

Camp New Hope

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## **Introduction**

Did you know that approximately 61 million adults in the United States live with a disability (Centers for Disease Control and Prevention, 2020)? The special needs population is growing and needs support from the community. Parents of special needs experience high stress due to needing multiple therapists and specialists due to multiple diagnoses. Nurses need to advocate for their patients and know their needs to receive their care, and help relieve a large amount of stress that parents carry. Patients with special needs require a large interdisciplinary team, including physical and occupational therapy, speech therapy, nutrition, providers in different specialties, case management, and many more people in the health care field. When caring for special needs, it is good to have a large background of different disabilities and how to go about their daily care, activities, communication, and providing safe and efficient care; caring for a special needs child can be exhausting for parents. Hence, a summer and weekend program allows them to break from 24-hour care and relieve some stress. Our group was blessed to serve at New Hope Camp, a summer and weekend camp for the special needs population in central Illinois. They are located on Lake Mattoon and provide a year-round experience for eight-year-olds and older with developmental and physical disabilities. They provide total care for their campers, such as helping with their activities of daily living, cooking, cleaning, and providing entertainment. The campers can do many activities, including fishing, boat rides, train rides around trails, playing on the playground, minigolf, games, crafts, and many more activities. Family members need breaks to relieve the stressful everyday duties of caring for a special needs child. The special needs population is growing, requiring significant support from nursing, physical and occupational therapy, speech therapy, nutrition, case management, and many more healthcare team members.

Sarah Evans:

### **Parental competence among parents with autistic children: A qualitative study**

Parents of children with special needs often struggle with lack of support, stigmas, misunderstandings about their child, and psychological distress related to health care. A qualitative research study found that care coordination across disciplines can help address and alleviate many of these challenges. Care coordination can enhance interdisciplinary, holistic care of the child and help bypass many barriers to health care access perceived by the parents (Wan-Yaacob et al., 2021). Many children with special needs have multiple diagnoses and require the care of multiple therapists and specialists. Additional training is necessary to teach these professionals how care coordination can improve health outcomes for children with special needs (Wan-Yaacob et al., 2021). If health care professionals learn to coordinate care, this will also help alleviate stress from the parents of special needs children. The study also found that care coordination can help families experiencing insurance problems and other financial difficulties (Wan-Yaacob et al., 2021). For example, suppose a physical therapist identifies the need for a child to have an adaptive bed to promote safety. In that case, they can consult with the primary care provider to obtain a referral. Asking other health care team members to write letters of necessity for the bed can encourage health insurance companies to approve the request. This type of care coordination can take some unnecessary stress off the parent. In the past, the parent would get a recommendation from the physical therapist, request the referral from the primary care physician, and then wait on insurance to approve or deny the claim. Without additional support from other health care team members, insurance would often work together with parents and meet these needs more effectively.

## **Behind the Scenes of Parents Nurturing a Child with Autism: A Qualitative Study in Malaysia**

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Claire Guyon:

### **Experiences of adults with intellectual disabilities accessing acute hospital services: A systematic review of the international evidence**

McCormick et al. (2021) found a sense of disrespect and undervaluing adults in the acute hospital setting while they were receiving care. People with disabilities may need more time to care for themselves due to their additional needs. Health care workers should be aware of this fact. Health care professionals must recognize that these patients deserve the same amount of respect and care as a healthy adult without a disability - whether it be physical or mental. This study aimed to find out about people's experiences with intellectual disabilities during their healthcare stay (McCormick et al., 2021). Study results revealed that healthcare professionals lacked proper communication with patients with intellectual disabilities (McCormick et al., 2021). Patients with intellectual disabilities deserve to be informed about their treatment plans and care. This research study recommended that hospitals engage with patients with intellectual disabilities, make changes to ensure proper and reasonable accommodations, and be aware that they should be valued as though they did not have a disability (McCormick et al., 2021).

#### **Implementing reasonable adjustments for disabled people in healthcare services**

According to Heslop et al. (2019), disabled people are most at risk for barriers to adequate health care. People who have an impairment do not define who they are as individuals. According to this study, people with disabilities are at greater risk of low income, substandard housing, and inadequate healthcare. The needs of disabled people should be addressed holistically by health care providers. Nursing and medical staff need to understand that these people may need a little extra attention, and they will need an explanation of their care that is easy for them to understand. Among the reasonable adjustments discussed was the possibility of

altering physical features to help benefit these people. Maybe that means installing an elevator to enable wheelchair users to access other floors besides the main floor. It is easier for disabled people to bathe by installing a shower or bathtub with a seat to avoid having to stand. In addition to the person with the disability, these adjustments can be beneficial to the caregivers or health care personnel to optimize the best possible quality of life for these people.

Jamario Jefferies:

**Nurses' experiences of caring for patients with intellectual developmental disorders: a systematic review using a meta-ethnographic approach**

Nursing students undergo rigorous coursework for two to four years throughout nursing school. The students participate in pediatric, maternal-obstetrical, mental-behavioral health throughout that time. New graduate nurses are well-versed in most specialties of nursing. However, nursing students and some nurses lack training in interacting, communicating with, and providing care for the special needs community and those with intellectual disabilities. Nurses are likely to experience an encounter, provide care, and advocate. Research has shown that some registered nurses (RNs) do not feel adequately prepared to support patients with intellectual disability disorder (IDD) (Appelgren et al., 2018). The health promotion of patients with IDD should be a universal concern to all nurses (Appelgren et al., 2018). A significant challenge in nursing patients with IDD is that the nurses do not feel adequately prepared to support their health needs (Appelgren et al., 2018). The researchers used a systematic review and meta-ethnography (Appelgren et al., 2018). Their results are that lack of awareness and knowledge is likely the breeding grounds for the sense of inadequacy in caring for IDD (Appelgren et al., 2018). Nurses should undertake appropriate under- and postgraduate education

alongside the implementation of nursing models focusing on patient-centered care that would help nurses care for patients with IDD.

### **Occupational Therapy in Children with Special Needs: Systematic Review Oral Health and Autism Spectrum Disorders: A Unique Collaboration between Dentistry and Occupational Therapy**

Children with special needs are significantly different from other children (Asya et al., 2020). Special needs children (SNC) are physically, psychologically, cognitively, and socially obstructed in achieving their goals and potential to the fullest such as autism (Asya et al., 2020). For their study, the researchers aimed to determine the provision of effective occupational therapy in children with special needs (Asya et al., 2020). Furthermore, their results indicated that all occupational therapy could help improve physical and mental development in children with autism (Asya et al., 2020). Children with autism can carry out daily activities like children, in general, and improve their quality of life. (Asya et al., 2020). In support of the finding in this first article, there is a noticeable correlation between children with autism and poor oral health (Como et al., 2020). As a previous dental professional, oral health is essential. Hindrances include difficulty tolerating home and professional oral care, sensory processing differences, uncooperative behaviors, communication impairments, and finding and accessing professional care services (Como et al., 2020). Researchers have noted that the collaboration between occupation therapy and dental practitioners can modify the dental environment and adapt dental protocols to reduce barriers (Como et al., 2020). In closing, the researchers noted a considerable difference in the temperament of children with autism throughout dental visits (Como et al., 2020).

Mallorie Mason:

## **Provision of Reproductive Healthcare to Women with Disabilities: A Survey of Obstetrician–Gynecologists' Training, Practices, and Perceived Barriers**

The definition of a disability is a physical or mental impairment that limits a person's significant life activity. Women with physical and cognitive disabilities are more likely to receive poor reproductive healthcare services than women without disabilities. Breast and cervical cancer screening for women with disabilities are less frequent than women without disabilities. Women with disabilities are more likely not up-to-date on their mammograms, pap smears, pelvic and breast examinations (Taouk et al., 2018). Women with disabilities experience lower education in family planning services, contraception counseling, and how to handle their pregnancies. A study conducted by Taouk et al. (2018) tried to explore obstetrician-gynecologist current awareness, attitudes, and training regarding the reproductive care of women with disabilities. The study aimed to identify barriers that explain the lack of reproductive care women with disabilities receive. The researchers used a survey questionnaire to identify the aim of their study. The sample size included 308 obstetricians- gynecologists. The study's findings concluded that training deficits, a deficit in knowledge, and unawareness of guidelines are barriers that can prevent obstetrician-gynecologists from providing confident reproductive healthcare to women with disabilities (Taouk et al., 2018).

## **Primary Care Providers' Perceived Barriers and Needs for Support in Caring for Children with Autism**

Children with autism spectrum disorder (ASD) have a high significant need for healthcare due to their complex developmental challenges, mental health conditions, and high rates for other co-occurring medical diagnoses (Mazurek et al., 2020). Children with ASD experience worse access to healthcare and unmet needs than other children with other

developmental conditions or no disabilities. Many primary care providers struggle with giving the best healthcare services to children with ASD. Many primary care providers receive little training in ASD in school, resulting in a lack of knowledge and confidence when caring for a child with ASD. A study conducted by Mazurek et al. (2020) examined the perceived barriers in providing care for children with ASD. The sample size of the study included 114 primary care providers. The 114 primary care providers answered questions through a survey. The study results concluded that the most significant barrier to providing care to a child with ASD was a lack of confidence in managing behavior, lack of time, and knowledge about autism resources. Fifty-seven percent of the primary care provider participants believe that lack of prior training in autism is a barrier when caring for a child with ASD (Mazurek et al., 2020).

Tresne McCarty:

### **Optimizing the Care of Children with Intellectual Disabilities in Hospital**

When caring for a child with an intellectual disability, the nurse must ensure value and respect for the child. The nurse must reflect on her own biases and know that each child needs support when hospitalized (Glasper, 2017). Dr. Edward Glasper (2017) wrote a research article explaining how implementing preadmission programs for children with disabilities is a way to prepare them for admission. The program includes child life specialists and play therapists, utilizing therapeutic play since it is vital to children's development (Glasper, 2017). Also, using Erikson's stages of psychosocial development determines the type of therapeutic play used for each child. For example, if toddlers have to have shots, they are more likely to be scared and nervous of needles. Using therapeutic play would include taking stuffed animals or dolls and giving them an injection to help ease the child's mind. Having a child life specialist and play

therapist mitigates any fears and phobias intellectually disabled children may have and ensures each child receives the highest level of care.

Another way to improve inpatient care for children with disabilities is to require hospitals to have a "flagging" system that makes intellectually disabled children more visible to the healthcare team (Glasper, 2017). The "flagging" system is a part of the child's electronic health record that includes the type of disability, likes, dislikes, and how they express pain (Glasper, 2017). Implementing this system is an excellent way for the healthcare system and families to collaborate. Parents and caregivers of children with disabilities will feel more at ease.

### **The Disparities of Healthcare Access for Adults With Autism Spectrum Disorder**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that impairs social communication and interaction skills (Calleja et al., 2019). The diagnosis of ASD usually develops in childhood by age 5 (Calleja et al., 2019). Individuals with ASD are known to be aggressive, disruptive, and exhibit self-injuring behaviors (Calleja et al., 2019). To accurately identify the disparities experienced by individuals with ASD, researchers must first determine the level and appropriateness of access to healthcare services (Calleja et al., 2019).

The goal is to promote health equality and reduce health disparities for individuals with disabilities. Individuals with intellectual disabilities have a higher prevalence of alcohol use, drug use, sexually transmitted infections, hypertension, and seizures (Calleja et al., 2019). These individuals have unmet healthcare needs due to the lack of access to appropriate healthcare services (Calleja et al., 2019). Having access to healthcare can improve these individuals' quality of life and bring them to an optimal state of health. Many intellectually disabled individuals suffer from psychiatric disorders resulting from social challenges, lack of appropriate

interventions, and challenges with accessing healthcare (Calleja et al., 2019). Thus, having access to healthcare also reduces their risk for comorbid psychiatric disorders.

### **Conclusion**

The special needs population is growing, requiring significant support from nursing, physical and occupational therapy, speech therapy, nutrition, case management, and many more healthcare team members. People with special needs face many different barriers, especially in the health care field. Camp New Hope does an excellent job advocating and caring for all the campers who walk through their doors. Many special needs patients lack care due to a communication barrier, requiring extra advocacy. Communication with the entire health care team when working with special needs patients is essential to ensure they get the most outstanding quality of care possible.

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