Beyond Early Intervention: A Pivot to Lifespan Participation for Children with Down Syndrome in Pediatric OT

OOTA Conference

October 17, 2026

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Session Objectives

- Understand the role therapies can play across childhood
- Identify strategies to support autonomy and self-advocacy
- Recognize the "F" words of child development

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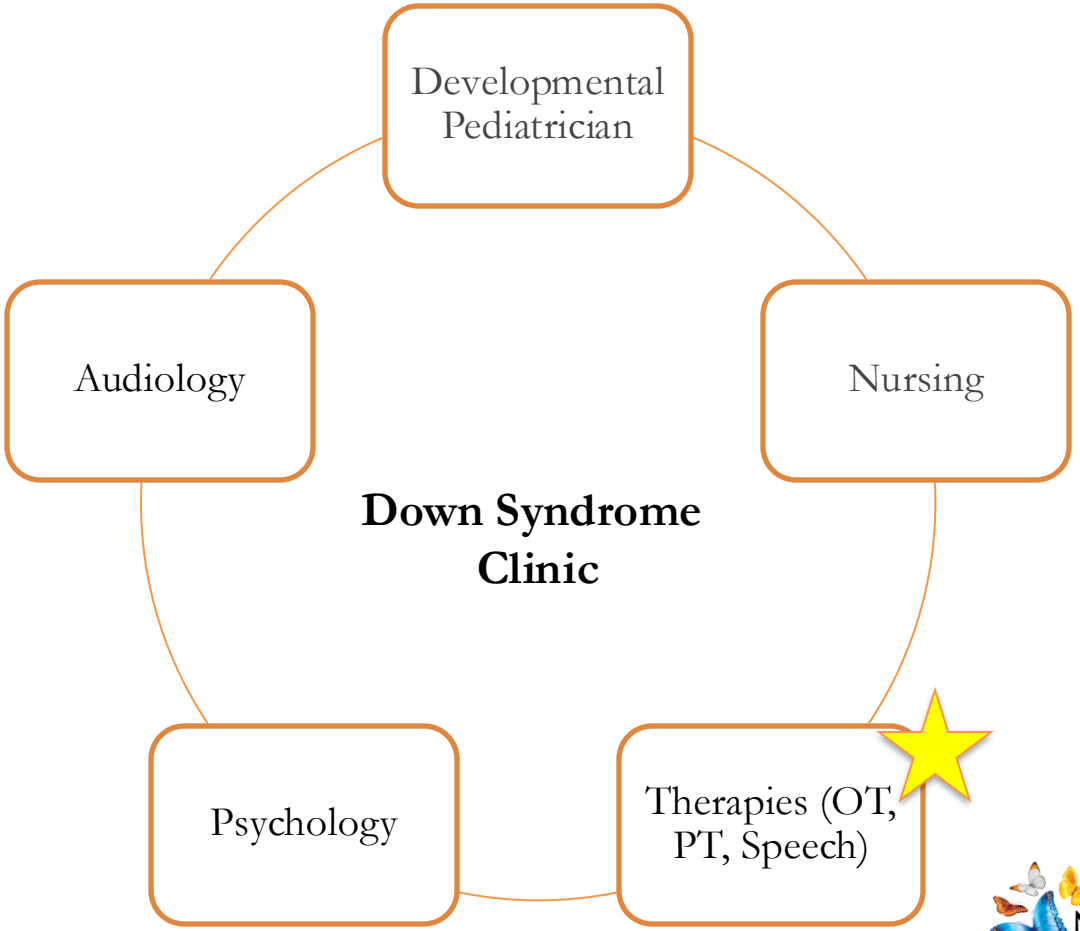

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OT Role Across Childhood

Early milestones

School

Community participation

ADLs

- Ex. Eating, dressing, etc.

IADLs

- Chores, meal prep, etc.

Transition post-graduation

(Garrels & Sigstad, 2023)



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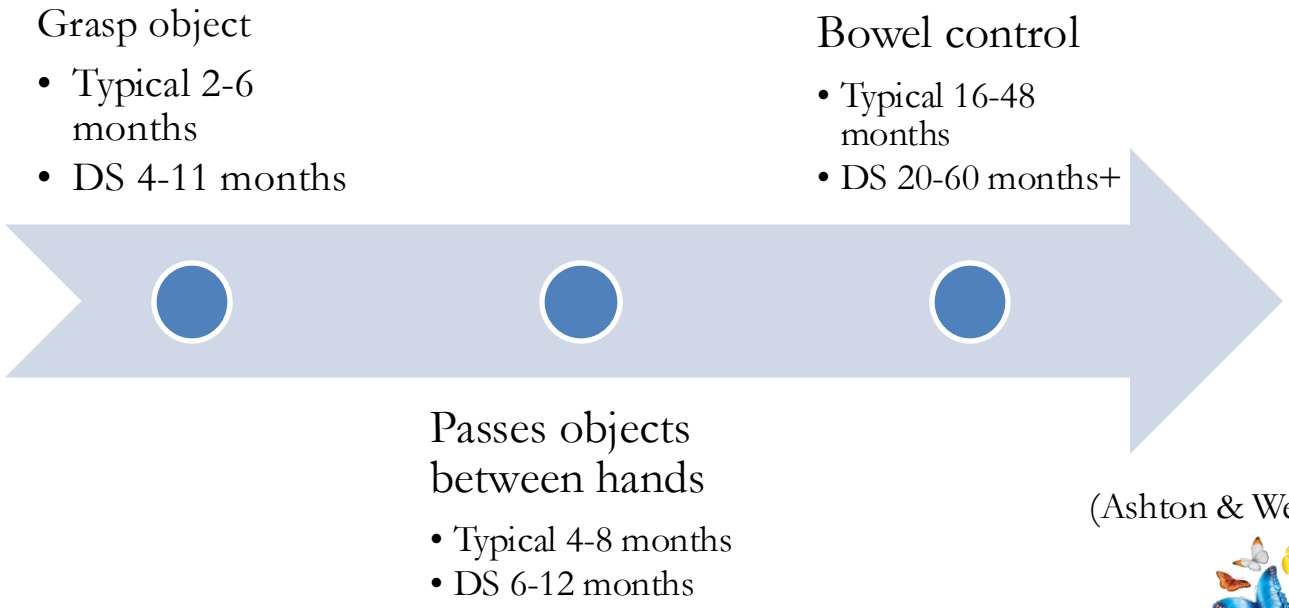
Skill Acquisition

- Similar progression with individual trajectories



(Ashton & Wentz, 2022; Kelly et al., 2026)

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Mindset Shift: Treatment Approach

Establish, restore (remediation, restoration)	Approach designed to change client variables to establish a skill or ability that has not yet developed or to restore a skill or ability that has been impaired (adapted from Dunn et al., 1998, p. 533)

Modify (compensation, adaptation)	Approach directed at "finding ways to revise the current context or activity demands to support performance in the natural setting, [including] compensatory techniques . . . [such as] enhancing some features to provide cues or reducing other features to reduce distractibility" (Dunn et al., 1998, p. 533)

(AOTA, 2020)

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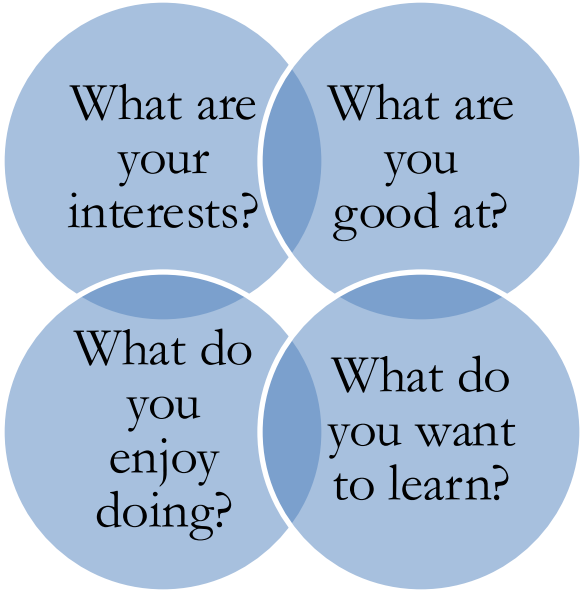
Self-Advocacy

Self-Advocacy is when you communicate for yourself about what you think is important



(Paradiz et al., 2018)

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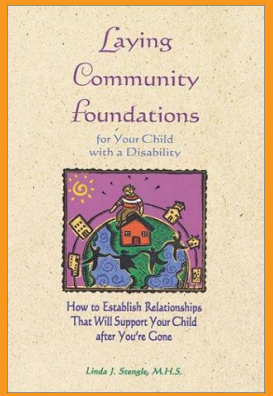
Autonomy is being able to make decisions for yourself and have control over your life



Autonomy and Dignity of Risk

- What if you never got to make a mistake?
- What if you never got to make a decision?
- What if you never got a chance?

(Stengle, 1996)

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'F' Words of Child Development

- Guide goal setting
- Help narrow down broad ideas
- Language is family friendly

(Rodrigues et al., 2026)

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'F' Words of Child Development

Function	Family	Fitness
• What people do • How things are done is not the focus	• The primary environment of the child	• Staying physically active • Exercise • Recreation

Fun	Friends	Future
• What children enjoy doing	• Relationships with peers	• Expectations and dreams

(Rodrigues et al., 2026)

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Future

- Promote choice making and self-determination
- See ability rather than disability
- Provide caregivers with resources
- Start planning transition early
- Person-centered
- Work or skill prep during school age years
- Everyone's path looks different

(Garrels & Sigstad, 2023)

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Resources to Support Evidence Based Transition Practices

Resource	Description
AOTA Micro Credential course: Supporting Educational Transitions From K–12 to Adulthood	Includes courses on leisure and social participation, health management, supported living, work, postsecondary education, and driving and community mobility
AOTA Transition Community of Practice	A group of scholars, academicians, OTPs, and students interested in supporting transition to adulthood
Council for Exceptional Children, Division on Career Development and Transition	Membership-based professional organization that holds an annual conference and publishes the journal Career Development and Transition for Exceptional Individuals 4×/year.

(Carrol et al., 2025)

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Resources

- Ashton, E., & Wentz, J. (2025). *Evaluating self-care milestones in children with trisomy 21 using a prospective caregiver survey*. *American Journal of Occupational Therapy, 79*(Suppl. 2), 7911500167p1. https://doi.org/10.5014/ajot.2025.79S2-PO162
- American Occupational Therapy Association. (2020). *Occupational therapy practice framework: Domain and process* (4th ed.). *American Journal of Occupational Therapy, 74*(Suppl. 2), Article 7412410010. https://doi.org/10.5014/ajot.2020.74S2001
- Carroll, T. C., Hollenbeck, J., Majeski, K., & Schwind, D. (2025). The crucial need for occupational therapy to prioritize postsecondary transition. *American Journal of Occupational Therapy, 79*(1), 2-8. https://doi.org/10.5014/ajot.2025.050944
- Garrels, V., & Sigstad, H. M. H. (2023). Caregivers' experiences with school–work transitions for their children with disorders of intellectual development. *International Journal of Environmental Research and Public Health, 20*(3), 1892. https://doi.org/10.3390/ijerph20031892
- Kelly, A., Morrison, R., Matta, N., et al. (2026). Review of early development in children with Down syndrome: Family and clinician partnership. *BMJ Paediatrics Open, 10*, e004028. https://doi.org/10.1136/bmjpo-2025-004028
- Paradiz, V., Kelso, S., Nelson, A., & Earl, A. (2018). Essential self-advocacy and transition. Pediatrics, 141(Suppl. 4), S373–S377. https://doi.org/10.1542/peds.2016-4300P
- Rodrigues de Sousa Junior, R., Oliveira Souto, D., Paleg, G., Teplicky, R., Hidalgo-Robles, Á., de Campos, A. C., Chagas, P., Longo, E., & Ribeiro Leite, H. (2026). Promoting clinical reasoning: Clinical application of the F-words lens tool for children with disabilities. *Pediatric Physical Therapy*, 38 (1), 144–149. https://doi.org/10.1097/PEP.0000000000000012
- Stengle, L. J. (1996). *Laying community foundations: For your child with a disability: How to establish relationships that will support your child after you're gone*. Woodbine House.

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Thank you! Questions?

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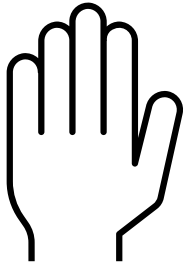

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