

CA-LEND Leadership Project

Inclusion of ID/DD Content in Nursing Education Curriculum Project Type: Policy

Project Team

Sergé R. Nelson, DNP/CA-LEND Scholar, Nursing
Cecily L. Betz, PhD, RN, FAAN/CA-LEND Faculty, Nursing
J. Carolyn Graff, PhD, RN/External Nursing Faculty
Mark Fisher, PhD, RN-External Nursing Faculty
Lucinda Hill, DNP, CNE-External Nursing Faculty
Julie LaMothe, DNP, External Nursing Faculty
Beth Marks, PhD, RN, FAAN- External Nursing Faculty
Regine Placide Reaves, PhD, FNP-External Nursing Faculty

2022 - 2023

Purpose & Goals of Leadership Project

- **Project Type:** Policy
- **Anticipated Leadership Project:** Submit manuscript(s) to nursing peer-reviewed journals to inform leaders of unmet medical and mental health care needs for persons with intellectual disabilities (ID) and developmental disabilities (DD)
- **Intended Audience:** Nurse Leaders, Nursing Professionals & Nursing Students
- **Proposed Impact:** To accelerate the inclusion of ID/DD content in Nursing education, practice, research and policy, to increase a competent nursing workforce and improve ID/DD persons health equity and outcomes across their lifespans

CLINICAL QUESTION: PICOT



In Nursing (P), will publishing ID/DD content driven manuscripts to peer review journals (I) compared to what content currently exist in nursing curricula (C), accelerate the adoption and inclusion of ID/DD content in nursing education curriculum to increase a competent nurse workforce(O) within a 24-month period (T)?

Background/Review of the Literature

Literary Analysis of Literature

- ERIC, PubMed, Scient Direct, Google Scholar database searches
 - Manuscript #1: 9 references
 - Manuscript #2: 30+ references
 - Manuscript #3: 20+ references

**References available upon request*

Background

- ID/DD persons represent the majority minority in the U.S.(17%), experience poorer physical and mental health outcomes compared to the general population (Cooper et.al., 2015; Doherty et. al., 2020)
- With more than 4x as many RNs in the U.S. as physicians (Statista, 11/2020), Nursing comprise the largest component of the healthcare workforce (4.2 million), are the primary providers of hospital patient care, & deliver most of the nation's long-term care (AANC, 2022)

Background/Review of the Literature

Background, continued

- Research suggests that RNs do not feel adequately prepared to support ID/DD patients (Applegreen et. al., 2018)
- Several studies have shown a lack of ID/DD content in education and training provided in nursing schools curriculum, continuing education and professional career development (Auberry, K., 2018; Sowney & Barr, 2006)
- Lack of funding to prepare nursing faculty to instruct ID/DD content in nursing school curricula (Smeltzer et al. 2010)
- Nursing leaders are posited to address the comprehensive needs of persons with ID/DD

Project Plan

- Phase I/Initiation: Project team assembled 10/2021); Goal is to 'Call to Action' nurse leaders to transform ID/DD nursing education, practice and policy to increase a competent workforce
- Phase II/Planning: Through the process of collaboration a strategy to raise nursing awareness of the need to 'ACT' to address knowledge gaps in ID/DD health disparities through nursing education and practice was adopted; Goal is to publish a total of 5-6 manuscripts over a 24-month period (10/21 & on-going)
- Phase III/Solution: Manuscript #1-Nursing Outlook (NO), 4/22;
Manuscript #2 - Nursing Journal of Education (JNE), 12/22;
Manuscript #3 - Journal identification, T.B.D. (5/30/23)



Available online at www.sciencedirect.com

ScienceDirect

NURS OUTLOOK 000 (2022) 1–3

NURSING
OUTLOOK

www.nursingoutlook.org

Closing the nursing leadership gap: Leveraging partnerships with people with intellectual disabilities and developmental disabilities

J. Carolyn Graff^a, Mark Fisher^b, Lucinda Hill^c, Regine Placide Reaves^d, Serge' R. Nelson^e, Cecily L. Betz^{f*}

^aCollege of Nursing, The University of Tennessee Health Sciences Center, Memphis, TN

^bFran and Earl Ziegler College of Nursing, The University of Oklahoma Health Sciences Center, Oklahoma City, OK

^cIndiana University School of Nursing, Indianapolis IN

^dSchool of Nursing & Health Sciences, University of Miami, Coral Gables, FL

^eHumanities Healthcare Solutions, Pasadena, CA

^fDepartment of Pediatrics, Keck School of Medicine, University of Southern California, Los Angeles, CA

ARTICLE INFO

Article history:

Received 2 July 2022

Accepted 21 July 2022

Keywords:

Developmental disabilities

Intellectual Disabilities

Nursing leadership

Health disparities

Monumental changes in health care are needed and highly likely when nurses lead, specifically in the health outcomes for individuals with intellectual disabilities (ID) and developmental disabilities (DD), their families, and the community. Individuals with ID/DD represent approximately 17% of the US population, and experience higher morbidity and mortality rates at earlier ages compared to the general populous (Cooper et al., 2015). Unfortunately, access to primary medical and mental health care services is even lower compared to persons without disabilities (Doherty

et al., 2020). The evidence demonstrates persons with ID/DD are disadvantaged in accessing needed health care, contributing to significant health disparities when compared to those without disabilities (Krahn, Walker, & Correa-De-Araujo, 2015). Health disparities in this disadvantaged population have failed to generate the attention and action of nursing leaders. It is time nurses and nursing listen to the needs of this population and act to address these unjust and preventable health disadvantages to improve their health and well-being.

Nursing's lack of informed attention and involvement in advocating for equitable and quality health care for ID/DD is evident and widespread in leadership, practice, and education. Major health initiatives advocated by national nursing organizations rarely address the health disparities associated with access to health care for individuals with ID/DD. The lack of nursing leadership has contributed to the disparities and a myriad of health care challenges individuals with ID/DD encounter. These leadership deficits have contributed to a failure to address common and often complex barriers this population encounters and limited advocacy success such as access to care. This absence of leadership has resulted in service and educational gaps that include a lack of accessible ID/DD specialty trained nursing

*Corresponding author: Cecily L. Betz, Department of Pediatrics, Keck School of Medicine, University of Southern California, 4650 Sunset Blvd. MS #53, Los Angeles, CA 90027.

E-mail address: cbetz@chla.usc.edu (C.L. Betz).

0029-6554/\$ - see front matter © 2022 Elsevier Inc. All rights reserved.

<https://doi.org/10.1016/j.outlook.2022.07.009>

AUCD 2022 Conference Washington, D.C., 11/13 - 11/16/2022

Nurse Leadership and Partnerships with People with ID/DD for Improved Healthcare

M.J. Fisher¹, C.L. Betz², L. Hill³, J.C. Graff⁴, S. Nelson⁵, and R. Reaves⁶



OVERVIEW

- Healthcare changes are needed in the areas of **access and health services for people with ID/DD**.
- Health disparities in this population have failed to generate **attention and action from nursing leaders**.
- This is a **Call to Action for strategic planning to improve health care** for people with ID/DD.

INTRODUCTION

Monumental **changes in healthcare** are needed - these are **likely when nurses lead**. Nurse leaders are poised to facilitate improvements in the access and provision of health services for people with ID/DD, their families, and the community.

- People with ID/DD experience higher morbidity and mortality rates at earlier ages compared to the general populous and their access to primary medical and mental healthcare services is lower compared to people without disabilities (Cooper et al., 2015; Doherty et al., 2020).
- Disadvantaged access to needed healthcare contributes to these significant health disparities (Krahn et al., 2015).

PURPOSE

The poster encourages nursing's involvement in and commitment to **generating pioneering models of care** focused on improving health outcomes of people with ID/DD.

NOW is the time for nurses and nursing to listen to the needs of people with ID/DD and act.



ISSUES #1 – NURSES and NURSING

Nursing's lack of informed attention and involvement in advocating for equitable and quality healthcare is evident and widespread in leadership, practice, and education.

ISSUE #2 – MODELS and STRATEGIES

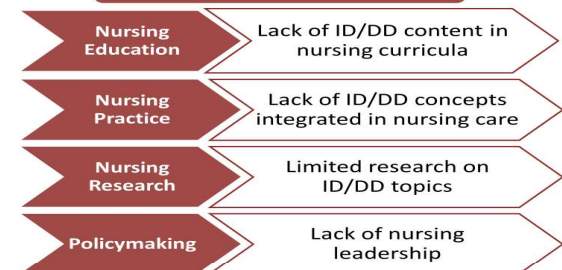
Leadership in ID/DD nursing and partnership with people with ID/DD to promote transformative changes and influence national nursing health care initiatives.

Connection with Conference Theme

National Nursing Involvement



Publications/Future Directions



Link to article in Nursing Outlook

References
Cooper, et al. (2015) - doi.org/10.1186/s12875-015-0329-3
Doherty, et al. (2020) - doi.org/10.3399/bjgpopen20X101030
Krahn, et al. (2015) - doi.org/10.2105/AJPH.2014.302182

We would like to acknowledge Amal Haji Assa for her assistance in preparing this poster. Amal is a PhD Candidate in Nursing Science at the University of Tennessee Health Science Center College of Graduate Health Sciences

For more information about the content on the poster, please contact Mark J. Fisher by email at Mark-Fisher@ouhsc.edu

Alignment with LEND Values

- Family- Person- Centered Perspective: LaTysa Flowers-Jackson
- Health Equity Perspective: Dr. LaVonna Lewis (email)
- Interdisciplinary Perspective: Dr. Sheila Rao & Dr. Larry Lin

Key Question	Common Themes
<i>How can nursing improve care and support for ID/DD individuals across healthcare systems?</i>	Cultural Competence: ↑ cultural awareness, attitude, knowledge and skills to address health equity through patient centered care (FPC, HE)
	Family Partnership: ↑ communication to develop meaningful plans of care and interventions representative of the patient-family needs and goals (FPC, ID)

Challenges & Next Steps

Challenges:

- Gain increased knowledge on federal/state nursing education policy(s) to advance ID/DD content to nursing curriculum, and identify MCHB partners to promote advocacy
- RN/APN underrepresentation in the CA-LEND (2018-2023: Statistical data shows nursing participation ~2%)

Next Steps:

- Letter of Intent submitted to WITH Foundation to develop certificate program for IDD nursing (4/2023)
- Complete manuscript #3, submit poster to present at AUCD 2023 Conference (5/2023)
- Submit Manuscript # 4 to Health Care Transitions, “Psychosocial Outcomes of Adults with Spina Bifida” (7/2023)
- Collaborate with CA-LEND to ↑ RN/APN engagement/participation

Acknowledgments

- Special thanks to Dr. Cecily L. Betz, for her generosity to share her expertise and resources to provide me a rich mentor/mentee experience; for her encouragement for me to step outside of my comfort zone to learn my voice!
- Special thanks to each co-author/contributor in the development of manuscripts for dissemination- each person is brilliant, proficient, giving and passionate about our shared work!
- Special thanks to the CA-LEND leadership, faculty, cohorts and supporters for their respective contributions to making the world of ID/DD health systems and services brighter!

