ENABLING A FULL LIFE: PARTICIPATION AT HOME AND IN THE COMMUNITY

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“Participation in the everyday occupations of life is essential to human development and life experience through which we acquire skills and competencies, connect with others and find purpose and meaning in life” (Law, 2002)
PREDICTORS OF ADULT SUCCESS

- Mastery of basic self care
- Participation in household responsibilities
- Community involvement outside of school


- Functional Mobility (94.3%)

- Toilet Training (96.6%)

- Self care skills – bathing, dressing, grooming (59.7%)
WHY IS SELF CARE A CHALLENGE?

- **Lack of opportunity**

- **Fine motor skills** - Dolva, Coster & Lilja (2004) found biggest deficit in five year olds with DS to be in fine motor related self care tasks

- **Sensory processing/body awareness** – Wuang and Su (2011) identified differences in sensory processing and modulation as linked to a decrease in self care status.
MILESTONES FOR CHILDREN WITH DS IN BASIC SELF CARE (FRANK, K. ET AL, 2015)

Basic Self Care – Self Feeding
95% of children have mastered this by.....

- Holds bottle 16-27m
- Finger feeds 20-22 m
- Spoon use 4-6 years
- Straw 3-5 years
- Open cup 5.5- 8.5 years
- Fork use 5.5-8.5 years

Toileting and Clothing management

- Toilet Trained 8.5 – 12 years
- Dress/undress 12- 16 years
- Zipper 18 years
- Button on pants 18 years
- Button on shirts 18 years
- Ties shoes 18+
• Work with an OT!
• Have functional IEP goals
• Provide regular practice in daily life routines
• Focus on participation rather than perfection
• Don’t try to tackle all of it at one time – prioritize goals
PARTICIPATION IN HOUSEHOLD RESPONSIBILITIES

- MF Amaral et al (2014) sees chores as a way to support many life skills in youth with DD, including taking initiative, learning responsibility, self efficacy and social competence.

- Helps reinforce sense of social belonging and prepares for a future of sharing space with others.
Parents of teens all felt household responsibilities were of value (DS, CP and TD)

Comparison of the three groups – DS was the lowest

25 in each group

Used CHORES tools to assess

Self Care

Strongest (50% or more) in:
- clean up after play
- put away own clothes
- make self a snack
- put laundry in hamper
- organize school belongings

Weakest in: self meal prep (0%), cleaning own room (12%)

Family Care

Strongest (20-30%) in:
- cleaning communal rooms
- set or clear table
- take out garbage
- care for plants and pets

Weakest in: Meal prep for family (0%), Laundry (4-12%), clean bathroom (4%)
<table>
<thead>
<tr>
<th>Task done independently</th>
<th>% having the skill</th>
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<tbody>
<tr>
<td>Dresses completely inc. footwear</td>
<td>59.8</td>
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<tr>
<td>Ties shoe laces</td>
<td>40.2</td>
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<tr>
<td>Takes initiative to dress</td>
<td>78.2</td>
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<tr>
<td>Undress and puts on pajamas (takes initiative)</td>
<td>81.6</td>
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<tr>
<td>Wash hands and face properly</td>
<td>60</td>
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<tr>
<td>Brush teeth, including toothpaste application</td>
<td>53.6</td>
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<tr>
<td>Adequate toilet hygiene</td>
<td>61.1</td>
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<tr>
<td>Makes bed with sheets</td>
<td>24.5</td>
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<tr>
<td>Uses knife and fork at meals</td>
<td>81</td>
</tr>
<tr>
<td>Sets table properly</td>
<td>61.7</td>
</tr>
<tr>
<td>Cleans up after meal – clear dishes, rinse</td>
<td>44.2</td>
</tr>
<tr>
<td>Initiates clearing up</td>
<td>36.1</td>
</tr>
<tr>
<td>Finishes tasks without reminder</td>
<td>32.7</td>
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<tr>
<td>Attention to task for at least 15 min</td>
<td>39.3</td>
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<tr>
<td>Tidies up toys and things – no prompts</td>
<td>39.3</td>
</tr>
<tr>
<td>Hangs clothes – no prompts</td>
<td>24</td>
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<tr>
<td>Offers to help other when appropriate</td>
<td>33</td>
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<tr>
<td>Walk several blocks without supervision</td>
<td>34</td>
</tr>
<tr>
<td>Prepares breakfast</td>
<td>55.5</td>
</tr>
<tr>
<td>Basic cooking (hot meal)</td>
<td>6.6</td>
</tr>
<tr>
<td>Alone for several hours</td>
<td>34.3</td>
</tr>
<tr>
<td>Use a key to get in the house</td>
<td>37.4</td>
</tr>
<tr>
<td>Use computer and TV</td>
<td>71.2</td>
</tr>
<tr>
<td>Use phone</td>
<td>32.9</td>
</tr>
<tr>
<td>Ask for help when needed</td>
<td>56.1</td>
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<tr>
<td>Write simple note or email</td>
<td>29</td>
</tr>
<tr>
<td>Pay cash in a store</td>
<td>12.1</td>
</tr>
<tr>
<td>Use debit card</td>
<td>8.7</td>
</tr>
<tr>
<td>Able to swim</td>
<td>83.9</td>
</tr>
<tr>
<td>Ride a bike (2 wheel)</td>
<td>40.5</td>
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<tr>
<td>Walk safely along the street near home</td>
<td>49.9</td>
</tr>
<tr>
<td>Walk along a familiar route</td>
<td>38.5</td>
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<td>Walk to a familiar address</td>
<td>18</td>
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<tr>
<td>Take a bus</td>
<td>5.9</td>
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WHAT WILL HELP?

- Start early!
- Remove supports as skills improve
- Prioritize goals based on family needs and appropriate expectations
- Make participation the goal – adapt or modify as needed
- Consult with an OT!
COMMUNITY PARTICIPATION

- Provides natural supports and social connections that go beyond school context
- Gives a motivating context for skill development
- Correlated with increased life satisfaction and success as adults
- Supports family life together
- Enriches our communities!
WHAT DO WE KNOW FROM RESEARCH?

- Limited diversity and intensity
- Primarily informal activities
- Correlation with higher cognitive, motor and communication skills – higher participation and enjoyment
- Solitary and sedentary leisure activities most common
- Success requires a goodness of fit between person factors and environment
- Not inclusive in community
EXAMPLES OF COMMUNITY ACTIVITIES

- Neighborhood outings
- Community events
- Organized Physical activities
- Unstructured Physical activities
- Classes and lessons
- Organizations/Groups/Clubs/volunteering
- Religious/Spiritual
- Getting together with other children
- Working for pay
- Overnight visits or trips
SELECTING GOALS

Factors to Consider

- Money/cost
- Transportation needs
- Supports available
- Physical layout
- Sensory qualities of environment
- Cognitive, motor, social, communication demands of activity
- Safety concerns
- Weather conditions
- Attitudes of other peers, adult leaders, organization

How to meet goals

- Start early - elementary years!
- Set incremental goals
- Adapt environment to support success
- Advocate for what’s needed – use tip sheets
- Ask your OT for help – activity analysis, break it down, coach for success
WRAP UP

- Traditional approaches have focused on “fixing” child and “normalizing” development
- Increasing research and success found in enabling participation in life activities – often through changing environment or adapting the task
References


