fit for each person on your list. Identify who is:
Ready, willing and able to have a relationship with my child.
Open, interested and willing but might want a few tips.
Willing on a limited basis for some activities.
Not available.
3. Talk about why you assigned people to groups as you did. Were you hasty in any of your assignments? Did you write people off too quickly because of an initial impression or experience? Give people the benefit of the doubt.
4. With four categories and only one of them identified as not available, where are you going to invest your energy? If you identify everyone as not available, then take it to the next level. What would need to be different for you to be more comfortable? How might this happen? Could you relax or change any of your own expectations to make those relationships possible?
5. With a mindset that there are people who will like and enjoy your child, what's next? Make room for introductions, invitations, shared activities, conversations, questions, requests that might become opportunities and relationships.
6. Pick just one of the people on your list. During the next few encounters, notice how you usually communicate about your child and your frame of mind in relation to your child. What would be the take away message this other person is probably receiving? Is there anything you want to change or add? Keep in mind the earlier ideas we shared about how to use language and conversation topics.

Guided Conversation: Coping with Disappointment

1. Caving-in and flaring-up are not our only choices. Make a list of the things you wish people would not say or do in relation to your child. Be as explicit in your description as possible. You are allowed to be as petty as you want about what you see or hear that you wish would not happen.
2. Describe what happens to you when these events occur. Specifically, what thoughts pop into your mind? What sensations do you notice anywhere in your body? What emotions are most predominant? These are reactions. Reacting is what we do without consideration. Responding is what we do when we remember to pause and consider how we want to be influential.
3. Identify two or three things you can do to remind yourself to pause rather than be reactive when unwelcome events happen.
4. Identify two to three things you can do to regain your composure, to feel confident, centered or calm or in order to respond and plant the seeds of influence.

Guided Conversation: What Others Need to Know

1. Parents often are receivers of information. They receive information that might be diagnostic, clinical or treatment oriented. Parents also share information. Parents decide who in their child's life has need for that information and whether to share it. Write down some of the language people have used to describe your child that is not automatically clear to someone when they hear it the first time. For example: sensory integration, neurological disorder, cognitively disabled, impairment, crossing midline, object permanence, tactiley defensive. Include acronyms and any other language that would be more easily understood in other words.
2. Think about the possible effect of not interpreting this language you just wrote down in other words. What impressions do you think people might have of your child if you only pass along to others the formal language or jargon that has been used?
3. Practice reframing information in other words to encourage interaction and relationships.

After hearing her niece described as spastic or having athetoid cerebral palsy, Aunt Carol wonders whether it will hurt her niece if she picks her up or tries to play with her. Provide information to Aunt Carol and answer her questions in ways that encourage interaction and relationships.

4. Let's talk about other words that provide usable information and help people in a child's life appreciate who s/he is. Consider language that will be relatable for a grandparent, a potential babysitter, a neighbor's child of about the same age or a dentist.

Embedding CORE Conversations into Practice

Below are suggestions for where and how to embed CORE conversations into early intervention and education. These are not intended as free standing examples, but are reminders of ways to go deeper with interactions and discussions.

Describing the Purpose of a Service Coordinator

Primary Messages

I want to support your family in getting to the places you want to go and participating in the activities you want to enjoy with the people you want to be with.

I want to understand your child as well as you do and be able to talk about her/ him with others in ways that help other people relate to her/ him easily.

Possible Questions to Ask

Where do you like to go?

Where would you like to go?

What activities would you and your child enjoy?

Who with?

Why is this important to your family?

What has happened when you have gone somewhere or tried an activity?

What are your concerns?

Listen For...

Words that indicate a concern---real or perceived.

Follow Up

This is a conversation that will be revisited with parents as the relationship grows over time.

Describing the Role of a Provider

Primary Message: I want to offer practical ideas, resources and strategies to support your child. One of my primary roles is to be a coach as well as a therapist for you and your child, so you can learn ways to interact and play with your child to benefit her/his development.

Possible Questions to Ask: What are the times of day that are going the most smoothly for the child and family? What times of day do you wonder if there is a better or easier way?

Listen For...: Specific concerns or questions. No areas of interest or general statements like "I don't know." If so, you might need to break the day into routines and activities.

Follow Up: Arrange to visit and coach during agreed times or activities of interest to the parent and child. Ask about home as well as community settings.

Discussing Child and Family Outcomes

Primary Message

I want to learn what is important to your child and your family.

Our discussions are not just about services; they are to learn what is important to you and why.

Possible Questions to Ask

What would you like your child to have the chance to do?

What kinds of activities or experiences do you miss?

Listen For...

Any confusion about the importance of considering both child and family outcomes, not just an emphasis on child skills.

Follow Up

Comment on what has been important to other families you have known as a conversation starter if families are unsure how to respond to your questions.

Identifying and Exploring Resources

Primary Message

I am here to help you be aware of both paid and unpaid resources. Resources are not only paid professionals and services. Resources are also the people, places and opportunities in your life. Some people might need support to relate to your child and family.

Possible Questions to Ask

Who in your life is ready, willing and able? Who is open, interested and willing? Who is willing on a more limited basis? Who is not available?

Listen For...

Any negative or limiting words in relation to what most people consider the ordinary or natural supports in their lives-- family members, friends, coworkers, neighbors, etc.

Follow Up

Help families identify the people and places that can be or are supportive and develop strategies for people, places and experiences that are draining or negative.

Checking in About Desired Shorter Term Outcomes

Primary Message

I will be having discussions with you on an ongoing basis. My goal is not to judge either you or your child, but instead to keep us on track toward your goals for your child and family, as well as to explore new resources and opportunities that may emerge.

Possible Questions to Ask

What has been happening with family and friends? Where have you been going? What have you been doing? What's your comfort level with a new opportunity or resource? What might help?

Listen For...

Words families use that indicate comfort and discomfort. Signs about how families feel about changes that are happening or that they wish would happen in their lives.

Follow Up

Keep asking

Anticipating Next Steps About Desired Longer Term Outcomes

Primary Message

I can be a resource to you in thinking about places where your child and family may spend time in the future.

You can help me understand what is important to you.

Possible Questions to Ask

What changes are coming up for your child, yourself and your other children? What could your child be practicing that might ensure her/his success with those changes? What are your concerns about trying something new?

Listen For...

Fear or worry about the future. Concerns about risks.

Follow Up

Discuss with families that with risks come opportunities. When we focus all our energy on eliminating risks, we also reduce or eliminate all opportunities.

Translating CORE Conversations into Meaningful Outcomes

What is likely to be helpful for families and providers?

Open conversations about CORE aspects in families' lives.

Support in learning how to talk about children to other people.

Support in figuring out the relationships parents want in their lives.

Support to remember the aspects of parenting that are important to families and how to maintain these elements in their everyday lives.

Once CORE Conversations happen, valuable information emerges that can support families in living the life they want to live, not just connecting them to services. This activity offers examples of ways to translate CORE information from families into outcomes. When figuring out what is important, consider identifying why some things are important to parents.

What the Parent Has Said Is Important: The mother likes to get out everyday to do shopping and see her neighbors.

Child or Family Outcome: The child will accompany parent to store, riding calmly in the stroller, for two 20-minute trips each week. The parent will make a weekly schedule to plan family outings for 2 to 3 days each week.

What the Parent Has Said Is Important: The child loves to play with his younger sister, but has been too rough. The father often has to intervene.

Child or Family Outcome: The child will stop when shown the Time Out sign when playing with his sister. The parent will have a 10 minute guided play time with both children 3 to 4 evenings each week.

What the Parent Has Said Is Important: The family wants to go to the library every month, but some people there seem uncomfortable with how active the child has been.

Child or Family Outcome: The child will read 2 picture books with an adult from beginning to end, calmly, while sitting together. The parent or provider will talk with the librarian to let her/him know that when the family is at story hour, they may need to get up and walk for a few minutes with the child.

What the Parent Has Said Is Important: Both parents really need a break, but are very hesitant to ask people to care for their three children.

Child or Family Outcome: The child will play independently with adult supervision for 15 minutes. The parent will contact her sister to do childcare for two of her children while she and her husband take a walk with one child once a week.

Worksheet

Translating CORE Conversations into Meaningful Outcomes for Parents and Children

What is likely to be helpful for families and providers?

Open conversations about CORE aspects in families' lives.

Support in learning how to talk about children to other people.

Support in figuring out the relationships parents want in their lives.

Support to remember the aspects of parenting that are important to families and how to maintain these elements in their everyday lives.

Teams can use this worksheet to discuss and consider how to use information gathered from your CORE conversations to plan outcomes for children and families.

What is important to the family?

How could this be written as a measurable outcome?

Barriers and Challenges

A commitment to a change in thinking and practice is often accompanied by barriers as well as benefits. How can families and providers support each other in taking next steps, getting through the barriers and working toward CORE relationships in their daily lives?

Many parents said they needed to get past their own perceived obstacles before they could really consider the CORE conversation questions. Rather than offering advice or resources, a useful strategy is often to ask what gets in the way of trying something new.

There are many times when families and providers have limited choices. CORE conversations provide an opportunity to notice and take advantage of choices that do exist and ones to work towards creating in the future.

What did parents say about challenges and barriers? Challenges to thinking about CORE relationships came in two categories.

Parents talked about barriers and limitations in their own thinking.

Not having enough usable information about their child's needs

Discomfort in dealing with differences

Values related to giving and receiving support

Personality differences that influenced the kinds of relationships they wanted in their lives

Fear of risks to their child outweighing the perceived benefits in trying new things

Thinking of themselves as "experts" about their children's needs

Difficulty asking for help, friendship, company, resources, time and attention

Balancing the needs of different family members and other daily obligations and responsibilities

Feeling exhausted by the demands of services, supports and multiple providers and interventions

Parents talked about barriers and limitations that they perceived in other people.

Resistance to either understanding or accepting the child's needs or disability

Differences in opinion or style about what the child needs or how to interact with the child

Not enough energy, time or interest

Someone on the team thinking of her/himself as "the expert"

Limited view of the child only seeing the disability

Fear of differences or the unknown

Lack of accurate information

Too often parents find themselves up against barriers in their own thinking or the limited thinking of others. Families and providers benefit from reminders about choices, the company of supportive others, humor, perspective and balanced information. Stories from other families who have worked toward the vision they hold for their child and family are also powerful.

Closing Thoughts

Parents and children will benefit from the courage to have conversations about what is really important to them in their lives. They have given a clear message that they want providers to help them explore possibilities.

The conversation strategies described throughout this guide offer a method of interacting that may take place between a parent and a provider, between parents or with anyone else in their lives. These conversations give new energy and underscore the importance of early experiences in setting the stage for families' perceptions about what to expect from service systems and possibilities for involvement in their communities.

While ordinary, natural relationships may at first be more challenging for parents to cultivate, they grow with time, awareness and energy. Relationships typically develop because of shared opportunities-- soccer, dance, school events. Friendships develop over years, months, weeks or for an afternoon. Relationships between children and adults other than their parents also take shape naturally, in ordinary ways, during everyday activities in the communities. Children and families can have opportunities to pursue their interests, make choices, have a say in how they spend their time and with whom they spend time. These experiences help children begin to have identities of their own in addition to being their parent's child.

For children growing up with disabilities, the natural flow of opportunities and connections to other people might not evolve so easily. Parents of young children who are not having these natural connections or supports and opportunities are likely to feel either lost or confused, sad or angry.

Even though at times it may have been harder, most families have told us that finding and enjoying ordinary opportunities, activities and relationships have enhanced their life as a family. The effort was worthwhile.

CORE conversations about CORE relationships can help people shift from treading water to moving toward points of interest. Some might start with social or recreational opportunities. As children get older, the opportunities parents want to pursue might be related to events in and out of school and with other children and adults.

Parenting is exhausting, exhilarating and most likely not always what was anticipated. Parents have made a long term commitment and are trying to build the resources to keep that commitment. Relationships provide at least some needed support.

CORE conversations will not take away the challenges that families encounter. Instead, conversations can guide parents in a direction that will eventually lead to natural supports.

Choices, information, companionship, stories and insight make a difference.

Remember to Ask:

Is this child and family going to the places they want to go?

Is this child and family participating in the activities they want to try?

Is this child and family feeling part of the community to the extent that they want?

Are people in this child's extended family and others getting to know this child?

Are this child and family having fun?

COMMUNITY

connections and participation

OPPORTUNITIES

to explore and pursue our interests

RECIPROCITY
in our relationships

ENJOYMENT
in our lives

The CORE of a Good Life: Guided Conversations with Parents on Raising Young Children with Disabilities
Molly Murphy, Ph.D. and Mark Sweet, Ph.D.
Edited by Beth Swedeen, Colleen Kurkowski Moss and Linda Tuchman-Ginsberg
Desktop publishing by Leah Zimmerman and Colleen Kurkowski Moss

If you have any questions or ideas, please feel free to contact us at:

Natural Supports Project
608.890.1687

www.waisman.wisc.edu/naturalsupports/

Waisman Center
University of Wisconsin-Madison
University Center for Excellence in Developmental Disabilities