

## BACKGROUND

**Fragile X Syndrome (FXS)** is the most common inherited form of intellectual and developmental disability (IDD) and a single gene cause of autism spectrum disorder (ASD). FXS phenotype includes anxiety, decreased communication / social skills, behavioral excesses, & sensory processing challenges (NFXF, 2017). Clinical trials have shown positive responses to treatment including sertraline - Zoloft (Hess et al., 2016).

Current FXS literature is well anchored in the medical model. Many outcome measures for FXS / IDD are focused on performance skills and show little progress over time. Raw scores (RS) reflect some point increases, yet standard scores (SS) show minimal to no change. Additionally, these traditional standardized assessments fail to capture occupational performance and context.

## RESEARCH QUESTION

How can **semi-structured interviews** reveal **occupational performance** changes in response to medication in a more contextually valid and sensitive manner when compared to traditional standardized outcome measures?

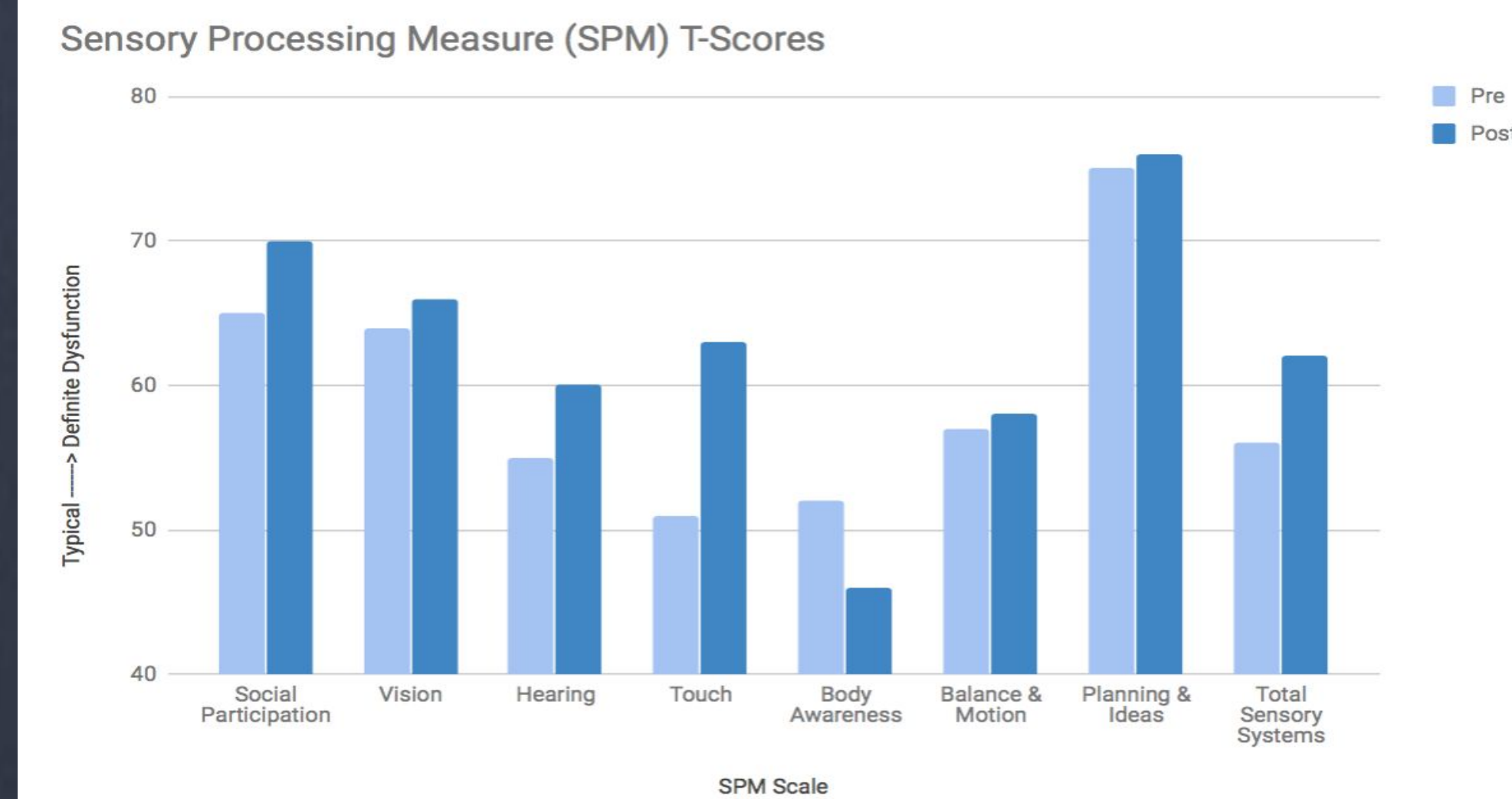
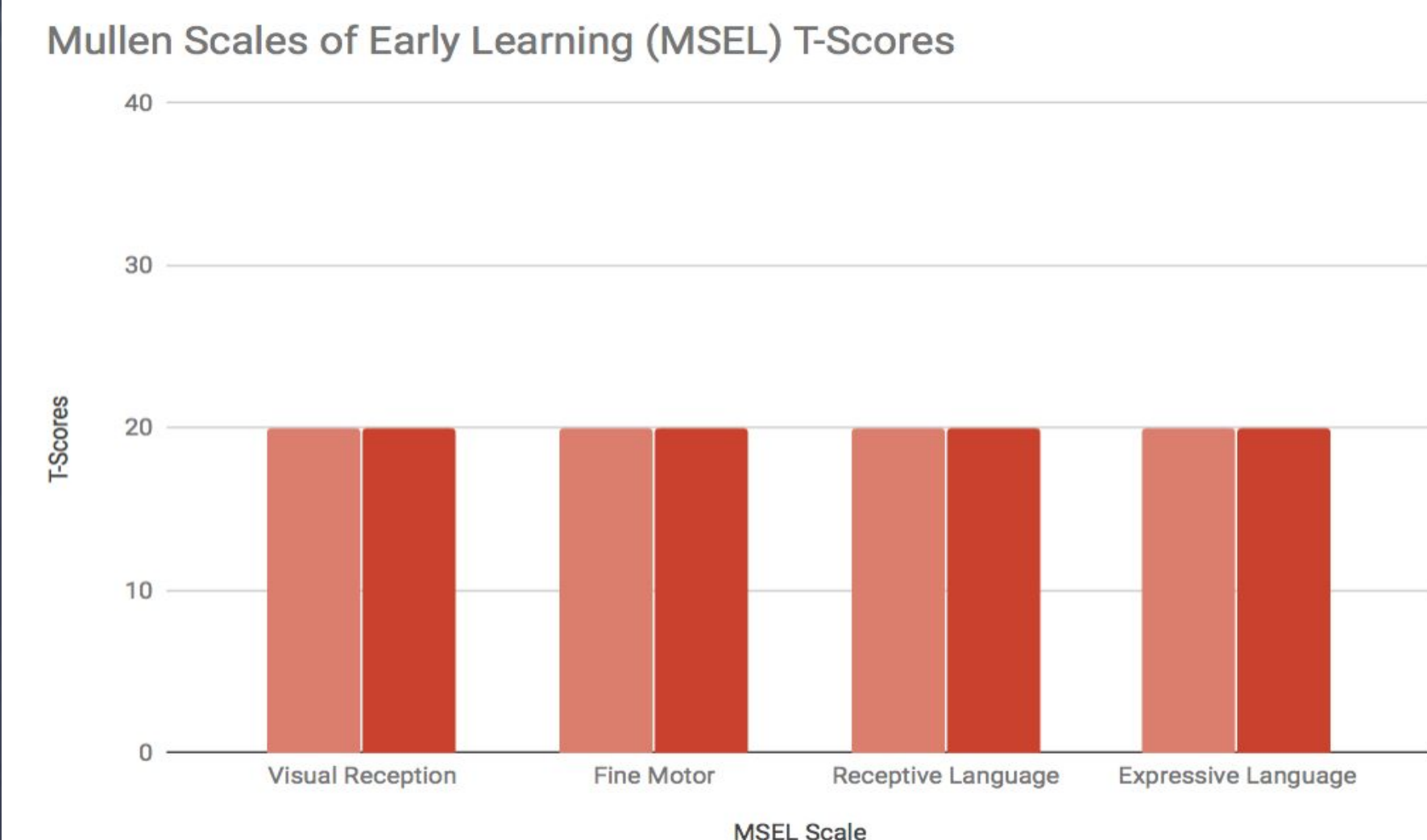
## MIXED METHODS: In-Depth Case Study Analysis

Standardized assessments and interviews given at baseline and 6 months post.

<b>Participants</b> (N=3)  UC Davis MIND Institute Sertraline Study	<ul style="list-style-type: none"><li>Families and children with full mutation FXS, 2-6 y/o, all received sertraline treatment</li><li>Mean IQ = 53.6</li></ul>
<b>Quantitative</b>  Standardized Assessments	<ul style="list-style-type: none"><li>Mullen Scales of Early Learning (MSEL)</li><li>Sensory Processing Measure (SPM)</li><li>RS examined, minimal change</li><li>SS reported in results</li></ul>
<b>Qualitative</b>  Semi-structured Interviews	<ul style="list-style-type: none"><li>Impact of FXS phenotype on family occupations</li><li>Constant Comparison Method (Strauss &amp; Corbin, 1990).</li><li>25% of total data (8 transcripts) coded to 100% consensus across 4 researchers</li></ul>

## RESULTS

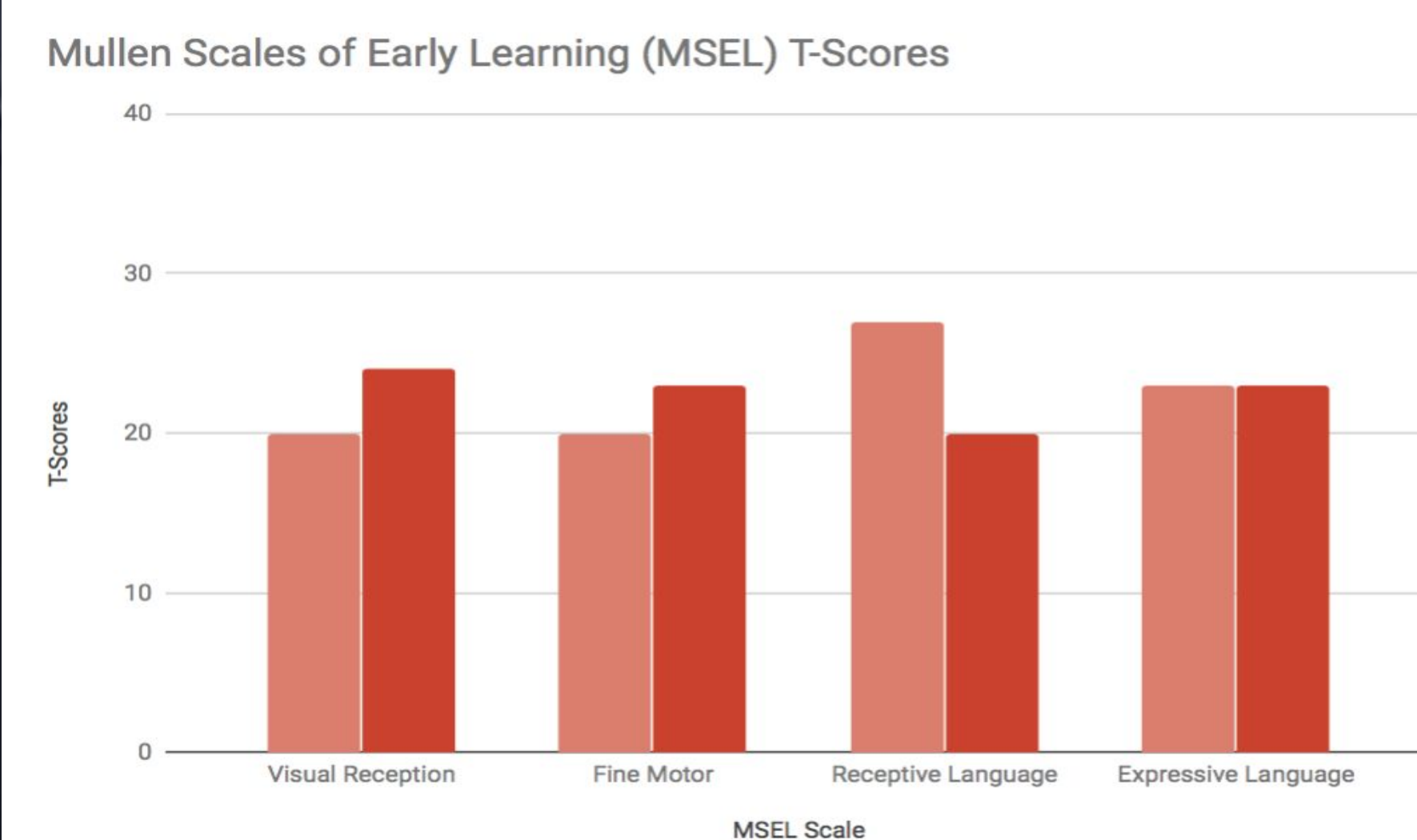
Isaac Age: 40 mo, IQ = 49



*The other thing is they feel like his language is improved. It's not showing so much on the testing...he kind of went from hardly saying anything to really starting to repeat things we say and he started to say more words of his own.*

*Sometimes it's simple. We have rocking chairs. In their place and our place. And we just sit down and walk with him. He likes the rocking motion sometimes. If you rock with him it will calm him down.*

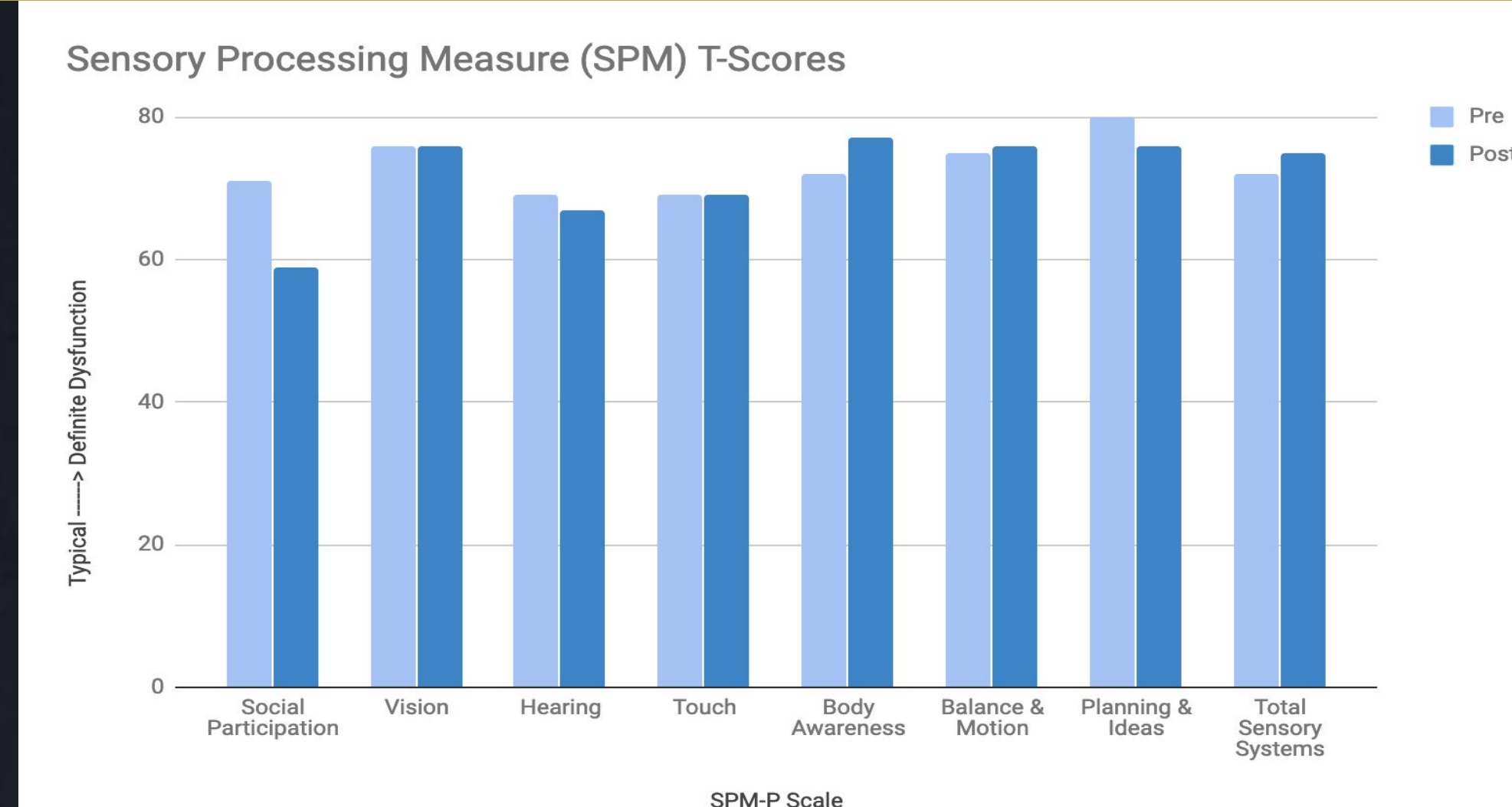
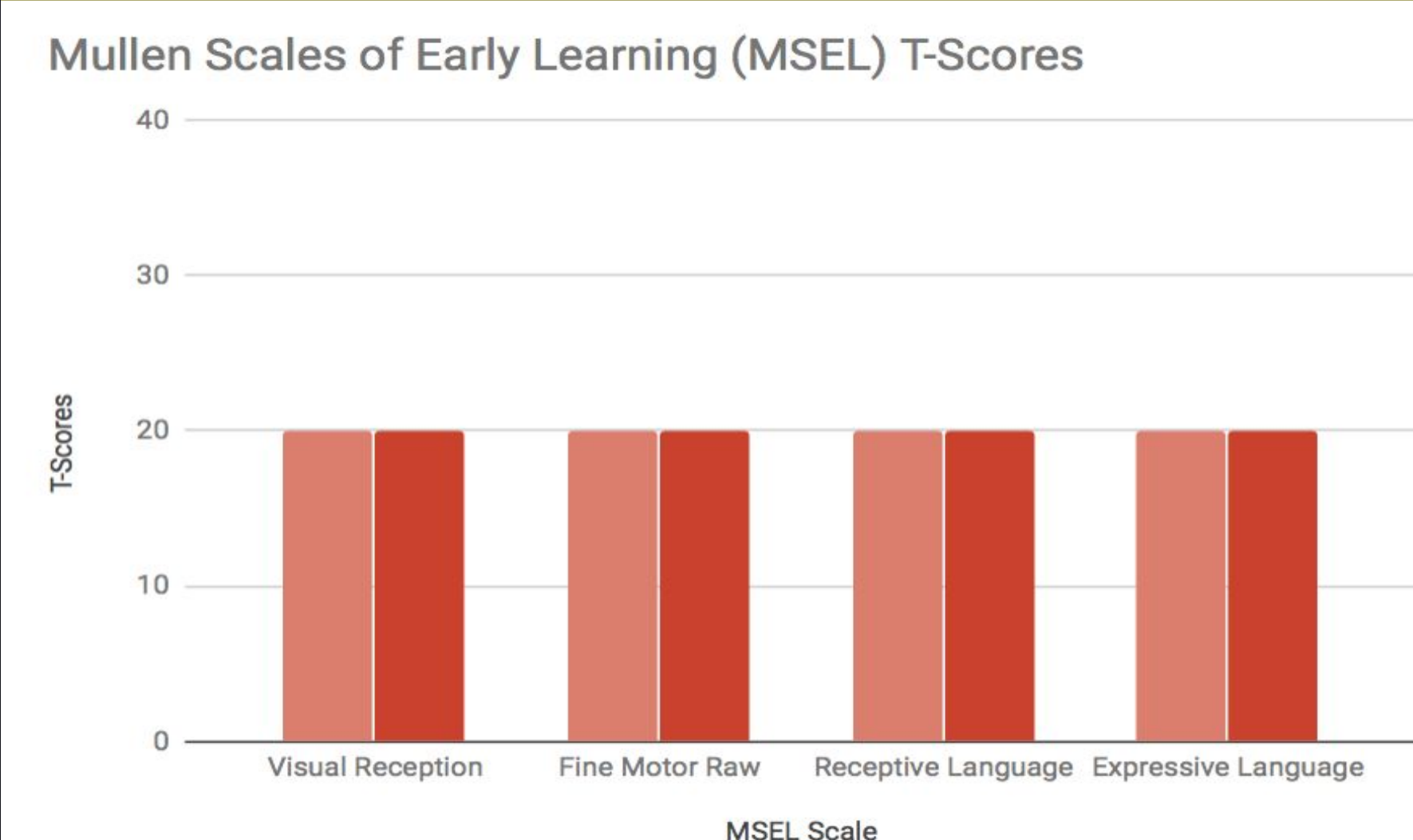
Derek Age: 41 mo, IQ = 56



*Yesterday he wanted yogurt, so he went to the refrigerator and said "eat." I opened it up and said "what do you want?" He grabbed his yogurt, and I said "you need a spoon." He went to the drawer. I opened the drawer for him because it's hard for him, so he can grab the spoon, and he said, "I eat."*

*We went out to dinner with our neighbors, and took him to a place he has never been before, and through the whole entire dinner at a restaurant, and was fine. He was completely fine. He sat and colored. So we can do more things like that.*

Shiloh Age: 65 mo, IQ = 56

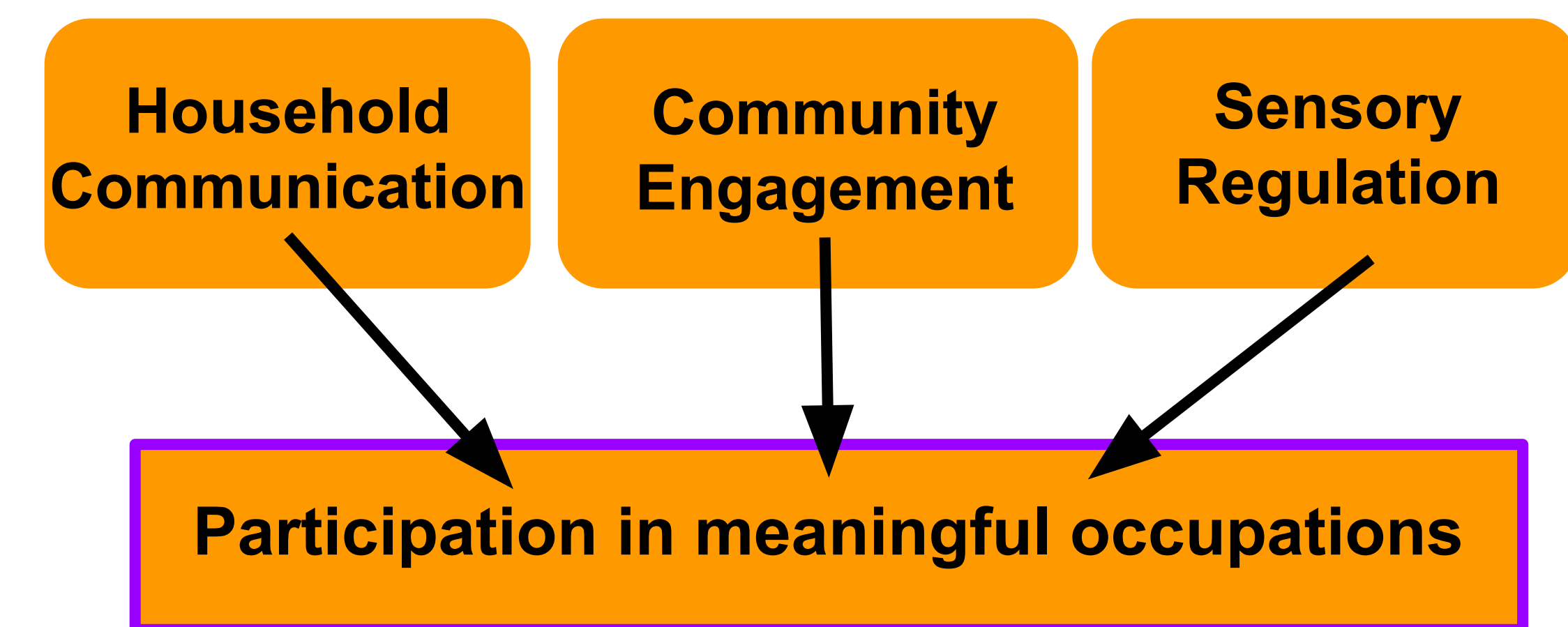


*I think he is doing great, if we don't understand what he is saying, show me a picture, show me what you are talking about and he will show you.*

*He's very good at routine, when he's done with his goldfish crackers he'll bring me the bowl or the cup on the counter in the kitchen. We've started having him set his place at the table. Things like that, chores, he loves to help me mop.*

## DISCUSSION

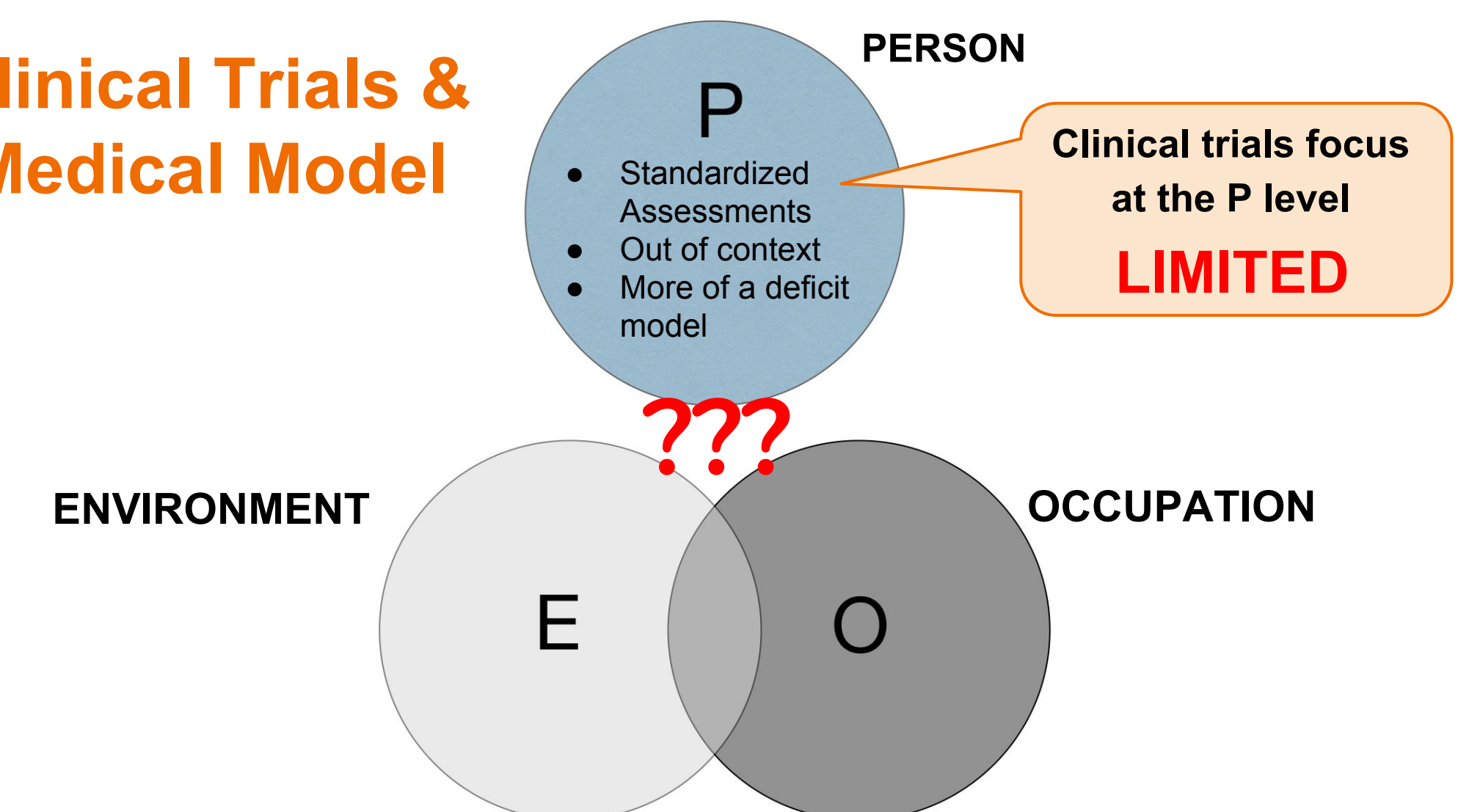
### Major themes - FXS phenotype



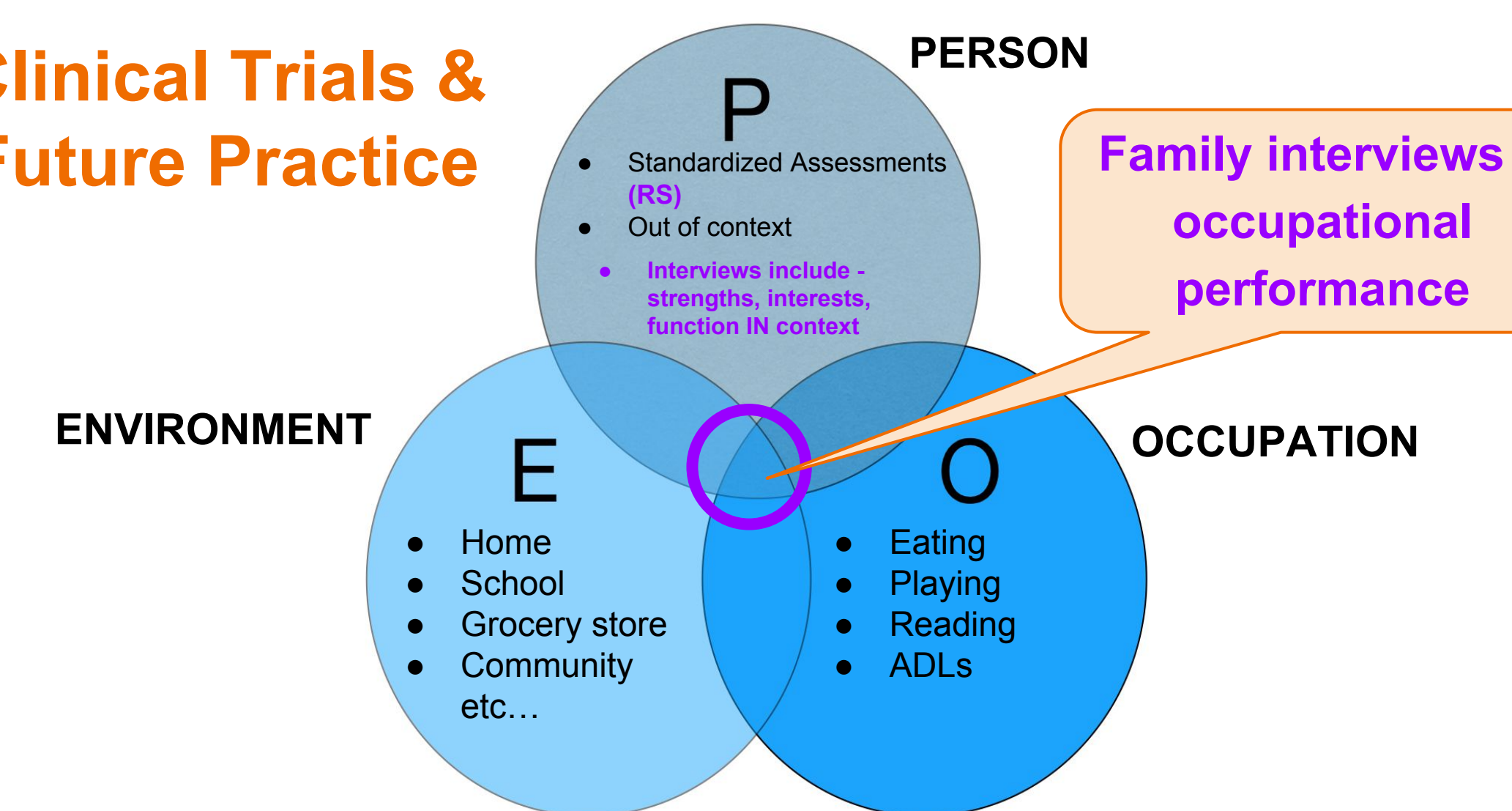
- Traditional standardized assessments have limited sensitivity to change for FXS.
- SS do not reflect the improvement families are reporting in their occupations and daily life.

## IMPLICATIONS FOR OT

### Clinical Trials & Medical Model



### Clinical Trials & Future Practice



## ACKNOWLEDGEMENTS

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