

Ask the Expert with Dr. Matthew Mason
*Mental Health Disorders and Trauma Amongst
People with Intellectual Disabilities*

Q. I am interested in learning about whether signs and symptoms of major mental health disorders and trauma/PTSD are typically different in people with intellectual disabilities? Are there different red flags we need to be looking for?

A. Listeners should look at the DSM-IV, which is an interpretive document created by the publishers of DSM-5 to help understand how mental health issues are expressed among people with different abilities. There are two things to think about. First off, if you know one person with a disability, you know one person. The capabilities of any person with a disability have a huge amount of variation. It doesn't mean they cannot express themselves. Some people have language or intellectual barriers. The approach is the same in almost any way you would assess someone else. You need to know their baseline performance levels, how they prefer to communicate, what their capabilities are. Need more than just direct information from the person. You also need input from the guardian, parent, etc. (who knows what typical patterns of behavior and communication are). There are a few things to keep in mind. For example, someone with symptoms of high arousal – this is a key issue of PTSD. They may present themselves as a person who is agitated or may engage in destructive behavior. If a person can't rely on using verbal skills to explain internal states, you may see changes from baseline. You need to keep an eye on behavior changes. Another example is a person who has a sudden change in how they use the restroom. For example, if they suddenly spend a lot more time in the restroom or avoid the restroom, it could be an indication of a mental underlying issue or experience of mental trauma. Look for a change in the pattern of the behavior.

Q. Do you have tips and insight on how to talk to and work with people with ID about their traumatic experiences and MH issues? (Do you use different words, analogies, etc. that seem to resonate well?)

A. Absolutely. I encourage you to specialize in providing therapeutic support for people with disabilities. It's an underserved area. You'll be busy for life; your expertise is needed. There is no specialized program that you go to in order get a different degree; it's a matter of finding a mentor or an internship. It's more of a training issue than an education issue. You need to know the baseline functional level of the person, how do they communication. Use simplified language, present verbal information at slower rate or repeat it. Don't try to talk down to the person, simplify the stream of information. Check for comprehension of concepts. Society teaches people with disabilities to be very agreeable. Need to be more concrete in your language, really emphasize non-verbal communication. More structural or directive than team therapy. More active-based learning, for example might use role-playing, visual materials, drawing or alternatives, etc.

Q. What are the signs of emotional abuse for people with intellectual disabilities?

A. Vast majority of people will have experienced some type of neglect or abuse. It is unfortunately common in our world. Always start with a change from baseline (difference in behavioral pattern, emotional state, physical state), you need to hone in on what the cause is. Alternative to talking about it – you may see change in behavior, physical aggression, verbal aggression, sudden decline in work or academic performance, or change in mood. Need to know how they typically interact with their world and how they respond. For example, if the person is usually very loud and boisterous, you need to rule out medical issues but also look at potential history of abuse. May see a change in how they react to people, how they avoid people, how they lash out, refuse to get out of bed, sleep disturbance, changes in personal hygiene or toileting behaviors.

Q. In social work and education, practitioners are trained to identify specific indicators of trauma exposure; how does that differ in children with cognitive disabilities? Are there identifiable responses in light of the intellectual/linguistic barriers you referenced in your lecture?

A. You look for changes in baseline. When working with children, match interview style and observation process with what is in kind with their developmental age and abilities. Never underestimate opportunity to learn by observation or interaction. Find a way into their world. Just like any other therapeutic approach, you have to figure out what the joining mechanism is and what the therapeutic in-site process would be for that person. Children with disabilities and non-disabled peers may respond very similar to trauma. One difference is professionals tend to treat them so differently that they assume a person with a disability would not have the same reaction. Do not assume based on persons level of ability that they are not experiencing changes in emotional responses or changes in how they interact with their own universe.

Q. What are the primary goals for facilitating transition into adulthood for older foster youth with developmental disabilities, obviously taking into account the broad scope of developmental disabilities?

A. Transitions are tough, especially if you're working across a lifespan. If you're looking at a youth transitioning into adult services, one of the biggest challenges is an immediate drop-off in services to begin with. While people are still in their educational years there is a much wider variety of early intervention and support, school-based intervention supports and foster care supports. As they age into adulthood, those resources dry up quickly. Most school districts are required to have some type of transition plan, but not all are created equally. It really is the parents' responsibility to safeguard their records and really drive the transition services. If they're going to wait for the school to initiate the transition services, they're going to come up short unfortunately. As people move into adult services, there is a greater burden on the caregiver, the family or the place their going to. It's not fair, it's not the most effective but that's simply the state of affairs. There are fairly few adult-based foster-care programs. They do exist but one of the questions is whether or not they are supplemental or primary services or whether you can substitute other services. I think the answer is probably yes you can substitute other services depending where you live. Developmental Disabilities Administration programs typically provide services mostly to adults, sometimes kids, and it really depends on whatever services they may already be providing.

Not everyone needs same level of support. Need to go back to what their essential lifestyle plan is. As a person transitions from foster care into other kinds of care, they're going to need emotional supports; they may need family systems approach. If you plan for it, you're going to have a better outcome compared to if you don't plan for it. I automatically make the assumption from a clinical perspective that any transition is automatically more stressful to the person. So when you're moving from one system to the next system it's important to know what the differences are in those systems. Whether it's education to adult services, whether it's child based to adult based, whether it's foster care to permanency, we need to know what those changes in those systems of care will be and make adjustments if possible.

Q. Can you share specific strategies that can be used with a person who has intellectual disabilities who has been exposed to trauma?

A. In addition to earlier examples on how you might use language, the idea is to start to modify standard intervention or interview practices. Specifically starting to move away from language-only based interventions. It's true that people with intact language are going to benefit primarily from talk therapy. If the person does not have a strong language ability, you need to modify how you use language. Language itself is as much a barrier for the therapist as it could be for the client. Seek alternative ways to interact with this person, this is crucial. If you know how the person typically interacts with their universe this is where you start. If they normally are very touchy and hands on, likes to touch others and are suddenly isolating themselves, what is it about physical touch that they're avoiding? Will they high five? Will they hug? Are they avoiding eye contact? Your looking at materials, hands on activities, experiential approach. Move away from primary emphasis of language. Important lesson here is therapeutic underpinnings are the same minus some of the language-heavy emphasis.

Q. What kind of support is available for caregivers/families of children who have intellectual disabilities?

A. There is a huge variation from location to location. You're not going to find a drop-in center for people who have been traumatized in most places. For family members, one thing that is very useful is direct education and skills training for the parents to start with. So just like this session, parents are working with someone (whether adult or child who has been exposed to trauma), they're not going to know how to support that person. Being able to give concrete ideas directly to family members, home visiting sessions, talking directly to the parent. This can be done by any kind mental health professional or child specialist (social workers, therapists, psychologists). Second strategy is to find respite opportunities for families. It will be a stressful time for families. Parents will do their best when they're feeling their best. Want them to know the most about the course for treatment and options for supporting people but also want them to have opportunities to regroup and refresh themselves. Finding respite services is very useful. Individual or family counseling is still a very useful methodology. Can be very short term or replacement or supplemental to education or home visit. Don't underestimate the use of counseling. Similarly support groups are important. My advice to family members who have experienced trauma is to find a support group. If there isn't one, start one. Just because there isn't one doesn't mean there aren't other people who need support. Shared learning and shared support is really important for families. Learn about person-centered and essential lifestyle planning supports. Two separate kinds of concepts, but definitely worthwhile investigating how to

interact with a person with a disability based on person-centered concepts and how to build plans that meet their needs as the primary person of interest and how families can plug themselves into the support plan. Having a plan is always useful.

Q. How do you help a stressed parent who has two children, one has an intellectual disability and the other doesn't?

A. The answer is similar to previous responses in some ways. Find supports, learn more about what you're dealing with, and learn key skills. It comes to the person with the intellectual disability, how do you communicate with them in a way that's most effective? Knowing that there's going to be a difference from working with the other child who doesn't have a disability. Family counseling would be a good idea. Excluding individuals with disabilities from family process is often a source of content. Looking at family systems. Parents may be stressed but then so is the family system, especially when you have more than one child involved. Have to take care of parents, take care of the children and the family unit as well. I realize that all of this is a challenge. Finding a therapist that has experience supporting children with disabilities or have experienced trauma is a huge problem in our industry. There's simply not enough.

Q. Are there benefits to using pharmacological treatments for individuals who are diagnosed with mental health illness? Can you tell us the affects of long-term use? Versus not using them at all?

A. This question is a trap. I will answer to the best of my abilities. There will always be people who agree or disagree to these approaches. The bottom line is that this is an almost entirely separate discussion because it's so deep down and so widely varied. I will always approach supporting people with disabilities or people with trauma from a multi-treatment option perspective. In other words, you do what works. When it comes to using pharmacological treatments, one of the traps for the industry is people with disabilities are at least three times more likely to be re-prescribed a psychoactive medication compared to their non-disabled peers. People with disabilities are at least two to three times more likely to have a co-occurring mental health disorder. The rubric that is used for prescription should be the same for any condition (whether its mental health, children, adults, etc.). First step is to always to modify environment, so to use the least intrusive approach to treatment (exploring behavioral implications of the person's issues from a behavioral perspective first before moving on to medication, which will inherently have side effects that are different and potentially lifelong. Always make sure any prescription is warranted. Know if you're going to prescribe with someone with a disability who has a different way of communicating, that is inherently more risky. We rely on the speaking person to tell us how they're feeling and what the side effects are. If you can't rely on verbal, you need to rely on observational. Must know what they're baseline response is in all areas. When you put together a treatment you need to know their communication style, the behaviors being targeted, how you're going to measure going ahead if they're communicating differently. Need to know any past responses to treatment, including adverse effects. And you need to have a timeline. One of the pitfalls is often once the person is prescribed medications and they have an intellectual disability, the timelines for use are far extended, maybe even lifelong.

The use of any medication will create side effects and the use of psychoactive medications, depending on the medication, could have extra pyramidal effects, neurological effects, and/or metabolic changes

(weight gain, diabetes, hyperglycemia, changes in mood states, changes in wakefulness, changes in alertness). The range of side effects are the same for people with disabilities as they are for their non-disabled peers, they are just simply more difficult to detect. So the emphasis on both the semantic analysis of the impacted drugs is just as important as the observational ones.

Q. Are there any early interventions that can help break that cycle and prevent health issues that are so common with people with disabilities?

A. One, this is an American problem as a whole. The recent CDC information about lifespan indicates that American lifespans are decreasing. A lot of that has to do with obesity. As a whole it's a societal issue. In other words, people need to exercise more and eat less or eat more healthy balanced meals. If you working with a person with a disability, they may be inherently as a result of their disabilities, less able than the non-disabled population to self-manage their own health issues. In other words they may be less able to self-motivate to go to the gym and exercise or their physical abilities may be less such that it requires different types of exercises. There are metabolic concerns that are genotypical that may be related to particular kinds of diagnosis depending on the disability.

The broader perspective is an essential lifestyle plan should take into account how the person can be healthy as a whole, what their diet is like. One of the examples is I could go into any given home where there's a person with a disability and ask are they eating a healthy meal and the person would say yes. But then I could go to their freezer without looking and pull out any random item and chances are it would not be a healthy alternative. So items that are processed, frozen, canned, packaged, microwaveable are not healthy options for any average person. But if you are a stressed parent you're much more likely to go the route of convenience because you can only stretch yourself so much. An emphasis on good nutrition and an alternative plan for exercise is crucial. If you are supporting a person who is using a psychoactive medication, almost universally all psychoactive medications cause changes in metabolism of some kind. Latest studies indicate almost any psychoactive will cause weight gain. Options for reducing the use of psychoactive medications will go part of the way towards keeping weight under control.

Q. Can you name some best practices of intake of these kids and how we can identify if they have a mental illness such as depression, anxiety or PTSD?

A. The best practice when you're working with someone with a disability of any kind is to go the multi-informed approach. You'll start with a medical history, psychosocial history, etc. But then you quickly need to move into the area of functional assessments. So whether you're doing a functional behavioral assessment or another kind of assessment it comes down to observational assessments of some kind. If you can't rely on the person themselves (whether they're a child or a person with a disability who communicates in a different way) you surely need to approach things from an observational perspective. In other words you may need to do direct observation for a period of time, particularly structured observations where they are tasks to do and you can assess the persons response to those tasks. If it's multi-disciplinary that's an especially good idea because a PT persons observation would be different from a psychologists' observation or a neurologist. The more types of observational professionals that you can get into the process, the better. Indirect assessments become very critical here as well, informant interviews, record assessments, checklists, rating scales. Those help you make a

broader approach. Some instruments specifically designed or vetted among disability populations (too many to go through). Ex. ABC checklist may be more useful than a non-structured checklist.

Q. Do you have information for seniors or older adults with disabilities and the services available for them?

A. This one is almost impossible to answer in some ways because it depends on where you are. But one of the things to think about is there are some types of diagnoses that inherently pose greater risk to dementia. If you're a person with diagnosed with Down syndrome, it is well known that people with Down syndrome have on average a much early on-set of dementia. One of the best practices we use is that everyone who is getting services from the state (DC) is screened for dementia at the very beginning. One of those instruments is the NTG early-detection screening for dementia, which can be used, its adapted from DSQ IID. I can share our link with you later. The Important part here is to establish baseline of function as early as you can. If you wait until the person is in their older years you can't necessarily establish a baseline and know where they're coming from in terms of change. When working with seniors or older adults with disabilities, starting off early with some of these assessments is crucial so you can track changes over time. If you haven't been able to, it comes back to observational opportunities. The NTG Group has great materials for supporting environments of people with dementia. Some of those are structural, some are nutritional, and some are informational. It's an area that gotten a great more depth to it over the last 5 years.

Q. Are there any materials in Spanish?

A. Yes there are lots of materials in Spanish, obviously not as much as English. Comparatively you can do a quick search. Couple sources – If you go to Trauma informed care national child dramatic stress network they have links for a lot of their materials, some of which you have to pay for, some of which you don't, that have been translated to Spanish. Also go to Casa del Libro and do a search for various books that span the whole market from assessment to adapting materials to practical implementation strategies. The reason I picked that particular reference is because a lot of their materials can be purchased from Amazon. There is a gap in the general professional literature in terms of translating English-based assessment materials to Spanish. It's not obviously driven just by the language but also the cultural concerns as well. The onus is on the individual clinician to find something that fits best; there may be a lot more choices depending on what kind of Spanish, what kind of language their using, country of origin, etc. There are a lot of cultural linguistic things that need to fit in as well; it's not as simple as finding an English-based textbook that's been translated to Spanish.