

**FAMILY QUALITY OF LIFE:  
PART III INTERVENTION**

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**REVIEW**

Occupational therapy practitioners view childhood disabilities through a lens that considers the dynamic and interconnected changes within the family.

The Person–Environment–Occupation (PEO) model guides intervention for pediatric disabilities with co-occurring socially disruptive behaviors.

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**REVIEW**

The family is recognized as a *system* and the community as a powerful *environment* that influence client outcomes.

Occupations are used as both treatment and outcome measures with which to establish habits and routines that support social participation and engagement.

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### REVIEW OF PREVALENCE

- Developmental disabilities affect approximately 10 million children in the United States alone (twice as many are males), or about 15% of the school-aged population—a 17% increase over the last decade.

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### REVIEW

- Two diagnoses with socially disruptive behaviors, attention-deficit/hyperactivity disorder (ADHD; 7% of the population) and autism spectrum disorder (ASD; 1.1% of the population), account for a significant shift in the reported prevalence.

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### REVIEW

- Additionally—or perhaps co-morbidly—about 16% of children in early elementary years present with symptoms of sensory over-responsivity, a form of sensory modulation disorder (Ben-Sasson, Carter, & Briggs Gowan, 2009), raising the prevalence of children with childhood disorders impacting success to upwards of 30% of the U.S. school-aged population

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## REVIEW – STATEMENT OF PROBLEM

By participating in occupation, humans develop, evolve, and establish their identities, and they find meaning in their lives. Yet, disability can disrupt engagement in occupation.

Family quality-of-life (FQoL) research focuses on both the internal attributes of family life (e.g., interaction, parenting) and the influence of the environment (e.g., community supports, medical home).

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## FQoL

The following are five factors of FQoL that become highlighted when a family is raising a child with a disability:

- Family interactions (i.e., marital satisfaction, being together at mealtime)
- Parenting (i.e., ability to assist the child)
- Support for the person with a disability (i.e., child treatments)
- Financial well-being (i.e., monetary resources)
- Physical and emotional well-being (i.e., coping with parental stress, caring for one's own health and social needs).

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## CONSIDERING INTERVENTION

PEO model

intervention plan focuses on the following evaluation findings:

- performance skills of the client
- the areas of occupation, activities, and tasks
- the environmental context as it influences the dynamic transactions.

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## PEO

- Outcomes are assessed according to the client's progress in occupational performance but interventions are established to reach beyond the child, and multiple options for change can be generated.

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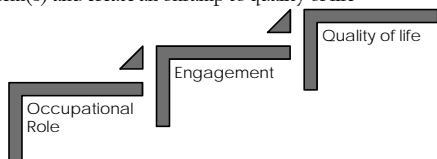
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There is a dynamic relationship between people, their occupations and roles and the environments in which they live, work and play

We need to be detectives to identify and solve the right problem(s) and create an onramp to quality of life




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## WHAT CONSTITUTES FAMILY QUALITY OF LIFE?

- What does it mean to have QoL within a family?
- What does it mean to have QoL for individuals within a family?
- How do these intersect?

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"Consideration of co-occupation supports an integrated view of the client's engagement in relationship to significant others within context" (AOTA, 2008, p. 269) and is an essential role of the occupational therapy intervention.

Families who are able to participate in meaningful occupations with friends and one another within their community have higher states of well-being (Lee et al., 2008).

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### FQoL

- Engagement in occupations....
  - Going to the store
  - Attending church or meeting
  - Going to a movie or out to dinner
  - Having a sleep over
  - Having a meal together
  - Going to school, doing homework
  - Getting dressed, taking a bath, helping carrying in groceries
- Others?

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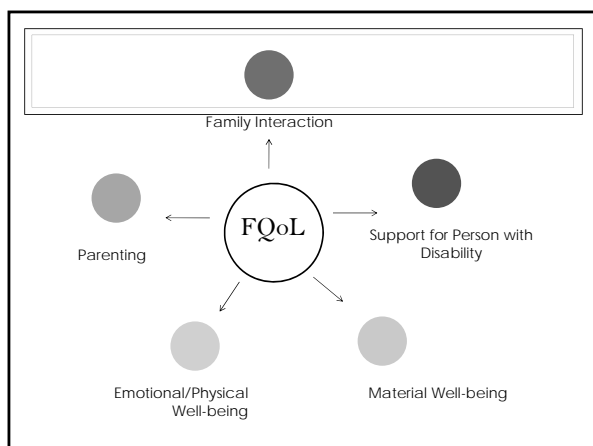
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### CASE 1: BOBBY

- Primary problem –
  - Family meals
- Parents report child 'wolves down food and leaves table', child picky eater
- Child reports family meals are too loud, food stinks, makes him nauseous to hear food in people's mouths...

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### WISER APPROACH

- What is the problem?
- Isolate what we know and seek to understand what we don't know
- Try a solution
- Evaluate
- Reflect

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### CASE 1: BOBBY

- Primary problem –  
W = Family meals
- Parents report child 'wolves down food and leaves table', child picky eater  
I = problem identified as family interaction
- Child reports family meals are too loud, food stinks, makes him nauseous to hear food in people's mouths...  
I = I need to know about auditory and other sensory processing
- S = I will try a solution aimed to reduce auditory and olfactory hypersensitivity
- E = I will assess family meal / interaction after
- R = I will reflect with the family on strategies

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### WHAT IS THE PROBLEM?

OTs collaborate with the parent to promote a PEO fit.

If the family doesn't eat meals together because of parent fatigue, the therapist might provide energy conservation and work simplification strategies.

If family meals don't occur because of child behaviors, that becomes the problem to focus on.

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### PERSON/ ENVIRONMENT/ OCCUPATION

- *Remediate/ rehabilitate* – focus on changing the underlying areas of deficit
- *Accommodate* – provide a support that enables function
- *Modify* – change the expectations of the task
- *Compensate* – table intervention on the problem until a future time

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### AREA AFFECTED: FAMILY INTERACTION

	Approach 1	Approach 2	Approach 3	Approach 4	Approach 5
	Rehabilitation	Compensation	Assistive technology	Change the task	Family Training
	Improve	Teach a 'work around'	Provide	Adapt / modify	Assist / compensate
Problem: Child sensitivity	Example: 1. Reduce hypersensitivities	Example: 1. Consider music, consider quiet meals, audit the noise level of the family	Example: 1. Try head phones/ear buds,	Example: 1. Consider eating quietly and sharing time each evening for family activity (walks, game night, etc)	Example: 1. Provide family education regarding sensory sensitivities and ways to balance the scales.
Problem: Parent fatigue	1. Improve endurance through exercise and de-stressing activities	1. Consider ready made meals to reduce care giver burden	1. Use home delivery for groceries	1. re-think parent task of meal prep, review what is a 'meals' (role clarification)	1. Provide education to children/ siblings / extended family on use of time / motion for meal related tasks.

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- Understanding what is required by the activity and the skills required to execute it is a critical element within occupational therapy evaluation and practice.

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### PROBLEMS

- Community participation
  - Isolation
  - Stigma
- Stress
- Family Impairment
- Disability support
- Physical and Emotional Wellbeing
- Parenting/ Caregiver burden
- Basic Needs
- Performance Patterns (habits, routines, rituals, roles)
- Enjoyment with family life
- Engagement / participation

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### PROBLEMS

Approach 1	Approach 2	Approach 3	Approach 4	Approach 5
Rehabilitation	Compensation	Assistive technology	Change the task	Family training
Improve	Teach a 'work around'	Provide	Adapt / modify	Assist / compensate
Example: 1.	Example:	Example:	Example:	Example:
Community participation Stress Basic Needs Performance Patterns (habits, routines, rituals, roles) Enjoyment with family life				

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## SUPPORT FOR PERSON

Approach 1	Approach 2	Approach 3	Approach 4	Approach 5
Rehabilitation	Compensation	Assistive technology	Change the task	Family Training
Improve	Teach a 'work around'	Provide	Adapt / modify	Assist / compensate
Example: Use sensory diet to reduce disruptive behaviors	Example: Consider alternating schedules with family work schedules	Example: Provide engine changes in backpack to promote emotional regulation	Example: Reduce expectations of task, select after care program with fewer children	Example: Provide training to care giver to promote successful strategies
Problems: Child care concerns due to disruptive behaviors Worry about the future				

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## PARENTING

Approach 1	Approach 2	Approach 3	Approach 4	Approach 5
Rehabilitation	Compensation	Assistive technology	Change the task	Family Training
Improve	Teach a 'work around'	Provide	Adapt / modify	Assist / compensate
Example: Complete F/Oot survey or PSI to see where area of need is greatest	Example: Consider quality of time vs quantity	Example: Use Fly Lady to promote small changes  Get house in order and take photos of 'just right' to reproduce and maintain	Example: Identify 'good enough' and work to achieve satisfying outcome	Example: Consider cleaning service if feasible
Problems: Not getting help with chores Limited time for parents to have 'adult time' Unsupportive spouse, not on same page				

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## EMOTIONAL AND PHYSICAL WELLBEING

Approach 1	Approach 2	Approach 3	Approach 4	Approach 5
Rehabilitation	Compensation	Assistive technology	Change the task	Family Training
Improve	Teach a 'work around'	Provide	Adapt / modify	Assist / compensate
Example: Reduce stress – conduct PSI and work to decrease stress levels through intervention	Example: Promote understanding of 'good stress' and reasonable stress	Example: Download apps for mindfulness and meditation / bioasures Consider My Fitness Pal	Example: Modify tasks in the day to remove primary stressors (i.e. declutter, take train rather than drive, etc.)	Example: Identify distressors for family (game night, walks) and implement one per day (or as scheduled).
Problems: No time for de-stressing No time for friends No time for self				

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## Stress busters

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## FINANCIAL WELLBEING

Approach 1	Approach 2	Approach 3	Approach 4	Approach 5
Rehabilitation	Compensation	Assistive technology	Change the task	Family Training
Improve	Teach a 'work around'	Provide	Adapt / modify	Assist / compensate
Example: Work with financial planner to create budget	Example: Identify essential therapies and work to assure benefit	Example: Use app to log spending Take advantage of online (free) intervention tools	Example: Check with insurer / providers to identify reimbursement options	Example: Take a course on financial management when raising a child with a disability
Problem: Cost of therapies				

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## FAMILY INTERACTION

- Identify social activities families wish to attend together and remove barriers to participation, such as taking walks or hikes, organizing family potlucks, going to the local pool, attending church, and participating in community meetings.
- Help families establish routines for having meals together at least three times a week.
- Recommend games and activities that will promote sharing and family cohesion, such as establishing bedtime routines, making and using a traditional "talking stick," and playing two truths and a lie (Whitney & Gibbs, 2013).

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### *PARENTING*

- Understand (and don't underestimate) caregiver burden.
- Make parent education part of your intervention plan, and provide education in parenting strategies.
  - For example, add 15 minutes to a therapeutic social skills group that is supervised by a student intern and use this time to work with parents to problem solve various barriers to achieving higher quality of life.

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### *EMOTIONAL AND PHYSICAL WELL-BEING*

- Provide strategies that help parents conserve their energy. For example, create a website or handout of cook-once, use-twice meals.
- Suggest de-stress activities families can do at home, such as after-dinner walks.
- Provide tips for supporting better sleep habits.

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### *SUPPORT FOR THE PERSON WITH A DISABILITY*

- Identify and share resources for respite in the community with families, such as Friday "Parents Night Out" drop off to bowl or play Laser Tag, or host a parents' night out at your facility.
- Create a webinar or blog or use social media that families can readily access to inform their community about their needs as a family as well as the unique, positive contributions they can make to communities.

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### FINANCIAL WELL-BEING

- Create a webinar or blog or use social media to share tips on establishing financial resilience (e.g., creating living wills, sharing purchases at shoppers clubs).
- Teach parents how to optimize your therapeutic intervention through community resources (e.g., karate, rock climbing, scouts, gaming tournament drop-in events).
- Encourage and facilitate sharing of resources (e.g., create a bulletin board at your facility for swapping resources, materials).

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### CASE 2: SAM

*Sam is 10 but won't leave me alone – we were recently at the grocery store and Sam began to scream for no apparent reason and dig his nails into my bare leg, drawing blood. As I wrestled with Sam to calm him down, everyone stared at me. I had a cart full of groceries and nothing at home for dinner – I had to get through the check out! I began to cry which made everything worse but I wasn't going to surrender my spot in the line. I guess I wasn't moving forward fast enough because the manager came over and rudely asked me to move forward in the line. I was humiliated and angry and my leg was throbbing.*

*When we finally got to the car with the food, I could hardly see to buckle Sam into the car – no wonder I'm exhausted all the time.*

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### WISER APPROACH

- What is the problem?
- Isolate what you know and need to know
- Try a solution
- Evaluate your outcome
- Reflect on what you learned

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## INTERVENTION

	Approach 1	Approach 2	Approach 3	Approach 4	Approach 5
	Rehabilitation	Compensation	Assistive technology	Change the task	Family training
	Improve	Teach a "work around"	Provide	Adapt / modify	Assist / compensate
Problem: Child	Example:		Example:	Example:	Example:
Problem: Parent Fatigue					

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## IN CONCLUSION

- Social isolation and stress in families is of critical concern. Childhood disability can interrupt all areas of occupation.
- We need to focus on the family rather and not just the child if we want to achieve optimal outcomes.
- Conceptualizing outcomes as the fit between the PEO transactions can foster quality of life in the family.
- Since families live and grow within a community, the capacity for the community to welcome and support these families is an area for further consideration and intervention.

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## IN CONCLUSION

If the profession is to assume responsibility for helping to develop children who can thrive and live life to its fullest, we must focus our interventions on interactivity between the child, the family, and the community in which these developing occupational beings live.

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QUESTIONS?



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