

Parenting with Down Syndrome: The Role Occupational Therapy Plays

Kalhie M Mayer, BS, OTAS; Aubrey Rubin, OTAS; Jessica Schatzan, OTAS, Sara Loesche, MS, OTR/L, CHT
Thomas Jefferson University Occupational Therapy Assistant Program

Background Information: Occupational therapy (OT) aims to address the needs of the whole person by promoting independence and overall wellbeing for those with intellectual disabilities (ID). Addressing sexual health and activity of a person with Down Syndrome (DS) is not often openly talked about. Sexual education is important for those with ID or DS to help reduce the risk of STDs/HIV, engage in meaningful relationships, and understand challenging sexual behaviors (D’Amico & Cahill, 2015; Kaushal, Baxi, Kadi, Karandae, & Baxi 2010). About 50% of women with DS are fertile while most men are sterile (D’Amico, et al. 2010). OT can play a pivotal role in preparing a person with ID to not only take care of him/herself, but also potential children. Having a positive therapeutic relationship between the occupational therapy practitioner (OTP) and parent can transfer to a healthy parent-child relationship (Walker, Pitonyak, Ramsdell, & Rogers, 2016).

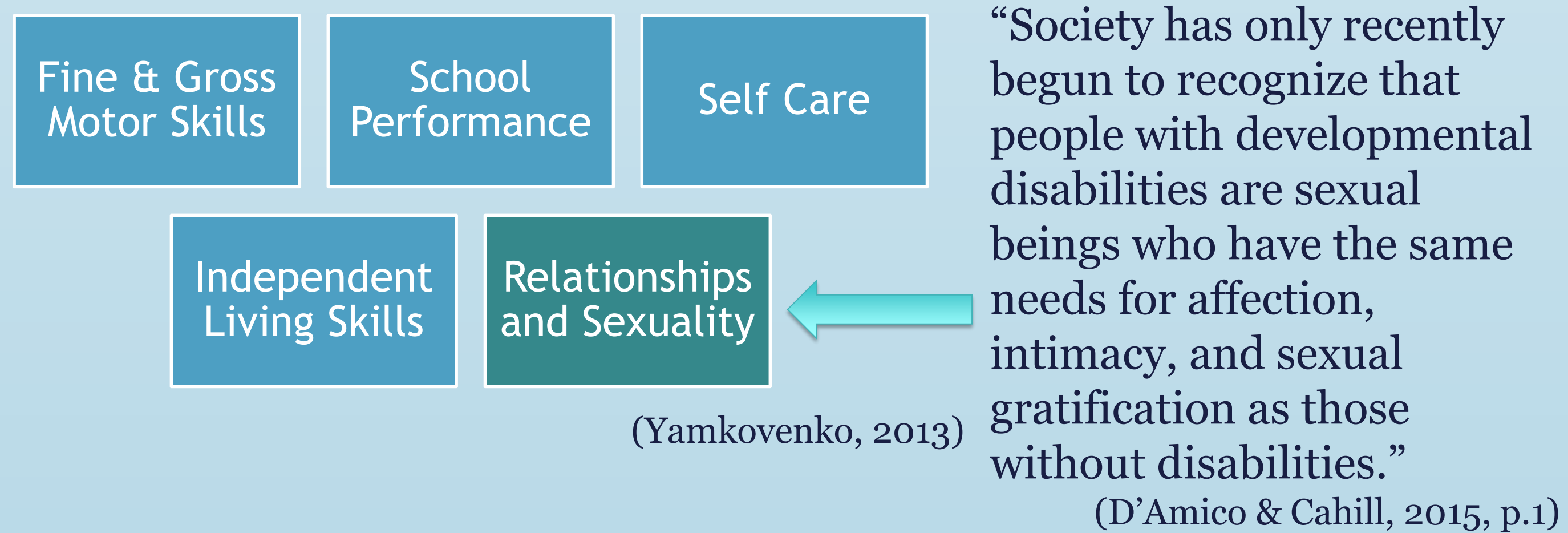
Relationships and Individuals with Down Syndrome

Percentages of Pregnancy in Mothers with DS

Table 1: Reported results of pregnancy in Down syndrome		
Paper	Parent	Offspring
Sheridan et al, 1989 ⁷	1 man with Down syndrome	1 normal male
Pradhan M, 2006 ¹	1 man with Down syndrome	1 normal baby
Bovicelli et al, 1982 ⁸	26 women with Down syndrome	10 normal 10 Down syndrome 2 mentally retarded 1 set of premature, nonviable normal twins. 3 malformed 1 slightly microcephaly 1 still born 2 abortion, phenotype unknown
Rani et al, 1990 ¹⁰	1 woman with Down syndrome	1 normal
Kristesashvili DI, 1988 ¹¹	1 woman with Down syndrome	1 normal
Grall JY, Le Goux AM, 1978 ¹²	1 woman with Down syndrome	Multiple malformations with normal karyotype.
ScharerS. Stengel-Rutkowski S, 1975 ¹³	1 woman with Down syndrome	Aplasia of the left fifth finger, chromosome analysis revealed few hyperdiploid but no G-trisomic cells.

(Kaushal, M., Baxi, A., Kadi, P., Karandae, J., & Baxi, D.,2010)

Areas an OTP Can Address with Individuals with DS



Importance of Sex Education for Individuals with ID

- ☐ Reduce risk of STDs and HIV/AIDS
 - ☐ Address sexualized challenging behaviors
 - ☐ Engage in meaningful relationships
 - ☐ Fertility: Understanding that up to 50% of women with DS are fertile while most men with DS are sterile, but not all
- (Kaushal, Baxi, Kadi, Karandae, & Baxi, 2010)

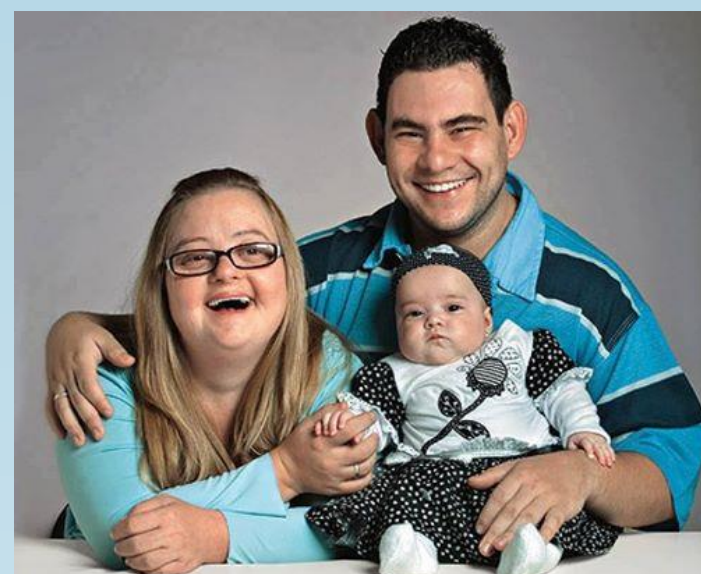
Case Stories of Parents with Disabilities: Lisa, Gabriela and Fabio

Lisa is a high functioning, independent woman with down syndrome. Lisa knew she wanted to have children and was so happy when she found out she was pregnant. Lisa’s pregnancy was considered high risk and she struggled through the pregnancy, She also went into labor four weeks early and was in labor for five days before she was induced. Her son Nic was born and he also had down syndrome. Lisa needed a lot of help and actually only had Nic at her house overnight three times a week with someone to help her. Lisa was also very involved in all of Nic’s therapy appointments. Nic was raised both by Lisa and Lisa’s mother Patti and he calls them both mom. Nic is a happy and healthy young man now, he is 23 years old and Lisa is now 53.

(Leticia, 2016)



Gabriela, Fabio & Valentina



Gabriela (who has DS) and Fabio (who has an ID) are a married couple from Brazil. Gabriela and her family were under the impression that her and Fabio had no chance of getting pregnant. Gabriella did not know she was pregnant until Fabio told Gabriela’s mom that he felt a kick from her belly; she was already six months pregnant. Soon Gabriela went into labor a month early but luckily the baby (Valentina) was fine and did not have any of her parents’ conditions. Because of certain laws in Brazil however, the courts would not let Fabio register as Valentina’s father because of his disability. After extensive legal battles and getting the media involved the courts allowed Fabio to be registered as her dad. Valentina is now 10 years old and living a happy life with her parents.

(Fabiosa, 2019)

Legal Obstacles for Parents with Disabilities

A 2015 ruling by the U.S. Department of Justice (DOJ) states that parents with disabilities must receive an individualized assessment when the safety of the child is in question, and that a person’s parenting ability cannot be fairly assessed without appropriate accommodations. OTPs can contribute by conducting performance-based evaluations focused on the occupations of parenting. This skill sets OT apart from other professions by using task analysis while taking into account context and environment.

(Walker, Pitonyak, Ramsdell, & Rogers, 2016).

Occupations to Consider

- Feeding & nursing; diapering; dressing; bathing; transporting

Client Factors to Consider

- Memory, reading level, processing abilities, sequencing skills

Potential Interventions

- Digital clocks & thermometers, pre-measured doses of medication, calendars with appointments, feeding charts, pre-mixed formula
- Adaptive cribs, alternative positioning for feeding, adaptive strategies for transporting children in early years
- Energy conservation, propulsion training, seating and mobility adjustments, adaptive technology

Conclusion: How Occupational Therapy Can Help

- OTPs can help individuals with Down Syndrome complete their activities of daily living so they can be independent and start a family
- Sex education is an very important area for OTPs to work on with individuals who have Down Syndrome or other intellectual disabilities
- OTPs play a huge role in helping people with Down Syndrome parent efficiently and effectively through various strategies such as recommending adaptations to support the occupations of a parent
- OTPs can be instrumental in advocating for individuals with Down Syndrome who have children through linking them with agencies, completing performance assessments, and testifying in legal proceedings
- OTPs can help to create a healthy social relationship between parent and child by creating a positive therapeutic relationship between themselves and the parent

Occupational therapy practitioners have the opportunity to foster positive parenting skills and feelings of self-efficacy for parents with Down Syndrome or other intellectual disabilities as well as nurture and support healthy parent-child relationships

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