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Developing through relationships

Autism

Even after 16 years in the field of autism, when I am asked the question, ‘What is autism’ I still experience the internal gasp or pause. Autism is a complicated disorder. It is often described as a behavioral disorder or a communication disorder. While clearly, there are observable behaviors noted from an individual on the spectrum, autism is neither of these. The most current research indicates that, autism is a developmental disorder, a disorder reflective of insufficiencies in neural development in the brain. Observable behaviors are reflective of mental processes and should not be evaluated or treated as behavior alone.

Understanding Development

In typical development, the infant has a primary job to observe, explore and sort out the input they are receiving and engaging in with their primary guides (parents and caregivers). They learn that they have an effect on their guides’ emotions and actions long before they have developed any spoken language or concrete motor skills. They take note of what their primary guides are doing and saying and start to notice patterns. These patterns provide meaning and significance into what and why a guide says and does. The infant learns to identify relevant information through interactive feedback. This period is critical in setting up the mental structure from which the infant learns to grow and develop throughout life. It creates a framework by which to sort and make sense of the world’s information.

This neural architecture increases in complexity over time as the infant learns to understand and categorize what he or she is seeing. He or she learns to participate in the interactive process gaining feedback along the way and using it for future experiences and situations.

For causes unknown, the same infant with an autism spectrum disorder will have varying degrees of difficulty processing the fundamental elements of these interactions. This leads the infant with autism to experience the world differently. Without the same central or shared focal points, no infrastructure for development matures in a shared or mutually focused way. Consequentially, the brain of this individual will have a different set of central information than the typically developing infant. Without having the benefit of experiencing life through and with others in the same way that a person who develops typically does, the individual with autism creates their own mental map based off of the things that they understand and what they were able to process.

Development of this relational infrastructure is all invisible in the sense that it happens on the inside. We make assumptions that the invisible has occurred for everyone in the

same way, but that is not always the case- especially in autism. Sometimes in autism it may be obvious that there is confusion in what the communicative partners are focused on. Other times, when interacting or observing a person on the spectrum, behavior such as language and academia can lead us to think that the infrastructure is the same. Language and academia can develop without the development of the mental map. This is where an understanding of brain development becomes important when supporting, teaching, and guiding individuals on the spectrum. With the latest research on the brain and brain development, understanding these principles becomes exciting and empowering as they are ways of creating and re-creating these opportunities. In addition to the development of the mental structure, through relationships, we experience the meaning, value, and joy found in relationships.

Quality of life

You are reading this article now because you have an interest in autism. Your investment is reflective of the care and desire for quality of life for your child, for yourself and family. Sometimes we lose sight of that big picture (or forget about it altogether) that the energy and resources spent on therapy is all about quality of life. The chaos, stress, mental energy, and resources that go into therapies and daily life with a person on the spectrum are extensive.

While there are many aspects to quality of life, one quality of life goal that I hear consistently is 'living independently'. Living independently is more complex than it sounds. Successful independence requires that one has a proficient level of being able to be interdependent or mutually supporting. This interdependence is not in a 'co-dependent' sense, but in a real world sense of daily life, daily interactions and activities. Anywhere one goes in what is considered a typical day requires levels of the ability to interact well and work well with others. Whether it's in a place of business, the post office or grocery store- no matter what we know, being able to understand and participate in mutual ways is critical to true independent living. Deriving meaning from interactions vs. obtaining information is a significant area that relates to quality of life. Taking this meaning and using it to make decisions about similar situations in the future is critical to successful dynamic functioning.

Many people may quickly describe independence as having a job and living on ones own. There are many complex mental processes involved in being independent. In areas some may consider 'solo' or personal areas, they still involve the critical need of a mental model and experience base that one can follow or draw from that includes perspective and previous learning from situations. Without having a wider perspective and experience with others, it can be harder to make decisions, make good decisions and identify when one has a decision. Through relationships, perspectives are shared, thought processes are modeled and meaning is obtained through interactions and verbal communications.

Quality of life also encompasses emotional life; one's happiness, fulfillment, and experience of life. One of the hardest things for me to see with the adults that I work with is the levels of loneliness that they experience. Despite being able to be around

people, they feel alone, disconnected and misunderstood. Not having the same developmental path or mental map makes it very hard to interpret and understand others and the feedback received. Quality of life also means enjoying life with others.

Many teenagers and adults that I have worked with have expressed feelings that they have of 'What am I missing that others seem to just 'magically' know?' These repeated experiences and growing awareness can lead to depression and anxiety around people.

Making the invisible, visible: Mindfulness

Sometimes we forget the rate of processing for us, is instantaneous. For someone with ASD, it takes much longer. Just because they may not be as fast to process, doesn't mean we should stop attempting to teach through natural relationships. Does it mean we should abandon teaching things developmentally and how we learned it because it is hard? Do we set up new or alternative ways of thinking or rules? How will that lead to the benefit of understanding the world around them if the ways they are being taught aren't reflective of what the invisible really is?

Critical elements to supporting development through relationships are to understand and know when to shift your awareness to an input vs. output focus. An input focus helps a person on the spectrum to make connections between the visible and invisible thoughts, processes, and decisions. It gives a person insight and a model for them to think about and use. I have an analogy that helps me to think about this concept. Just like a computer, we cannot expect software to run that hasn't been installed. Focusing on input is like the installation. Now it isn't 'fast' like a literal installation, it takes time. Development is a process.

A wonderful thing about the brain (and there are many), is that it is never too late for a person (autism or no autism) to grow and develop. There is no cure for autism, but there are many ways to support a person to grow.

People with autism are not exempt or incapable from developing relationships. They often present co-occurring obstacles that impede on this development. These co-occurring conditions add difficulty to the individual's ability to process feedback, putting them at a further disadvantage.

In many cases, nutrition and health related obstacles impact their ability to learn from others. These obstacles should to be prioritized and addressed accordingly. Health is always the priority. In some cases, it may be a co-occurring medical condition that needs to be addressed first or simultaneously. Once the co-occurring conditions are managed, the individual will be in a better, more mindful place to learn and grow.

Behavior is not a co-occurring obstacle. It is a reflection of one operating from a different mental map. Teaching behavior without a dynamic model process structure doesn't lead to developmental growth. It may change the observable behavior, but doesn't grow the developmental processes.

A focus on quality of life and relationship building requires mindfulness. It requires adjustments in one's daily life to be in an effective position to be mindful. Teaching process oriented thinking requires us to begin to focus on process.

Below are some suggestions on how to get started on your journey towards mindfulness.

Spend time together

Spending time with a person on the spectrum- doing life with them and sharing your map of the world is a powerful tool to provide insight on things that they may not have ever noticed, understood or found valuable. The same is true in the reverse. Spending this kind of time together, you will learn about the person on the spectrum. Learn about what they have learned to be central elements to their thoughts. Identify areas of thinking that you can provide insight on. The learning process is two-fold and makes each of us better and clearer. Relationships offer the opportunity for the passing of knowledge and sharing wisdom.

Evaluate your goals

I recommend sitting down and reflecting on your values, family values and goals prior to selecting therapies. The reason for this is to gain clarity on what it is you are working so hard for and why. Once you have sight of this, you will be able to evaluate what you are doing is in line with those values and goals or not.

Choose a therapy that focuses on balanced treatment planning. It is important to have thorough evaluations of more than just cognitive, physical or communication milestones. There are social-emotional / psycho-social pieces that are missing (the invisible) that need to be evaluated. An obstacle assessment is also critical, as it helps to prioritize what the pressing needs are and creates some structure in which to proceed with therapies.

The research on therapies for children and adults with autism and outcomes for adults on the spectrum is slim compared to research on other therapies for other conditions. While there is some valid and insightful research on therapies, I have not seen any one therapy to have a *wealth* of research to show one is better or more effective than another. Developmental research and understanding does have a wealth of research and lays a solid base for understanding autism better by understanding typical development and what is happening that is different.

Slow down

Shift your attention to your own thinking process. Ask yourself why you are doing things and how you knew to. Think about your own thinking.

Don't assume the person you are interacting with understands the why or has the 'same' why that you are focused on.

Share your thinking out loud. This provides insight to the individual with autism into what you are thinking about / your intentions/ your why.

Slowing down your interactions is critical. Your child already has a difficult time processing elements of your interactions. Speeding through or rushing makes it significantly harder for them to process relevant details. More is not necessarily better. It is the quality and effective experience that makes an interaction valuable. Focus on the process vs. product.