

Transcript of “Precision Part II” – prerecorded video message from Virginia Spielmann as part of the STAR Institute Sensory Symposium in Denver, Colorado, October 6th, 2023¹.

Well, good afternoon. I hope you enjoyed the morning as much as I anticipated, and I think I probably have enjoyed it!

I'm going to talk a little bit more about our call to be providers of precision health care. But this time, it's going to have a slightly different emphasis. I said I would talk later about the importance of phenotypic subtypes in research and in healthcare. And so, let's just talk about that for a minute.

[The Importance of Subtyping]

A phenotypic subtype or a cluster group is what researchers strive for when they look for a sample that is relatively homogenous. It's a group of people who have similar characteristics to one another, often within a diagnostic population. Dr. Jean Ayres in her 1989, SIPT [Sensory Integration and Praxis Test] manual² released information, where she was starting to be able to characterize cluster groups. And these were related to praxis and movement and have been researched and verified in different ways by different groups over time, like Dr. Mulligan^{3,4}, Dr. Mailloux⁵ and other people. The reason we do this is so that we can really try to be precise about what helps who and so it improves our client stratification [see Figure 1 below], better identification and classification of clients based on their similarities and their characteristics. It also helps with our treatment selection because that research can then inform what we do. And this is what I was talking about before, when I was talking about that, that we need to move through looking at co-occurring neurodivergences, comorbid conditions, and so on. So, when we understand different phenotypic subtypes better, we can tailor our treatment better, and also hopefully predict and anticipate what people might go through. And obviously, that's got great benefit as we look to support the health and well-being of our clients. So, examples in medicine would be different cardiac phenotypes, so that there can be targeted interventions for those groups, different tumor subtypes would enable personalized treatment, and then subtypes in neurology would guide therapy selection. And so, it's an important part of trying to deliver precision health care, and in research design. What we want is to explore this power, without oversimplifying how we characterize our clients. It is an aspect of helping us understand our clients better. So, it might help us predict it might help us choose better interventions. And it certainly helps us with our research, it helps us to be more accurate and

¹ Spielmann, V.A. (2023, October 6-7). *Precision Is ... Part II* [Conference presentation]. STAR Sensory Symposium, Denver, Co, United States.

² Ayres, A. J. (1989). *The sensory integration and praxis tests*. Los Angeles: Western Psychological Services

³ Mulligan, S. (1998). Patterns of sensory integration dysfunction: A confirmatory factor analysis. *The American Journal of Occupational Therapy*, 52(10), 819-828.

⁴ Mulligan, S. (2000). Cluster analysis of scores of children on the Sensory Integration and Praxis Tests. *The Occupational Therapy Journal of Research*, 20(4), 256-270.

⁵ Mailloux, Z., Mulligan, S., Roley, S. S., Blanche, E., Cermak, S., Coleman, G. G., ... & Lane, C. J. (2011). Verification and clarification of patterns of sensory integrative dysfunction. *The American Journal of Occupational Therapy*, 65(2), 143-151.

precise. It doesn't replace paying attention to the individual. It's a part of that bigger picture of clinical reasoning.



Figure 1. Stratification of Health Care Data in Precision Occupational Therapy, from Spielmann, V. (2023) Precision Is... STAR Sensory Symposium, Denver, Colorado. Oct 6-7, 2023.

[Neurotype Specific Subtyping]

Phenotypic subtypes have been being used in research since, well, probably for nearly 20 years now; and *personalized medicine*, if you've ever heard that phrase has a lot to do with this type of research. It needs so as we try and characterize these groups more and more with the better technology that we have, it should be integrated into our clinical practice. Karla Ausderau, for example, and her group⁶ are doing some research on looking at autistic subtypes and cluster groups of how sensory-motor development looks in autism. And that's something we haven't done before. I believe Dr. Schaaf⁷ is doing that as well and has recently published a very comprehensive article on that.

Why hasn't that happened before? Well, there hasn't been a recognition that the autistic population might have *an autistic developmental trajectory that is specific to that group*. Previously, we've only been applying neuromajority norms to autistic populations. And so that means that a lot of the data on subtypes and phenotypes and so on, is based on people inside the bell curve, inside that 68% of people who experience the world very similarly, and for whom

⁶ Ausderau, K. K., Furlong, M., Sideris, J., Bulluck, J., Little, L. M., Watson, L. R., ... & Baranek, G. T. (2014). Sensory subtypes in children with autism spectrum disorder: Latent profile transition analysis using a national survey of sensory features. *Journal of Child Psychology and Psychiatry*, 55(8), 935-944.

⁷ He, J. L., Williams, Z. J., Harris, A., Powell, H., Schaaf, R., Tavassoli, T., & Puts, N. A. (2023). A working taxonomy for describing the sensory differences of autism. *Molecular Autism*, 14(1), 15.

the world is on the whole designed. But if we're saying now that we recognize that the neurodivergent population, and the autistic identity is valid, then we need to look at the autistic developmental trajectory and learn as much as we can about that. Because then what we can do is we can tailor make the experiences, much as Dr. Jean Ayres talks about in the blue book that these children have to be organizing and optimize what's available to them so that they can grow and master their own bodies and become and develop gross and fine motor mastery. So that they can move around in the world with success and engage in occupations as they see fit. So there's this whole aspect of characterizing these groups that contributes something very, very important as it helps us improve our client outcomes, and target our interventions. And we've got this new, these new advances in technology. And it seems like some of the research funding from NIH and places like that is really focused on this.

This is the sort of thing that Dr. Joanne Flanagan's [doing in her] work^{8,9}, where she's looking at identifying sensory motor differences in autism as early as possible, because that will really help us then say, well, this child is quite likely autistic. And that might mean they need these kinds of experiences, and not the experiences—the one size fits all experiences—that we tend to put our preschoolers in. That could be, I humbly suggest, counterproductive, and in fact, contraindicated for the autistic child or the child with sensory integration and processing differences.

[Subtyping Does Not Replace Individualization]

It does have weaknesses, this whole piece, there's a complexity of human experience that it's really hard to honor when you're trying to create homogenous groups. And that's got to be taken into account. It's also very resource intensive work. But that's why it's only *part* of your clinical reasoning process. So, one of the things that we need to think about then is how we're going to update our cluster groups and subtypes and so on. And, as you all may have noticed, in the presentation about the STAR Frame of Reference¹⁰, there was no mention of the Miller [2007]¹¹ nosology. And with Dr. Miller's blessing¹², and full knowledge, we're retiring the nosology, as is. Nosology actually means disease schematic; a way of understanding a disease. And so as we move away from a purely deficit way of looking at differences in the sensory integration process, we're also moving away from language like nosology. The nosology was designed to be a contribution to clinical reasoning in the field, but we need the new data from the new tests to tell us about phenotypic subtypes in 2023 and beyond. And that's not what we'll be doing within STAR Institute. So (at STAR) we're retiring it and what we'll be creating in its place, and we are in the process of creating is an andragogical tool, which is a lot of syllables, or a health literacy tool, if you like, really a resource for everyone to get educated about and to

⁸ Flanagan, J. E., Schoen, S. A., & Miller, L. J. (2019). Early identification of sensory processing difficulties in high-risk infants. *American Journal of Occupational Therapy*, 73, 7302205130. <https://doi.org/10.5014/ajot.2018.028449>

⁹ Flanagan, J., Demchick, B., Landa, R. Delany, J. & Reinoso, G. (submitted) Early play behaviors in infants at elevated likelihood for Autism Spectrum Disorder. *American Journal of Occupational Therapy*

¹⁰ Parkins, M. (2023). *The STAR Frame of Reference*. STAR Sensory Symposium, Denver, Colorado. Oct 5-7th, 2023.

¹¹ Miller, L. J., Anzalone, M. E., Lane, S. J., Cermak, S. A., & Osten, E. T. (2007). Concept evolution in sensory integration: A proposed nosology for diagnosis. *The American Journal of Occupational Therapy*, 61(2), 135.

¹² Miller, L. J., Witten, M., Ahn, R. R., & Schoen, S. A. (2019). Assessment of Sensory Processing Disorder: The Interplay of Sensation, Affect, and Relationship.

educate others on the importance of the sensory integration process for health and well-being. We're going to use very, very relatable language and we're going to layer the way that the information is presented. So it's going to be a kind of *have you ever thought about how you feel / what you feel?* document that will get increasingly complex as you go through it, so it should be suited for families, laypeople, individuals with the lived experience, as well as for training clinicians as they go through their own journeys, and our colleagues from other fields. And we're doing all of this, because we want to keep the main thing, the main thing.

[The Main Thing]

This event is about celebrating the importance of the diversity of perspectives we have in the field and the value everyone adds with the niche that they feel or the niche that they fill. And the perspective that they have. Humans are incredibly complex and **we need data driven, phenotypic subtyping to help us with the work that we do**, but it's just a part of the work that we do, we also need to really work on our therapeutic use of self, we need to really work on how the sensory integration process intersects with mental health. And there's so many things that STAR Institute is committed to, we're very, very committed to supporting the neurodiversity affirming movement and way of delivering sensory integration therapy, we believe that they're inherently compatible. And there's a lot of pieces that we're going to be concentrating on. So as we go on today, we're going to really try to pay attention to the full picture of the sensory integration process, *we're not just going to stop at modulation* and that was never the STAR Frame of Reference or the nosology's emphasis either. It's really important that we also look at praxis, at postural development and so on. So, we're going to hear a bit about those pieces this afternoon [Figure 2, below]. As well as these, these other aspects and these other perspectives that are so helpful and so important as we strive to find our true north.

1:05 PM MT	Precision is...	Dr. Virginia Spielmann
1:15 PM MT	Conceptualizations (Part 4) <ul style="list-style-type: none"> • Optimal Engagement Model • Praxis and Posture – Integration Through Movement 	Dr. Grace Baranek Dr. Emily Campi Dr. Sharon Cermak
1:55 PM MT	BREAK	
2:15 PM MT	Screening Tools and Standardized Report Measures <ul style="list-style-type: none"> • DCD-Q & Little DCD-Q • Sensory Processing Measure-2 • Sensory Profile Questionnaire-2 • Sensory Experiences Questionnaire • Adult/Adolescent Sensory History • The Classroom Sensory Environment Assessment (CSEA) 	Dr. Renee Watling Dr. Diane Parham Dr. Sharon Cermak Dr. Grace Baranek Sarah Sawyer Dr. Heather Kuhaneck
3:45 PM MT	BREAK	
4:05 PM MT	Standardized Assessments <ul style="list-style-type: none"> • SOSI-M & COPr • EASI • SP3-D 	Dr. Renee Watling Dr. Gustavo Reinoso Dr. Zoe Mailloux Dr. Shelley Mulligan

Figure 2. Afternoon schedule of STAR Sensory Symposium, Day One, Oct 6th, 2023.

[Close]

So, I hope you enjoy this afternoon's presentations. I know I am really looking forward to them. And again, thank you so much, everyone for being here and thank you to our speakers for so generously giving your time so that we can learn from each other.