Beyond the dental chair:

Toward a systems-led, biopsychosocial framework to underpin oral health supports for people with intellectual and developmental disability.

Associate Professor Nathan Wilson





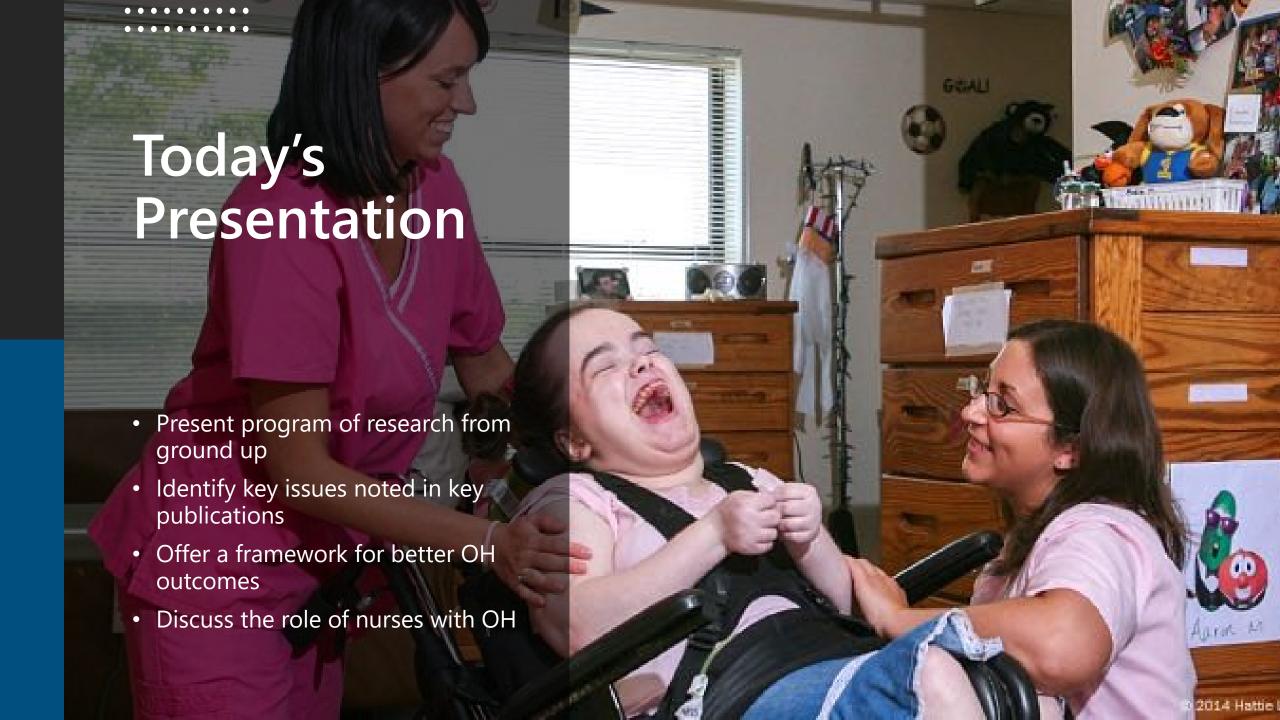
My Background: Health and wellbeing of people with intellectual and developmental disability

Main areas of focus

- Disability Workforce
- Chronic illness and lifelong disability
- Participation
- Key partnerships with disability services and peak bodies

Past and Current Projects

- NDIS Every Nurses' Business
- Role of nurses who work with people with IDD
- Autism CRC driving and public transport access
- Mentoring programs at Men's Sheds for young adults with IDD
- Reducing psychotropic medication
- Oral Health and IDD



What do we know about oral health and people with intellectual and developmental disability?

Oral health (OH) status very poor

Problems with independence in OH

- Lack of OH literacy
- Access barriers to OH and other health services
- Often multiple chronic and complex co-morbidity
- Heavy reliance on caregivers Few models of effective caregiver training
- Evidence for interventions very low to low needs a combination of regular check-ups and targeted individualised effective intervention/s (Waldron et al., 2019).

Review 1: OH Problems

JOURNAL OF INTELLECTUAL & DEVELOPMENTAL DISABILITY, 2018 https://doi.org/10.3109/13668250.2017.1409596



LITERATURE REVIEW



Oral health status and reported oral health problems in people with intellectual disability: A literature review

Nathan J. Wilson^{a,b,c}, Zhen Lin^a, Amy Villarosa^{a,b,c,d} and Ajesh George^{a,b,c,d,e}

^aSchool of Nursing and Midwifery, Western Sydney University, Richmond, Australia; ^bCentre for Oral Health Outcomes, Research Translation and Evaluation (COHORTE), Liverpool, Australia; ^cIngham Institute for Applied Medical Research, Liverpool, Australia; ^dSouth Western Sydney Local Health District, Sydney, Australia; ^ePopulation Oral Health, University of Sydney, Sydney, Australia

ABSTRACT

Background: People with intellectual disability (ID) experience poor oral health and are at greater risk of dental decay and periodontal diseases. This impacts on their general health and wellbeing. This review summarises the research literature about oral health status and contributing factors to poor oral health

Method: We conducted a literature review using "intellectual disability" and "oral health" as our two core areas of focus.

Results: People with ID had poorer oral health, greater numbers of tooth extractions, more caries, fewer fillings, greater gingival inflammation, greater rates of endentulism, and had less preventative dentistry and poorer access to services when compared to the general population. Anxiety during dental procedures was a key issue for females with ID.

Conclusions: Further research is needed to identify, pilot and test appropriate and effective interventions that can reduce this preventable health disparity. The design of an ID-specific dental anxiety scale is another priority.

KEYWORDS

Oral health; health disparities; dental services; gender; intellectual disability; dental anxiety

- Poorer oral health, greater numbers of tooth extractions, more caries, fewer fillings, greater gingival inflammation, and greater rates of endentulism
- less preventative dentistry and poorer access to services when compared to the general population
- Anxiety during oral health care Wilson et al., (2019a).

Review 2: OH Solutions

- Caregivers play a vital role in the provision of oral health support, emphasising the effectiveness of educational interventions for caregivers.
- Uncertainty regarding the efficacy of specific tooth brushing interventions for people with IDD.
- In cases of more severe IDD and/or dental-related behavioural problems, dental treatment under general anaesthesia was often both a necessary and effective method of oral health care provision.
- Outreach and exclusive oral health services as successful strategies for increasing the limited access of people with IDD to oral care services.

Wilson et al. BMC Public Health (2019) 19:1530 https://doi.org/10.1186/s12889-019-7863-1

BMC Public Health

RESEARCH ARTICLE

Open Access

Countering the poor oral health of people with intellectual and developmental disability: a scoping literature review



Nathan J. Wilson 1* D. Zhen Lin 2 D. Amy Villarosa 3, Peter Lewis 2, Philop Philip 4, Bashir Sumar 2 and Ajesh George 3.5.6 D

Abstract

Background: People with intellectual and developmental disability (IDD) have poor oral health and need support to maintain optimal oral health outcomes. Little is known about how, when and where to intervene for this population. Thus the aim of this review was to summarise the existing evidence surrounding improving oral health outcomes for people with IDD.

Methods: A scoping literature review was conducted focusing on 'oral health' and 'intellectual disability'. Systematic searches of five electronic databases were conducted in line with the study aims and two authors independently examined all records for relevance, with consensus achieved by a third author.

Results: A small number of approaches and interventions were identified to support people with IDD to independently maintain optimal oral hygiene. Identified studies highlighted that caregivers play a vital role in the provision of oral health support, emphasising the effectiveness of educational interventions for caregivers. However, there was uncertainty regarding the efficacy of specific tooth brushing interventions for people with IDD. In cases of more severe IDD and/or dental-related behavioural problems, dental treatment under general anaesthesia was often both a necessary and effective method of oral health care provision. The findings also identified outreach and exclusive oral health services as successful strategies for increasing the limited access of people with IDD to oral care services.

Conclusions: A uniform approach to supporting oral health for people with IDD is unlikely to succeed. A system-based approach is needed to address the diverse needs of the population of people with IDD, their caregivers and service context. Further high quality evidence is required to confirm these findings.

Keywords: Intellectual disability, Oral health, Health disparities, Dental interventions, Gender, Nursing

DSWs as Oral Health Champions: gen-U/DHSV

Original Research

Qualitative Insights from A Novel Staff-Led Oral Health Champions Program Within a Residential Service For People With Intellectual and Developmental Disability



Journal of Intellectual Disabilities 2022, Vol. 0(0) 1–18 © The Author(s) 2022 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/17446295221095654 journals.sagepub.com/home/jid

Nathan I Wilson, PhD @

Associate Professor, Australian Centre for Integration of Oral Health (ACIOH), School of Nursing and Midwifery, Western Sydney University, Richmond, NSW, Australia

Zhen Lin. B.Nurs

Research Assistant, School of Nursing and Midwifery, Western Sydney University, Richmond, NSW, Australia

Margery Pithouse, BA Hons

Practice Advice Manager, gen-U, East Geelong, VIC, Australia

Bonnie Morrison, B.Sc. Dip Ed

Health Promotion Officer, Dental Health Services Victoria, Carlton, VIC, Australia

Bashir Sumar, M.Sc

Lecturer, School of Nursing and Midwifery, Western Sydney University, Richmond, NSW, Australia

Ajesh George, PhD

Professor, Australian Centre for Integration of Oral Health (ACIOH), School of Nursing & Midwifery, Western Sydney University, Ingham Institute for Applied Medical Research. Sydney Dental School, University of Sydney, Liverpool, NSW, Australia

- DHSV and gen-U developed oral health champions program
- Champions agreed to role for one year
- Input from experts; Classroom based education session for DSW champions, 3 follow-up sessions.
- Champions to lead practice change through peer-led approach
- Research/Gvt/service partnership to explore champions' perspectives of the program

OH Champions Cont ...

- Enhanced individual knowledge and led to a number of reported benefits to the people with IDD
- Challenges being a champion and effecting change where routines and practices were sometimes entrenched
- Initial, and follow-up, workshops promoted awareness that oral health was more than just cleaning teeth and in fact altered the personal practice of some of the champions
- No insight into any notable effect on the oral health status of any individuals with IDD no outcome measures

Wilson et al., (2022a)

Smiles for Life – **Westmead Special Needs Dentistry Unit**





Evaluation of Smiles for Life: A Caregiver Focused Oral Health **Education Programme**

Nathan J. Wilson 1,*0, Tiffany Patterson-Norrie 1,2, Cheryl Bedford 3, Natalie Bergstedt 3, Lia Marri Mendoza 3, Amy R. Villarosa 1,2, Ajesh George 1,2,40 and Avanti Karve 3

- Australian Centre for Integrated Oral Health (ACIOH), School of Nursing and Midwifery, Western Sydney University, Penrith, NSW 2751, Australia
- Ingham Institute Applied Medical Research, Liverpool, NSW 2170, Australia
- Department of Oral Medicine, Oral Pathology and Special Needs Dentistry, Westmead Centre for Oral Health, Westmead Hospital, Westmead, NSW 2145, Australia
- School of Dentistry, Faculty of Medicine and Health, The University of Sydney, Surry Hills, NSW 2010, Australia
- Correspondence: n.wilson@westernsydney.edu.au

Abstract: Background: People with an intellectual and/or developmental disability are at increased challenges, despite oral health education in this professional group being vital. Future studies may benefit from reviewing the efficacy of a more tailored educational intervention.

risk of adverse oral health outcomes and often require support from caregivers to assist in maintaining or seeking treatment for their oral health needs. However, caregivers and support workers are often family members with limited formal oral health training. Hence, the aim of this pilot study was to review the outcomes of the 'Smiles for Life' oral health education workshop with reference to their knowledge, attitudes, and practices of caregivers of people with an intellectual or developmental disability. Methods: A single group pre-test post-test intervention design was used to explore the preliminary effectiveness and appropriateness of the Smiles for Life oral health education workshop. Results: A total of 244 participants completed both the pre and post knowledge test. Oral health literacy scores decreased following the post test. Those with higher levels of education achieved higher post-training knowledge scores. Overall, caregivers reported satisfaction on the material presented however, it could be improved with more practical demonstrations. Conclusion: Providing an oral health education tool that caters to the diverse caregiver audience presents a unique set of

- Smiles for Life education program for paid and unpaid carers classroom session with short "hands on" component
- No evaluation undertaken, but pre-post data were collected
- Collaboration between researchers and Westmead team
- Matched pairs n=244
- Knowledge decreased after the program, more so in carers with fewer educational qualifications
- Content was pitched at too high a level led to confusion

Wilson et al., (2022b)



Citation: Wilson, N.J.; Patterson-Norrie, T.; Bedford, C.; Bergstedt, N.; Mendoza, L.M.; Villarosa, A.R.; George, A.; Karve, A. Evaluation of Smiles for Life: A Caregiver Focused Oral Health Education Programme. Disabilities 2022, 2, 564-574. https://doi.org/ 10.3390/disabilities2040040

National DSW Survey - Demographics

Demographic Characteristic	n (%)
Gender [†]	
Male	28 (21.2)
Female	104 (78.8)
Age (mean ± SD, median) [‡]	44.3 ± 12.3, 46
Highest educational qualification [†]	
None	3 (2.2)
High School	25 (18.7)
Certificate/Diploma	60 (44.8)
University	46 (34.3)
Employment Status [†]	
Full time	53 (42.1)
Part time	53 (42.1)
Casual	20 (15.9)
Years working as a DSW/nurse (mean ± SD, median) [‡]	11.5 ± 10.5, 9
State/territory of employment ⁺	
New South Wales	49 (37.4)
Victoria	31 (23.7)
Tasmania	33 (25.2)
South Australia	1 (0.8)
Western Australia	1 (0.8)
Northern Territory	1 (0.8)
Queensland	15 (11.5)
Dwelling type for clients [†]	
Larger residential	7 (5.6)
Home based living	32 (25.4)
Group home or semi assisted living	87 (69.0)
Age of clients [†]	
Up to 17 years	9 (6.8)
18-64 years	121 (91.7)
Older than 65 years	2 (1.5)

National DSW Survey - Knowledge

It is recommended that all individuals should clean their teeth once per day (False)

Dry mouth can lead to poor oral health outcomes (True)

People with IDD are more at risk of gum disease (periodontitis)
(True)

People with IDD should only visit a dentist if they have an oral health concern (False)

People with IDD have poorer oral health than the general population (True)

Poor oral health is NOT linked to certain bacteria in the mouth (False)

Some medications can promote poor oral health (True)

People with IDD do NOT need regular oral hygiene if they are fed via feeding tube (False)

Poor oral hygiene can be linked to increased risk of chest infections (True)



National DSW Survey - barriers

Section IV: Barriers	Strongly Disagree	Somewhat disagree	Neutral	Somewhat agree	Strongly Agree	Total cases
a) I don't have enough skills to provide oral hygiene care for my clients	36 (25.0%)	42 (29.2%)	25 (17.4%)	30 (20.8%)	11 (7.6%)	144
b) There is a lack of guidelines/policies to inform expected oral hygiene care	26 (18.3%)	27 (19.0%)	26 (18.3%)	49 (34.5%)	14 (9.9%)	142
c) There is a lack of adequate oral health training programs	18 (12.7%)	11 (7.7%)	26 (18.3%)	55 (38.7%)	32 (22.5%)	.42

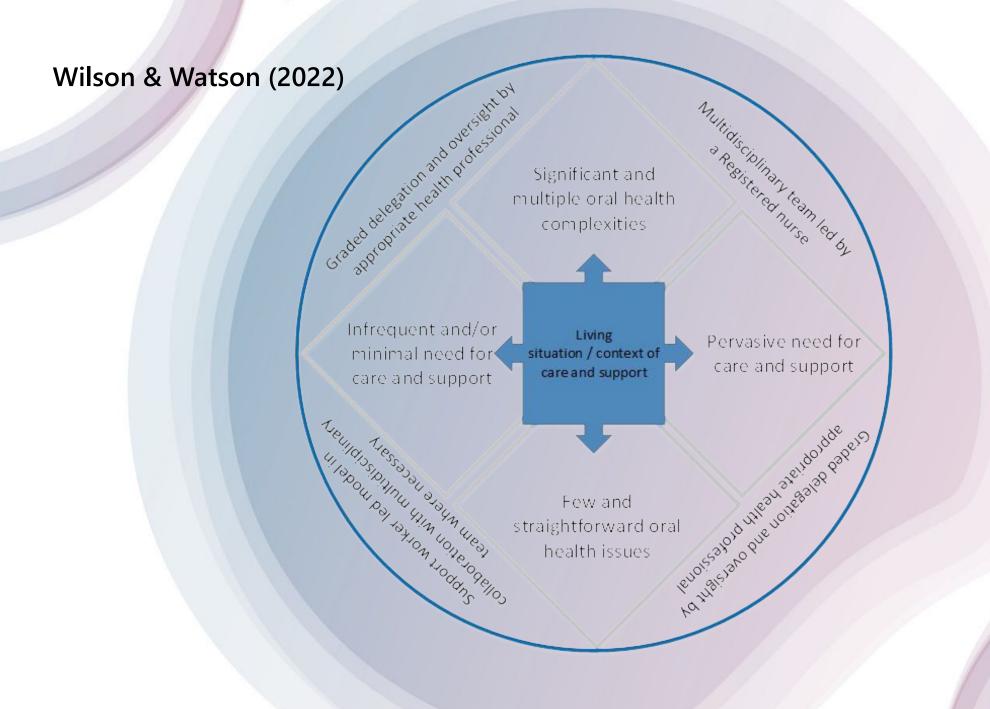
National DSW Survey - Training

Section V: Training	Yes	No	Total cases
a) Have you ever received any oral hygiene training	36 (25.4%)	106 (74.6%)	142
c) Did your practice change after training?	30 (88.2%)	4 (11.8)	34

Potential Solutions?

- Australian context NDIS workforce are a largely unregulated workforce
- Our goals:
 - Scope breadth and depth of the problem
 - explore workforce knowledge and barriers
 - Explore and test potential solutions that will "fit" in the NDIS landscape
- Next steps:
 - NHMRC grant application focussed on children
 - Grant to develop and test systemsbased caregiver intervention





Summary of needs

- Develop interventions to increase the knowledge and improve the practice of carers
- Develop interventions to increase the knowledge and improve the practice of people with IDD who can perform OH self-care
- Create policy/procedure change at a national level around OH and IDD

References

- Waldron C, Nunn J, Mac Giolla Phadraig C, Comiskey C, Guerin S, van Harten MT, Donnelly-Swift E, Clarke MJ. (2019). Oral hygiene interventions for people with intellectual disabilities. Cochrane Database of Systematic Reviews, Issue 5. Art. No.: CD012628. DOI: 10.1002/14651858.CD012628.pub2.
- Wilson, N. J., Lin, Z., Villarosa, A. & George, A. (2019a). The oral health status and reported oral health problems in people with intellectual disability: A literature review. *Journal of Intellectual and Developmental Disability, 44*(3), 292-304. doi: 10.3109/13668250.2017.1409596
- Wilson, N.J., Lin, Z., Villarosa, A., Lewis, P., Philip, P., Sumar, B. & George, A. (2019b). Countering the poor oral health of people with intellectual and developmental disability: A scoping literature review. *BMC: Public Health, 19*, 1530. https://doi.org/10.1186/s12889-019-7863-1
- Wilson, N.J., Lin, Z., Pithouse, M., Vaughan, B., Sumar, B. & George, A. (In press). Qualitative insights from a novel oral health champions programme for staff working within a residential service for people with intellectual and developmental disability. *Journal of Intellectual Disabilities*.
- Wilson, N.J. & Watson, J. (2022). Toward a systems-led, biopsychosocial framework to underpin oral health supports: Commentary on "Evolution of oral status in adults with intellectual and developmental disabilities: A longitudinal study" (Figueira et al., 2021). Research and Practice in intellectual and Developmental Disabilities. DOI: 10.1080/23297018.2022.2051199
- Wilson, N.J., Patterson-Norrie, T., Bedford, C., Bergstedt, N., Mendoza, L.M., Villarosa, A., George, A. & Karve, A. (under peer review). Evaluation of Smiles for Life: A caregiver focussed oral health education program. *Disabilities*.

Thanks:

N.Wilson@westernsydney.edu.au

http://www.acioh.com/