



Conversations About Your Child

THEMES FOR A LIFETIME

Written by Mark Sweet PhD
January 2015

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131 West Wilson St. Suite 700
Madison, WI 53703
Disabilityrightswi.org

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As the parent of a 16 year-old son with autism, I still vividly remember his two-year check-up when we received the diagnosis from his pediatrician. As we dove into self-education mode, we were quickly overwhelmed by all of the “helpful” recommendations from parents and providers in the countless books and articles we read. I wish a more pragmatic guide like this one had been available to us at the time. As I read *Conversations about Your Child – Themes for a Lifetime*, I was continually drawn to one powerful concept – Point of View.

I’m embarrassed to admit that over the years I had become brow beaten into the concept of compliance. Treatment plans, IEPs, ISPs, and daily routines for my son were written with goals predicated on compliance to rules and expectations. When my son had a meltdown, I would receive a phone call or report frequently focusing on a negative behavior. Seldom was there any information or perspective on what my son might have been trying to communicate prior to the behavior. He was constantly caught in a cycle of behaviors and consequences. It was only when I began to consider his point of view, that I was able to have more meaningful conversations with family, educators, caregivers, and therapists. Most importantly, this concept has allowed me to simplify my strategies to support my son, and in turn, offer guidance to others who support him.

CHRIS L’HEUREUX

I’m a parent of four children, two who do not experience disabilities and two who do. When my children were still young, I would have liked someone to tell me that after I listened to what experts and others said, I could think about whether their ideas were a good match for my child in the long run. I could have agreed when I thought something was a good match and respectfully disagreed when I thought their recommendations were not a good match for my child. I could have tried to help them better understand my children if I thought their ideas were not going to meet their needs.

I am an important team leader for my children. Others come and go, but I’m still here. I’m still trying to help other people get to know and understand my children so that they can be the best they can be. If I had this booklet when my first child who experiences autism was diagnosed, one of the most important messages I would have taken away is that as parents, we can have input into all of the recommendations that are made and make our own. As it says in the booklet, we can accept what we find helpful and usable and let the rest be. This entire booklet could be helpful for you.

JO CAULEY

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Conversations About Your Child— Themes for a Lifetime

Read this material as though we are in conversation. Add your thoughts and questions. Imagine a few other parents. Include some of your extended family and friends. This material is not intended to be a text on childhood, disability, parenting or a comprehensive guide on anything. This material is offered to help you think about the experiences you want for your family, including a child who has been described as having a disability. **As you read, think about how you might be able to use the ideas discussed now and maybe in an ongoing way in the years to come.**

You had a baby. Now, you have your child. You did not have Down syndrome, autism, traumatic brain injury, attention deficit disorder, intellectual disability, developmental delay, cerebral palsy or any other sensory or disability category. If a medical concern arises, a medical decision might have to be made. Most decisions should be about your whole child and her/his participation in your family, your neighborhood, your school district and your community. **One goal is to increase the likelihood that people who have contact with your child will support her/his wellbeing throughout life.** That word – wellbeing – will be one of our themes for a lifetime.

Along the way, you will probably receive information about your child's skills and abilities, developmental milestones, assessment scores and comparisons to what other children of the same age are doing. You might be told what your child is not doing and what you should do about that. Some of what you hear will be described in terms of needs, as in *s/he needs to... or you need to...*

Some of these needs statements will come from professionals and some might come from those within your own family. Some information will be communicated as direction, some as concern or fear, some will be gentle, and some you might experience as shaming or blaming. You can decide if what is offered is helpful or not. **Just because someone's intention is to be helpful does not mean that you will experience it as helpful.** Accept what you find usable; let the rest be.

You might hear comments or judgments about your child's behavior and suggestions about what you should do to change it. As you read this material, there will be an attempt to put all of this into a relatable context. All of life happens in context. All of your child's life is happening in a context and s/he has a point of view (POV) about it. As you read, **you will notice two themes: wellbeing and POV.** Each of them matters now and will continue to matter throughout your child's lifetime.

Depending on your child's current age, there have already been or might be referrals to specific organizations or programs. There might be strong messages that your child should be seen by one person or another; or, that you should sign up for one program or another. There might be a lot of paperwork and what seem like too many nosy questions. Some of

this might be conveyed with urgency.

You are not required to adopt anyone's sense of urgency. You can take the time you need to think and consider what will be helpful. One goal of this material is to help you **consider the information you receive through the filter of your family's wellbeing**. In the spirit of keeping it simple, accept what you find helpful and usable, let the rest be.

In the years to come your child will make many transitions. Other people will come into her/his life with designated roles. Each will take a snapshot from their particular angle; therapist, day care worker, aunt, teacher, neighbor, grandparent. Some will be around for a long while and most for shorter periods of time. They will have personal and professional advice. Most will not have a full picture of who your child is. **One of the ongoing, long-term advocacy roles for any parent is to invite others to wonder what it is like to be your child from her/his POV.**

Within all of the messages you receive should be congratulations and expressions of affection and love for you and the young member of your family. Along the way you will meet some remarkable people who genuinely want to support your family in ways that you find helpful. Others might not know how to offer support in ways that you can use. The good news is that you can teach them. ■

Looking Back

Parents of children with disabilities have been trying to create meaningful paths for their children and families for a long time. After the first federal public law authorizing “free and appropriate public education” for children with development disabilities was passed in 1975, one model of “service delivery” emerged and dominated. It was later described as a medical model. That meant that professionals tested children to find out what skills and knowledge were missing (i.e., what was wrong). The tested areas included: gross motor skills, fine motor skills, expressive speech and language, receptive speech and language, social play, intellectual development and more. Each of these had its own professional associated with it, e.g., physical therapist, occupational therapist, and speech and language therapist. As the child got older, teachers assessed general knowledge and understanding of numbers, letters and other symbols.

This was a deficit model that resulted in attempts to teach the missing or delayed skills by bringing children to professionals. The theory, and it was just a theory, was that if the missing skills were taught, someday, the child would apply them in ordinary daily activities at home, with friends, in neighborhoods, on playgrounds, in the community, around schools, etc.

What proved to be a problem for too many children was that they either did not learn the missing skills; or, they did not transfer use of them to the places and activities where they were needed. Teaching children away from their homes, neighborhoods, day care, playgrounds and school classrooms—the places in which the skills would usually be applied—proved not to be an effective approach for many children. It was however a convenient model for service providers. Through the filter of this medical or therapeutic model it was often reported that the child was “not ready” to participate with typical children of the same age in their usual places engaging in their usual activities.

Here is how it might have happened. Max learned to take turns with a therapist in a small quiet room when playing with building blocks. Later, when Max was in a room with other children who were reaching, stacking and knocking over blocks, he sat still and did not touch the blocks. Taught the same way as Max in a therapy room, when Lily was with other children she grabbed as many blocks as she could get her hands on and did not let other children touch them. When another child reached for blocks she hit them. Neither Max nor Lily transferred what they learned to do with a therapist in a separate room into the contexts in which their participation most mattered.

Move ahead a decade to the mid-1980s and there was an attempt to think more about the skills and abilities that would enable smoother transitions. A “next environments” approach started at the secondary school level. A guiding question became: *What skills and knowledge would students leaving high school need to enter their next environments, the post-*

school life of adults? A “domain” approach emerged that considered transition to adult living as having domestic, vocational, recreational and community domains. The thinking was that these were the next environments in which a student should be prepared to participate. It was and still is a good idea now referred to as a “transition plan.” Consider what can happen to a good idea.

Next environment thinking found its way to the transition from middle school to high school asking the question: *What skills and knowledge would students leaving middle school need to enter high school?* The approach went younger still with the question: *What skills and knowledge would a kindergarten child need to move to first grade?* Eventually, it became: *What skills and knowledge would a child entering kindergarten need when making the transition from early childhood, Head Start, day care or home to be successful in kindergarten?*

Can you imagine what went wrong with this very good idea? There was a “push-down effect” that resulted in expecting more and more mature participation from younger and younger children. Those who did not achieve it were deemed “not ready” for that next setting or activity. There were expectations to sit still when many young bodies were filled with energy. There were expectations to listen quietly when many thoughts were bursting to come out.

With the next environment approach, parents of young children were asked by caring teachers what kind of vocational life they wanted for their adult children when they left school at the age of 21. This was an impossible question to answer beyond generalities even though the intention of the question was in the right direction. Most parents were trying to manage family life during that day, week or month. Beyond saying *I want my child to be happy and doing something s/he enjoys*, it was just too big a question.

At this time in 2014, there is still a divide among day care programs, preschools and even kindergartens about whether they offer an academic or play approach. Those who offer an academic approach report that they are preparing children for the next environment, first grade, *where children will be expected to...* While the intention is to create a meaningful learning experience and context for children, the result for too many children has been a bumpy road and a difficult beginning to what becomes their school experience.

Children learn best and acquire skills and knowledge by playing, mostly around and with each other. Through play children discover what their bodies can do, how objects can be used, how to be social with other children and adults, how to communicate, how to cope with the emotional ups and downs of daily life, and how to get their needs met. It does not have to be either play or academic learning. Humans of any age learn best when they have interest in some aspect of an activity and can enjoy something about what they are doing.

When we are curious, motivated, enjoying what we are doing and have the kinds of social opportunities that suit us, we participate and learn. It starts in early childhood, continues through the school-age years and well into adulthood as what is now called life-long learning. When we participate with curiosity, by default, we learn. When we are unmotivated, forced, not enjoying what we are doing, not feeling good about ourselves, or not

understanding what we are told to do we are likely to rebel or withdraw or find other ways to engage ourselves. This is one reason why trying to understand a child's POV matters so much.

For some young children, support teachers and therapists might come to their homes. A more contemporary dilemma is whether in-home workers create medical models of service within a child's home by working one to one with the child using materials brought into the home; or, whether they infuse themselves into the ongoing activities of the household or community along with a parent to help maximize the child's participation in ways that offer therapeutic benefit. Participation is the goal.

Adam used to have an in-home worker who brought her own bag of stuff to use with him. The worker would take Adam into the living room while his at-home parent was doing something else. Then, the worker would leave with her stuff. The parent reported not really knowing what Adam and the in-home worker were doing. She said that *she didn't want to be in the way*.

Then, Adam got a different in-home worker. When she came to the house, Adam, the worker and either Adam's mother or father played with Adam using his stuff. On one occasion, when Adam moved toward a cardboard box that was not intended as one of his playthings, they helped him climb in and out of the big box because it was there and Adam was curious. Then, they went to the kitchen and together got a snack ready. During these ordinary activities, the in-home worker could notice and offer suggestions about Adam's gross motor development, fine motor development, receptive and expressive language, social interaction, eating, nutrition, and more. This infusion approach made in-home support meaningful for Adam and his family because when she left Adam's parents could apply whatever suggestions they found helpful and usable.

Think about how you can increase the likelihood that others will have your whole child's wellbeing in the front of their minds by inviting them to think about your child's POV. ■

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Your Child Has a POV

Whatever else is ever said about your child, one thing you can know for sure is that s/he has a POV. Even when it is not easy to determine, that unique POV is there and worth wondering about at all ages. Our culture is still prone toward what sound like rude questions and comments about children. *What's wrong with her? Why is he like that?* That's likely to pinch a few nerves. It might also be a clumsy expression of genuine interest.

Out once with a five-year old boy, someone asked *what's wrong with him?* Peter had a cold. He was also on the autism spectrum. He was making a lot of sounds in an attempt to clear his nasal passage and incorporated some flapping of his hands. While my strongest hunch was that the questioner was asking whether Peter had a disability, that information would not answer his most direct question – *what's wrong?* From Peter's POV about what was happening, he was having trouble breathing comfortably.

I decided to answer as best I could from Peter's POV. *He's pretty uncomfortable with this cold. He's trying to figure out how to breathe easier.* While I suspected the questioner was asking about a possible disability, he could relate to the answer given. It was a relatable answer. **Most inquiries about a child are not accurately answered with a disability label or category because the child's actions are attempts to assert or accomplish something or to cope with a situation.**

When Kenzie sits on the grocery store floor trying to bounce grapes, she is not there because she has Down syndrome; she is there because she enjoys trying to bounce things. When talking about your child the shortest answer might seem to be a diagnosis, category or classification. *On the autism spectrum, Down syndrome, CP (cerebral palsy), ADD (attention deficit disorder) and nonverbal* are quick answers. What if there was a more relatable way to help others understand, talk about and get to know your child?

POV is not only an intellectual position taken after study and deliberation by adults. When we don't know what is going on in the minds of young children and what they are feeling; before they have the methods or emotional maturity to tell us, we can respectfully wonder about their points of view. **We can practice curiosity and empathy. We can wonder what a child is thinking, understanding, feeling in her/his body, and wonder about her/his emotions. We can wonder what might be helpful at any point in time.** After a child is identified or even suspected of having a namable disability, too often we wonder less about their thoughts and feelings and assume that the disability is the explanation for all their actions. When we let disability lead as the headline we risk losing the whole child and her/his POV.

Sometimes, we lose that wonder and curiosity about a child based on age. Adults are often curious about newborns and very young children. What does this cry mean and what

about that facial expression? Why is s/he saying *no* and refusing to do now what s/he did happily yesterday? So many good questions about the child's POV. Then, when they get to be around two years old we want them to *behave, be good, sit still, and wait quietly*. We start to have expectations that many children cannot achieve. ***What is happening from her/his POV can be among the most frequent and helpful questions you ever ask.***

Movement and sound are your child's earliest efforts to communicate, interact or cope with whatever is happening. When you think about your lives as adults, movement and sound are still your coping tools. The earliest interactions of children might be with their own fingers, toes, lips and tongue. Their interactions might extend to you and other people; to the items that are within reach for some and those that are in view for others. Where a child's eyes, hands, feet and mouth are engaged are points of interest from her/his POV.

Adults love when a child looks at us with interest or recognition and maybe reaches out. That recognition can be intoxicating. When a child does not easily make that kind of eye to eye contact the feeling can be one of rejection. That feeling is an assumption that you do not have to hold on to. It is not based on evidence that s/he does not care about or depend on you; it only means that this child's eyes are not looking at your eyes. All the rest is fiction. You do not have to subscribe to fiction or assumptions.

Adults sometimes lose usable information about a child's interests and curiosities by focusing on what a child is not doing. A child's attention is not where we want it to be so we don't notice what has attracted it, what is of interest. When we try to commandeer a child's attention and force it on what we think matters, we might miss learning where there is already interest and engagement - possibly on something that matters from her/his POV.

The power to interact and communicate with a child can sometimes be easier when sharing a point of interest with a child than by trying to commandeer that child's attention or assuming that s/he does not have a POV. Adam's cardboard box was not originally thought of as one of his toys, but by noticing his interest, his father was able to make the box a point of joint interest and provided a reason for Adam to interact. Because of his father's attention to Adam's interest, Adam started to understand when and about what he could communicate with his father.

Julie was born with cerebral palsy. At six years old, she did not have control of her movements including the movements needed to swallow or speak. First she was Julie; then she became a *CP child, a wheelchair child, totally dependent, nonverbal, low-functioning, and severely disabled*. Most reports said that she tested as prenatal.

The writers of reports about Julie were not bad or ill-intentioned people. However, they were not thinking about the power language has in our perceptions of children (and adults) and how those perceptions influence our interactions and expectations. Those characterizations (*totally dependent, nonverbal, low-functioning, severely disabled*) became synonymous with the name Julie. What expectations do we have of someone characterized as *dependent, nonverbal, low-functioning, severely disabled*?

Part of supporting Julie's wellbeing was remembering that she was whole. What adults could not test, e.g. what she knew or did not know, represented a limitation of our abilities

and assessment tools. Just because a child is described as *nonverbal* does mean that child is without thoughts, questions and preferences. The reports and assessments were incomplete because they did not even try to represent Julie's POV. **The limitations of our assessment tools should never reflect poorly on a child.**

During the course of ordinary activities it became apparent that Julie took a snooze when classical music was played. She cried when she heard the traditional twangs of country banjos. She was indifferent to children's music. And then it was noticed that Julie lit up when she heard Aretha Franklin sing. After she was acknowledged as a girl who had a POV about the music she heard people started to accept that this child who tested as prenatal and was described as low functioning had a POV about the temperature of her food, how close people were when they spoke to her, their volume, where they placed their hands and how much pressure she felt when they facilitated her movement. **Julie had a POV about every aspect of her life. ■**

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

What is it Like to Be (Your Child's Name)?

There will be times when you just want your child to fit in, to understand something, to manage her/his energy and emotions. It might be that you just want to feel that you fit it. When an activity is not unfolding the way you hoped it would, try to stay curious. Wonder what this moment is like from your child's POV. **Genuine curiosity can get you through a lot of difficult moments** (and we'll talk later about how inviting others to be curious with you can result in some strong allies).

You can develop a usable and reflective portrait of your child in the contexts in which s/he participates so far. The answers to these questions are likely to change over time and you should revise this portrait as your child ages and/or changes. You can invite others in your life, including other children, to help you answer these questions. You do not need guaranteed, all the time, answers; you are looking for current trends. **The invitation to consider your child's POV is always a good practice.**

- What makes her/him laugh or smile?
- What often catches her/his interest? Interest might be indicated by what s/he is looking at, listening to, reaching for or trying to move toward?
- What conditions or events does s/he actively try to avoid or move away from?
- What situations do you most often associate with your child feeling upset or stressed?
- When your child is upset or stressed, what does s/he most often find soothing?
- When something matters to your child, what does s/he most often do?
- Does your child seem to have sensory sensitivities related to hearing (sound), vision (light), touch (skin or body contact), taste or smell? What have you noticed?
- When it comes to basic wellbeing, i.e., sleeping, eating, bowel movements, urination, and feeling secure, what do you notice?
- What is your child's general temperament on a continuum from bold, energetic and adventurous on one side and timid, tentative and cautious on the other?
- How does your child usually and most comfortably relate to other children?
- How does your child usually and most comfortably relate to adults? ■

Given the answers to these questions, what might it be like to be your child in a particular situation and receive support as it is currently offered?

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

The “B” Word—Behavior

One of the most dreaded words in conversation about a child is behavior. The word is innocent enough, neutral even. It’s a vague and ultimately unhelpful word. That being said, we all know that when the word behavior is used about a child you care about, your chest might start to tighten. You might start to feel defensive (what do you know) or doubt yourself (*if I were a better parent...*). So, let’s examine the word behavior.

Behavior just means action; behavior is what we do. Drinking milk is behavior. Spilling milk on the dog is behavior. Throwing a ball for Mom to catch is behavior. Throwing a ball at the baby is also behavior. Everything your child does is action and it is all behavior. Depending on where, when, why, with whom and for how long the action might be occurring defines whether the behavior is valued or not. An adult (mature) POV of action in context will be different than a child’s (immature) POV about the same action. A risk is that with impatience, adults can bring quick reaction and judgment to a child’s actions and miss wondering what the child might be trying to accomplish.

Context is everything else. Context is what else is happening as well as how it is experienced and understood. Context includes where a child is and what s/he is doing; what s/he is expected to do. What s/he sees, hears, smells, tastes, feels and thinks is context. What does s/he understand? What are the child’s emotions? What is the child’s comfort or discomfort? Context includes the present and the past because children have memories even if they can’t talk. Ultimately, we can try to respectfully guess what the child is trying to accomplish or cope with when we take the time to consider context factors from the child’s POV.

Stress is the feeling of being off balance. Children, even babies, experience stress. The emotion every human experiences every day from the day they are born is grief – disappointment. Needs and expectations are not met as we want them to be or as fast as we want and we feel sad, frustrated, confused, angry, disappointed, at wit’s end.

Coping is what we do in an attempt to restore balance or feel more at ease. Yelling, crying, grabbing, hitting, kicking, running, refusing, sleeping, eating are all possible methods of coping with stress. (Any of these sound familiar?) They are adaptive actions and even when not valued are attempts to feel relief. If you think this is easy, consider your last couple of weeks. Have you yelled at anyone, stopped talking to anyone, eaten too much or slammed anything? That is you as an adult attempting to cope with things that you can’t control. Learning to cope with life’s disappointments is a lifelong practice.

You could easily make the case that much of what we witness in children as unwelcome actions are their earliest attempts to be assertive and to communicate about what matters to them. Children are trying to communicate what they want more of and what they want less. By intention or by accident they are letting us know what they think and how they feel. Even actions by a child that are not intended to be direct messages have

message value. You can teach others that any and all discussions of behavior will happen as part of the larger consideration of expressive communication and your child's POV about what is happening or has happened by the questions you routinely ask.

Many people will suggest that you *get your child under control; make "it" stop* (the behavior). Consider Mattie's situation. Mattie's parents were told that she was aggressive. The plan was to remove Mattie from situations when she was aggressive. If she was outside, she would have to sit by the door until it was time to go back inside. If she was inside she would have to sit on a chair away from the other children. Missing from this scenario is any consideration of Mattie's POV. We do not know what she is doing that is described as aggressive. If we do not know what she is thinking or feeling, what she understands or what she is trying to accomplish how can we support her well?

What is it like to be Mattie and receive "support" as it is currently offered? In order to teach Mattie how to communicate more clearly and safely we have to at least try to understand her POV and her message. When you hold the view that your child should always be considered in context in order to better understand her/his POV, there is a better likelihood that others will at least participate in the process with you. **Asking other people in your child's life to think about her/his POV can be a very influential practice. ■**

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

“Wanting Energy” & How You Can Clash With Your ____ Year Old

Adults don't think the way children think; the way they used to think when they were children. Our lives would be quite chaotic if we did. It might even seem unnecessary to point this out, but when you notice the surprise (and exasperation) that so many adults feel when children do not do what was expected of them, the discrepancy between an adult's POV and a child's POV is worth mentioning.

Adults don't have the same emotions that children have about daily excitements and disappointments. Children don't have the same concerns about adults' schedules and plans. One of the most basic elements of maturity is learning the importance of time and place; i.e., when, where and with whom certain choices about your actions make sense. Along the way we learn about rules, roles, procedures, community standards, and eventually have to understand the limitations and responsibilities set by law. But we cannot impose all of those expectations of correctness and appropriateness on children.

You might be someone who grew up with adults whose answer to a why question was *because I said so*. That was the only information you got; you were supposed to be satisfied and do what you were told. There are children for whom that answer is just not enough. They are not trying to be bad. **They are trying to make sense of confusing situations; and many are trying to feel safer.**

An adult's POV often has an element of time; i.e. what time it is on the clock and how this moment fits into a schedule for the day or the week. Adults consider what activity is supposed to happen at a particular time or in a sequence of activities; first this activity and then the next.

As an adult you have expectations about how an activity should unfold. You might have certainty about what you want to happen and how your child should participate. You will notice when s/he is not *behaving* within your expectations. You might notice what is *incorrect, inappropriate, uncooperative or noncompliant*. Adults characterize the child and the child's actions. **Adults often react to manage the child's behavior without thinking about what the child is coping with or trying to accomplish.**

What happens from your adult POV when your plans and expectations are not met and the child's actions, behavior, are not what you want to see or hear? In fact, the behavior is not only different than what you wanted to see and hear, it might be confusing, disturbing, annoying, loud, embarrassing or something else that is not what you wanted. **This is an adult POV manifesting as energy; wanting energy, as in *I wanted this situation to be better, easier or different. I want this child to be better, easier or different.***

What happens to your voice when you are feeling the stress of events not happening the way you hoped they would? What happens to your heart rate, your muscle tone, your sense of time? What thoughts pop into your mind, uninvited? What emotions arise? If you find your voice a little louder, your heart rate a little faster, your muscle tone a little tighter,

and your patience running low you are in a very large club. This is what we are calling wanting energy—the adult version.

While taking control based on your wanting energy, there is your child (at any age) who has been experiencing the same situation from her/his POV. A child's POV often starts with how comfortable they feel in their bodies, in their clothes, in their chairs; how much energy they feel and whether they have a way to use it. Their senses are being drawn in directions that might have nothing to do with what you planned. Their senses include what they see, hear, feel, smell and taste. What they see and hear might not be what you would like them to see and hear. What they decide to touch, smell and taste might not be what you would have them touch, smell and taste.

A child is not acting with the same understanding about places, things and people as adults. They are not small adults. They are children. Adults see objects as having one use, e.g., markers are for creating color on the paper. Children are not so limited in their thinking. A child might be curious to find out how the orange marker tastes, or how it feels when rolled up and down the leg. A child might appreciate the rolling features of the marker even more than the coloring features. A child might enjoy the coloring features and decide to decorate her arm or another child's face.

A child might not understand an adult's schedule based on clock time. Putting things away because someone says *it's time* or *you need to* does not necessarily have meaning to a child who has not grasped the concept of time or of schedule. Their emotions might shift at any moment. Excitement, disappointment, frustration, confusion, amusement, fearfulness, and more can arise at any moment. **No matter how connected you are to your child, you cannot know everything that is contributing to your child's POV.**

What coping skills does your child have to manage the suddenness of emotions and the expectations of adults? There is no way that even an attentive and loving parent can know what a child is thinking and feeling all of the time. It is not a comment on parenting; it is a truth about the fact that every being has a unique and separate POV about the events in her/his life. The good news is that we can respectfully guess.

Your child is trying to make sense and be engaged—from her/his POV. Your child has wanting energy too. The wanting energy of an adult can clash with the wanting energy of a child. You might actually feel like you are in a contest with your own child. If you have ever felt like crying or yelling in reaction to a 2, 3, or 6 year old you are in good company. It is understandable that we characterize children; *wild, difficult, just doing it for attention*, etc. It is easy and understandable but not very helpful.

It's important to remember that **your child has a POV that is influencing her/his actions.** Adults start thinking about winning (e.g., *s/he can't get away with that*) rather than helping the child to understand or cope with something – to learn. Without considering a child's POV we cannot provide meaningful instructional and emotional support. Instead, we use power to control the child. Your child is trying to make her/his life work all the time. **You do not have to consider a child's POV, but supporting a child well can be greatly enhanced if you do. ■**

↓ adult POV

↓ child POV

→ time /schedule

→ sensations

→ activity

→ rules & expectations

→ understanding

→ curiosity

→ what s/he didn't do

→ emotions

→ what s/he did wrong

→ coping & history

wanting energy →

← wanting energy

Enter: Power & Control and Brain Lock

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Brain Lock and Characterization

We talk about newborns as good babies or *fussy* babies. These are characterizations rather than accurate descriptions or reports of action. As they get older we continue to characterize children as a short cut. Some of the characterizations we use to talk about young (and not so young) children include: *stubborn, shy, noncompliant, inappropriate, whiny, attention-seeking, out of control, a handful, demanding, challenging*, and more. We might say of a child's actions, *it's behavioral*. So, what is the flaw in this short cut language of characterizations?

There are two significant flaws with characterizing a child. First, **characterizations do not report what the child is doing; the actions**. Any five children can be characterized as *stubborn* or *out of control* but they are engaging in different actions. Characterizations only let us know what kind of a value judgment someone is placing on the child. Some people substitute one characterization for another. While one person might call a child out of control someone else with a different value system might say the child is *adventurous* or *spirited*. One person might see the goal with a child characterized as *hyper* is to get her to sit still. Another interpreted her young son being called hyper to mean *he has the energy of an athlete*; she looked for ways to help him use his energy. With characterizing, we learn something about the person characterizing but not much about what the child is doing or why.

The second flaw with characterizing is that it does not acknowledge that we are talking about a child who has both a POV and a purpose. The wanting energy of an adult who characterizes a child's actions becomes the goal to make "it" (the action) stop. **Compliance becomes the goal and at least temporarily our brains lock around that characterization**. Nita becomes the *stubborn* one. Jared is the *wild* and *out-of-control* one. Kayla is *aggressive*. Brianna *is just doing it for attention*. He is *challenging*. She has *challenges*. These are examples of brain lock that are generated from an adult POV. No children would use these characterizations to describe themselves or their attempts to make sense of the situations they find themselves in. Children are just trying to make things work and feel safe.

It is also worth noting that children would not describe themselves as adults characterize them because **children know they have purpose even when they cannot tell adults what it is**. There are ways that you can respectfully guess about your child's POV and there are ways that you can invite others to consider her/his POV as well. You can create allies in looking out for your child's wellbeing now and as s/he gets older.

If you heard that a child was a *wanderer*, i.e., s/he left where s/he was supposed to be without permission, you have a choice between trying to control the child's movement as the goal; or, you could try to understand her/his POV. A basic question about POV might be: **is this child moving toward something or away from something?** Knowing the difference could make engaging the child in a meaningful way a whole lot easier.

Sheila was described as a *wanderer*. Her behavior was targeted for change. She was expected to stay where she was told to be until given permission to move. When Sheila tried to move from her assigned place in the room and especially if she went near a door, she was physically blocked or brought back. When asked if anyone knew whether she was moving toward something that she wanted or away from something that she wanted to avoid, her adults said that she was leaving without permission and that was not allowed; they had to keep her safe. This was a child without a symbolic method of communication; Sheila did not speak. **Her actions were her messages** and no one was trying to understand her message or her POV.

They agreed to let Sheila move when a consultant was in the room. She got up and left the room without being stopped. She moved with direction and purpose. She found the door with the symbol that indicated it was a bathroom for girls. She went in. A couple of minutes later a toilet flushed. When she came out of the bathroom, her clothes were in place. She returned to her room and resumed what she was doing before she left. This was the first day Sheila's clothes remained dry during the time she was in this program.

While there were scheduled toilet breaks, Sheila did not use the toilet at those times. Here was a child who knew when her bladder was full, how to find the correct bathroom, how to adjust her clothes and redo them, and how to return to her starting place. On this day, it was unclear what her hygiene practices were. What she did not understand was asking for permission, expressive communication. All of that was learned because the question about whether she was going toward or away from something was explored to better understand her POV.

Social science suggests that we look and listen to confirm what we already think and believe. If we think he's *wild and out of control* we approach him in order to restrict and contain his actions. If we think she is a *runner* or a *wanderer* we fail to imagine or consider that she has purpose.

If it is true that we look and listen to confirm what we already think and believe it means that we have to be aware of our thoughts. We would probably approach a child we think of as *highly distractible* differently than a child we think of as *curious*. Our thoughts matter because they influence how we think about, approach and interact with the child. A locked brain is not helpful. So, how can you invite a locked brain to open even a little bit? ■

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Six Questions Worth Asking About Your Child's POV to unlock a brain that might be your own

In a behavioral climate we like children to do what they are told to do, when, where, for how long and with whom and to stop when they are told that it's time to stop. We characterize children easily and might ask *what's wrong with her/him* when they don't comply. Or, we ask *how can we make it stop?* All of this is so ordinary, human and culturally driven.

Children are trying to make their lives work from the moment they are born.

That's an important thing to remember. Children are not trying to be unpleasant or hard to get along with. Children want to feel safe and engaged; they want to make discoveries and they want to have fun. They are learning what they are capable of doing.

Sometimes children pursue their goals in unwelcome ways. What might change if we actively tried to imagine what it is like to be a specific child and to consider situations from her/his POV? Not from any child's POV but your child's POV given her/his current skills and abilities, interests and curiosities, temperament, and coping skills. In this section you will learn six questions that can help you better imagine what it's like to be your child and then to think about what you could do or not do to support her/him in meaningful ways.

Whenever we think or talk in characterizations we are strengthening a locked brain. Whenever there is a characterization, the first question worth asking is ***what am I seeing or hearing that I'm describing as...*** *stubborn, shy, fearless, noncompliant, inappropriate, delightful, whiny, attention-seeking, wild, out of control, a handful, demanding, challenging.* In order to answer the question, what am I seeing or hearing, I have to think. One of the best ways to invite a locked brain to open even a little bit is to invite thinking, to be a better reporter.

In order to answer this question more specifically, you have to remember what was seen and heard that led to the characterization. When you ask, *what am I seeing or hearing*; find the verbs, the action words that most accurately report exactly what the child was doing. In response to *what are you seeing or hearing that you are describing as being a brat*, someone might say, *she grabbed the pail away from another child.* That is specific; the child's action was clear. **The answer should not characterize what the child did; the answer should report what the child did.**

If you had to hire a small actor to portray your child, you couldn't just say *be a brat.* The actor would not be able to portray this particular child. She would need more specific action words. When you have a clear description of actions, ask the second question about context.

Remembering that each and every action (behavior) takes place in context, ask about that. ***When am I more likely to see or hear my child engage in the actions I reported? When is she more likely to grab the pail away from another child?*** You are asking about an increased likelihood not a guaranteed event. Before we know exactly what the child is doing we might say it happens *all the time* or *continuously* because that's how it feels. When there is not imminent danger, we have time to consider a more revealing approach.

If you are not sure when s/he is more likely to do the reported actions, consider a week-at-a-glance calendar. When you observe your child engaging in the actions that you want to understand better from her/his POV, notice the time of day and location, the activity, the stuff, the people, etc. It can seem as though your child's actions of concern are *coming out of nowhere*. We might think *everything was fine and then...* The reality is that **human behavior does not come out of nowhere**.

There is something in the environment, something your child is experiencing or has experienced in the past that is setting the stage for what you are seeing and hearing. Or, there might be something that is internal, something your child senses (sees, hears, feel, tastes or smells) or is thinking about that is setting the stage. It is not always easy to draw a straight line between what your child is doing and what is setting the stage for the child to initiate that particular action(s).

Another helpful question related to context might be, **when is my child engaged and not ...** (grabbing a pail, crying, flailing or screaming *no*)? Actively look for the times of engagement because this offers information about your child's interests and comfort. This question can also help with the adult frustration that might accompany feeling as though your child is doing something that you find difficult or confusing *all the time*.

Sometimes the brain is locked pretty tight. We need practice being curious from this child's POV. Rather than reacting to make her stop, let's wonder more about the situation from your child's POV so that we can offer meaningful support and instruction.

If you find it hard to get beyond it comes out of nowhere, let yourself wonder, **if I wanted to provoke the actions that I'm concerned about, what conditions would I create?** If, for example, I say: *it's time to put that away; clean up; no* (to a request); stop (what you're doing); you need to share. If I move closer, move faster, raise my voice, put my hands out – would these actions have an effect? At this point, it is not your intention that is being questioned it is your child's POV about what is happening that you are trying to understand. With that understanding you might be able to approach from a different angle.

What are you seeing and hearing; when is s/he more likely to engage in those actions of concern? The third question might require you to respectfully guess about your child's POV. **What does your child probably understand about this situation?** We often assume that a child understands more than s/he might. It is not uncommon for adults to say of a child, you're *behaving like a baby* when we mean *like a child* and we are correct. This is a child participating in a childlike way. We get swept up in our wanting energy for this child to be easier and more mature in that moment.

First, let's think about the amount of abstract language we might be using. If I held up a book and asked you what was in my hand, you would say a book and think it was a pretty obvious question. When you can pick something up, see it, touch it and have direct experience with it, delivering the answer to the question what is it is easy. What might your child understand when someone says stop, wait, be patient, take turns.

These are not as easy to understand as book, ball, door, and toothbrush. They are abstract. You cannot pick them up or touch them. *Relax, settle down, and don't worry*. Consider

the adult language that your child might not understand. Directions stated in the negative, i.e., what not to do, leave the child with no clear or usable information. **It is so much easier for a child to learn what s/he can do, what s/he can touch, how s/he can participate.**

If you are an adult who grew up with *because I said so* as the only explanation you ever received, you might be questioning all of this. In fact there are still children who learn from adults whose only attempt to help them understand an expectation is to say because I said so. If that is your approach, ask yourself if that approach is working with this child. If it is, that makes your life that much easier. If that approach is not working out for your child or you, maybe it would be helpful to try another approach.

What does your child understand about specific places and what they are for; what actions are OK in each place? The park is not the same as the grocery store, as Grandma's house or church or... why is a ball OK to throw outside but not inside and if a ball is OK to throw why not a spoon or socks. Adult expectations are not the same as what a child understands. The learning curve for your child will be her/his own. What does this child understand about places, activities, expectations, things, people (and their authority), time and so much more?

Without trying to make a respectful guess about what a child understands, we can't know how to support her/his learning. When we make the mistake of assuming that s/he understands something our impatience might be higher because then we think s/he understands and s/he is deliberately being bad; withholding better behavior. For young children it is a helpful basic default that s/he probably does not understand even if s/he seemed to understand yesterday. Understanding in young children should not be thought of as permanent.

The fourth question also requires some respectful speculation; **what is your child experiencing?** Experience happens in the nervous system as sensations and in the mind as thoughts and emotions. Think about the ordinary experience of giving a direction to your child, not getting the response you wanted and maybe repeating the direction louder and maybe with a little attitudinal edge to it, moving closer and taking hold of a child's hand by the wrist. Your intention is to move things along. Time is ticking. It does not get more ordinary from an adult's POV.

From your child's POV what is happening? How does the child's nervous system experience the louder voice, the possible attitudinal edge to it, the facial expression, and the image of a larger body moving toward her/him? When the child's wrist is held, how does s/he experience the sensation of that physical contact? If the child tries to pull away and the adult squeezes a little tighter even with no intention to create discomfort or fearfulness what the child experiences might be both. Might there be an emotional reaction to the pressure and anxiety about what might happen next? Do muscles tighten? Does heart rate speed up? Does panic set in? Does the child feel safe? Are there tears? While our intention is to be helpful and supportive, the child's experience might be something else. This child has her/his own POV. When there are two points of view, it is not only intention that matters. The intention to be helpful might be experienced as confusing or scary. When the body is uncomfortable fear, confusion, frustration or anger might arise.

When a child is characterized as wild and out of control, there might be an assumption

to stay close, restrict, even restrict by using hands-on strategies without thought to how your child might experience and react to such support. What is it like to be your child and receive support as it is being provided? In some children, this can become a pattern of fear and resistance rather than trust and participation. It can be a helpful practice to wonder what a child might be experiencing.

Here is the pivotal (fifth) question: **What is your child trying to accomplish or cope with when s/he ___?** Isn't this what we would love to know for sure? When our wanting energy is about frustration, impatience and confusion, maybe even a sense of helplessness, we give an emotional answer. We tell ourselves that s/he is being *naughty* on purpose or *just trying to get a rise out of me*. Even young children might be characterized as *manipulative*.

One of the beauties of this question about what your child might be trying to accomplish is that in order to answer it you have to acknowledge that your child has a purpose. That seemingly simple fact can easily be lost when we are focused on our own (adult) emotions and wanting energy. We forget to consider the child's POV. A situation can dissolve into opposing wanting energies and offer no real support to help a child understand, accomplish or cope with something.

There is a popular practice called time-out that is often misunderstood and misapplied. When using time-out in reaction to a child's actions, there is often no consideration given to a child's POV. One child pulls another child's shirt. Adult says *no pulling* and removes the child to the side of the room. Too many children are removed from learning opportunities because we are focusing on their unskillful actions with no curiosity about what those actions are trying to accomplish. If this child is trying to make a request (*play with me* or *I want the ball now*), but no one knows that, we miss an important opportunity to teach the child how to better understand a situation and interact more skillfully.

The sixth question involves imagining that your child has ease of communication and social maturity. **With ease of communication, in the situation reported, what would your child say or assert?** Even children who have symbolic methods of communication including speech, technology, pictures, or manual signs might not be able to express exactly what they want, don't want, feel or what they are coping with. Given the fact that well educated adults often struggle to communicate clearly and effectively, this should not be a huge surprise.

We do not have that many functions or purposes for communicating. We want things (requests), we do not want some things (rejections), we express thoughts and make comments, and we express emotion. Now that you have tried to answer the preceding questions and have at least some guesses about what your child might be trying to accomplish or cope with, let yourself respectfully guess what s/he would say with not only ease of communication but emotional maturity. *I want... I don't want... I think... I feel...*

These six questions are the practice of empathy and compassion. Asking and answering them alone or with others can make a world of difference. When you consider when in the day a child is experiencing stress you can be more attentive with both instructional and emotional support at those times. When you have some respectful guesses

about what your child is trying to accomplish, assert or cope with you can help her/him learn to achieve these goals more skillfully.

Then, based on your child's POV, what could you do or not do? Think about the situations you considered in the previous section; the situations in which you are trying to figure out how to provide meaningful instructional and emotional support so that your child experiences more clarity, participation and safety. What could you do or not do:

___ to help her/him **Avoid**

___ to help her/him **Understand**

___ to help her/him **Participate & Learn**

___ to help her/him **Cope**

___ to help her/him **Assert** more skillfully

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Wellbeing Now and Later

In addition to POV, wellbeing is our other theme. Each person's wellbeing has some basics like a place to live and enough to eat. For children it certainly means adults the child can depend on. When the Gallup organization was trying to learn how adults around the world thought about their own wellbeing, they surveyed people in over 150 countries around the globe and report that their sample represents 98% of the world's population (*Wellbeing: the Five Essential Elements* by Tom Rath and Jim Harter). There is something important to be learned from this study that touches on the lives of children in general and children whose learning and participation in the ordinary activities of other children might be questioned.

Gallup learned that there are five essential elements to human wellbeing after acknowledging the need for shelter and food and enough money to pay for both. These essential elements included career wellbeing, social wellbeing, financial wellbeing, physical wellbeing and community wellbeing. The most significant of the five was described in their report as career wellbeing and was defined as having things you like to do every day. Consider how this information overlaps with what is considered best practice in all areas of learning and disability for children (and adults).

Best practice related to most areas of delay or disability is reported as finding what engages a child's curiosity and energy, then using these areas of interest and that energy to teach. This is a different approach than the kinds of rote, repetitive and often isolated learning experiences that many children find frustrating. When a child's actions are unwelcome, it is worth asking, *does s/he have opportunities to learn by doing things s/he enjoys every day*. This one question has long range value from very early ages through adulthood.

Just do it has been a winning motto for Nike sports products but it is not necessarily a good way to approach a child. One of the most used opening lines with children is you need to. You need to sit, stand, stay, stop, move, listen, come, go... Remember the push down effect that was described previously, the phenomenon of expecting more and more mature participation from younger and younger children. When we do not notice our uses of power to control a child it stands to reason that we do not see ourselves as having anything to do with that child's unwelcome reactions.

When adults engage in conversation using the six questions outlined in the previous section to respectfully guess about a child's POV, they might start to wonder if the child is bored, confused or anxious (afraid). People sometimes speculate that a child is trying to feel engaged, understand something, feel better or relieved, have fun, or avoid feeling badly. Adults can make very different decisions about support and interactions with children after considering the child's POV and thinking about her/his wellbeing.

Another of the identified elements of wellbeing was social wellbeing; i.e., having strong relationships. Think about the relationships of childhood. While strong family relationships

are important, there are things to be learned by engaging with other children, being of similar size and interests. Best friends for an hour, a day, a few months, a year or longer all have value. **It is important that children learn to have reciprocal interactions with other children and adults.** Reciprocal interactions is used here to describe give and take as compared to those in which one person is always told what to do, when to do it, how to do it and for how long. Even young children need opportunities to feel that they are contributing and affecting people and situations by their actions. Consider your child's opportunities to learn by engaging in reciprocal interactions as compared to always being directed, corrected and quizzed.

Think about your child's energy, physical abilities as well as any limitations; any comfort concerns. In the Gallup survey, what was learned about physical wellbeing was not that individuals needed perfect health, fitness or physical ability. Wellbeing was defined by adults as having enough energy to do what they enjoyed doing, sometimes with people they enjoyed. Think about the effects of being a child with a lot of energy, not being able to use that energy, and not having the coping skills to deal with adult expectations to be still. Forgive the comparison, but adults are sometimes better at recognizing the restless energy and needs of pets than children.

Consider how these factors of wellbeing for adults around the world can be helpful for you in thinking about your child's wellbeing now. When you think about where other children of the same age go and what they do there, you have a way to think about what might matter to your child. Life is not all or nothing and neither you nor your child has to be limited. **It is not true that a child has to have the exact same skills and understanding as another child to at the very least participate in an activity.** The question does not have to be, can your child participate? The important question is how could your child participate? And, you do not have to be the only one thinking about these questions. That is why you cultivate a pool of allies; to help you think about how your child can participate. ■

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Participation is a Worthwhile Goal

The urge to teach young children what not to do is strong. Guiding a child in what not to do is actually less clear to the child than what they can do. *Don't touch. Leave that alone. Stop doing that. Be good. Be patient. Wait.* These directions leave children very little information to work with. None of these describes in a physical way, what the child can do. **Action goals are easier to teach and easier for a child to learn.**

Think about any place or activity that you would like your child to be part of. It's easy for a person's mind to block further thinking. We might slip into, *s/he can't... s/he's nonverbal... too slow... doesn't understand...* etc. Notice yourself blocking the more important questions, **how could s/he participate?**

Deliberately look for the edge of your child's skills. When getting dressed, what parts of the process is s/he doing and what parts are you doing to assist? If your child by virtue of her/his age or skills needs a considerable amount of assistance, you might think about a child as **actively trying to assist by ...** as a goal. If not actively assisting, maybe your child is **cooperating by ...** or allowing you to make the effort. In some situations a child might be actively **resisting by...**

Your child might resist going into a playgroup. Since it's new for him you suspect that he is sensitive to the sounds of other children moving and using louder voices. The more adults do to get him inside, the more he resists. Maybe his learning edge is watching from some distance. Maybe allowing time to watch what the other children are doing; seeing their faces, what they are doing, and connecting their sounds with happy faces is this child's current edge of participation. When watching/seeing has been satisfied, this child might initiate moving closer to the action and the amount and kind of participation might change. For every activity, there are many ways a child might participate.

One child might want to jump into a pool and another might be willing to wet her hands from 10 feet away from the pool. Still another might step into a wading pool. One child might not want to use finger paints but be curious about chalk or markers to participate in essentially the same activity. One child might not be using the potty or dressing on her own but learn to carry her change of pants to the bathroom.

Whatever the activity, what is a way that this child at this time in her/his life can be an active participant – with something to do? A child who is wheeled into the bathroom and needs physical assistance to move out of her wheelchair can be encouraged to hold onto the diaper against her belly on the way in. This child can have a role that might help

her to understand where she is going and why she is going there by having an active and meaningful way to participate in the activity.

There can be a wide gap between what adults think is meaningful and what a child experiences and understands as meaningful. Most everyone who has contact with your child will have the intention to be helpful. What they say and how they say it, what they do and how they do it, what materials they use and how they use them will all be with the intention to be helpful. As important as it is to have a positive intention, sometimes the intention to be helpful is not enough. **Our purpose should be to support a child's participation in ordinary activities of family and social life. Enjoyment during engagement can build comfort, curiosity and confidence.**

One part of setting a learning goal is naming what you hope your child will learn to do. The other important part of the goal is considering how you can help your child learn to accomplish that goal. Asking *how* is an equally important step. You might identify an important goal but if the approach to teaching or engaging your child is not one that s/he can enjoy, or if the challenge is too much too fast, it will not result in learning.

Nothing anyone does or suggests that you do with your child should be too complicated for you to understand. There should be a practical and immediate explanation that makes sense to you. When a proposed activity or goal seems unclear to you, ask *what will my child be able to do now as a result of the instruction s/he is receiving?* The immediate benefit should be that s/he is better able to participate now in something that matters to her/him.

There might also be a wide gap between a desired outcome (what activity you hope your child will be able to participate in after instruction) and a method of achieving that outcome. Improving your child's participation in ordinary daily life in and around your home is a reasonable goal. Think about the activities that take place in each part of your home, inside and outside. Within each part of your home, what activities do you want your child to learn how to participate in? You do not have to name every skill you want your child to improve. **Think about the activities that occur regularly and wonder how your child could at least participate.**

The same approach can be used for places and activities away from home that your family frequents. How can your child participate at the grocery store, the mall, in the car, at the park? What can s/he touch, hold, look at, talk or be told about, etc. ■

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Is it an Outcome or a Method?

People can lock horns over methods (how) before they agree on outcomes (what). Receiving a direct message from your child such as *I want to go outside, I don't want broccoli, I saw a deer, I'm excited* is a desired outcome—assuming that you want your child to learn how to communicate what they want, what they don't want, what they think and how they feel. Speech therapy is only one method of trying to help a child achieve that desired outcome.

Movements to participate in building with blocks, carrying an empty milk carton to the trash, climbing steps to get into the house are all possible desired outcomes. Physical and occupational therapy sessions are possible methods of helping a child achieve them.

There is often a blurring between methods and outcomes. It would be nice to think that one method automatically leads to the desired outcome. In practice, not every child learns to communicate with family and friends as a result of speech therapy. Not every child learns to move in order to play and transport her/himself as a result of physical or occupational therapy. First think about what you hope your child will learn to do, being as specific as possible in naming the places and the activities. Then, think about how your child might learn to accomplish that goal. **First ask what; then ask how.**

Whenever a method is suggested, it can be helpful to ask, **if my child is supported in this way, what is the likelihood that s/he will learn to participate in activities around our home and places we like to go?** If my child has speech therapy, what is the likelihood that s/he will tell me what s/he wants to eat, when s/he wants to play outside or what s/he is excited about? There are no guarantees, but there are reasonable guesses about likelihood. If my child makes progress during a therapy session with one adult what is the likelihood that s/he will express herself with other children or adults outside of that therapy session?

Selecting a method of support should have some basis in what you are learning about your child. If s/he is generally able to transfer what s/he learns in one setting with one person and apply it in other setting with other people, then that method of support might be of benefit. If you learn that your child does not usually make that transfer of learning, select a more immediate and specific method. Sometimes, the guidance and ideas of a professional can infuse what parents and other adults do with more immediate benefits for the child. ■

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Expectations

Observations and comments by others might feel judgmental or critical. **When someone says something about your child that strikes an emotional nerve, breathe it in; then exhale whatever unpleasant emotion the comment stirred up. Take care of yourself.** Just because something is said doesn't make it well-said or even accurate. It's one person's impression at a moment in time. It might be pretty flimsy for you to invest in. You do not have to adopt anyone's impressions, judgments, opinions or characterizations as your own. Try to **acknowledge just what's true**, just that much, without experiencing it as a permanent statement about your child or you. For example, if someone says your child is *loud*, but you did not appreciate the way it was said, you can still acknowledge if the observation had some truth to it (i.e., *she sure can be*).

Is the speaker striking a nerve a family member, a paid person in your child's life, a neighbor, or a stranger at the grocery store? **Decide whether this is a person you want to influence or just let be and move on.** Consider where you are and who else is around. Is this the right time for you to engage with this person or would you want to arrange for another opportunity? Maybe you want time to think about what you want to achieve.

For many people there is a reactive urge to defend (your child or yourself) and refute a poorly worded comment. On some occasions you might feel overwhelmed enough to counter what was said with indignation or insults. You might feel weighted down enough to go along with someone else's characterization. Another option is to decide whether you want to practice trying to be influential with this person. There might be a chance to invite others to think about a situation from your child's POV. First, think about your expectations.

Not enough positive regard is awarded to genuine ignorance. Ignorance just means that we have not yet learned or understood something. There are lots of people who pretend to know more than they do and act in defensive ways when someone tries to point out their ignorance. As a parent, there will be hundreds of times when something arises that you have not been faced with before. It is not unkind to say that each parent is on a learning curve about each child they are raising. So, with being a parent comes some areas of ignorance. Many people in a child's life will also have areas of ignorance.

When others say things that seem a little off base or are completely incorrect, there might be a little tension in your chest or head that feels like it could blow at any time. The problem is not the other person. **The problem might be in expecting that others should demonstrate the level of knowledge, civility, compassion, curiosity or initiative that you value.** That mindset is an understandable wish rather than a reasonable expectation.

You might be surprised by some of the people who offer what you most want without you having to do anything. Others might disappoint you. In reality, no one is required to live up to your expectations; they are your expectations. Even those closest to us and who

we think we should be able to depend on might let us down by not measuring up to our expectations. It can be helpful to notice your expectations and realign them so that you are not in a frequent or continuous state of disappointment or anger. **Other people are not the culprit of negative emotions; expectations might be.**

Notice the expectations you have for the people in your life. Go through your family members. What expectations do you have of your child's grandparents, aunts, and uncles? What expectations do you have of your other children, friends and neighbors, acquaintances and contacts in the various places you are a regular in your community? What expectations do you have of people in service or support roles? The fuming you might be doing or the disappointment you might be feeling are real but probably not helping you get through the day.

Appreciate those who support you well and in a manner that is helpful. Try not to take it personally when someone is ignorant. Ignorance is not a reason to blow up a relationship. Ignorance is a genuine opportunity to invite a new or different way to think about someone, in this case your child. ■

What, if anything, did you find of interest in this section?

Who might be a good person to have a conversation with about these ideas and practices?

Creating the Allies You Want

Have you ever heard *parents are the experts about their children*? What a burden and a potential trap. There's a difference between having a lot of knowledge about a child and being an expert about every aspect of that child's working systems. You had a child; you did not become a physical therapist, speech and language therapist, occupational therapist, pediatrician, nutritionist, etc. More importantly, you don't have to have all these areas of expertise and training to be a very good parent. You might want access to people who have those areas of training and a way to communicate and collaborate about your child as allies.

Given the mix of family members, friends, other parents and the array of people who have professional training, it can help to develop the kind of filter that helps you find what you can use. Worried people might invite your worry. Angry people might invite your anger. The people who lead with *what's wrong* might focus your attention away from the whole child.

Think about how you can benefit from collaborating with allies. There will come a time when you are informed that you are part of an "educational team" for your child. People will talk about setting goals. It can be useful to think about how you want to make good use of the information and experience that is available to you. Practice with early childhood people and day care staff. Some parents adopt somewhat passive roles, receiving information without question or not knowing how to talk about specialty areas.

Do you think about yourself as influential? Trying to be influential might include inviting others to think in a new or different way by considering additional information or by reexamining existing information. When people say of a child's actions, *it's just behavioral or s/he is just doing it for attention* they miss something important. The child is trying to assert, accomplish or cope with something that matters from her/his POV. It is dismissive and lacking in curiosity not to wonder what that POV might be.

At the beginning of this document it said "one goal is to increase the likelihood that people who have contact with your child will support her/his wellbeing throughout life." Consider making a list of your current allies, people who are willing to think about your child's POV and wellbeing. In addition, who are the people you might want to invite to be allies? Think about the people already in your life and the roles they have or could have with your child. Include those that you might like to have more connected to your child. You have a starting impression of who each person is and how s/he relates to your child.

- Is this person ready, willing and able now to think about your child's POV?
- Is this person ready and maybe waiting for an invitation or encouragement to support your child by thinking about her/his POV?

- Is this person ready on a limited basis to support your child by thinking about her/his POV?
- Is this person not available at this time to support your child by considering her/his POV?

Now, you have at least a few people to engage as allies in your efforts to ensure your child's wellbeing. Who could you start to include in your thinking process about your child's POV?

You never have to be reactive; you can acknowledge and respond. When someone says your child is (a characterization) you can ask questions with genuine curiosity. You can, for example, ask the Six Questions worth Asking about Your Child's POV to invite thinking.

What are you seeing or hearing that you are describing as...?

When do you notice that s/he is more likely to engage in those actions?

What do you think s/he understands about those situations (when s/he is more likely to engage in those actions)? What does s/he probably understand about the place, the activity, the materials, the expectations, the reason or the relationships?

What do you think s/he might be experiencing in her/his body (e.g., tightness, restlessness) and what emotions might be active (e.g., excitement, fear, disappointment, confusion)?

What do you think s/he might be trying to accomplish, assert or cope with?

If s/he had ease of communication and maturity, what do you think s/he would say at these times? What would s/he be trying to communicate that s/he wants more of or less, what thought or emotion?

In order to answer any of these questions, the person you are asking has to slow down and think, just as you did. These questions can become part of ordinary conversation. These are not clinical or therapeutic questions. They are the questions we ask when we care about someone and want to understand what is happening or has happened to them better. They are also extremely influential questions because they invite someone to think about your child's POV. **A disability label or characterization should not distract us from wondering what a child is trying to accomplish, assert or cope with.**

You have the right and responsibility to ask that any professional person's comments, suggestions or recommendations be made practical and usable. You can teach everyone who interacts with you about your child how you would like to receive information not by

being directive or even corrective. **You can teach the people who talk with you how to be your ally by asking with genuine interest the kinds of questions that will result in the most usable and helpful information for you.**

Ask that information be offered within the context of your child's current daily life and the life of your family. If something is not clear, you can ask: *given what we know about what matters to her/him and how s/he learns, how is what you are suggesting or doing going to be of benefit now? How will this help her/him to participate in regular activities now? How will s/he benefit from this approach when you are not here?*

If you ever feel that a worker's time with your child is just a blip in your week, it's time to reassess how time and resources are being used. A babysitter is with your child so that you can do something else. When someone is coming into your home to support your child's learning it should be in ways that will matter both to your child and to you. What happens should be because you have deemed it as possibly helpful because it will enable a kind of participation that you welcome. **What people do with your child should be of benefit even when that person is not there.** It is not a time for you to do other things so they can be alone with your child.

The relationship with an in-home worker is very different than a babysitter. Think about the paid people who are in your child's life. This list might include teachers, therapists, and in-home workers. They have titles and roles. Can you answer easily what they are contributing to your child and family? If you primarily see them as doing something for and with your child that you have been told will be beneficial but you can't really tell if it matters and they are really just a blip in your week, it is worth more consideration.

The life of a family has some rhythm and pace. There are mornings when you are getting ready to start your days. There are the transitions from one place to another or from one activity to another. There are activities in the kitchen, the bathroom, the living room, near the laundry machines. Maybe there is a yard or neighborhood park. Within an apartment building there might be some common areas. Finding ways to include your child in the ordinary activities of childhood and your family's life should be a big part of what professionals help you to achieve. Do not let them be just a blip in your week.

You as a parent can be The Reminder that conversation is about your whole child, who is a member of a family, who lives in a neighborhood, who has groups in which you want her/him to participate. As s/he gets older, your child's interests and preferences about the places and activities will become even more important. You have particular knowledge that should be considered by everyone else. ■

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Keeping it Simple & Relatable

The elements of wellbeing can be helpful now and throughout your child's life. Is s/he doing things that are enjoyable every day? When s/he is introduced to things that are not favorites or comfortable activities, are they being presented in ways that help her participate in enjoyable ways? There's nothing that says a child who likes to sing (even badly) cannot be invited to sing while taking a bath, if bathing is not her favorite time of day.

To create allies, you want to have people in your circle who are always willing to notice your child and respectfully guess about her/his POV in any situation. No child is 100% known or even knowable to another person, even to a parent. It does not mean that you are not attentive; it simply acknowledges that even a young child has her/his own nervous system, thoughts – her/his own POV. We can speculate about how a child is experiencing the world, but even for children who are communicating with ease, not every experience is spoken. ■

Laugh When a Situation is Funny

Try to keep a focus on your child's sense of wellbeing and opportunities. Your child's sense of belonging to various **C**ommunities, **O**pportunities, **R**elationships, and **E**njoyment are essential. Your **CORE** sense is also essential. You too might want a sense of belonging to the communities that matter to you, to have the opportunities that enrich you, the relationships that nourish you, and enjoyment in all of the above.

So much is going to happen. In years to come you will be able to look back and laugh at many situations that in the moment do not strike you as funny. In the moment, laughter might sometimes be hard. It can be very helpful to be an observer of the things that are happening to and around you and notice that someday, you might find them funny. Given the option, laugh sooner rather than later. Why wait? That's the whole message. There is enough to be serious about. When a situation is funny, allow yourself to laugh. ■

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Parting Thoughts

As a new teacher I had three supervisors with very different approaches to supporting young children based on their training and areas of expertise. Each of them had something of value to teach me but at the time it was unclear how I was supposed to prioritize what they were telling me.

First was the behaviorist who told me everything I was supposed to say and do to bring about the right actions; adult cue, child response. Compliance was the goal. I was told that if the child was not demonstrating the right responses, behaving, I was probably not a good behaviorist.

Second was the nurse who had a focus on what went into the child's body and what came out. I was to pay close attention to what each child ate and drank. On the other end, I was supposed to adhere to fixed toilet schedules to achieve the proper results. I spent a lot of time answering questions about bowel movements.

Third was the person who asked about fun. She wanted to know what each child liked to do and what made them laugh. One day when I had a group sitting still and listening to me she asked why I was talking and they were quiet; why they were so still. I didn't tell her that I was doing what the behaviorist told me to do. Her direct message was *they're children. Your job is to enjoy them and help them to be active while having fun.*

It is so easy to be distracted by "the plans" and "the programs" and "the curriculum." It is easy to be distracted by what a child is not doing and as easy not to notice what s/he is doing that matters to her/him.

If you've read what preceded these remarks then you know which of these three mentors had the strongest and most lasting influence. The advice given at the start of this booklet was to consider what is helpful and let the rest be. That statement applies to all the ideas in this booklet also; take what is helpful and let the rest be. ■

A wish to all for bright futures and some pleasure every day.



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**131 West Wilson St. Suite 700
Madison, WI 53703
Disabilityrightswi.org**