

# Introduction to a guide to understanding My Kind of Mind

*Shifting thinking: understanding atypical neurodevelopmental profiles in children, youth and adults with complex care needs.*

Fetal Alcohol Spectrum Disorder is a common but complex neurodevelopmental disability. The complexity, in part, reflects diffuse brain injury i.e. the disability can manifest from mild to severe in multiple areas of brain function so people present with different strengths, deficits and needs. We must also factor in postnatal experiences that can include trauma from family displacement and mental health conditions with genetic and/or environmental origins.

We have limited energy and resources and the care of someone with complex needs can be overwhelming. I am delighted to share tools to help caregivers, teachers, therapists and other advocates understand and respond to atypical neurodevelopment so we can move quickly to provide the loving supports and effective services that are needed.

“a guide to understanding My Kind of Mind” lets a child, youth or adult identify the range of ways they experience the world. It clarifies sensory responses, identifies memory strength and processing capacity, and explores social and interpersonal skills. The booklet captures talents and wishes and provides a pathway for client-inform planning that contributes to consensus building and cooperation.

Each of the 13 themed questions explored in the “My Kind of Mind” booklet is informed by research and best practice: where a shift in our response can ease struggles, improve relationships, and enhance the quality of life. A companion card “at a glance” encourages the development and advancement of interventions based on the individual’s profile. It reminds *us* that success comes from a shift in thinking, and encourages and reinforces reimagined accommodations, realigned expectations, and creatively supportive environments required regardless of the genesis of the neurodevelopmental diagnosis.

Both tools facilitate the replacement of the generalized approach that can complicate and confuse our efforts to support individuals with FASD and other conditions. They simplify, validate and operationalize our understanding of neurodevelopment by looking through a fresh lens. The booklet and card provide a tangible way to:

- engage individuals and their caregivers who have been misunderstood and poorly served;
- explain an individual who may struggle with abstract concepts and whose uneven memory, processing and comprehension interfere with their ability to explain their needs;
- give permission to stop doing what is unhelpful so we can focus on what is needed;
- use learning preferences and strengths to design and implement appropriate accommodations and scaffolding and to advocate for realigned services and more effective use of resources;
- take the pathology out of what is a neurodevelopmental disability; to get to what is important so we can reset expectations and build practical responses;
- inform a consensus in service partnerships so we accept who is in our care, understand real needs, identify priority concerns and opportunities, and begin the planning process for a lifespan of support when required.

## Questions’ theory:

“My Kind of Mind” is designed to meet a variety of caregiving, educational, therapeutic, and advocacy needs. The booklet gives us insight into less visible challenges that impact individuals with atypical neurodevelopment and impede their ability to realize their potential. It was inspired by caregivers who talk about putting together binders of information to help explain their loved one but where salient information may still be missed or confused.

The 13 questions explore key elements of neurodevelopment: attention, processing, memory, cognition, sensory, executive/adaptive function, social communication, sleep, medication and emotional regulation. There are no right or wrong answers, just what works best; what is easy, medium or hard; and open-ended questions that capture life's challenges, strengths, interests and engagement with others.

Use it; talk about it; share it; mark it up; learn and revise.

*When I first started thinking about how to synthesise complex neurodevelopmental profiles, building a tool that would fit in a clinical file was top of mind (hence the size of My Kind of Mind). But as I got feedback on its usefulness and helpfulness, I knew it should be dog-eared and coffee-stained with notes and ideas in the margins.*

### Tips

- It is ok to complete My Kind of Mind in one sitting or over time.
- Some individuals complete the booklet on their own but it can be a valuable springboard to client engagement (and relationships) to: observe their thinking processes, watch for insight, prompt for details (if it feels right); talk about how you will take the information and apply it.
- Consider using a pencil, though smooth pens, smelly markers or crayons are fine too. Answers to questions 1-7 will likely stay the same (unless there is some insight that tightens the accuracy of a response); questions 8-13 may change.
- Whether they complete it on their own or with help definitely have them talk about their responses; refer to it at different times; talk about your ideas to do things differently; ask them what might be helpful.
- Let them keep the booklet or put it somewhere for reference. Transfer information from Q.1 to Q.7 onto an “at a glance” card. That is where you begin to reflect on what you can do to build successful, informed strategies.
- “at a glance” cards are for parents, teachers, therapists etc., to remind us of what brain function is in play and promote a change in our response. The cards let us review and evaluate what is working and revise strategies when something isn't. This clarifies our role in understanding and addressing client need and informs the implementation of effective, evidence-based care.

### More about the “At a glance” companion tool

Good information begets better outcomes. Looking at FASD a thinking and skills deficit rather than oppositional behaviour provides a pathway to inventive responses. This requires a shift in thinking and perspective, and a reassessment of assumptions: failure or lack of cooperation is a sign of missing or underdeveloped skills rather than willfulness. This is an important insight because the onus then falls on us to rethink, reframe and reset our expectations, programs and policies.

Implementing different ways of doing things is hard so the “at a glance” is a visual guide to help all stakeholders reimagine, plan and practice new approaches and accommodations. It prompts us to consider areas of neurodevelopmental strength and vulnerability and challenges us to provide a new way of helping. The cards scaffold and accommodate *our thinking and planning* to reinforce best practices.

Success for individuals with FASD occurs because their environment is structured in a way that supports them. We need to understand unique neurodevelopmental profiles and focus on what works and stop doing what doesn't. It is my hope that My Kind of Mind is a guide to help us do just that.

*Respectfully, warmly,*

*Sheila*