Children with Disabilities: Advocacy & Education

Pamela Herendeen, DNP, PPCNP-BC
Associate Professor of Nursing
St. John Fisher College
Senior Nurse Practitioner
Golisano Children’s Hospital

Speaker Introduction

• Dr. Pamela Herendeen is a PNP who has practiced for more than 25 years; serving a population of high risk, vulnerable families. Dr. Herendeen has also been an educator for many years. She is currently a professor of nursing at St. John Fisher College in Rochester, N.Y. teaching undergrad through doctorate levels.

Disclosures

This speaker has no disclosures

Learning Objectives

• Recognize the lack of educational resources for children with intellectual & developmental delays
• Describe the innovative educational model discussed
• Identify resources to utilize in the clinical practice and nursing educational curricula

Prevalence

• Recent estimates of children with intellectual & developmental disabilities (IDD) is at 17% of the population (CDC, 2019)
• Prevalence of autism has also grown significantly; in 2018 CDC estimated 1 in 59 children were diagnosed; grew from 1 in 150 children in 2000 (Nierengarten, M., 2019).
• Spending on disability related services is high; however it has been noteworthy that the benefits outweigh the cost financially & clinically; however, financial barriers remain significant

A Bit Of History

• Helpful to know where we have been, to guide where we are now, and going forward
• Throughout history, people with disabilities have been treated differently
  • Examples include:
    • Killed or abandoned in ancient Greece
    • Infanticide during the Renaissance
    • Drowned & burned during the Spanish Inquisition
    • Divided into a group called “helpless poor” by Queen Elizabeth in 1601
    • Kept in cells in early colonial America
    • Dehumanized in orphanages & asylums in Europe and America; often shackled
    • Institution for Idiots founded in Massachusetts in 1800s
    • Involuntary sterilization of people with developmental disabilities in 1907 so not to pass on inferior traits; considered defective and interfering with process of natural selection
    • Aversion, seclusion, victimized, restrained, abused
More History

- In World War 2, adults with disabilities were allowed to join the workforce proving their competence
- Civil Rights Movement in the 1960’s created a more favorable environment for people with differences
- Appropriate education was advocated by Presidents’ Truman, Kennedy, Johnson, Reagan, Ford, Bush, Clinton, Bush
- Public Law 94-142, Education for All Handicapped Children Act of 1975, drastically changed laws
- Each decade added more provisions and improved attitudes; not just allowing, but welcoming children with differences into the classroom

What About Willowbrook?

- Willowbrook was a state supported institution for children with disabilities on Staten Island; it ran from 1947-1987.
- Willowbrook had a maximum capacity of 4,000 residents, but by 1965 there were more than 6,000 living at the school.
- The residents housed there suffered violations of human and civil rights in various forms of severe abuse, neglect, and violence; known as the “snake pit”
- Many unethical medical experiments were conducted, including injecting healthy children with live hepatitis to observe the disease course
- WABC-TV’s Geraldo Rivera conducted an investigation inside Willowbrook to determine living conditions and the extent of abuse that had gone on.

Willowbrook

- In 1965 Senator Robert Kennedy toured the facility and described it as “children living in filth, dirt, rags; rooms less comfortable and cheerful than cages we put animals in the zoo in”
- Recommendations were put forth and conditions improved slightly
- In the 1970’s, a journalist posing as a social worker, along with social workers that worked at Willowbrook, uncovered deplorable conditions; these observations were published
- Geraldo Rivera then picked up the story “The Last Great Disgrace” for which he won a Peabody Award; he also hosted other TV specials on Willowbrook
- In 1983, public outcry and new legislation forced the closing of the institution with the last children leaving in 1987
- Subsequently, it was noted that the institution housed murderers and kidnappers as employees; at least one body was found buried

What Happened Next?

- After Rivera’s reporting, a class action lawsuit was filed against NYS by the parents of Willowbrook patients.
- 1975: NY Governor Carey signed consent decree
  - Established that residents of Willowbrook had a constitutional right to be protected from harm and required NY state to take immediate steps to improve the lives of those who lived there and to “ready each resident...for life in the community at large” and called for the placement of Willowbrook residents in the “least restrictive and most normal living conditions possible.” These included making sure residents were provided with basic necessities like clothing, given opportunities to leave their beds, interact with the community, and be provided with therapy and vocational services.

What Happened Next?

- The shameful legacy of Willowbrook guided a generation of policy makers and advocates to the profound recognition that to be truly free from harm, individuals with disabilities must be provided with services in the least restrictive environment that meets their needs in places that most look, feel, & operate like a home
- We have come a long way...but much change is still needed
- It is in the education that we need to address this change
New Visibility

- Unfortunately this visibility did not automatically translate into acceptance to all school personnel, community, other parents and students
- Dependent on prior background and experiences, cognitive levels, social skills, educational levels, comfort level & self esteem
- Many parents & students still try to hide disabilities secondary to fear of being judged and viewed differently “labeled”

Brief List of Policies

- 1947-President’s Committee on National Employ the Physically Handicapped Week established: Truman
- 1954-Brown vs. Topeka Board of Education had a major impact on integration and civil rights movements
- 1962-Executive Order by Kennedy removed the word “physically” from the President’s Committee name to include other disabilities
- 1965-ESEA Federal Education Law applied to funding K-12 for development of resources: Johnson
- 1973-Rehabilitation Act prohibited businesses to discriminate employment on basis of disability (Section 504)

Policies

- 1975-Education for All Handicapped Children Act mandates all children with disabilities be granted a free & appropriate public education in the least restrictive environment
- 1990-Americans with Disabilities Act of 1990 (ADA) A Dream Actualized
- 2004-Individuals with Disabilities Education Improvement Act of 2004
- Gradually barriers have been erased by removing inaccessible facilities and replacing with appropriate environments

Is There a Need For More Education?

- Many general health care providers describe inadequate training to appropriately diagnose and care for children with IDD
- Providers also express a lack of knowledge on how to prescribe necessary services, what resources are in the area, what patients are eligible for these resources, and how to obtain them
- Hospital nurses often at a loss how to manage these children when in‐patient; their illness and environmental change often escalate already challenging behaviors

The Why: Individuals with IDD experience poorer health outcomes, and are at greater risk of disparity and poorer social health determinants including:

- Complex health conditions
- Decreased cancer screenings and preventive services
- Poorly managed chronic diseases
- Undetected vision problems
- 7 x more likely victim of sexual assault
- Additional mental health problems
- Limited access to healthcare services
- Being unemployed
- Under educated
- Lower income

Healthcare Needs

- Individuals with IDD have a greater need for healthcare; however, disability has been found to be a risk factor for dissatisfaction and disappointment with healthcare encounters.
The Patient

- Patients with IDD are recognized as an underserved population that experience significant disparities in healthcare.
- Medical advancements are allowing IDD individuals to live longer, but with increasing secondary chronic illnesses.

How Can I Be Better?

- One way in which medical encounters can be improved is through enhanced communication.
- Effective nurse/provider-patient communication is essential for establishing strong patient relationships and working to eliminate health disparities.

Communication

- Regardless of the patient or diagnosis, it is important to remember that the basis of communication with IDD patients is treating them with dignity and respect.
- Every child with IDD is strongly recommended by the AAP to have a medical home.

Building Rapport

- Always begin your interview by explaining the purpose of the encounter and establish communication preferences. The patient may require the use of assistive communication devices or interpreters.
- Practice triadic communication. Depending on situation, you may address the child along with the caregiver; use their caregiver to help facilitate communication.

Relationships

- Effective communication and a positive provider/patient relationship begins with dignity and respect; regardless of the patients’ cultural, socioeconomic status, background, or abilities.
History Taking

• Explain the purpose of your questions
• Be sure to focus on the patient’s chief complaint – do not focus solely on their disability.
• Ask questions directly to the patient if possible; otherwise the caregivers.
• Allow the caregiver to fill in information or provide additional details that the patient may not be able to give.
• Take advantage of the knowledge/insight that the individual/caregiver can provide about their health and disability.

Screening Tools

• ESAC (Early Screening for Autism & Communication Disorders)
• Infant/Toddler Checklist
• SWYC/POSI (Survey of Well-Being of Young Children/Parent’s Observations of Social Interaction)
• ASQ (Ages & Stages (AAP recommends screening at 9 month, 18 months & 30 months)

The Exam

• It may be necessary to adapt the physical exam
  • Do not avoid any component of the physical exam that you think may be difficult to complete or hard for the patient to comply with – patients and caregivers expect the same kind of treatment and attention
  • Offer assistance when it is needed; wait until that offer is accepted before stepping in.

Emergency Department Setting

• High environmental stimulation
• Results in increased anxiety, agitation, aggression, fear
• Providers/nurses not always knowledgeable/experienced
• Consider wherever possible reducing environmental stimuli (dimming lights, lower monitor volume, limit traffic, soft voices)
• Provide excellent communication to family
• May need to prioritize
• Child Life Therapist helpful

Timing Is Everything

• Appointments for patients with IDD will most likely take more time. It may be helpful to schedule appointments at the very beginning or end of the day depending on practice and patient
• Most importantly, talk with the family to gather their input on the best time of day for them to come in
Hospital Setting

- Similar situation to ED but may be a prolonged stay
- Staff nurses, residents, providers all are requesting and need training in caring for this population of children
- Child Life essential
- Set up a schedule with patient/parents regarding meds, rounds, procedures whenever possible
- Discuss what has worked in the past for certain meds and procedures
- As with any child; painful procedures should not be done in the room, but a procedure room; combine whenever possible
- Reduce environmental stimuli whenever possible

Assessment & Diagnosis

- Do not assume that there is a correlation between symptoms and disability – patients with IDD have many of the same secondary and chronic conditions as the general population.
- Beware of ‘diagnostic overshadowing’. Often, symptoms are automatically attributed to the patient’s disability.

Child Abuse & Children with Special Needs

- Every year about 700,000 children are confirmed victims of child abuse/neglect in the US
- Encompasses physical, sexual, psychological, medical
- Children with special needs may increase caregiver burden
- These children require additional levels of experience, expertise and resources; very fragile
- Difficult to determine if the disability is the precipitator of the abuse; or whether abuse caused the disability
- Landmark study in 2000 noted that children with disabilities were nearly 4 times more likely to be abused (Sullivan & Knutson, 2000)

Risk Factors & Causation of Child Abuse for this Population

- Lack of social support for caregivers
- Societal stigma and ignorance within communities
- Caregiver stress
- Increased abuse among children with a low IQ, limited verbal skills, anxious or withdrawn-easy targets
- Children who are dependent on others for assistance with self care are at a higher risk (used to frequent touching and may not recognize inappropriate contact or very trusting of others)
- Often these children have challenging behaviors that don’t respond to traditional methods of discipline
- Family may be experiencing additional physical, economic, emotional and social demands—overwhelmed
- Group homes
- Perpetrators believe that the child with disabilities will not be believed

Treatment & Plan

- Explain your findings in appropriate terms.
- Assure understanding of both the patient and the caregiver. Avoid medical jargon and make sure to use clear, concise language.
- Provide patients and caregivers with appropriate materials to take home with them. Try to use adapted literature that uses visual aids and is in “easy read” format.
- Easy read materials are written at an elementary reading level, include visual aids and are written in clear and concise language
- AAP strongly recommends that children with IDD are enrolled in a medical centered home that will provide ongoing, lifelong care that is comprehensive, coordinated, family centered

Autism

- Careful history and physical exam
- Careful attention to family history, observable behaviors, parent reported behaviors, eating/sleeping patterns
- Evaluate risk factors (advanced parent age, sibling, meds/supplements taken during pregnancy)
- Specific tools include *M-CHAT (Modified Checklist for Autism in Toddlers), SCQ (Social Communication Questionnaire), STAT Screening Tool for Autism in Two Year Olds)
- Consider referral to an autism center; genetic testing (chromosomal array & Fragile X)
Autism

Interventions include:
• Services preschool and school
• Therapy including motor skills, speech, parent training, behavioral training
• Treatment of co-morbidities
• Sensory processing
• Social communication skills
• Elopement prevention: nearly 50% of children with ASD attempt wandering from a safe place; especially attracted to water. 17% of wanderers result in death

Special Olympics

• Special Olympics (SO) has developed strategies and principles to support these individuals with health disparities and barriers
• Research conducted by SO confirmed that there are significant health disparities between individuals with differences compared to the general population
• Four strategies include:
  • Welcoming Spaces
  • Communication
  • Awareness & Training
  • Sustainable and Intentional Inclusion
• For a full list of principles and initiatives, along with more details go to: https://media.specialolympics.org/resources/health/inclusive
  • https://cdc.gov/ncbddd/disabilityandhealth/disabilitystrategies.html

The Generous Gift

• On October 30, 2018, at St. John Fisher College (SJFC) in Rochester, N.Y., Tom Golisano of The Golisano Foundation, announced the creation of The Golisano Institute for Developmental Disabilities Nursing, thanks to a 5.8 million dollar gift. SJFC is fully committed, allocating significant in-kind support
• The Institute will be fully integrated into the SJFC Wegmans School of Nursing and is designed to transform the healthcare and support of individuals with intellectual and developmental disabilities

Golisano Institute for Developmental Disabilities Nursing

Vision
• Improving the health care and outcomes for individuals with IDD through the provision of reliable quality care that promotes their well being
• Academia
• Leadership
• Advocacy
• Partnerships
• Health Policy

Mission
• To generate an international cadre of health care professionals prepared with the knowledge, skills and competencies to effectively support individuals with IDD throughout the life span and across settings

Team Collaboration Model

• Director & Co-Director
• FNP, PNP, Psych NP to start with
• Partnering agencies in the area
• Relationships have been forged with experts in the field locally, nationally & internationally
• Formal partnerships in Ireland, Spain, Slovenia will be utilized; along with the network of Golisano hospitals, community health centers and Special Olympics
• Many more partnerships in progress....

Center Of Excellence in Developmentally Disabilities Health Care

• Support
  • Internationally Recognized Curricula
  • High Impact Learning Practices
  • Micro-Credential/Badging
  • Undergraduate and Post Masters Certificates
• Scholarship
  • Collaborative ventures
  • Best Practices
  • Sharing ideas and more collaboration
• Leadership
  • Golisano Summers Fellowship Program; in the process of being developed for the future
  • Summit planned for this summer to gather information from international leaders to determine what a fellowship program should include
  • An Advisory Board formed and will meet for the first time this spring
Integration
• Curriculum development
• Will cross all programs: undergraduate, graduate, and doctoral
• A variety of learning methodologies will be utilized
• Students will be placed in a variety of clinical settings to enhance their learning
• Collaboration will be key

The Need
• Essential to build a nursing workforce with necessary knowledge is critical for nursing to make a sustainable impact translating knowledge to practice to improve the health and health outcomes for children families and communities
• The nursing profession is in an influential position to reframe how health care is delivered for this population
• Current advancements in health care have helped to improve the life expectancy of individuals with disabilities; however quality health care is still a challenge
• This population has difficulty finding timely medical treatment, age appropriate health care, transition from peds-adult care, and specialists
• Current health care inequities are often due to the limited number of health professionals trained

The How
• To initiate integration, faculty with expertise in curriculum development to collaborate with experts in the field
• Work closely with peer faculty to determine what information needs to be delivered and when
• Considerations will include level of student, course, method of delivery, clinical setting
• Starting this semester, we began with one of the main team members presenting a class in certain courses, at both undergrad and graduate levels
• Faculty working with the team to also integrate key components throughout the course for reinforcement and application

Methodologies
• Lecture & discussion
• Avatars being developed for undergrad and grad scenarios
• Clinical settings
• Guest lectures from experts in the field
• Case studies
• Parents of disabled children

Short Term Outcomes
• Identify and create a physical presence for the Institute
• Establish an advisory board
• Begin to develop and implement an integrated, technology enriched curriculum that weaves specific skills across all levels
• Micro-credential format for a credit bearing undergraduate and graduate elective course
• Simulation training
• Establish nurse practitioner residencies in collaboration with the Complex Care Center in Rochester
• Scholarship through publications and presentations

Short Term Outcomes
• Establish an information center of best practices
• Increase access to quality health care at the regional level
• Continue to create collaborative relationships, locally, nationally and regionally
• Work with professional nursing organizations to add content on the care of this population to their agendas
Long Term Outcomes

- Enhance access to reliable and quality care for people with disabilities nationally
- Contribute to the field of IDD health care
- Implement the Summer Fellow Program
- Offer post graduate certificates in IDD health care in a hybrid format
- Convene national symposiums for interdisciplinary thought leadership in the field
- Continue to recruit and collaborate with national expertise on IDD
- Collaborate with other nursing schools nationally with the objective of all nursing curriculums are rich with curriculum on individuals with IDD
- Patient consultations, especially with in patients or long term health settings, schools utilizing phone, on-line, site visits and telehealth technology

The Long Term Dream

- Establish a center in Rochester that will offer multiple services for individuals with IDD
- Currently looking for a location that will house not only office space for the members of The Institute, but also offer space for conferences, the fellows program, and other local, regional, national, and international meetings
- Services that may include assessments, therapy, education, meeting space for families and so much more…
- A national center of excellence to serve and educate nurses, providers, community on the best care for individuals with differences

“There is no greater disability in society than the inability to see the person as more.”

Robert M. Hensel

References