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The Role of Occupational Therapy in the Transition Process for Young Adults with Developmental Disabilities

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Focused Question

What is occupational therapy's role and best practice in assisting families with young adults with developmental disabilities transition out of the home into the community, secondary education, or supported independent living?

Case Scenario

This critically appraised topic (CAT) focuses on occupational therapy's role and best practice in assisting families with young adults that have developmental disabilities in making the transition out of the home into the community, secondary education, or supported independent living. The transition experience is unique to each individual, as there are both supports and barriers to the process.

Transitioning out of the Home and Developmental Disabilities

According to the Centers for Disease Control and Prevention [CDC] (2022), a developmental disability is defined as a condition due to an impairment in physical, learning, language, or behavioral areas. Developmental disabilities begin during one's developmental period and may impact one's daily functioning. Developmental disabilities typically are present throughout a person's lifetime. A few examples of developmental disabilities include but are not limited to autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), and cerebral palsy (CDC, 2022). Because these conditions can impact one's daily functioning, living independently can pose barriers to these individuals. For this paper, a young adult will be defined as being between the ages of 18 to 25.

During this time in their life, most young adults with developmental disabilities will eventually make the transition out of the home. In order for this transition to be successful, both the parents and the young adult must be aware of the services and resources available before, during, and after the transition. These resources and services can include higher education, social or community activities, and work opportunities. These resources and services allow young adults with developmental disabilities to better advocate for themselves (Benson et al., 2021; DuBois et al., 2020; Højberg & Steffensen, 2008). During the young adult years of an individual with a developmental disability, utilizing resources and developing self-efficacy skills and self-determination skills are vital in increasing the young adult's level of independence (McPherson et al., 2016).

Family Role for Young Adults with Developmental Disabilities

Familial involvement, specifically parental involvement and parent-professional collaboration, can positively impact young adults with a developmental disability during the transition from school into the community (Francis et al., 2019). According to Dubois et al. (2020), Families of young adults with developmental disabilities often worry about their child's safety, whether their child is being adequately accommodated for in the community, their inclusion in social events, and experiencing potential bias associated with having a disability. In more recent years, there has been an increase in families becoming the caregivers and sole decision-makers for their young adult with a developmental disability as well as being their main support system for engaging with the community due to these worries (Dubois et al., 2020). During this time in a young adult's life, the individual's family holds a vital role due to societal norms and expectations of how the family contributes in the upbringing of a young adult with developmental disabilities. (Renwick et al., 2019). Additionally, the role a family plays in their child's care and transition may depend on culture and their view of social norms. With this support, young adults with developmental disabilities may feel comfortable at home with their families and therefore may not express a desire to live independently (Renwick et al., 2019). To



increase the desire to become more independent, occupational therapists work alongside other members of the transition team to help the young adult build self-determination skills as self-determination skills are key to a successful transition for both the family and the young adult as this is best practice (Benson et al., 2021).

Occupational Therapy's Role in the Transition Process

According to Francis et al. (2019), Occupational therapy can assist young adults with developmental disabilities to establish the means necessary to transition to new settings, establish their roles in those settings, and work to allow them to participate in activities that will support independence in daily living. As previously stated, as young adults with developmental disabilities make the transition out of the home, the young adult and their family often face difficulties because the family may have had a significant role in providing care for their child depending on their relationship, culture, and the type of developmental disability. Other barriers to this transition process include, but are not limited to parental exhaustion after years of searching for information, resources, and advocating for their child, the parent's ability to "let go" and allow their young adult to engage in independent decision making and experiencing the natural consequences of these decisions, and communication barriers and changes during the transition process (Francis et al., 2019).

Occupational therapists can assist families and young adults during this transition out of the home. Researchers Keptner et al. (2016) found that occupational therapists can enhance the quality of life for incoming university freshmen making the transition out of the home by improving occupational performance and performance satisfaction through occupational intervention. Furthermore, those with developmental disabilities benefit from occupational therapy services by improving communication, comprehension, motor skills, and other functional abilities (Eismann et al., 2017). For the families of young adults with developmental disabilities, occupational therapists can assist them during the transition by facilitating involvement in paid work experience, giving them instructions for daily living skills or social competence, and assisting with technology needs (Eismann et al., 2017). Despite proven benefits, Eismann et al. found that fewer than 7% of students with developmental disabilities received OT services, and occupational therapists have a limited role in transitions. The lack of documentation of the OT role in the transition process seems to be a common consensus within the literature (Benson et al., 2021; Eismann et al., 2017; Keptner et al., 2016; McPherson et al., 2016; Merz et al., 2020; Nota et al., 2007).

When considering a particular theory, the Model of Human Occupation (MOHO) is a suitable model for this paper's focus question. The MOHO focuses on volition, which is the motivation for occupation; habituation, which is the process of occupation being organized into patterns or routines; and performance capacity, which is the physical and mental abilities that underlie skilled occupational performance (O'Brien, 2017). More specifically, a person's volition and self-determination is what will help the process of transitioning from living at home with one's family to independent living. An individual's interests, values, and personal causation will play a role in the type of role and environment they transition to (O'Brien, 2017). This will also play into habituation as this transition period will change and possibly cause a need for intervention for a person's daily habits, roles, and routines (O'Brien, 2017). One's performance capacity, how a developmental disability affects these abilities, how their family's helped them to accommodate, and how an occupational therapist can assist with this also play a role in this transition period (O'Brien, 2017). Lastly, the constraints and demands of a new physical and

social environment are something an occupational therapist can address by referencing MOHO (O'Brien, 2017).

Purpose Statement

Currently, there is an overall lack of evidence examining the effects of occupational therapy services in the transition process for young adults with developmental disabilities. During the transition process, a young adult becomes more independent. Their families are also making a transition, as they are assisting their young adults in moving out of the family home, and thus, their role as a caregiver is reduced. Occupational therapists are available to provide support for this population, educate them about the resources available within the community, and teach them how to utilize these resources to maximize their independence in daily living. The purpose of this CAT is to define occupational therapy's role and best practices to assist families and young adults ages 18 to 25 with developmental disabilities make this transition out of the home.

Data Collection

The literature search took place from February 18th, 2023 to February 27th, 2023. In the course of the literature searches, a combination of allied health and multidisciplinary databases were utilized, these included Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and Google Scholar. Articles were excluded if they were written for a population outside of the age range of 18-25 years old. The following terms were used to search the databases: "occupational therapy," "occupation-based," "young adults," "adolescents," "transition," "community," "developmental disabilities," "developmental," and "independence." To ensure a refined search, the terms "AND" or "OR" were added between keywords to create database search phrases. With the given parameters, few research studies resulted from these searches. When additional limitations, filters, or exclusion criteria were applied, even fewer results were shown. To compensate for the lack of results, an additional ancestry citation approach was used.

Types of Articles Reviewed

A total of 44 articles were reviewed. Of the literature selected for further analysis, 14 research articles were reviewed more in-depth. One was a Level I systematic review (Santiago & Perez, 2021). Two were a Level III pretest-posttest study design (Højberg & Steffensen, 2008 & Keptner et al., 2016). Two were a Level IV study design (Eismann et al., 2017; Merz et al., 2020). Two were a mixed-method sequential explanatory design (McPherson et al., 2016; Neece et al., 2009). One was a mixed-method exploratory design (Nota et al., 2007). Four were Level N/A studies that used either a qualitative grounded theory approach or a phenomenological approach and semi-structured interviews (Arvidson & Jonsson, 2006; Benson et al., 2020; DuBois et al., 2020; Francis et al., 2019; Renwick et al., 2019). Other resources reviewed included government websites and fact sheets (CDC, 2022), a video analysis (Thompson & Broome, 2021), and two textbooks (Atchison & Powers Dierette, 2023; O'Brien, 2017).

Literature Synthesis

Theoretical Base

The purpose of this critically appraised topic (CAT) was to grasp an understanding of occupational therapy's role in assisting families with young adults with developmental disabilities transition out of the home. This included transitioning into the community, secondary education, or supported independent living. This CAT was grounded in an occupational



perspective using the theoretical-based model, Model of Human Occupation (MOHO). This is because, according to O'Brien (2017) MOHO is, "aimed at explaining aspects of healthy occupation problems that arise in association with illness and disability to help therapists design meaningful and effective interventions" (p.96). This relates as occupational therapists help those with developmental disabilities create interventions during the transition process so they can successfully participate in their meaningful occupations.

In addition, volition plays a significant role in the transition process. A person's volitions and habituation can determine where they transition and what kind of occupations they would like to target during the transition process (O'Brien, 2017). Furthermore, volition can be affected by the completion of new tasks and those with developmental disabilities often feel a sense of accomplishment when they complete these tasks, motivating them to continue (Thompson & Broome, 2021). With this, the concept of self-determination is important as the individual will need to make more choices and will have more control over their lives once they have transitioned out of the home. In a sequential explanatory mixed-methods study, researchers McPherson et al., (2016) concluded through qualitative interviews and the quantitative use of Arc's Self-Determination Scale (SDS) and the General Self-efficacy Scale (GSE) that a strong sense of self-determination in an individual with a developmental disability was correlated with improved life outcomes. Allowing individuals to find their roles in life helps them gain a sense of independence with ADLs and IADLs and allows them to establish habituation, which was found in the results of two-part qualitative thematic video analysis completed by researchers Thompson & Broome (2021). When looking at those with developmental disabilities transitioning to greater independence, ensuring that the proper resources are available for them to have transferable capabilities is important for promoting competence, performance capacity, and enhancing overall participation (Thompson & Broome, 2021).

Impact of Developmental Disability on Occupational Participation and Performance

Developmental disabilities can hinder occupational participation and performance in various ways based on the type of developmental disability, the severity of the disability, one's familial support, and the support of one's community to list a few factors (Benson, et al., 2021; Dubois et al., 2020; Francis 2019 et al.). Virtually all areas of occupational performance can be impacted by a developmental disability. For example, an individual with an intellectual disability such as autism spectrum disorder or down syndrome may struggle the most in the areas of occupation within social participation, education, home establishment and management, safety and emergency maintenance, employment seeking and acquisition, job performance and maintenance, social and emotional health promotion and wellness, and caring for others according a textbook chapter by Young & Suarez (2023), which focused on intellectual disabilities. On the other hand, an individual with a physical developmental disability such as cerebral palsy may struggle more with completing activities of daily living (ADLs) and instrumental activities of daily living (IADLs), functional mobility, education, leisure, physical activity, symptom and condition management, and driving and community mobility according to a textbook chapter by Boisselle (2023), which focused on cerebral palsy.

With these potentially impacted occupations listed above, it is clear that individuals with a developmental disability may face challenges living independently or transitioning to supported living as a result of these impacted occupations. According to a grounded theory secondary analysis, done by researchers DuBois et al. (2020), which gathered information about engagement in community life for those with developmental disabilities through semi-structured interviews. The study findings indicated that the social networks for individuals with a

developmental disabilities are comprised mainly of family members and service providers. In addition, DuBois et al. (2020) found that social inclusion and community integration are important factors to consider for this transition process to increase one's social participation and overall success in the transition process. Ultimately, while having a developmental disability can have the potential to impact participation in all areas of occupation, it is important to consider the unique life experiences of individuals with a developmental disability as they may experience different barriers or supports in their occupational participation. With that being said, there is evidence to support that positive familial support has a positive impact on a young adult's transition process and can lead to increased occupational participation (Benson, et al., 2021; DuBois, et al., 2020).

Family Role/Parental Experiences During the Transition Process

There is evidence to support that familial involvement during the transition process can lead to a more successful transition making the transition process a more positive, supportive process for both the family and the young adult (Benson et al., 2021; Francis et al., 2019). With this, there can be barriers in providing occupational therapy services that fit both the client's and family's needs and expectations. Barriers can include but are not limited to parental exhaustion due to years of seeking out resources for their child, having access to limited services, disagreements with professionals in what they think is best for the young adult, communication breakdowns between parents and professionals, and parents having an overall distrust in professionals (Francis et al., 2019). In a qualitative study by Francis et al. (2019) that captured the lived experience of 26 parents during their young adult's transition through semi-structured interviews; parents identified strategies to support parental involvement during the transition process that included setting high expectations for their young adult to motivate them, providing emotional support for both the young adult and their parents, and providing ongoing information about their young adult's progress to keep parents in the loop and prevent the parents from feeling disconnected from their child as they gain more independence. By utilizing these strategies, occupational therapists can work to not only fit the needs of the young adult but include the family's needs when looking at potential interventions (Francis et al., 2019).

Role of Occupational Therapy in the Transition Process

Benefits of Occupational Therapy

For individuals with developmental disabilities, having an occupational therapist on the transition team has the potential to lead to better outcomes. This is because, according to Benson et al. (2021), an occupational therapist can assist the individual in learning skills to advocate for themselves and help the individual find ways to participate in occupations that are most important to them. Additionally, under the theoretical model of MOHO, an occupational therapist can use their skills to understand a person's volition (O'Brien, 2017). According to O'Brien (2017), understanding a person's volition, or motivations, makes the process more client-centered. This helps the therapist to ensure that the client and their family are reaching their desired goals, and they can therefore create transition interventions that better reach these goals (O'Brien, 2017). This assists in the overall well-being of the client and can lead to better outcomes. How a person's well-being relates to transition satisfaction was demonstrated in a study when researchers Neece et al. (2009) found, in a mixed methods sequential explanatory study examining the transition experience and parental involvement of 128 young adults with disabilities, that as more measures of well-being for the families were met, the more satisfaction a person had with the transition process.



Furthermore, occupational therapists can provide assistance with assistive technology needs, provide assessments or training in areas of work, leisure, and daily occupations, and assist in involvement in work experience (Eismann et al., 2017). Because occupational therapy utilizes a holistic approach, occupational therapists are able to assist with this wide variety of occupations and roles (Arvidsson & Jonsson, 2006). This is also important to keep in mind when working with different cultures, as roles and meanings of occupations can alter depending on societal and cultural norms. (Arvidsson & Jonsson, 2006; Benson et al., 2021).

Limitations of Occupational Therapy

Although there is a sufficient amount of literature on occupational therapy's role and best practice in assisting families with young adults with developmental disabilities transitioning out of the home, larger sample sizes in future studies need to be included to obtain more evidence to support interventions as certain data reported may not be reflective of all populations (Benson et al., 2021; DuBois et al., 2020; Merz et al., 2020; Nota et al., 2007). Even though occupational therapy can positively impact the transition process, Eismann et al., (2017) found that less than 7% of young adults with a developmental disability received occupational therapy services, emphasizing that occupational therapists have a limited role in the transition process. Occupational therapy's role in helping establish skills for independent living and support has great importance that needs to be better understood and advocated for. It is imperative that occupational therapists establish their role and importance on the interdisciplinary team when working with young adults with a developmental disability.

Summary

Overall, 44 research articles were reviewed, and 14 were chosen for further review. The literature included information on optimizing life success for those with disabilities, the transition process for adolescents with developmental disabilities, the impact of aids on independence and autonomy, and familial roles during the transition process. The following are some main points:

- Developmental disabilities can hinder health and education as well as low self-esteem. This can result in a lack of social participation for an individual trying to become independent, but with the proper support and resources one's social engagement and overall social participation can increase (Benson et al., 2021; Boisselle, 2023; Dubois et al., 2020; Francis et al, 2023; Young & Suarez, 2023).
- Occupational therapists play a role in the transition process by helping establish one's necessary roles and routines (Arvidsson & Jonsson, 2006; Eismann et al., 2017; McPherson et al., 2016; Renwick et al., 2019) and providing support in all environments such as home, work, and community (Benson et al., 2021; Dubois et al., 2020; Nota et al., 2007; Renwick et al., 2019).
- Occupational therapists should utilize a client-and family-centered approach in developing interventions that include but are not limited to creating programming for social and community participation, employment, and independent living (Benson et al., 2021), utilizing interventions that can improve self-efficacy skills and self-determination (Benson et al., 2021; McPherson et al., 2016), and utilizing interventions that promote improvements in areas of occupation such as activities of daily living and/or instrumental activities of daily living to improve one's performance capacity and their overall independence in their occupations (Benson et al., 2021).

The objective of this CAT was to examine the way occupational therapy played a role and applied best practice to meet the needs of adolescents and their families with developmental



disabilities to make the transition to independent living with the use of volition and habituation. A review of the literature gathered suggests that there is limited information on the most effective best practice for occupational therapists at this time due to small sample sizes and lack of research, but there are some current best practices that occupational therapists can use with this population.

Clinical Bottom Line

The focus question of this CAT is, what is occupational therapy's role and best practice in assisting families with young adults with developmental disabilities transition out of the home into the community, secondary education, or supported independent living? Current literature supports a client and family-centered transition and recognizes the impact and support the family can provide for the individual during this time (Benson et al., 2021; Francis et al., 2019; Neece et al., 2009). Although a family-centered transition is best practice, barriers to familial involvement include but are not limited to, parental exhaustion due to years of seeking out resources, parents having a lack of information about their child's care, having limited access to services, disagreements with professionals, communication breakdowns between parents and professionals, and an overall distrust in professionals (Francis et al., 2019). In addition, it seems that few individuals with disabilities and their families received occupational therapy services despite evidence showing that it is beneficial (Benson et al., 2021; DuBois et al., 2020; Eismann et al., 2017; Merz et al., 2020; Nota et al., 2007). The barriers of many not receiving OT services during the transition highlight why it is important for occupational therapists to take the time to build rapport and use person-centered assessments in getting to know their clients and their family during the transition period.

As previously stated, the addition of occupational therapy services when transitioning can be beneficial. The occupational therapist, with the addition of other professionals, can aid in providing support for the family, teaching new skills, advocating, and more (Benson et al., 2021). These strengths of having OT services show the importance of involving OT in the transition process. In addition, the collaboration between and the active participation of relevant stakeholders can also positively impact the transition process as this ensures that each member of the transition team understands their role (Benson et al., 2021; Francis et al., 2019).

More specifically, occupational therapists' role in the transition process for those with developmental disabilities is to support clients by creating individualized goals through coaching life skills (Santiago Perez & Crowe, 2021) Current best practice utilizes facilitating learning where the client is being taught to acquire, retain, and apply knowledge and skills to independent living (Benson et al., 2021; Dubois et al., 2020; Eismann et al., 2017; McPherson et al., 2016; Merz et al., 2020; Renwick et al., 2019). Theoretically, it could also be beneficial to look through this transition process through the lens of MOHO. This is because the person factors (volition, habituation, performance capacity) of those with developmental disabilities can impact their transition out of the home into the community, secondary education, or supported independent living (O'Brien, 2017). Further, an occupational therapist can help develop and strengthen one's habituation, which can allow the individual to become accustomed to their surrounding environment promoting competence and self-efficacy in their roles and routines (Arvidsson & Jonsson, 2006; O'Brien, 2017).

As noted above, there are benefits to having occupational therapists involved in the transition process for those with developmental disabilities. Still, there is a lack of documentation regarding occupational therapy's role in the transition process. This poses a problem, as an occupational therapist needs to back up their practice with the best evidence in



order to illustrate to other professionals and stakeholders the importance of their role. This being said, occupational therapists would benefit from further research being done in this area of practice, with specific emphasis on the role of occupational therapy.



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