NLN EDUCATION SUMMIT

ASK & MOSAIC
Interprofessional Disability Education for Nursing Students

Allison P. Edwards DrPH, MS, RN, CNE, CDDN

Conflicts of Interest and Disclosures:

Neither the planner(s) or presenter(s) indicated that they have any real or perceived vested interest that relate to this presentation.

OBJECTIVES

- Define the ***prevalence of disabilities*** and understand the impact of negative attitudes, deficient knowledge and skills of health care providers on existing disparities of this population.

- **Describe the *educators' role*** in establishing disability education utilizing established objectives derived from national competencies and existing curricula and resources.

- Identify, discern and evaluate valuable interprofessional didactic and clinically immersive experiences- and their impact and outcomes on student's attitudes, knowledge and skills for care of people with disabilities

Acronyms

- **ASK:** **A**ttitudes/**S**kills/**K**nowledge
- **MOSAIC:** **M**entoring **o**ur **S**tudents to **A**chieve **I**nterprofessional **C**ollaboration
- **PWD:** people with disabilities
- **PWID:** people with intellectual disabilities
- **IDD or ID:** intellectual and developmental disabilities/intellectual disabilities
- **ASD:** autism spectrum disorder
- **CP:** cerebral palsy
- **DS:** Down Syndrome
- **SCI:** spinal cord injury
- **NDD:** neurodiverse or neurodevelopmental disability
- **TBI:** traumatic brain injury
- **ADA:** Americans with Disabilities Act


KEEP
CALM
AND
EMBRACE
DIFFERENCES

Americans with Disabilities Act's (ADA) Definition of Disability

- a physical or mental impairment that substantially limits one or more major life activities
- a record or history of such an impairment, or
- is regarded/perceived by others as having such an impairment.

The American with Disabilities Act of 1990
http://www.ada.gov/pubs/ada.htm

Categories of Disabilities

BROAD RANGE encompassing many facets
ACROSS LIFESPAN

Intellectual/ Developmental Disabilities: or syndrome specific- autism, Down Syndrome (DS), cerebral palsy (CP), Fragile X

Functional Disabilities or Progressive: traumatic brain Injury (TBI), Alzheimer's, Parkinson's, multiple sclerosis, vertebral injuries, myasthenia gravis, amyotrophic lateral sclerosis (ALS)

Cognitive Disabilities: intellectual/developmental disability (IDD), attention deficit hyperactivity disorder (ADHD), dementia/Alzheimer's, TBI, CP

Chronic Disabilities or Acquired: acute (spinal cord injuries); cerebral vascular accident (CVA), ALS, amputee


DEVELOPMENTAL DISABILITIES
Intellectual Disability
Down Syndrome
Fragile X Syndrome
Cerebral Palsy
Attention Deficit Hyperactivity Disorder
Autism Spectrum Disorder
Fetal Alcohol Syndrome
Epilepsy

INTELLECTUAL DISABILITY:

Defined as a below-average cognitive ability with 3 characteristics:

1. I.Q. is between 70-75 or below
2. Significant limitations in the ability to adapt and carry on everyday life activites such as self-care, socializing, communicating, etc.
3. The onset occurs before age 18

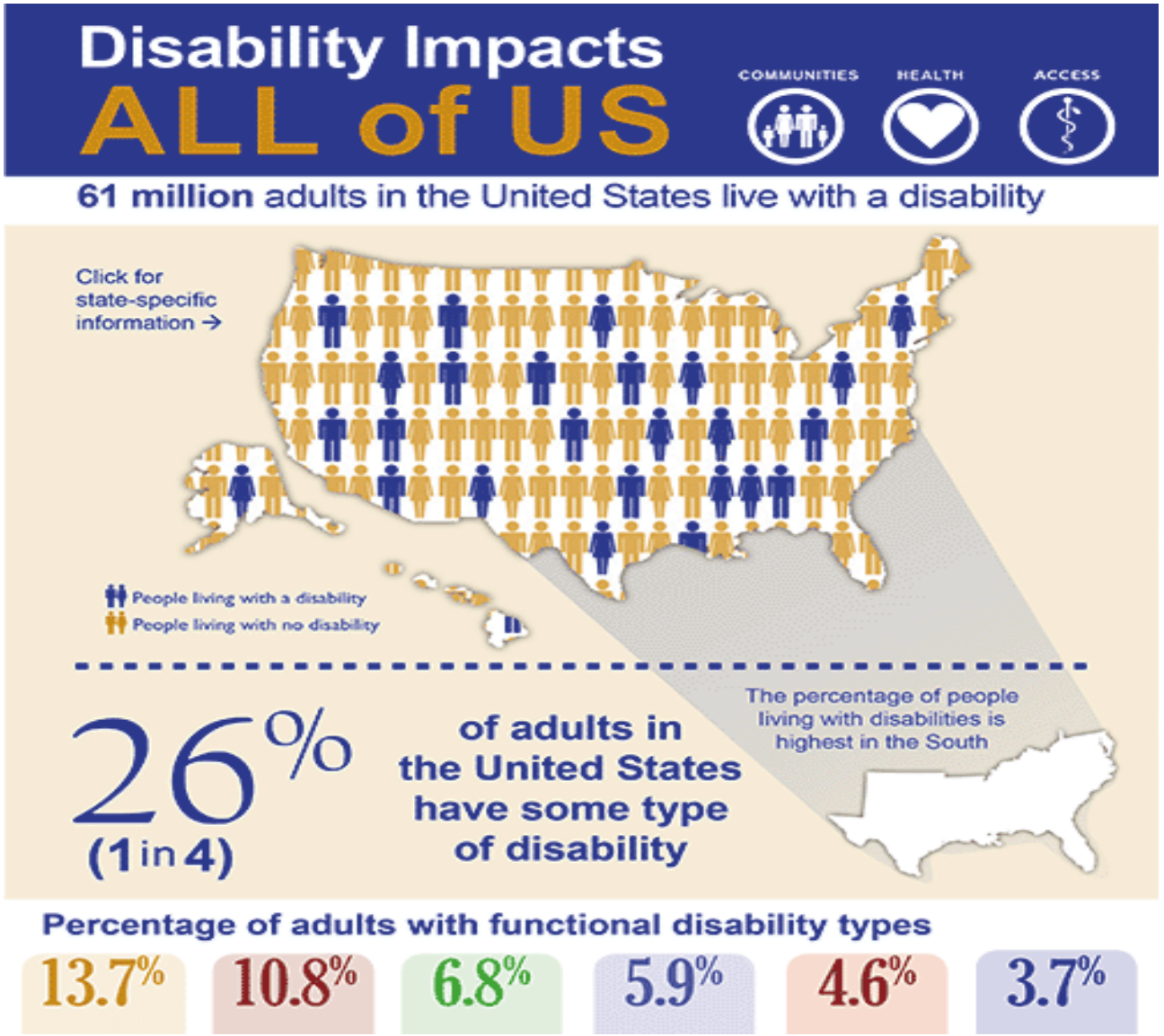
DEVELOPMENTAL DISABILITY:

A broader term that includes ASD (autism spectrum disorders), epilepsy, cerebral palsy, developmental delay, fetal alcohol syndrome, and other disorders that orccur during the developmetnal period (birth to age 18). The major differences are in the age of onset, the severity of limitations, and the fact that a person with a developmental disability may or may not have a low I.Q.

Features of mild, moderate, severe and profound Intellectual Disability

	mild	moderate	Severe/profound
IQ range	50-69	35-49	<35
% of cases	85%	10%	5%
Ability to self care	Independent	Need some help	Limited
Language	Reasonable	Limited	Basic or none
Reading and writing	Reasonable	Basic	Minimal or none
Ability to work	Semiskilled	Unskilled, supervised	Supervised basic task
Social skill	Normal	Moderate	Few
Physical problems	Rare	Sometimes	Common
Aetiology discovered	Sometimes	Often	Usually
Academic skill	6th grade or higher	2nd to 3rd grade	-

Percentage of US Population with a Disability



Link: *CDC Disability Infographic*

Disability and HEALTH

Adults living with disabilities are more likely to

	With Disabilities	Without Disabilities
HAVE OBESITY	38.2%	26.2%
SMOKE	28.2%	13.4%
HAVE HEART DISEASE	11.5%	3.8%
HAVE DIABETES	16.3%	7.2%

CDC Program Goals

Reduce health disparities for IDD and PWD with mobility limitation in US by:

- ☑ Establishing/expanding partnerships with organizations that serve PWD
- ☑ Training healthcare professionals on best practices for preventative care
- ☑ Linking PWD with preventative care/health promotion in community
- ☑ Identifying gaps in resources and tools to promote health
- ☑ Implementing and evaluating evidence-based health behavior interventions
- ☑ Disseminating findings
  - *HOUSTON-WE HAVE A PROBLEM*- Program only addresses sites in **10** states
  - *Georgia-Massachusetts-Michigan-Missouri-Montana-New Hampshire-New York-Ohio-Oregon-Utah*

Link: State Programs –CDC


syndrome
autism
disorder
awareness
learning
brain
medicine
inclusive
healing
hope
strategy
equality
diagnosis
human
condition
social
childhood
cognitive
problem
biology
diagnose
teaching
schooling
children
information
intervention
child
behavior
kids
neurology
language
disability
care
tolerance
aspergers
adapt
spectrum
symptoms
communication
neurological
rights
lifestyle
handicap
development
therapy
lifestyles
intelligence
imagination
support
pediatric
disease
family
types
educate
people
speech
literacy
training
education
treatment
abilities
health
autistic
service
trauma
mental

Disparities are Expensive

- In 2015, disability-associated healthcare expenditures accounted for 36% of all healthcare expenditures for adults residing in the United States, totaling $868 billion, with state expenditures ranging from $1.4 billion in Wyoming to $102.8 billion in California.

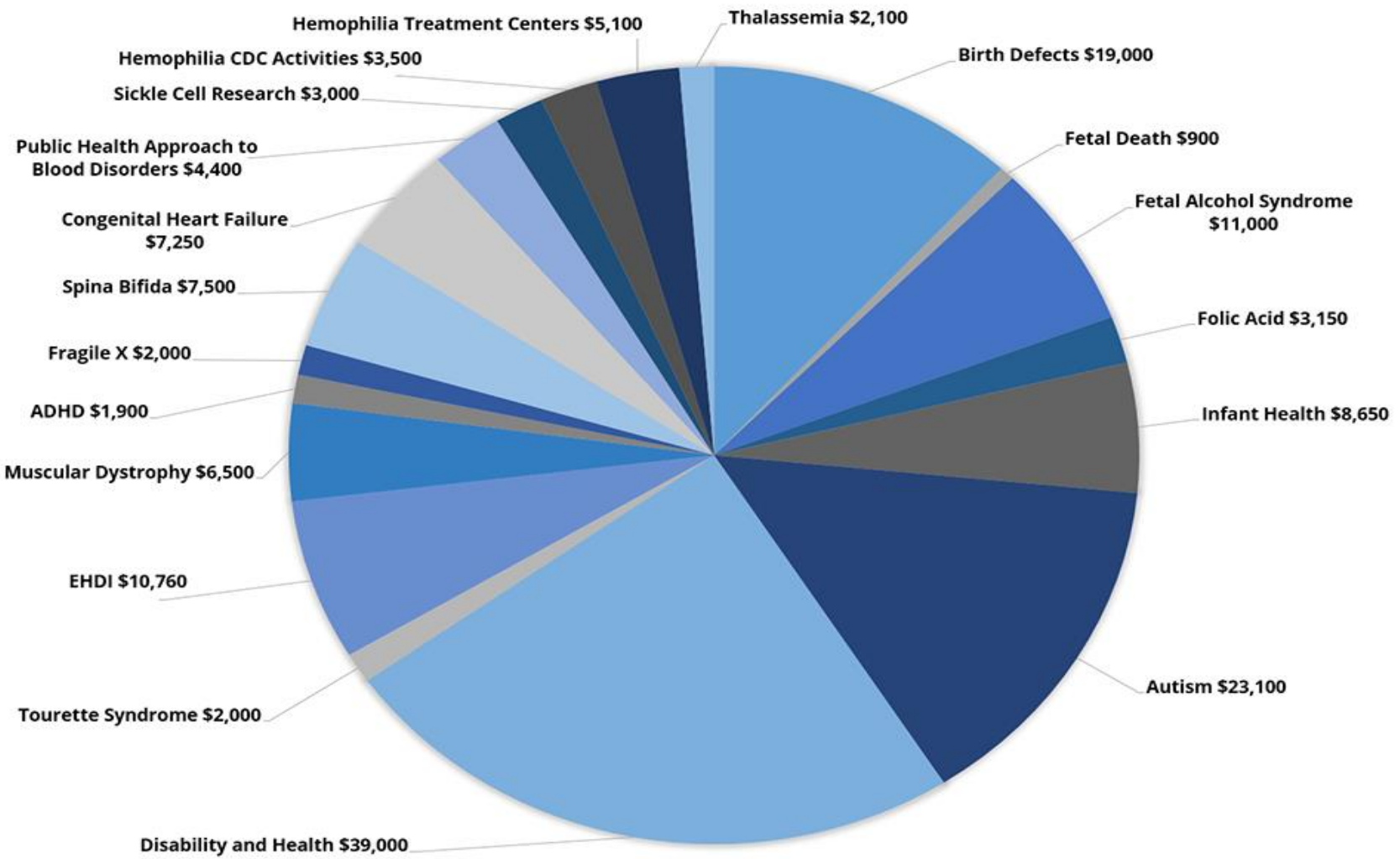
- Of the national total expenditure
  - Medicare paid $324.7 billion.
  - Medicaid paid $277.2 billion.
  - Non-public sources paid $266.1 billion.

- Healthcare spending for people with disabilities is determined by the *cost of health-related services* and *the number of services used*. Both vary across states and over time, which contributes to differences in healthcare spending across states.

Link: Disability Reference Cost Data-CDC

CDC's: National Center on Birth Defects and Developmental Disabilities 2022 Appropriation

$177,060,000: funds are currently supporting surveillance, research, and prevention activities addressing issues with the greatest public health burden and implementing strategies to improve health outcomes.



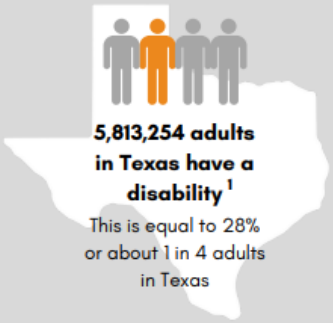
*All dollar amounts are in thousands.

Link: [Fiscal Year 2022 Budget | About Us | NCBDDD | CDC]

CDC's National Center on Birth Defects and Developmental Disabilities

DISABILITY IMPACTS **TEXAS**

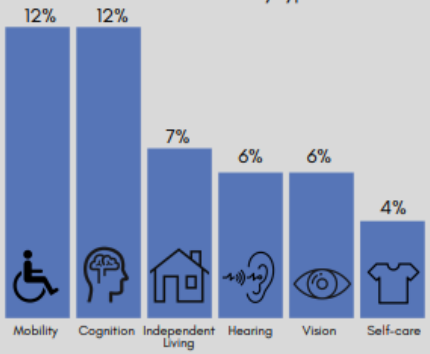
Everyone can play a role in supporting more inclusive state programs, communities, and health care to help people with, or at risk for, disabilities be well and active in their communities. Join CDC and its partners as we work together to improve the health of people with disabilities.



5,813,254 adults in Texas have a disability [1]

This is equal to 28% or about 1 in 4 adults in Texas

Percentage of adults in Texas with select functional disability types



Disability Types

Mobility: Serious difficulty walking or climbing stairs

Cognition: Serious difficulty concentrating, remembering, or making decisions

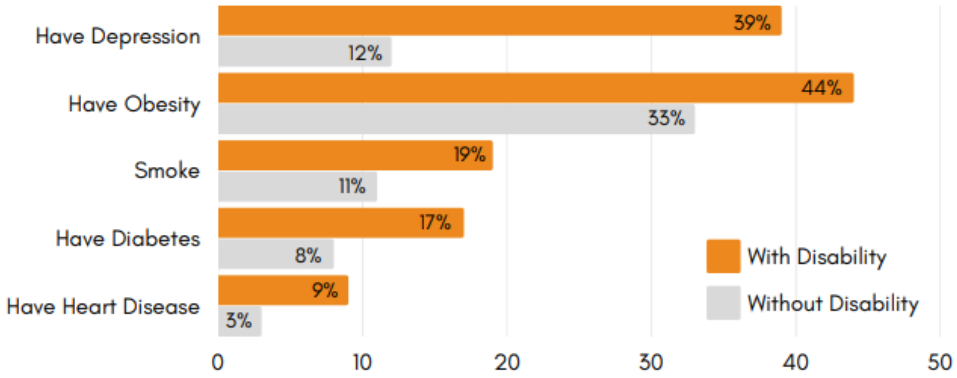
Independent living: Serious difficulty doing errands alone, such as visiting a doctor's office

Hearing: Deafness or serious difficulty hearing

Vision: Blind or serious difficulty seeing, even when wearing glasses

Self-care: Difficulty dressing or bathing

Adults with disabilities in **Texas** experience health disparities and are more likely to... [1]



Visit dhds.cdc.gov for more disability and health data across the United States.

DISABILITY HEALTHCARE COSTS **IN TEXAS** [2]

- About **$56.7 BILLION** per year, or up to **32%** of the state's healthcare spending
- About **$17,189** per person with a disability

Common Causes of Preventable Death in People with DD

**referred to as the Fatal Five*

1. Aspiration/Respiratory illness
2. Seizures
3. Bowel Obstruction
4. Infection/Sepsis
5. Gastroesophageal Reflux (GERD)
6. Cancer
7. Heart Disease

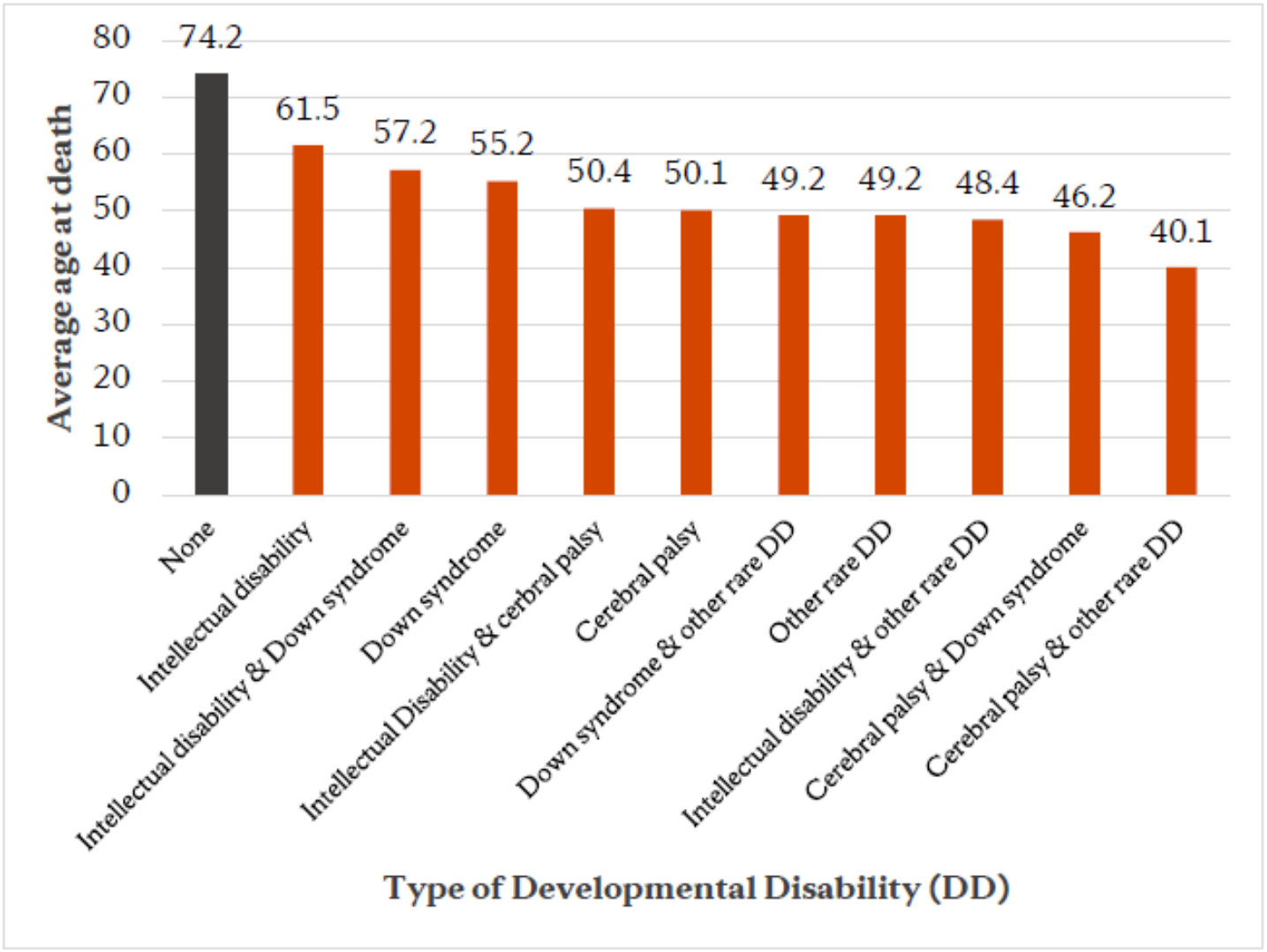
Public Service Announcement: Australia

End
Deadly
Disability
Discrimination

Our health counts

Up to half of the deaths of people with intellectual disability in Australia are preventable – let's fix this.

Figure 1. Adults with Developmental Disability Die at Much Younger Ages than those without DD



Data Source: U.S. Centers for Disease Control and Prevention Multiple Cause-of-Death Mortality Files, 2012-2016, (N=13,059,883 deaths); *Chart*: Dalton Stevens

Vulnerable Population

- PWD are a vulnerable population experiencing multiple barriers including:
  - inaccessible health care facilities
  - communication issues
  - lack of adequate medical information
  - lack of health care provider's understanding of their disability

Havercamp & Scott, 2015 and Krahn et al., 2015

PROBLEMS in the Healthcare Setting

- ***UNDERSTANDING*** baseline capability
- ***COMMUNICATING*** effectively
- ***ACCOMMODATING*** sensory needs
- ***RESPONDING*** to behaviors/distress
- ***PLANNING*** transitional recovery
- ***PROVIDERS FEEL INADEQUATELY PREPARED TO CARE FOR THIS POPULATION***

Common experiences reported by people with disabilities (PWDs)

- Communication between HCPs and PWDs is often ineffective; HCPs fail to communicate ***directly*** with PWDs
- HCPs often assume that quality of life of PWDs is poor and believe that PWDs cannot be healthy
- HCPs often fail to recognize experience, knowledge and expertise of PWDs about their *own* health and disability
- PWDS have a higher incidence of health disparities than non-disabled peers

Krahn et al., 2015 and CDC Disability Infographic

Barriers to Health Care for People with Disabilities

Aggravating factors to barriers for PWD

- Negative attitudes
- Inaccurate and inadequate knowledge
- Lack of educational preparation
- Limited skills in diagnosing, treating, and providing care

Which impact and contribute to negative healthcare outcomes, quality of services and disparities for PWD

Cleary & Doody, 2017; Galli et al., 2016; Kritsotakis et al., 2017; Velonaki et al., 2015

- Provider disability bias contributes to inequitable access of health care services and outcomes for PWD

VanPuymbrouck et al., 2020

Relevance and rationale for disability education

- ***Deficiencies in educational curricula*** are frequently mentioned as an unaddressed need and contributory to inadequate PWD care.
  (Ankam et al., 2019; Krahn et al., 2015;VanPuymbrouck et al., 2020).

- Multiple studies ***validate the impact of disability education and clinical exposure*** on healthcare professionals' attitudes, confidence, competence, and comfort in the care of PWD and PWID.
  (*Anderson et al., 2011; Castro et al., 2017; Edwards et al., 2022; Edwards & Hekel, 2021; Edwards & Nash, 2023; Hensel et al., 2015; Levett-Jones et al., 2017; Smith et al., 2016).*

- Adequate health care professional education has been shown to positively impact both ***attitudes and confidence*** -boosting health care provider's assurance in their abilities to communicate and care for PWD.
  (Brown et al., 2016, Bu et al., 2016, Edwards & Nash, 2023; Geckil et al., 2017; Levett-Jones et al., 2017; Smith et al., 2016; Symons et al., 2012).

- ***Frequent and repeated clinical exposure*** caring for PWD has been studied and noted as successful in building confidence and improving attitudes of health care providers.
  (Karl et al., 2013).

CORE COMPETENCIES ON DISABILITY FOR HEALTH CARE EDUCATION

- Alliance for Disability in Health Care Education (2018). *Core Competencies on Disability for Health Care Education.* Peapack, NJ: Alliance for Disability in Health Care Education. http://www.adhce.org/

- Establishes the baseline expertise required to provide quality care to patients with disabilities.

Core Competencies on disability for health care education

1. Contextual & Conceptual Frameworks on Disability
2. Professionalism & Patient-Centered Care
3. Legal Obligations & Responsibilities for Caring for Patients with Disabilities
4. Teams & Systems-Based Practice
5. Clinical Assessment
6. Clinical Care Over the Lifespan and During Transitions

Full Document Link:
Core Competencies on Disability for Health Care Education

Significance of interprofessional education (IPE)

Value of clinical immersion and IPE

- Address health needs among disciplines for PWD with patient as *navigating* team member
- Efficiency in *identification of challenges* with services and providers and facilitates determining strategies
- Teamwork dynamics improve-flexibility, adaptability, referrals, use of evidence based practice and *supportive decision making* promoting '*mutual goal setting*' among members and PWD

Zomordi et al., 2017

ASK	MOSAIC	Concept	Time ASK 90 hrs	Time MOSAIC 28.5 hrs	Content	Teaching Method
✓	✓	Introduction to disabilities	7 hours	2 hours	Communication etiquette, ADA, prevalent disabilities, comorbidities	Lecture, Videos, Discussion, Didactic
✓		Facility Onboarding	2 hours	0 hours	Facility specific HIPPA	Online modules
✓	✓	Disability Experience	1	.5	Video Clips from a variety of PWD	Self-reflection writing activity, recognition of implicit bias, phenomenological approach
✓		Sensory Deficits	2	0	CDC online modules **Part 1** Physical and sensory disabilities & **Part 2** developmental disabilities	Online self-paced modules-asynchronous
✓	✓	Clinical Care	4	4	Virtual Grand Rounds and Oral Care videos; interprofessional care planning using a case study	Online self-paced modules-completed asynchronously; interactive, IP care planning and discussion using case studies
✓	✓	Advanced Fatal Five	6	6	*requires subscription ***Link***: *Fatal Five Subscription Resource*	Online self-paced asynchronous module
✓	✓	Clinical Practicum	64	16	*See comparison	Skill application; experiential learning
✓		Weekly debriefing	1	0	Response to prompts	Discussion board; reflection
✓		Case Study	3	0	Preparation and presentation to peers of selected patient	Didactic; discussion

Disability Site Rotations Comparison

Inpatient/Outpatient Settings (secondary/tertiary):

- Shriner's Hospital (OR/ICU Burn care)
- The Institute for Research and Rehabilitation (TIRR)- Urology/Clinic
- Occupational Therapy

Primary/Specialty Care Settings:

- Transition Medicine Clinic- intellectual and developmental disabilities
- TIRR Amputee Clinic-acquired disability
- UT Pediatric Neurology (Autism)
- UT Pediatric 'Chosen' Clinic (Complex)
- UT Neurocognitive Disorders
- UT Pediatric Dentistry

Community Settings:

- The Center for Pursuit
- Brookwood Community
- Jewish Family Services

Academic Settings:

- Rise School
- Arbor School
- Friends of Down Syndrome
- Monarch School

Primary/Specialty Care Settings:

- Transition Medicine Clinic- *intellectual and developmental disabilities*
- TIRR Amputee Clinic-*acquired disability*
- UT Pediatric Neurology (autism)
- UT Pediatric 'Chosen' Clinic (Complex)
- UT Neurocognitive Disorders
- UT Pediatric Dentistry

Dental Students:

- ***Any 2 rotations from the above list *excluding amputee clinic***
- ***2-hour course credit***

ASK Fellowship:
Attitudes/Skills/Knowledge

MOSAIC-
Mentoring Our Students to Achieve Interprofessional Collaboration

Impact and Outcomes of ASK/MOSAIC Curricula

(ASK) <u>Qualitative</u> findings: themes-perspective shift, impact on practice, revelations from experience

- *Students unanimously reported the experience impacted their future nursing practice; findings represented changes in comfort, confidence, awareness and motivation to care for and advocate for PWD. (Edwards & Nash, 2023)*

(ASK) <u>Quantitative</u> findings: comparing moderate and intense levels of clinical exposure

- *Clinical group experienced a larger increase in skill scores compared with the control group ($p = 0.0154$). Mean pre- and post-test scores for attitudes within the fellowship **(69.78, 75.11)** and clinical (67.62, 74) group increased more than the control **(66.92, 68.29)**. (Edwards et al., 2022)*

(MOSAIC)) Summative findings: from intense exposure

(2) *nursing* cohorts Fall/Spring n=10 (1) *dental* cohort=15

Knowledge Based Pre-Test Average *47.2/100

Knowledge Based Post-Test Average *65.2/100

28% increase

Harvard Project: Disability Implicit Attitude Test-*inconclusive*

**dental students did not participate in summative evaluations*

SWOT analysis of MOSAIC

- Atypical interprofessional experience
- Case study evaluation facilitated interprofessional work group analysis & group think
- University system clinics eliminated need for clinical affiliation agreements
- Exposed nursing to important discipline critical to health promotion/prevention of disease in this population

- Lack of synchronous interprofessional clinical experiences
- Faculty expectations inconsistent for clinical rotation and assignment completion
- Separate learning management systems (Canvas) could not be integrated
- Course structure-elective versus independent study resulted in varied student engagement (grade vs no grade)

- More asynchronous interprofessional assignments and interaction-ie: discussion boards
- Encourages future collaborative discipline grant experiences
- Incorporate clinical coordinator/assistant role in future grant budgets to assure synchronized interprofessional experiences and consistent course completion monitoring

- Curriculum calendar and progression alignment between disciplines challenging
- Differing discipline specific academic policies ie: elective vs independent study and maximum allowable course credits per semester
- Faculty time in coordination
- Differing rotation expectations

References

Alliance for Disability in Health Care Education. (2018). Core Competencies on Disability for Health Care Education. Peapack, NJ: http://www.adhce.org/.

Anderson, E. S., Ford, J., & Thorpe, L. (2011). Learning to listen: improving students' communication with disabled people. *Medical Teacher*, *33*(1), 44-52. doi: 10.3109/0142159X.2010.498491

Ankam, N. S., Bosques, G., Sauter, C., Stiens, S., Therattil, M., Williams, F. H., & Mayer, R. S. (2019). Competency-based curriculum development to meet the needs of people with disabilities: a call to action. *Academic medicine*, *94*(6), 781-788. doi:10.1097/ ACM.0000000000002686 PMID:30844926

Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., et al. (2016). The perspectives of stakeholders of intellectual disability liaison nurses: A model of compassionate, person-centred care. *Journal of Clinical Nursing, 25*(7-8), 972-982. doi:10.1111/jocn.13142

Bu, P., Veloski, J. J., & Ankam, N. S. (2016). Effects of a brief curricular intervention on medical students' attitudes toward people with disabilities in healthcare settings. American Journal of Physical Medicine & Rehabilitation, 95(12), 939; 939-945; 945. DOI: 10.1097/PHM.0000000000000535

Castro, S. S., Rowe, M., Andrade, L. F., & Cyrino, E. G. (2018). Developing competencies among health professions students related to the care of people with disabilities: A pilot study. Interface: Comunicacao, Saude, Educacao, 22(65), 551–563. doi: 10.1590/1807-57622016.0684

Cleary, J., & Doody, O. (2017). Nurses' experience of caring for people with intellectual disability and dementia. *Journal of Clinical* Nursing, 26(5-6), 620-631. doi:10.1111/jocn.13431

Edwards, A. P., & Hekel, B. E. (2021). Appraisal of disability attitudes and curriculum of nursing students: a literature review. International Journal of Nursing Education Scholarship, 18(1). https://doi.org/10.1515/ijnes-2021-0029

Edwards, Allison & Nash, Angela. (2023). Transformative Care for People with Disabilities: Empowering Senior Nursing Students with Competency Based Clinical Education-A Qualitative Study of the Impact. Nurse Education Today, 126, 105822. doi:10.1016/j.nedt.2023.105822

Edwards, Allison P., Cron, Stanley, & Shonk, Cameron (2022). Comparative effects of disability education on attitudes, knowledge and skills of baccalaureate nursing students. Nurse Education in Practice, 61, 103330–103330. https://doi.org/10.1016/j.nepr.2022.103330

Galli, G., Lenggenhager, B., Scivoletto, G., Molinari, M., & Pazzaglia, M. (2015). Don't look at my wheelchair! the plasticity of long-lasting prejudice. Medical Education, 9(12), 1239-1247. https://doi:10.1111/medu.12834

Geçkil, E., Kaleci, E., Cingil, D., & Hisar, F. (2017). The effect of disability empathy activity on the attitude of nursing students towards disabled people: A pilot study. Contemporary Nurse, 53(1), 82-93. https://doi.org/10.1080/10376178.2017.1292143

References *Continued*

Havercamp, S. M., & Scott, H. M. (2015). National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. Disability and Health Journal, 8(2), 165–172. https://doi.org/10.1016/j.dhjo.2014.11.002

Hensel et al., 2015 D. Hensel, C. Malinowski, P.A. Watts Implementing a pediatric camp clinical for pre-licensure education. Nurs. Educ. Perspect., 36 (1) (2015), pp. 60-61. https://doi.org/10.5480/12-871.1

Karl, R., McGuigan, D., Withiam-Leitch, M. L., Akl, E. A., & Symons, A. B. (2013). Reflective impressions of a precepted clinical experience caring for people with disabilities. Intellectual and Developmental Disabilities, 51(4), 237-245.ii] https://doi.org/10.1352/1934-9556-51.4.237

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American journal of public health*, *105*(S2), S198-S206. https://doi.org/10.2105/AJPH.2014.302182

Kritsotakis, G., Galanis, P., Papastefanakis, E., Meidani, F., Philalithis, A. E., Kalokairinou, A., & Sourtzi, P. (2017). Attitudes towards people with physical or intellectual disabilities among nursing, social work and medical students. Journal of Clinical Nursing, 26(23-24), 4951– 4963. https://doi.org/10.1111/jocn.13988 PMID:28771877

Levett-Jones, T., Lapkin, S., Govind, N., Pich, J., Hoffman, K., Jeong, S. Y. S., ... & Everson, N. (2017). Measuring the impact of a 'point of view' disability simulation on nursing students' empathy using the Comprehensive State Empathy Scale. *Nurse education today*, *59*, 75-81. https://doi.org/10.1016/j.nedt.2017.09.007

Project Implicit®. Harvard University. Accessed March 8, 2019. https://implicit.harvard.edu/takeatest.html.

Smith, P., Ooms, A., & Marks-Maran, D. (2016). Active involvement of learning disabilities service users in the development and delivery of a teaching session to pre-registration nurses: Students' perspectives. Nurse Education in Practice, 16(1), 111-118. https://doi.org/10.1016/j.nepr.2015.09.010

Symons, A. B., Fish, R., McGuigan, D., Fox, J., & Akl, E. A. (2012). Development of an instrument to measure medical students' attitudes toward people with disabilities. Intellectual and Developmental Disabilities, 50(3), 251-260. https://doi.org/10.1352/1934-9556-50.3.251

VanPuymbrouck, Laura, Carli Friedman, and Heather Feldner. "Explicit and Implicit Disability Attitudes of Healthcare Providers." Rehabilitation psychology 65.2 (2020): 101–112. https://doi.org/10.1037/rep0000317

Velonaki, V. S., Kampouroglou, G., Velonaki, M., Dimakopoulou, K., Sourtzi, P., & Kalokerinou, A. (2015). Nurses' knowledge, attitudes and behavior toward Deaf patients. Disability and health journal, 8(1), 109-117. https://doi.org/10.1016/j.dhjo.2014.08.005

Zomorodi, M., de Saxe Zerden, L., Nance-Floyd, B., Alexander, L., Wilfert, R., & Byerley, J. (2017). Impact of an interprofessional population health course and clinical immersion experience: Students and practice outcomes. Journal of Interprofessional Education & Practice, 9, 91-94. https://doi.org/10.1016/j.xjep.2017.08.008