Parenting with Down Syndrome: The Role Occupational Therapy Plays

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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

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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. OTs 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, seating, and mobility adjustments, adaptive technology

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 Pattie 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.

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. Gabriela 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 Valentine’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.

Conclusion: How Occupational Therapy Can Help

• OTs 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 OTs to work on with individuals who have Down Syndrome or other intellectual disabilities

• OTs 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

• OTs 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

• OTs 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

References


