THE UNIVERSITY OF MELBOURNE

inclusiondesignlab

oral health and intellectual disability community of practice

research design
project report

THE UNIVERSITY OF MELBOURNE

The University of Melbourne has a strong commitment to research, teaching and community engagement that seeks to understand the issues that concern people with disability, their families and support systems, and to co-produce policies, practices and technologies that address these concerns. Professor Keith McVilly's team, in the School of Social and Political Sciences and working across the university, focuses on applied research in partnership with community sectororganisations to develop and test innovative solutions to real world problems that have potential for upscaling and wider application. His team is also concerned with fostering the next generation of leaders and practitioners, and connecting students with peoplewith lived expertise as part of their university education.

inclusiondesignlab

Inclusion Designlab is Inclusion Melbourne's centre for policy, research and development, and quality. Its vision is to bring together people with a disability, community organisations, government, and the world's leading disability researchers to develop cutting-edge models of practice, choice and citizenship.

It does this by developing, trialling, and implementing new systems of support and communicating its insights through a range of media. Inclusion Designlab is also a significant contributor to public policy and inquiries. Its focus areas include LGBTIQA+ inclusion, oral health, voting, political citizenship, and access to justice.

April 2020

> This report has been prepared by University of Melbourne and Inclusion Designlab for Melbourne Disability Institute following the completion of a six-month research design project funded by a seed-funding grant from the Institute.

introducing oral health and people with intellectual disability: a community of practice for effective intervention

Goal

To research and identify, through collective problem solving, best practice solutions for Australian dental professionals to more effectively include people with intellectual disability in their clinical practice

Objectives

1 > To expose dentists to a range of self-advocate and interdisciplinary voices

2 > To identify enablers and barriers in provision of dental services to people with intellectual disability in public and/or private dental settings

3 > To systematically audit and review a range of existing dental health resources designed for people with disability

4 > To develop education, training and communication resources for dental professionals to more effectively include people with intellectual disability in their regular practice

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Participants

> Dentists and other oral health professionals
> Special Needs Dentists
> Self-advocates with intellectual disability
> Allied health professionals
> Behavioural therapists
> Residential services managers
> Disability rights advocates
> Leading practice experts involved in dental health initiatives for people with disability
> Academics

Participant tasks

Participants will attend Community of Practice meetings to gain interdisciplinary knowledge, set practice goals, review a range of existing oral health resources and materials, and contribute to the development of new resources, materials and tools.

Details of CoP meetings

Duration	2 Hours
Frequency	Quarterly over 18 months
Venue	Inclusion Melbourne
Evaluation	Quantitative (Survey) Qualitative (Interviews)

Significance

Most dental patients with intellectual disability can be treated successfully in general dental clinics. However, this does not often occur, placing enormous cost and demand on hospital services and the limited number of specialists in Special Needs Dentistry. This could be due to lack of codesign, interdisciplinary approach and gaps in dental professionals' education with respect to managing people with intellectual disability.

This research will be among the first to bring together an Action Research process involving dental health professionals, disability practitioners, and people with intellectual disability to coproduce solutions to address the gaps in dental practice.

Benefits

• Dentists will have an opportunity to further their own professional development with respect to the inclusion of people with intellectual disability in their practice

• Dental and oral health practitioners will acquire knowledge and skills to apply in their practice

• Resources produced will be disseminated nationally and available online

• Disability professionals will develop their understanding of oral health and how to best work with dental professionals

• Both dental and disability professionals will have an opportunity to learn about dental service experience and expectations of people with intellectual disability

• People with intellectual disability will learn about the importance of dental health and preparation required for dental appointments

• This action research will have a potential global impact as it involves collaboration of peak dental and disability organisations, government bodies and academics

project team

University of Melbourne

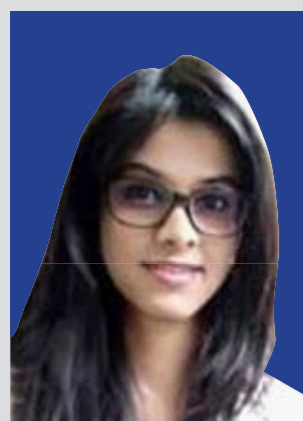**Prof Keith McVilly**
Professorial Fellow in Disability
and Inclusion

Dr Hanny Calache
Melbourne Dental School

Dr Alana Roy
Research Fellow

Inclusion Melbourne

Dr Tejashree Kangutkar
Research Fellow

Nathan Despott
Manager, Policy and Projects

Jenna Hepburn
Project Coordinator

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Project background and previous work

The *Oral Health and people with Intellectual Disability: A Community of Practice for Effective Intervention project*, henceforth called the *Community of Practice project*, represents the expansion of work that commenced with the Your Dental Health project, a partnership of Inclusion Melbourne, Carrington Health, Centre for Developmental Disability Health (CDDH, Monash Health). *Your Dental Health* saw oral health professionals, allied health professionals, disability support professionals, and people with intellectual disability (ID) collaborate to develop high quality oral health resources for people with intellectual disability, support professionals and oral health professionals.

The project's resources are available at **www. inclusiondesignlab.org.au/dental**. Resources include a world-first 'dual read' guide for people with intellectual disability, their supporters and advocates.

The project also surveyed 100 dentists at the 2017 Australian Dental Congress regarding enablers and barriers to provision of dental healthcare for people with ID.

In 2019, the *Your Dental Health* team and the Australian Society for Special Care in Dentistry (ASSCID), along with individuals from across the allied health sector, launched the ADA-endorsed *Oral Health* and *Intellectual Disability Guide*. This guide outlines key protocols and recommendations for family members, health professionals and support workers to use in achieving optimal oral health outcomes for people with an intellectual disability. The guide demonstrates that interdisciplinary collaboration combined with a modest amount of knowledge regarding disability and oral health on the part of the collaborating professionals are key components in removing barriers and improving oral health outcomes for people with an intellectual disability.

The Your Dental Health project's work now includes articles in the Victorian and Federal editions of the Australian Dental Association's journals, a feature in the Bite Magazine for Australian dentists, and an interview in the Dental Tribune.

> Your Dental Health: A Guide for People with a Disability, their Family Carers, Friends and Advocates

> Your Dental Health website:
> An online resource containing the above publications and a suite of videos, including short videos that can be shown to people with disability before treatment to aid familiarisation and desensitisation, autism-friendly animations, and a pathway video produced in partnership with Monash Health for dentists illustrating the ways in which they can work collaboratively with disability support professionals during treatment planning.

The focal point of the Community of Practice project will be the treatment pathway available on pages 8-9 of *Oral Health and Intellectual Disability* (2019). The pathway promotes interaction at each point of the journey, from preparation and appointment planning, through to familiarisation, in-chair treatment, and post-treatment home care. This interdisciplinary pathway acknowledges the skills of well-trained direct support workers, rules relating to restrictive practices, the systems that exist in most group homes, the potential of general dentists, and the power of simple but effective post-treatment planning.

The *Community of Practice* project, a joint initiative of University of Melbourne and Inclusion Melbourne with support from the Disability and Oral Health Collaboration,is an opportunity to implement, test and trial the pathways, interventions, and interdisciplinary perspectives developed thus far. The project will be delivered with academic rigour and produce additional high quality, ecologically valid resources for the disability, dentistry and allied health sectors.

Research design project

A six-month research design project, funded by a generous MDI seed-funding grant, ran from October 2019 to March 2020.

The seed-funding period coincided with a number of key events in the life of the *Disability and Oral Health Collaboration*, in particular two ASSCID and ASID seminars in Melbourne at which members of the research design project team presented major findings to two of Australia's most prominent disability peak organisations.

The research design phase also saw the production of a joint submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Led by Inclusion Melbourne, this unprecedented joint project of Deakin University, University of Melbourne, the Australian Society of Special Care in Dentistry, the Australian and New Zealand Academy of Special Needs Dentistry, and the Australian Academy of Paediatric Dentistry resulted in a joint meeting with two Royal Commissioners and a summons to provide evidence to the Commission's Health hearing on Monday 24 February 2020. Two of the Community of Practice project coordinators, Nathan Despott and Mr Richard Zylan, presented at the hearing.

The submission is available at www.inclusionmelbourne.org.au/projects/your-dental-health

The submission focused on the theoretical and practice gaps that exist between dentistry and the disability sector. The following items (listed under the heading 'Gaps' in the Submission) are particularly relevant to the interaction of dentistry and disability support practice. The following is taken directly from the joint Submission:

d. The extent to which oral health issues in people with critically neglected oral health contributes to their poor general health and gives rise to circumstances (e.g., unnecessary use of restrictive practices) that compromise their civil and human rights should not be underestimated.

e. When dental professionals do not understand the systems and communication pathways that exist 'behind' the supporters and staff members who accompany a person with ID to dental treatment, they will be unable to effectively engage and utilise the support network.

f. Rather than problematising poor oral health as the fault of the individual, a focus on the broader systemic gaps across the oral health and disability sectors is needed. The practices, systems and tools required to support people with intellectual disability to have good oral health – regardless of their self-care skills – already exist in the various practice frameworks in the disability sector, however the effective training and coaching of these frameworks and the inter-disciplinary communication that is required to connect these practices, systems and tools is lacking.

g. Oral health records need to be communicated to family members, non-dental healthcare professionals, and direct support staff who might not have any training in oral health. The difference in frequency between visits to the dentist and doctor can sometimes be 1:20. Communication regarding oral health needs to occur in a documented and/or recorded manner:

(1) Between people with intellectual disability and their dentist

(2) Between people with intellectual disability and their GP

(3) Between supporters and people with intellectual disability

(4) Between dentists and GPs

(5) Between dentists and supporters, particularly accommodation staff and families

(6) Between GPs and supporters

These activities allowed the research design project to build significant interest in the Community of Practice project through the national broadcast of segments of the team members' Royal Commission hearing in Sydney, as well as through the development of the submission itself as more than 40 dentists and special needs dentists reviewed or contributed to the document before it was completed.

Research design project deliverables:

The research design project achieved all projected deliverables within the six-month period outlined in the application for seed funding. Copies of most of these items have been reproduced in this report.

Deliverable	Description	Included in this report
HREC Application	The HREC application was completed by University of Melbourne research staff and submitted in late November 2019. The HREC application required refining at two points and was approved in early March 2020. The HREC application included a project plan, information about data storage and security, pre and post questionnaire forms for Community of Practice participants, session plans, details of content to be delivered by subject matter experts, and an appendix list of resources and tools.	✓ (Adapted)
Pre and post questionnaire*	Questionnaires were developed for the purposes of data collection before the commencement of the CoP and afterwards. The questionnaires allow the project to produce ecologically valid evidence about the impact of the CoP sessions on the oral health practice and outcomes of oral health and disability support professionals.	✓
Fact sheet for dental CoP members*	A basic fact sheet for recruitment of CoP participants was produced in PDF format.	✓
Session plans for CoP sessions	The project team developed a series of session plans outlining the learning outcomes and content for each CoP session. These session plans contain an outline of themes from previous sessions, core content to be delivered by a subject matter expert, details of exemplar resources to discussed by CoP members, and goal setting.	✓
Advisory Group*	Members of the Advisory Group were recruited through a series of face to face or online meetings. It was determined by the Project Coordinators that the Advisory Group should consist of a range of professionals and experts, including a person with intellectual disability, with prior connection to the project. This included representatives of North Richmond Community Health, ASSCID, ASID, the University of Melbourne, Deakin University, and ANZASND. Recruitment of the Advisory Group is now complete	N/A

Deliverable	Description	Included in this report
Advisory Group Terms of Reference and Agreement*	A plain language Terms of Reference and Agreement was developed. This document also contains a significant overview of the project, project background, and relevant information about oral health and intellectual disability.	✓
Plain language statement and consent form for CoP members*	Developed as part of HREC application.	✓
Updated project plan, budget and timeline	Completed.	✓
Subject matter expert list*	Interdisciplinary subject matter experts have been recruited and have submitted session plans for the respective CoP presentations.	✓ (In Session Plans)
Resource index and report*	Inclusion Melbourne project coordinator Jenna Hepburn performed a search of global resources available to industry (dentists, disability support professionals, and advocates) and people with intellectual disability. These were indexed and assessed. This report will be provided to the Advisory Group and CoP members.	✓
Easy language resources for CoP participants with intellectual disability*	Planning complete. To be produced during project implementation according to the needs of participants.	✓
Grant applications	Inclusion Melbourne's grants and communications officer submitted an application for a $680,000 grant from the NDIA's ILC mainstream health grant round with the hopes of securing sufficient funding to run the CoP project over three years. The team was not successful with this grant. Indeed, no oral health projects and no projects with significant research components were funded. The project team determined that the most appropriate strategy moving forward was to apply for a range of $50-100,000 grants to deliver a shortened pilot iteration of the project, allowing for the development of initial evidence and literature that could be leveraged to apply for national research funding. To date, six such small grant applications have been lodged.	✓ (Summary)
CoP Overview poster	Planning complete. Graphic designer will produce poster upon commencement of pilot or full project.	

*These deliverables are external stakeholder-facing documents and have therefore not yet been distributed to and/or signed by Advisory Group members or Community of Practice participants. However, all Advisory Group members have been recruited and have been provided with copies of the initial project plan.

Additional outputs

In addition to the joint submission to the Royal Commission, presentations at seminars, and the above list of required deliverables, the research design project also completed a range of additional activities that will greatly enhance the outputs and eventual outcomes of the Community of Practice project once implemented. These are:

Deliverable	Description	Included in this report
Literature review report	The University of Melbourne research staff developed a report based on a literature review developed by Dr Kangutkar. This report will be provided to all members of the CoP in addition to the current *Your Dental Health* resources to ensure they are aware of the current knowledge/evidence base.	✓
Literature review fact sheet	One-page summary of literature review findings, including aims and objectives for CoP project.	✓
Mapping of VET module content	Dr Kangutkar investigated and mapped the content in the oral health vocational education and training (VET) modules available to students completing Cert III, Cert IV and the Diploma in Individual Support (Disability) or Community Services. Key findings of this exercise were: • There are currently 6 modules, all electives for Cert III and Cert IV, and almost all electives for the Diploma. • These modules are seldom chosen by students taking the VET courses. • Most of the modules contain a small amount of vital information with potentially frequent application, coupled with other information that may be irrelevant for most students. • A single, efficient, compulsory module containing the core content already available in resources such as the *Your Dental Health* dual-read guide and *Oral Health and Intellectual Disability* guide, with a strong focus on interdisciplinary planning, communication and preventive care, would most likely guarantee superior outcomes. Elective modules would still be required for a small number of trainees. • Many organisations and support providers do not require staff to have a VET qualification, indicating that an efficient single core module could be adapted into a micro-credential for university students, or a CPD module for allied health professionals working with people with disability. Interest for such an undertaking has already been generated through discussions between the CoP research design project team, RMIT University and Deakin University. • The CoP would be an ideal environment in which to develop the base content for a single module.	✓
Development of Community of Practice pilot plan	The possibility that large grants ($600,000+) may not be available in the near future led to the development of a plan for a pilot iteration of the project. This project pilot would allow for the development of initial evidence.	✓
Pilot budget	Completed based on pilot with three CoP sessions.	✓

research plan

Research aim:

To identify, through collective problem solving (ie. a Community of Practice –CoPapproach), best practice solutions for Australian dental professionals to more effectively include people with intellectual disability in their clinical practice.

Research questions:

1. What are the enablers and barriers to the provision of effective dental services to people with intellectual disability in regular public and/or private practice dental surgery settings?

2. What resources are currently available to support the inclusion and effective treatment of people with intellectual disability in regular public and/or private practice dental surgery settings; what is the relevance and quality of these resources; and how might these resources be improved and made more accessible?

3. What additional resources are required to support the inclusion and effective treatment of people with intellectual disability in regular public and/or private practice dental surgery settings?

4. How might the content of best-practice resources be communicated to dentists and oral health practitioners, so as to translate knowledge into practice through information dissemination, training and education?

5. How might education and training best be made available to dentists and oral health practitioners at various stages of their professional development, including during pre-service and in-service education?

6. What is the effect on dentists and oral health practitioners as a result of their participation in a CoP with respect to their: (a) professional goals in relation to the inclusion of people with intellectual disability in regular public and/or private practice dental surgery settings; and (b) their engagement with patients with intellectual disability?

Research objectives:

1. Exposing dentists to a range of self-advocate (patient) and interdisciplinary voices; and subsequently identifying enablers and barriers to the provision of dental services to people with intellectual disability in regular public and/or private practice dental surgery settings;

2. Systemically auditing and reviewing a range of dental health resources in a CoP setting; and subsequently developing new training and educational resources for Australian dental professionals for use beyond the CoP, to more effectively include people with intellectual disability in their regular dental practice, including a training module: (a) for tertiary dentistry and oral health therapy students, and (b) for use in Continuing Professional Development (CPD) for registered dentists and oral health therapists;

3. Developing communication resources relating to the mainstream treatment of people with intellectual disability for the dental profession more broadly;

4. Translating resources and knowledge into practice;

5. Evaluating the CoP approach in effecting a change in the engagement of dental professionals with people with intellectual disability by: (a) setting and reviewing professional goals to be undertaken by participants between CoP meetings; and (b) tracking and reviewing changes in dental professionals' engagement with patients with intellectual disability.

Project outcomes:

The researchobjectives will contribute to the long-term aims of the overall programme of research:

1. To increase the volume of patients with intellectual disability being treated by regular dental professionals in community dentistry and private practice settings, and reduce hospital admissions

2. To improve the oral health, and therefore the overall health, of Australians with intellectual disability

3. To create innovative, efficient communication and referral pathways between the dentistry and disability support sectors that will drive better outcomes.

Research design

This program of research will be undertaken as Action Research (AR). In AR those involved in the everyday practice of the topic of inquiry under investigation take the lead on investigating that topic. As practitioners with expertise in their own field, they reflect upon questions that arise from their own practice, and question their own beliefs, assumptions, and practices with the goal of understanding, developing, and improving their practice.Furthermore, the practitioner-researchers seek to uncover gaps in both their own knowledge and the literature informing their practice, and in turn generate and test solutions to address these knowledge gaps.

The Communities of Practice (CoP) approach is predominantly a qualitative action research methodology, often employed in social and community research.It is a powerful action research model given it combines aspects of participatory community development, focus groups comprised of experts in the topic of inquiry, peer review, peer mentoring, and a degree of collegiality not often seen in other research models. The CoP approach allows for both robust formative and summative evaluation, and often produces rich data that can be observed and collected in situ. This means that CoPs can achieve both traditional research and applied aims at the same time.

In the current context, the CoP approach will provide an environment conducive to the:

a. Inclusion of numerous interdisciplinary experts spread across the CoP meetings

b. Delivery of evidence-informed training to CoP members at each CoP meeting

c. Effective co-design in the revision of existing resources, and the development of new resources

d. Opportunities for reflection on professional practice, together with the setting and review of professional goals (which could later inform educational resources for other practitioners)

e. Evaluation of both the CoP process and outcomes for participants

Background and method

A) Background:

Overall health of people with intellectual disability

People with intellectual disability (ID) have some of the poorest health outcomes, including vastly lower life expectancy and higher rates of preventable disease and death than for the general population (Trollor J, Srasuebkul P, Xu H, et al, 2017).This is despite health targets, including dental health targets, having long been established (Beange H, Lennox N & Parmenter T, 1999).

Oral healthcare of people with intellectual disability

Most notably, poor oral / dental health sits at the intersection of most of the causes and complications identified in research into the overall health of people with ID (Ummer-Christian R, Iacono T, Grills N, Pradhan A, Hughes N, & Gussy M 2018). Good oral / dental health is required if people with ID are to function to the best of their abilities, experience optimum health and wellbeing, and be included and participate fully in their communities.

Need for interdisciplinary approach to improve oral health of people with intellectual disability

Most dental patients with ID can be treated successfully in the general dental clinic. However, this does not often occur, placing enormous cost and demand for services on hospitals and the few special needs dentists in Australia. There is currently a paucity of co-designed, interdisciplinary resources that focus on the prevention and treatment of oral / dental diseases in people with ID, particularly resources that connect and promote collaborative practice between dentists, general medical practice, allied health practitioners, disability support professionals, people with intellectual disability, and families.

B) Significance of this research:

Purpose

This research will address gaps identified in the literature with respect to increasing the knowledge and confidence of dental practitioners to more effectively manage the dental health of people with intellectual disability in general practice settings, and minimise current reliance on both general anaesthesia and unnecessary (costly and at times traumatic) hospital admissions for people with ID. Notably, this research will be among the first to bring together in an Action Research process, oral health / dental practitioners, disability practitioners, and people with ID to co-produce solutions to the problems faced in current oral health / dental practice.

Gaps in existing practice

Notably, research has highlighted the gaps in dental practitioners' education with respect to managing people with intellectual disability. These gaps include:

- Lack of pre-service and in-service professional development programs for practicing dentists to increase their knowledge and confidence to treat people with intellectual disability

- Dentists' lack of awareness of the oral health needs of people with intellectual disability, and how these interact with their psycho-social and behavioural support needs

- Dental practice models for people with ID that emphasise community-based practice and the use of the least restrictive alternatives in practice (e.g., avoiding unnecessary general anaesthesia)

Research design and method

A) Participants (and Recruitment Targets):

The CoP approach will engage an interdisciplinary group of professionals, and include people with intellectual disability, as follows:
- 5-10 general dental / oral health professionals (at least 4 dentists)

- 2-3 self-advocates with intellectual disability with dental service consumer knowledge and experience in action research.

- A range of interdisciplinary professionals:

  i. A behavioural therapist with expertise in the management of restrictive practices

  ii. A residential services manager who works in group homes with people with ID

  iii. Special needs dentists

  iv. Leading practice experts previously involved in dental health initiatives for people with disability (e.g., GPs with disability expertise, community health professionals, community dental practice managers)

  v. Leading academics previously involved in dental health initiatives for people with disability (including health an allied health researchers)

  vi. Disability rights advocates.

B) Recruitment:

A purposive sample of dentists, disability support professionals, people with intellectual disability, and disability advocates will be recruited for their knowledge, skills and experiences in the field of dentistry and / or disability services. This will be achieved via an invitation to participate using an approved Plain Language Statement (PLS) circulated among a network of people who have previously been involved in oral health initiatives for people with ID.

For the oral health professionals, recruitment will be facilitated through collegiate organisations;including clinical, teaching, and research centres.

For the participants with intellectual disability, the project partners have developed networks over many years and will invite people known from their participation in previous community development projects.All such persons will be competent to provide individual informed consent to participate, having previously participated in similar activities and by virtue of their demonstrated independence in their domestic and / or employment situations.However, all will be asked to discuss their participation with a person they know and trust if this might assist them in making a decision to participate.

For the interdisciplinary professionals,recruitment will be facilitated through collegiate organisations; including clinical, teaching, and research centres.

C) Participant incentives:

Participants will be provided with morning tea and coffee at the CoP events.Participants will be provided with invoiced direct payment, EFT or an equivalent voucher to compensate them for their time.

D) Participant task(s):

Community of Practice (CoP) meetings will be held quarterly, over an 18-20 month period at a central location in Melbourne, most likely Inclusion Melbourne's offices in Armadale. The CoP will employ an action research methodology, and as such the participants will be largely responsible for the leadership of the CoP and its associated activities.

Each session will run for approximately two hours.Refer to the Community of Practice (CoP) session plans for an outline of each session.These are subject to review and further refinement by the project's Advisory Group.

Participants will be asked to review a range of resources, materials and tools during and between the CoP sessions.

Participants will be asked to consider and contribute to the development of a range of new resources, materials and tools as the project unfolds over the 18-20 months.

Dental professionals will participate in pre/post self-assessments (basic quantitative and short interview/qualitative data collection conducted by a research fellow who will have participated in the CoP) to understand and track changes in their engagement with patients with intellectual disability, particularly with respect to:

- Attitudes towards the inclusion of people with ID in mainstream dental practice

- Practice activities (e.g., procedures) & volume of patients with ID seen in practice

- Oral health outcomes for patients

- Referral systems and communication between GP, dentist, special needs dentists, disability professionals, supporters, and other experts

- Restrictions, barriers, and enablers

- Professional development goals going forward

Note:Participants (including dental professionals) will be instructed not to provide any information that might identify an individual patient from their practice, or which might breach patient confidentiality.

E) Data/Material Collection Technique(s):

Data collection and analysis

Data will include the narrative of participants (as recorded in the minutes and associated documentation), the issues participants document and bring to the CoP (eg. goal attainment scaling on self-report questionnaires, interviews and short surveys), and the products produced by the CoP (eg. educational / informational resources).
Minutes from the CoP meetings will be collected. Field notes and journal entries will be written by participants throughout the program of research to track processes, interdisciplinary collaborations, challenges and outcomes. These will be referred to by participants in subsequent group discussions and individual interviews. Dental professionals' pre/post questionnaires will also be available for analysis.

F) Data Analysis:

This project will incorporate both qualitative and quantitative methods to investigate multiple topics of inquiry and test multiple hypotheses relevant to its overall objectives.The analysis will be predominantly qualitative in nature. The CoP participants will be largely responsible for the collective analysis of data, with the support of a university-based research fellow (providing technical support as required and being responsible for the collation of data and write-up). With respect to the quantitative analysis it should be noted that given the form of the data and the number of participants, these analyses will be predominantly descriptive, and we will focus on the evaluation of the strength and significance of relationships among variables rather than attempting to ascribe cause and effect.

Minutes from the CoP meetings will be analysed using inductive thematic analysis, to track emerging learnings and the resolution of challenges.Dental professionals pre/post self-assessments will be analysed both qualitatively and quantitatively.However, it is envisaged that quantitative analysis will be limited to descriptive analysis, given the relatively small sample size.

Following participation in the CoP, we predict that dentists will report:

1. Increased knowledge concerning people with intellectual disabilities and how best to support them during dental treatment (e.g. quantitative and qualitative data compared pre and post CoP, adapting: Saeed, Daly, and Newton [2012]https://doi.org/10.1111/j.1754-4505.2012.00269.x)

2. More positive attitudes towards people with intellectual disabilities in the context of dental practice (e.g.quantitative and qualitative data compared pre and post CoP, adapting: Abraham, Yeroshalmi and Margulis [2019] https://doi.org/10.1111/scd.12346; and DeLucia and Davis [2009] http://www.jdentaled.org/content/73/4/445)

3. Increased confidence in communicating with patients with intellectual disabilities, and engaging with their families and support staff (e.g. quantitative and qualitative data compared pre and post CoP, adapting: Aalboe and Schumacher [2016] http://www.jdentaled.org/content/80/1/58)

4. Increased confidence in treating people with intellectual disabilities in their general practice (e.g. quantitative and qualitative data compared pre and post CoP, adapting: Puryer, Woods, Terry, Sandy, and Ireland [2018] - https://doi.org/10.1111/eje.12271; and Popat, Thomas, and Farnell [2016] - https://doi.org/10.1038/sj.bdj.2016.495)

5. Increased numbers of people with intellectual disabilities being treated in their general practice (e.g.comparison of the number of patients treated pre and post CoP)

6. Decreased referrals to hospitals for routine dental work (e.g., comparison of the number of referrals to hospital / in-patient services pre and post CoP)

7. Increased instances of communication between dentists and other health and allied health professionals (e.g. comparison of the number of interdisciplinary communications in writing or by telephone pre and post CoP)

8. Attainment of professional development goals as they pertain to the treatment of people with intellectual disabilities (e.g. use of individualised Goal Attainment Scaling techniques)

Risks, benefits and monitoring

A) Potential Risks

Participants will discuss topics related to oral health care, with the risk of disclosure of information that could identify patients.

Some topics raised in discussion could be of a sensitive nature and though within the ambit of professional discourse, could cause distress among participants.

An imbalance of power could arise between participants with different backgrounds (e.g. dentistry, disability services, people with lived experience of disability), effecting their form and degree of participation.

Presenters could give clinically inappropriate information.

Presenters might not be available to present on the day scheduled due to ad hoc cancellations.

B) Risk Management Strategy

The project has an Advisory Group that will provide on-going oversight.The Group will anticipate difficulties and plan strategies on an ongoing basis.So too they will review and address any problems that arise in a timely way. Any breach of the HREC approval will be brought to the attention of the HREC.

Discussion of issues in a way which might identify an individual person will be actively discouraged (group rules).All case studies will be deidentified unless a person is sharing their own lived experience.However, there will also be an agreement to maintain confidentiality of group discussions as they might relate to actual people that will form part of the Consent to participate.The group rules relating to confidentiality will be outlined at the commencement of each CoP meeting.

Participants will be provided with referral information concerning sources of support relevant to their circumstances as a dental practitioner, disability practitioner or person with a disability.These will include professional counselling services available to the general public, services available on referral from a GP, and services offered by their respective employers (e.g. an Employee Assistance Programme – EAP).

In formulating the group rules, there will be explicit discussion of potential power imbalances and ableism, and the group will actively develop management strategies and be encouraged to 'call out' any potential ableism. Facilitation of CoP meetings will be led by a professional, with experience in CoP facilitation, while people with disabilities will co-facilitate meetings.

Each session will be pre-planned.There will be an emphasis on the requirement for evidence-based presentations.Guest presenters be required to provide references supporting their subject matter. Course content will be reviewed by multiple project partners to ensure credibility of content and any questions referred to the Project Coordination Group for final adjudication as required.

The schedule will provide for several presenters at each CoP, and where possible, alternative presentations will be planned well in advance.

Risks, benefits and justification

A) Expected Benefits

This project is anticipated to have benefits for the participants in so far as they will have an opportunity to further their own professional development with respect to the inclusion of people with intellectual disability in general dental practice.Dental and oral health practitioners will acquire knowledge and skills to apply in their own practice. Disability practitioners will develop their understanding of oral / dental health and how best to work with the dental profession.

Furthermore, both dental and disability professionals will have an opportunity to learn from people with disability and have an opportunity to experience relating to them as experts in their own lived experience (in contrast to the usual dependent role of 'patient').

People with disability will learn more about the importance of dental health and, notably have an opportunity to develop their skills and efficacy in teaching professionals about their support needs.

This project will benefit both the dental health and disability sectors with respect to the co-design of informational and educational resources.

This project will advance our understanding of how CoP methodology might contribute to science and the development of an informative and practical evidence-base at the intersection of health and community service settings.

B) Justification of Risks by Expected Benefits

There are minimal risks, if any, to participants in this program of research. In contrast, the anticipated benefits of the research to professionals and people with an intellectual disability are anticipated to be far-reaching and wide-ranging in terms of the contribution to policy development and service delivery. Furthermore, consistent with the principles of the United Nations Convention on the Rights of Persons with Disabilities (2006), this project will serve to draw attention to and reinforce the inherent rights and abilities of people with disability to direct matters effecting their own lives.

Governance and monitoring

A) Governance

The project will be facilitated by two teams and will take the form of a Community of Practice utilising participatory approaches to research. The project participants will guide and direct the content and themes throughout the project, leading to the development of the information resources. The two teams are noted below:

A Project Coordination Group will conduct the core activities of the project. An Advisory Group will meet regularly to monitor the project. The Advisory Group will compromise at least one person with an intellectual disability.

Project Coordination Group

- Professor Keith McVilly (Lead investigator) University of Melbourne, School of Social and Political Sciences, Level 4, John Medley Building (191) The University of Melbourne VIC 3010

- Dr Alana Roy Research Fellow The University of Melbourne

- Dr Tejashree Kangutkar Research Assistant The University of Melbourne

- Nathan Despott Manager, Policy & Projects Inclusion Melbourne

- Jenna Hepburn Project Co-ordinator Inclusion Melbourne

Advisory Group

Comprised of Project Coordination Group and the following representatives. Please see the Advocacy Group Terms of Reference and Agreement.

- Dr Richard Zylan Dentist

- Professor Hanny Calache Honorary Senior Fellow, Melbourne Dental School The University of Melbourne

- Dr Joanne Watson Lecturer, Disability and Inclusion Deakin University

- Dr Kerrie Punshon Special Needs Dentist, President ASSCID

- Dr Helen Marchant Special Needs Dentist Western Special Needs Dentistry

- Alyson Bettega Senior Oral Health Therapist North Richmond Community Health

- Cameron Bloomfield Member Rainbow Rights and Advocacy (LGBTIQA+ self-advocacy group for people with intellectual disability, supported by SARU)

- Dr Katy Theodore Dentist Dental Health Services Victoria

- Dr Mathew Lim Special Needs Dentist

B) Monitoring

The research will be conducted in Melbourne and monitored by the Advisory Group, also based in Melbourne. The project will be subject to reporting to the University of Melbourne HREC.A final report will be made to the Melbourne Disability Institute and the project funder.

Consent

Obtaining informed consent

Explain how you will obtain informed consent from participants.

Written consent will be obtained from all participants. Plain language statements, consent forms and the right to withdrawn forms will be provided.

For participants with intellectual disability, all will be competent to provide individual informed consent to participate, having previously participated in similar activities and by virtue of their demonstrated independence in their domestic and / or employment situations.However, all will be asked to discuss their participation with a person they know and trust if this might assist them in making a decision to participate.

Future use of data

Tiltle?	Title?	Title?
YES	Consent will be **specific**	> Data / materials / tissues will be used only for this research project (i.e. **no future use**).
	Consent will be **extended**	> Data / materials / tissues used in this research project may also be used in future projects that are closely related to this project, or in the same general area of research as this project. This is clear in the PLS.
	Consent will be **unspecified**	> Data / materials / tissues used in this project may also be used in any future research. This is clear in the PLS.

Approval for Extended Consent(detailed on the PLS and Consent Forms) is requested given the data and findings of this project are anticipated to contribute to future research involving an up scaling of the project if funding becomes available.

Conflicts of interest

It is possible that researchers and project partners may have prior professional relationships with some participants (e.g. dentists, people with intellectual disability and guest speakers). However, it should be noted that the disability community regularly engages in forums involving people who have pre-existing relationships in the form of client-practitioner.

The plain language statement makes it clear that agreement to participate or the decision to decline participation will in no way effect current or future relationships or the provision of services.

People with intellectual disabilitywill be encouraged to discuss their participation with an independent person they know and trust.

In addition to the usual sources of ethical guidance for research, the team will also refer to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the Disability Discrimination Act 1992, the NDIS Practice Standards, and the Victorian Charter of Human Rights and Responsibilities Act.

Information for participants

Participants will be informed of the project via fact sheets, recommended reading, Plain Language Statements and consent forms.Following return of consent forms, all participants will be contacted by the Project Coordination Groupprior to commencement of CoP sessions to discuss the plain language statements and consentforms to ensure that each participant has understood the CoPprocess and program of research.

Dissemination and data management

Providing Results to Participants

- Formal and informal community-based discussions with all participants.
- Promote website, resources and materials via well-established sector channels, contacts, social media.
- Plain language summaries will be provided for people with intellectual disabilities.

Reporting Project Outcomes

- A report will be provided to the Melbourne Disability Institute and funders.
- Dissemination of materials via website, well-established sector channels, and social media .

- Presentations will be given to relevant interested parties in the disability and health sectors, including local community dental practices.
- Presentations at peer reviewed conferences (oral presentations/poster presentations/workshops).
- Manuscripts will be prepared for peer reviewed publications.

Data management

A) Privacy and Confidentiality

Participant privacy will be maintained in the strictest confidence, except if there is concern that the participant is in danger, or if a court directs otherwise.

No identifying information will be released by the University as part of the research report.

When writing reports, presenting project findings, or publishing articles, only aggregate data will be reported and, if needed to contextualise reporting, and to protect the anonymity of participants, only 'constructed case study examples', based on composite data, will be used.

The fact that some data collection will take place in group settings is acknowledged in the Plain Language Statement, and consent to participate will include an agreement to maintain the confidentiality of issues raised in a group context.

B) Security and Storage of Data

Hard-copy data will be stored by the CI in a locked filing cabinet.Following analysis, only de-identified digital data will be stored. Digital data will be stored in password-protected files.

C) Retention

De-identified digital data will be maintained for 5 years post publication of any peer-reviewed papers.

community of practice session plans

Session 1: Introduction to holding inclusive Community of Practice Meetings

Introduction to the COP – 20 minutes

Presentation from experts: Eva Sifis and Cameron Bloomfield, Voice at the Table – 30 minutes

The self-advocates will introduce themselves and describe their life experiences, including interactions with health professionals and dentists. Eva will discuss the differences she has observed in health care before and after her acquired disability.

Introduce the Dental Health Services Victoria 'filling the gap' videos and play the first few minutes, making sure that the participants know how to access these and watch them after the session.

https://www.dhsv.org.au/professionals/health-promotion-resources/videos/filling-the-gap

Introduce and show a video on the Social Model of Disability, leading a discussion on Australia's uptake of the model.

Social Model of disability:

The United Nations definition of disability reflects the social model of disability and is outlined below:

Disability includes long-term (lasting 6 months or more) physical, mental health, intellectual, neurological or sensory impairments which, in interaction with various attitudinal and environmental barriers, may hinder full and effective participation in society on an equal basis with others.

Lead a discussion dispelling any assumptions, fears or discriminations the participants may be in possession of.

Discussion points for the community of practice:

What do we mean by disability:

- People who are blind or people with vision impairment
- People with learning or intellectual disability
- People who are Deaf or hearing-impaired
- People who are neurodiverse
- People with lived experience of mental illness and/or emotional issues
- People with an acquired brain injury
- People with mobility and dexterity impairment

Statistics from the Australian Network on Disability:

- Over 4 million people in Australia have some form of disability. That's 1 in 5 people.
- In 2011, 2,733 people in City of Port Phillip, reported needing help in their day-to-day lives due to disability.
- 43% of people over 55 years have one or more disabilities.
- 2.1 million Australians of working age (15 – 64 years) have disability.
- People with disability are twice as likely to be in the bottom 20% of gross household incomes.

Barriers and what people with disability think about before they get to an appointment / service

- Think about your surroundings
- What information is on your website?
- Is your website accessible?
- Accessible car parks / pathways to the entrance
- Signage – can people find you easily?
- If you invite someone to your office, ask for access requirements

Inclusive communication

- Don't ask us inappropriate things
- Treat us as adults
- People with disability are at different acceptance levels - be mindful
- We are all individuals and each disability does not mean the same thing for everyone
- Attitude – What we say and how we say it
- Awareness – Know your customer
- Ask – People with disability will know what they need

Conclusion:

– List the benefits of your Actions
– List any challenges or Barriers
– How will you measure success?

Review currently existing resources – 20 minutes

- NSW Government, 2017. **Don't DIS my ABILITY – Day in the life**. New South Wales Government. Family and Community Services. Don't DIS my Ability Campaign. https://www.youtube.com/watch?v=cQubRDJlGJg
- Shape Arts, 2017. **Social Model of Disability**. National Disability Arts Collection and Archive – Disability History Month. https://www.youtube.com/watch?v=24KE__OCKMw&feature=youtu.be
- You Me Us, 2017a. **Accessible Information**. https://www.youtube.com/watch?v=ZZ9nN9ComIQ&feature=youtu.be
- You Me Us, 2017b. **Customer Service**. https://www.youtube.com/watch?v=-o8q2v4bUW0&feature=youtu.be
- You Me Us, 2018. **Amanda's Story**. https://www.youtube.com/watch?v=iu_BUEjZfC8

- 13WHAM ABC News, 2015. Dentists train for special needs patients. https://www.youtube.com/watch?v=AmCoDMOBS2U
- Aldred, M., and Talacko, A., 2009. Oral and Dental Problems in Scleroderma and Sjögren's Syndrome. Scleroderma Australia http://sclerodermavictoria.com.au/wp-content/uploads/2015/12/Scleroderma-Australia-Oral-And-Dental-Problems.pdf

Questions:

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up – 20 minutes

Questions:

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 2: Introduction to Community of Practice and Disability rights

2

Previous session: Overview and follow up – 20 minutes

Oral health and intellectual disability Information for Dental COP Project

Presentation from experts: Eva Sifis and Cameron Bloomfield, Voice at the Table – 30 minutes

Aims:

1. For COP participants to understand the 'big picture' and the need for collaboration with people with lived experience and other sectors

2. For dental practitioners to understand how the disability sector works and interacts with the dental sector

3. For dental practitioners to begin to understand the dental pathway for a person with intellectual disability

Content Outline:

1. Why cross-sector collaboration is key
   - People with disability have poor health and fewer resources
   - Good healthcare relies pm respect, communication, and collaboration between the person with intellectual disability, the key worker/family, and the dental practitioner/other health care
   - Demystifying communication with patients, key workers/family and why this is important for successful ongoing oral health

2. Introduction to the disability sector
   - Introduction to overlapping support plans in the life of a person with disability, and where dental advice 'fits' in with this
   - The nature of the disability workforce (i.e. may be long term, may just be there for that shift) and that they often do not have any health training
   - Oral health often not prioritised due to competing priorities
   - Restrictive practice in the disability sector

3. Ideal treatment pathway for a person with intellectual disability
   - Access to services (preparing, accessing, transport, other supports etc)
   - In the clinic (such as interaction between people involved)
   - Communication, behaviour, and consent
   - Management or care at home

Review currently existing resources: – 20 minutes

- Angwin, L, Leighton, D, & Despott, N. 2015a. **Your Dental Health: A Guide for People with a Disability, their Family Carers, Friends and Advocates**. Inclusion Melbourne. https://inclusionmelbourne.org.au/wp-content/uploads/2019/04/IM-Dental-Health-Publication-COMPLETE-2.pdf

- Inclusion Melbourne, 2019. **Your Dental Health**. Webpage https://inclusionmelbourne.org.au/projects/your-dental-health/

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 3: Residential services: Lived and practice experience

3

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Karen Woods, Bayley House – 30 minutes

Sharing lived experience and practice from residential disability services from the perspective of a supervisor of a group home for people with an intellectual disability.

Aims:

1. To introduce dental practitioners to life in a residential service for a person with intellectual disability

2. For dental practitioners to understand the working environment of residential house staff

3. To explore the current oral health practice of residential staff and interactions with dental professionals

Content Outline:

1. Life in a residential accommodation service
   - Day in the life of a person with disability living in residential accommodation
   - Opportunities and challenges of living in disability residential accommodation

2. Working in someone's home
   - Day in the life of a disability support professional who works in residential accommodation
   - Opportunities and challenges of supporting people in disability residential accommodation

3. Oral health and disability residential accommodation
   - Current practices for oral health when supporting people
     - Lower and higher support needs
   - Supporting a person to a dental appointment
     - Process of
     - Who usually attends appointment?
     - Pre and post care/support

Review currently existing resources: – 20 minutes

- Dental Health Services Victoria (DHSV), 2007b. **Supporting Every Smile**. https://everysmile.dhsv.org.au/

- Dental Health Services Victoria (DHSV), 2008. **Promoting oral health for people living in disability accommodation services**. https://www.dhsv.org.au/__data/assets/pdf_file/0003/3747/disability-resource-toolkit-das.pdf

- Dental Health Services Victoria (DHSV), 2010. **Brushing up on oral health for disability residential services**. https://www.youtube.com/playlist?list=PLcAjB30TLQlFEyZCGBjgKktIk7Jsm0dcW

- Children's Hospital of Pittsburgh, 2011. **Home Dental Care for People with Disabilities**. Brian Martin, DMD, Chief of Pediatric Dentistry of Children's Hospital of Pittsburgh. ACHIEVA and Pennsylvania Developmental Disabilities Council. https://www.youtube.com/watch?v=4wu8gl5AZkA

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 4: Special needs dentistry

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Dr Helen Marchant and Dr Kerrie Punshon, Western Special Needs Dentistry – 30 minutes

Overview of special needs dentistry and consideration including registration process and formal guidelines.

Content TBC

Review currently existing resources: – 20 minutes

- Southern Association of Institutional Dentists, 2013. **Special Care Advocates In Dentistry Modules: SAID Professional Modules**. http://saiddent.org/modules.php

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 5: Restrictive practices and positive behavior support plans

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Dave Relf, National Disability Services – 30 minutes

Participants will discuss the NDIS, quality, safeguarding, positive behaviour supports and restrictive practices in relation to special needs dentistry.

NDIS, quality, safeguarding, positive behaviour supports and restrictive practices.

- **Introduction to positive behaviour support**
  - A Human Rights based approach
  - Quality of life
  - Behaviours of concern and communication
  - Understanding the function of behaviour
  - Antecedent control
  - The behaviour cycles
- **Restrictive practices**
- What is considered restrictive?
- Understanding the concept of the least restrictive alternative
- Misuse/overuse of restrictive practices and the impact on the person.
- Overview of national legislation

- **NDS Recognising Restrictive Practices films**
- **Provision of relevant resources.**

A restrictive practice power point will be provided. A human rights framework will be outlined, and a behavioral cycle model will be discussed.

Seligman, M. E. (2011). Flourish: a visionary new understanding of happiness and well-being. Policy, 27(3), 60-1.

Horner, R. H., Dunlap, G., Koegel, R. L., Carr, E. G., Sailor, W., Anderson, J., ... & O'Neill, R. E. (2005). Toward a technology of "nonaversive" behavioural support. Research and Practice for Persons with Severe Disabilities, 30(1), 3-10

Office of Professional Practices: http://www.dhs.vic.gov.au/__data/assets/pdf_file/0011/845345/Toolkit-section-1-Why-develop-good-quality-plans-0913.pdf

Review currently existing resources: – 20 minutes

- NDS, 2017. Considering Additional Risks. National Disability Services: Zero Tolerance. https://www.nds.org.au/zero-tolerance-framework/considering-additional-risk

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 6: Parent Perspective & Expert in dentist treatment planning

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Dr Richard Zylan, parent of a person with disability, private dentist with expertise in treatment planning. – 30 minutes

Expert in dentist treatment planning. Review forms. Discuss experiences as a parent and techniques in the dental surgery.

Content TBC

Review currently existing resources: – 20 minutes

- Zylan, R., Despott, N., Tracy, J., Shnider, W. 2019 Oral Health and Intellectual Disability: A Guide for Dental Practitioners. Inclusion Melbourne, https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf
- Inclusion Melbourne and Monash Health, 2017. Dentistry and Disability. https://www.youtube.com/watch?v=kdgL3U8JBUc

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 7: Supported Decision Making

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Dr Joanne Watson, Deakin University – 30 minutes

What role can Supported Decision Making play in achieving good oral health for people with intellectual disability?

Australia's signing and ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) represents an important step towards promoting, protecting and ensuring human rights for Australians with disability. Article 12 of the Convention challenges the use of substitute decision-making or guardianship. In response to the UNCRPD, supported decision-making has emerged as an alternative paradigm to substitute decision-making, consistent with Australia's obligations under Article 12 of the UNCRPD. Supported decision-making is an interdependent process whereby a person with intellectual disability is supported to have their preferences acknowledged, interpreted and enacted.

Like everyone, people with intellectual disability face a range of decisions relating to health, including oral health. For example, a person may have preferences relating to a range of aspects of oral health care, such as, how hard the bristles on their toothbrush are, who supports them in cleaning their teeth, the level of sedation given during dental treatment, or the music played during a dental procedure.

A Supported decision-making approach provides supporters with a range of tools to implement with people with intellectual disability so their preferences relating to oral health care can not only be acknowledged, but interpreted and then responded to, within the context of their oral health care.

Aims:

1. To introduce participants to the UNCRPD and Australia's specific obligations under Article 12 of the Convention;

2. To provide participants with knowledge regarding supported decision-making mechanisms specifically within the context of oral health care.

Tools and Resources:

Watson, J. (2019). The role of speech-language pathology in supporting legal capacity **Journal of Clinical Practice in Speech-Language Pathology**, Vol 21 (1).

Gooding, P., Koritsas, S., Duffield, L., Watson, J., &Hagiliassis, N. (2016). Sean's decision. Decision-making support for people with cognitive disability. In **Decision-making support: Building capacity within Victoria**. Melbourne: Scope (Australia).

Watson, J., Koritsas, S., &Hagiliassis, N. (2015). **Supported Decision-Making for People with Cognitive Disabilities: A series of information sheets for service providers**. Scope. Melbourne.

Watson, J., & Joseph, R. (2015). People with severe to profound intellectual disabilities leading lives they prefer through supported decision-making: Listening to those rarely heard. A guide for supporters. A training package developed by Scope. (Version 2) Melbourne: Scope.

- Watson, J, 2016. Representing the rights of persons with disabilities. Deakin University. Presented at Financial Counselling Australia Conference 2016. https://www.youtube.com/watch?v=qMerG7CULJE

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 8: Disability, Sexual Assault and Dentistry

Previous session: Overview and follow up – 20 minutes

8

Presentation from expert: Dr SharonneZaks, private dentist specialising in trauma – 30 minutes

Q & A session regarding specialist dentistry and sexual assault resources.

Key Discussion points:

Understanding the parallels between dental practices and experiences of sexual assault

- Focus on sexual organ; the mouth
- Penetration (hands, fingers, instruments etc)
- Mouth filled up
- Being/feeling unable to speak
- Staying open for a long time
- Being immobilised
- Feeling powerless and vulnerable
- Unpredictability
- Feeling under someone else's control; they can do anything they want to you
- Infliction of pain
- Horizontal body position
- Close proximity of faces, bodies
- Smell of latex
- Fear of being judged/ criticised
- Dissociate during the experience, especially regarding GA

Definitions of sexual assault

Legal definitions of crimes of sexual violence including sexual assault:
https://www.legalaid.vic.gov.au/find-legal-answers/sex-and-law/sexual-assault

CASA definitions:
https://www.secasa.com.au/assets/Documents/what-is-sexual-assault-.pdf

https://www.secasa.com.au/assets/Documents/legal-definitions-of-rape-and-indecent-assault.pdf

https://www.secasa.com.au/assets/Documents/what-are-the-myths-and-facts-about-sexual-assault-.pdf

Centre Against Sexual Assault Dentist Survey
2018 CASA survey data, report and analysis:
https://www.secasa.com.au/assets/Documents/casa-dental-survey-report-2018.pdf

Review currently existing resources: – 20 minutes

- Zaks, S 2018d. Why oral health is important Sharonne Zaks Dental. https://youtu.be/YLvQ8BTaQCM

- Zaks, S 2018e. How to choose a dentist you can trust. Sharonne Zaks Dental. https://youtu.be/ylMtCXX7URk

- Zaks, S 2018f. Visiting the dentist: Full length version Sharonne Zaks Dental. https://youtu.be/CJhsyvwnRwQ

- Zaks, S 2018g. Visiting the dentist: Advice from survivors: Part 1/7: How did you meet your dentist? Sharonne Zaks Dental. https://youtu.be/CcTTm0WLrug

- Zaks, S 2018h. Visiting the dentist: Advice from survivors: Part 2/7: Common Reactions: Panic attacks and dissociation Sharonne Zaks Dental. https://youtu.be/Ym1qAXis9OM

- Zaks, S 2018i. Visiting the dentist: Advice from survivors: Part 3/7: What is your greatest fear about going to the dentist? Sharonne Zaks Dental. https://youtu.be/l1zW6hvicRY

- Zaks, S 2018j. Visiting the dentist: Advice from survivors: Part 4/7: Do you have trouble with brushing or flossing? Sharonne Zaks Dental. https://youtu.be/o2e7Gg9y6mU

- Zaks, S 2018k. Visiting the dentist: Advice from survivors: Part 5/7: What coping strategies do you use when visiting the dentist? Sharonne Zaks Dental. https://youtu.be/cPtKwcta4Wk

- Zaks, S 2018l. Visiting the dentist: Advice from survivors: Part 6/7: What would you like to tell dentists about working with survivors? Sharonne Zaks Dental. https://youtu.be/1kbjnt5Iuro

- Zaks, S 2018m. Visiting the dentist: Advice from survivors: Part 7/7: What advice do you have for survivors? Sharonne Zaks Dental. https://youtu.be/PLO2R1v-T1g

- Zaks, S. 2018a. Trauma informed dental care: Dentist Lecture 1. Sharonne Zaks Dental. https://www.youtube.com/watch?v=ooGK3LJ1puA&feature=youtu.be

- Zaks, S. 2018b. Trauma informed dental care: Dentist Lecture 2. Sharonne Zaks Dental. https://www.youtube.com/watch?v=lns7TraKnAE&feature=youtu.be

- Zaks, S. 2018c. Trauma informed dental care: Dentist Lecture 3. Sharonne Zaks Dental. https://www.youtube.com/watch?v=57W7gDc25eM&feature=youtu.be

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 9: Voice of a self-advocate with complex communication

9

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Karleen, self-advocate with complex communication – 30 minutes

Exploring dental practitioners understanding of engaging people with complex communication need. Explore strategies to better support a person with complex communication within dental practices.

Aims:

1. For dental practitioners understand the difficulties of accessing good dental treatment for a person with complex communication

2. To explore strategies to better support a person with complex communication within dental practices

Content Outline:

1. Complex communication

- Shared experience from a self-advocate about a good, and a bad, visit to a dentist
- What made these good/bad experiences?
- What could be done to make all experiences good experiences

2. Communicating

- How you can explore the best way to communicate with a patient

Review currently existing resources: – 20 minutes

- National Institute of Dental and Craniofacial Research (NIDCR). 2009a. **Practical Oral Care for People with Autism**. National Institutes of Health Publication No. 09–5190, U.S. Department of Health and Human Services. https://www.nidcr.nih.gov/sites/default/files/2017-09/practical-oral-care-autism.pdf

- National Institute of Dental and Craniofacial Research (NIDCR). 2009b. **Practical Oral Care for People with Cerebral Palsy**. National Institutes of Health Publication No. 09–5192, U.S. Department of Health and Human Services. https://www.nidcr.nih.gov/sites/default/files/2017-09/practical-oral-care-cerebral-palsy.pdf

- National Institute of Dental and Craniofacial Research (NIDCR). 2009c. **Practical Oral Care for People with Down Syndrome**. National Institutes of Health Publication No. 09–5193, U.S. Department of Health and Human Services. https://www.nidcr.nih.gov/sites/default/files/2017-09/practical-oral-care-down-syndrome.pdf

- National Institute of Dental and Craniofacial Research (NIDCR). 2009d. **Practical Oral Care for People with Intellectual Disability**. National Institutes of Health

Publication No. 09–5194, U.S. Department of Health and Human Services. https://www.nidcr.nih.gov/sites/default/files/2017-09/practical-oral-care-intellectual-care.pdf

- The Royal College of Surgeons of England. 2012. **Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities**. Faculty of Dental Surgery, The Royal College of Surgeons of England. https://www.rcseng.ac.uk/library-and-publications/rcs-publications/docs/oral-health-care/

- Dental Health Services Victoria (DHSV), 2007a. Disability Awareness Guide. https://www.dhsv.org.au/__data/assets/pdf_file/0012/3144/disability-awareness-guide.pdf

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 10: Expertise in developmental disability medicine

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Dr Jane Tracy, CDDHV, Monash Health – 30 minutes

Aims:

To highlight the interrelated nature of disability, social support, general health and oral health. Key issues and strategies to address them will be highlighted.

Outline:

- Good health is the foundation for optimal function, independence and participation.

- The interplay between disability, social and practical support, general health and oral health needs to be understood in order to contribute to people with disability achieving and maintain optimal health and function.

- This presentation will focus on the implications of developmental disability for health services, and how understanding those implications informs practice.

- Good healthcare for people with complex needs associated with disability requires a multidisciplinary team with respect and communication between team members to ensure the person's goals and issues are addressed.

1. **Inclusion Melbourne** have produced a comprehensive set of excellent resources for dentists and other oral health professionals; people with intellectual disability and their families and support practitioners.

   https://inclusionmelbourne.org.au/projects/your-dental-health/

2. **The Inclusion Melbourne resources include: Oral health and Intellectual disability**

   Oral Health and Intellectual Disability

   www.ada.org.au/News-Media/News-and-Release/Latest-News/New-oral-health-and-disability-guide-for-dentists

3. **Dental Health Services Victoria have brought** together relevant information and resources into one easy-to-use website accessible to anyone with an interest in supporting someone with a disability to maintain their oral health

   https://everysmile.dhsv.org.au/

4. **Centre for Developmental Disability Health**

   Medical assessment service for adults with intellectual disability. Requires referral from GP.

   www.cddh.monashhealth.org

Review currently existing resources: – 20 minutes

Questions

– What did you think?
– How did you feel?

– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 11: Oral Health Therapist perspectives

Previous session: Overview and follow up – 20 minutes

Presentation from expert: Alyson Bettega, North Richmond Community Health – 30 minutes

Explore the 'big picture' and the need for collaboration with people with lived experience and other sectors. Discuss dental pathways for a persona with an intellectual disability

Content TBC

Review currently existing resources: – 20 minutes

- Holt K, Barzel R, eds. 2020. **Oral Health Services for Children and Adolescents with Special Health Care Needs: A Resource Guide** (4th ed.). Washington, DC: National Maternal and Child Oral Health Resource Center. https://www.mchoralhealth.org/PDFs/cshcn-resource-guide.pdf

- Boston Children's Hospital, 2013. **Dental Care for Children with Special Health Care Needs - Boston Children's Hospital**. The Department of Dentistry, Boston Children's Hospital. https://www.youtube.com/watch?v=uZR3dx3iq5o

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session 12: Oral Health and Hygiene, Overview of a speech pathologist

Previous session: Overview and follow up – 20 minutes

A speech pathologist will share knowledge, skills and insights from the field in regard to speech pathology, intellectual disability and dentistry. Expert case examples will be discussed with a question and answer session.

Presentation from expert: Dr Jane Tracy, CDDHV, Monash Health – 30 minutes

Background:

Speech pathologists can play an important role in educating people with disabilities and their supporters regarding oral health and hygiene. A key aspect of a Speech pathologist role in the lives of people with disability is support around dysphagia (difficulty with eating and swallowing). A serious complication associated with dysphagia is aspiration pneumonia. Aspiration pneumonia occurs when food, saliva, liquids, or vomit is breathed (aspirated) into the lungs or airway leading to the lungs, rather than swallowed into the oesophagus and stomach. Aspiration is a major concern in its own right, however, when it is coupled with poor oral health, the likelihood of bacteria being aspirated into the airway and lungs is particularly concerning and life threatening. This clear relationship between aspiration pneumonia and poor oral health, making a Speech pathologist an important part of a multidisciplinary support team regarding oral health care.

Aims:

1. To provide participants with knowledge regarding the important link between oral health and oral motor and sensory skills can play in aspiration pneumonia;

2. To facilitate discussion regarding the importance of good oral health on chewing, swallowing, speaking and social interaction;

3. To provide participants with some of the logistical, attitudinal and educational challenges faced by disability support workers and family carers in maintaining good oral health for those they support;

4. To provide participants with an understanding of the role Speech pathologist can play in supporting the development of oral motor and oral sensory skills with a view to increase oral health care and maintenance.

Case Study 1: Anne Maree

Anne Maree Broccio is a 48-year female client attending Bayley House 3 days a week.

Anne Maree has severe anxiety around dental work and visiting dentists.

She has refused to access dentistry services for a prolonged period of time and has very poor dental health.

Anne Maree lives at home with her stepmom and she is in the process of being appointed a guardian for the purposes of medical decision making, particularly in regard to orthopaedic specialists' recommendations for her to undergo total right hip replacement due to severe pain and risk of dislocation.

Health History (as per her GP Health summary)

Date of Birth: 13/07/1970
Allergies: NIL known
Legally Blind
Intellectual Disability
Asthma
Moyamoya disease

MoyaMoya disease

Moyamoya disease is a disease in which certain arteries in the brain are constricted. Blood flow is blocked by the constriction, and also by blood clots. A collateral circulation develops around the blocked vessels to compensate for the blockage, but the collateral vessels are small, weak, and prone to bleeding, aneurysm and thrombosis. On conventional X-ray angiography, these collateral vessels have the appearance of a "puff of smoke. (Wikipedia) MoyaMoya disease has caused Anne to sustain multiple ischemic strokes from a young age. Her strokes have led Anne Maree to become legally blind and caused right-sided weakness, sensory loss and impairments in cognitive functioning.

Past health history:

- Stomach reconstruction (9 years old, unsure of cause)
- Brain surgery (5 years old)
- Asthma
- Stroke
- Moyamoya disease
- Renal Impairment – 9/11/2015
- Pain Management – 26/07/2017
- Osteoarthritis of Hip – 26/07/2017
- Iron Deficiency – 22/06/2016

Current health concerns

Mobility: Anne Maree has been diagnosed with developmental dysplasia and secondary advanced osteoarthritis of her right hip.

Anne Maree refuses surgery due to anxiety around medical procedures.
She is using Bupredermal Transdermal Patches for pain management.
Anne Maree is in the process of being appointed a Guardian to assist with medical decision making.

Dentistry: Anne Maree has not accessed dental services for a prolonged period of time and has very poor dental health. Anne Maree refuse to attend dental appointments.

Anne Maree reported that she had a bad dental experience with her last appointment as she is unable to open her mouth wide enough due to the strokes that she suffered at a young age. This information has not been medically verified.

Questions:

Could Anne Maree be asked about her past dental experience

- Had she been to just one dentist or several?
- Was the visit focussed on getting something done?
- Did something happen to make her not want to go back to the dentist?
- Does she have dental pain?
- How does she feel about her teeth? Do they cause problems? Do they affect other areas of her life?

Could a staff member / support be asked in relation to Ann Maree

- What are the difficulties with supporting Anne Maree in getting dental treatment?
- What is the reality for clients like Anne Maree from an oral health point of view?
- What do you think could / should be done to help people like Ann Maree get dental care?
- Need or role for interdisciplinary intervention? – From a disability sector point of view what do you think?

Review currently existing resources: – 20 minutes

- The Royal College of Surgeons of England. 2012. **Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities**. Faculty of Dental Surgery, The Royal College of Surgeons of England. https://www.rcseng.ac.uk/library-and-publications/rcs-publications/docs/oral-health-care/

- Archer Dental, 2013. Oral Hygiene Instruction for Caregivers. Archer Dental https://www.youtube.com/watch?v=vc4hG_8t9nA

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Presentation from expert: To Be Confirmed – 30 minutes

A occupational therapist will share knowledge, skills and insights from the field in regard to oral health and intellectual disability. Expert case examples will be discussed with a question and answer session.

Content TBC

Review currently existing resources: – 20 minutes

- Oral Health Foundation, Unknown a. **Oral health and physical disabilitie**s. https://www.dentalhealth.org/oral-health-and-physical-disabilities

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Presentation from expert: Jenna Hepburn, Inclusion Melbourne – 30 minutes

Participants will be introduced to evidence-based disability practice. How to engage and support people with intellectual disability will be discussed. Applications for PCAS and specific techniques will be discussed.

Aims:

1. To introduce dental practitioners to evidence-based disability practice and why it is important

2. For dental practitioners to understand how disability support professionals support and engage people with intellectual disability

3. For dental practitioners to begin to understand how they might be able to apply some PCAS techniques within their practice – through discussion and reflection

Content Outline:

1. Introduction to person centred active support

- Person-Centred Active Support is a way of providing just the right amount of assistance, to enable a person with intellectual disability to successfully take part in meaningful activities and social relationships.

- How to determine if a support worker knows/uses PCAS/evidence-based practice

2. Evidence behind practice

- PWID have the same rights to be part of society and have good QoL as other people

- Developed in the 60's, based on evidence that engagement in meaningful activities and social relationships improves peoples QoL

3. Engagement

- Average level of engagement of PWID with higher support needs (10 minutes in every hour)

- Barriers to engagement

4. Essentials of Active Support

- Every moment has potential (for engaging a PWID)

- Little and often (it may take multiple occasions and short bursts to become comfortable and confident in a task/activity etc)

- Graded Assistance

- Maximising choice and control (managing risk, encouraging participation etc)

5. Discussion

- Reflection and discussion around how they may be able to use PCAS in their practice

- Discussion of what resources, posters etc would be helpful in a dental practice.

Review currently existing resources: – 20 minutes

- Elliott, I., Nunn, J., and Sadlier, D, 2005. **Oral Health & Disability: The Way Forward**. National Disability Authority https://www.dentalhealth.ie/assets/files/pdf/rnd16_dentalfinal.pdf
- Greystanes Disability Services and La Trobe University, 2015. Every Moment Has Potential. Commonwealth of Australia. http://www.activesupportresource.net.au/

Questions

- What did you think?
- How did you feel?
- How did it respect the rights of people with disability?
- Was it useful?
- What would you keep?
- What would you change?

Discussion of new content – 30 minutes & Goal setting and wrap-up : 20 minutes

Questions

- What were our three take-away points?
- What was missing from today?
- How will you implement what you've learnt? (1 or 2 items.)

Appendix: Additional resources

Session No.	Area of expertise	Additional resources to be added	Link
1	Disability rights advocates	Your Dental Health for People with Intellectual Disability	Link
2	Your Dental Health project coordinator	COP Dental Inclusion for PWID	Link
3	Residential Services Manager	Your Dental Health - Community of Practice	Link
4	Special Needs Dentist	Transforming Practice in Oral Health and Intellectual Disability - Interdisciplinary Professional Development and Capacity Building	Link
5	Your Dental Health project coordinator	COP Oral Health, Cognitive Impairment, Acquired Brain Injury	Link
6	Supported Decision Making expert	Expression of Interest	Link
7	Sexual assault expert		Link
8	Voice of self-advocate with complex	2020 grant guidelines not yet available	Link
9	Medical GP (Disability)	2020 grant guidelines not yet available	Link
10	Oral Health Therapist perspectives	2020 grant guidelines not yet available	Link
11	Speech pathologist	2020 grant guidelines not yet available	Link
12	Occupational therapist	Resubmit in June for November funding	Link
13	Restrictive practices, PBS and BSPs	2020 grant guidelines not yet available	Link

project timeline

Item	Activity	Steps	Timeframe	Participants
1	Establish Project Plan, Research Strategy, and Advisory Group.	• Establish governance structure and members • Development of Terms of Reference • Finalise Project Implementation Plan and Project KPIs • Development of Research Strategy • Establish Advisory Group • Commencement of Quarterly Steering Committee meetings • Finalise COP Plan and Objectives	MDI Seed-funding period. Completed.	• University of Melbourne • Inclusion Melbourne • Deakin University • ASSCID • NRCH • Self-Advocates with ID
2	Communities of Practice (COP)	• Commencement of Quarterly Advisory Group meetings • Recruit COP Participants • Schedule meetings and invite participants • Conduct COP meetings / participatory action research • Employ and test strategies • Information compilation • Evaluation	Mid 2020 to December 2021	• Inclusion Melbourne • University of Melbourne • Deakin University • ASSCID • NRCH • Dentists and interdisciplinary professionals • Self-Advocates with ID • Subject Matter Experts
3	Translation / Content Development	• Development of formal Continuing Professional Development (CPD) material, other resources and visual tools • Trialling/testing • Finalisation and Production of CPD material	October 2021 to April 2022	• Inclusion Melbourne • University of Melbourne • Deakin University • ASSCID • NRCH • Self-Advocates with ID
4	Dissemination, Communication & Training	• Workshops with key stakeholders • Presentations at relevant dental and disability conferences • Publications in peer reviewed journals • Presentations at regular meetings of key stakeholders in the oral health and disability sectors • Publications in relevant newsletters	May 2022 to November 2023	• Inclusion Melbourne • University of Melbourne • Deakin University • ASSCID • NRCH • Self-Advocates with ID
5	Evaluation	• Evaluation of all developed programs	December 2022 to January 2023	• Inclusion Melbourne • University of Melbourne • Deakin University • ASSCID • NRCH • Self-Advocates with ID
6	Reporting	• Compile all information and data • Analyse and assess • Develop all required reporting/formats	February 2023	• Inclusion Melbourne • University of Melbourne • Deakin University • ASSCID • NRCH • Self-Advocates with ID

project budget

Budget Line Item	Year 1 Total	Year 2 Total	Year 3 Total
Personnel Expense			
University of Melbourne – Professor Keith McVilly	30,000.00	30,000.00	30,000.00
University of Melbourne – Alana Roy – Project Coordinator (0.4 FTE)	39,520.00	39,520.00	39,520.00
Inclusion Melbourne – Nathan Despott – Project Coordinator (0.4 FTE)	49,400.00	49,400.00	49,400.00
Deakin University – Professor Hanny Calache	15,000.00	15,000.00	15,000.00
Deakin University – Dr Tejashree Kangutkar – Project Assistant	5,000.00	5,000.00	5,000.00
Dynamic Dentistry – Dr Richard Zylan – Project Advisor	2,600.00	2,600.00	2,600.00
Deakin University – Dr Joanne Watson – Project Advisor	2,600.00	2,600.00	2,600.00
Bayley House – Karen Woods – Project Advisor	2,000.00	2,000.00	2,000.00
Dentists (Allowance 6 dental practitioners per COP meeting – 8 Meetings per annum for 18 months @ $150 per meeting, Year 3 allowance may be used to supplement additional dentists in Years 1 and 2)	7,200.00	3,600.00	4,000.00
Self Advocates with intellectual disability (Allowance 4 people attendance at COP, based on 8 meetings per annum for 18 months @ $100 per meeting, Year 3 allowance for review)	2,400.00	1,600.00	1,200.00
Interdisciplinary CoP participants (Allowance 4 per COP meeting – 8 meetings per annum for 18 months @ $150 per meeting, Year 3 allowance for review etc)	4,800.00	2,400.00	2,000.00
Subject Matter Experts (Allowance 2 people attendance at COP, based on 8 meetings per annum for 18 months $400 per meeting, Year 3 review etc)	6,400.00	3,200.00	2,800.00
ASSCID – Dr Kerrie Punshon – Project Advisor	2,470.00	2,470.00	2,470.00
Western Special Needs Dentistry – Dr Helen Marchant – Project Advisor	2,470.00	2,470.00	2,470.00
North Richmond Community Health – Alyson Bettega – Project Advisor	1,900.00	1,900.00	1,900.00
Rainbow Rights & Advocacy – Cameron Bloomfield – Co-leader	1,710.00	1,710.00	1,710.00
Administrative Assistance	6,000.00	6,000.00	8,000.00
Subtotal	**175,470.00**	**171,470.00**	**172,670.00**

Activity / Project Operating Expenses (Non Staff)			
Resource Development	10,000.00	20,000.00	20,000.00
Venue Hire	7,200.00	3,600.00	1,200.00
Catering	1,200.00	600.00	200.00
Printing	3,000.00	8,000.00	8,000.00
Travel allowance for people with ID	500.00	500.00	500.00
Interstate Travel (5 x $1000 trips)	5,000.00	5,000.00	5,000.00
Subtotal	26,900.00	37,700.00	34,900.00
Activity / Project Operating Expenses (Non Staff)			
Instructional Designer for the development of CPD content	1,900.00	7,600.00	7,600.00
Graphic Design (Allowance)	5,000.00	8,000.00	8,000.00
Videography	5,000.00	10,000.00	10,000.00
Subtotal	11,900.00	25,600.00	25,600.00
Total (Annual)	11,900.00	25,600.00	25,600.00
Total (Full Term)			682,210.00

pilot plan

The Project Coordination Team's work expanded to include development of a plan for a pilot of the Community of Practice project. This plan will be executed should an application for a smaller grant be successful, particularly a grant of $50-100,000. Published findings of the pilot would be used as the basis of an application for larger research funds, such as an NHMRC grant.

Overview of Pilot:

- Two Advisory Group meetings: pre- and post-CoP meetings
- Location: Inclusion Melbourne offices, Armadale

- Recruitment of 10-15 participants as per long version of the project
- Pre- and post-CoP meeting questionnaires
- Pre-reading for each CoP session
- 2-3 CoP meetings (funding dependant)
- Basic resource development
- Research Report
- Lodgement of funding application for long version of project

Oral Health and Intellectual Disability: Community of Practice Project Pilot

Pilot adaptation: Two community of practice meetings, including resource testing and limited development of resources. Expansion to three meetings dependent on funds.

Two advisory group meetings – 1 hour per meeting

Two advisory group meetings will be held.
One before commencement and one after conclusion of the pilot CoP meetings.

These meetings will be held at Inclusion Melbourne. Video conferencing option will be available for distant advisory group members.

Confirm experts and pre-reading material – 30 minutes / expert presentation

Four or five experts will be chosen from those listed in the full CoP project. Each expert will be confirmed for participation in the pilot project through email, phone, or face-to-face contact with a member of the Project Coordination group. They will be provided with a comprehensive description of their role as an expert speaker and a fact sheet highlighting key components of pilot CoP project prior to confirmation.

Each expert will present for 20-30 minutes on their topic.

Experts for the pilot CoP:

- Your Dental Health project coordinator
- Special Needs Dentist.
- Dentist/parent of person with disability
- Person with disability
- One area chosen from the full CoP project plan.

Participants – 30 minutes / expert presentation

The CoP approach will engage an interdisciplinary group of professionals, and include people with intellectual disability, as follows:

- 5-10 general dental / oral health professionals (at least 4 dentists)
- 2-3 self-advocates with intellectual disability with dental service consumer knowledge and experience in action research.
- A range of interdisciplinary professionals:
  - A behavioural therapist with expertise in the management of restrictive practices

- A residential services manager who works in group homes with people with ID
- Special needs dentists
- Leading practice experts previously involved in dental health initiatives for people with disability (e.g., GPs with disability expertise, community health professionals, community dental practice managers)
- Leading academics previously involved in dental health initiatives for people with disability (including health an allied health researchers)
- Disability rights advocates.

Recruitment – 30 minutes per participant (approx. 10 hours)

A purposive sample of dentists, disability support professionals, people with intellectual disabilities, and disability advocates will be recruited for their knowledge, skills and experiences in the field of dentistry and / or disability services. This will be achieved via an invitation to participate using an approved Plain Language Statement (PLS) circulated among a network of people who have previously been involved in dental health initiatives for people with ID.

Recruitment of dental health professionals will be facilitated through collegiate organisations; including clinical, teaching, and research centres.

Participants with intellectual disability will be recruited through existing relationships with the project partners. The project partners have developed networks over many years and will invite people known from their participation in previous community development projects.All such persons will be competent to provide individual informed consent to participate, having previously participated in similar activities and by virtue of their demonstrated independence in their domestic and / or employment situations. All participants will be asked to discuss their participation with a person they know and trust if this might assist them in deciding to participate.

Recruitment of interdisciplinary professionals will be facilitated through collegiate organisations; including clinical, teaching, and research centres.

Pre-CoP data collection – 45 minutes / participant

The data-collection methodology proposed for the pilot CoP project is mixed methods.

Quantitative data will be collected through the administration of a survey questionnaire whereas qualitative data will be collected using semi-structured interview.

Pre-CoP questionnaire and semi-structured interview will focus on collecting data on:

• participants' thoughts, knowledge, perspective and attitudes about the role of oral health of people with intellectual disability;

• difficulties experienced in providing adequate oral healthcare to people with intellectual disability;

• recommendations on best practice and strategies for improving oral health of people with intellectual disability; and

• suggestions for improving existing oral health interventions for people with intellectual disability

Community of Practice Meetings – 2.5 hours per CoP meeting

Option 1:

Session 1:

• Introduction to the pilot CoP project

• Oral Health pathway for people with disability

• Review of treatment planning resources

• Perspective of a Self-Advocate with disability

Session 2:

• Overview of the disability support profession

• Introduction to restrictive practices

• Introduction to Special Needs Dentistry

• Perspective of a parent, and dentist

Option 2:

Session 1:

• Introduction to the pilot CoP project

• Oral Health pathway for people with disability

• Overview of the literature review

• Review of treatment planning resources

• Perspective of a Self-Advocate with disability

Session 2:

• Overview of the disability support profession

• Disability standards, skills, practice, and Positive Behaviour Support

• Introduction to restrictive practices

• Review of current resources

• Perspective of a parent, and dentist

Session 3:

• Introduction to Special Needs Dentistry

• Review of current resources

• Expert topic to be chosen from full CoP project plan

There will be pre-reading required prior to each CoP meeting. The pre-reading will be the content listed in the session plans as review current resources.

Post-CoP data collection – 30 minutes/ participant (approx. 10 hours)

Pre-CoP questionnaire and semi-structured interview will focus on collecting data on:

• Participants' thoughts, knowledge, perspective and attitudes about the role of oral health of people with intellectual disability;

• Difficulties experienced in providing adequate oral healthcare to people with intellectual disability;

• Recommendations on best practice and strategies for improving oral health of people with intellectual disability;

• Suggestions for improving existing oral health interventions for people with intellectual disability; and

• Seeking feedback on the project

Basic resource development – 35 to 40 hours

Resources will be co-designed and developed based on the analysis of CoP content, and the pre-post data collection. The informational and educational resources will benefit both the dental health and disability sectors.

This project will advance our understanding of how CoP methodology might contribute to science and the development of an informative and practical evidence-base at the intersection of health and community service settings.

Report writing   – 20 hours

A research report will be produced consisting of a process analysis as well as the findings of the research. The process will be documented systematically to ensure transparency and study trustworthiness.

The report will include:

• Research context

• Research method

• Recruitment strategies

• Details of CoP meetings

• Data collection and analysis

Lodge NHMRC application   – TBC

Using the research findings and process analysis, the Project Coordination team will develop and lodge an application with the NHMRC for the full CoP project will full academic evaluation.

pilot session plans

Option One – 2 CoP Meetings

Session Plan 1:

Aims:

1. For COP participants to understand the 'big picture' and the need for collaboration with people with lived experience and other sectors.

2. For dental practitioners to begin to understand the dental pathway for a person with intellectual disability

3. For dental practitioners understand the difficulties of accessing good dental treatment for a person with complex communication or cognitive disability

Introduction to project – 10 minutes

Presentation from expert: Nathan Despott, Inclusion Melbourne – 30 minutes

Why cross-sector collaboration is key:

- People with disability have poor health and fewer resources

- Good healthcare relies pm respect, communication, and collaboration between the person with intellectual disability, the key worker/family, and the dental practitioner/other health care

- Demystifying communication with patients, key workers/family and why this is important for successful ongoing oral health

Ideal treatment pathway for a person with intellectual disability:

- Access to services (preparing, accessing, transport, other supports etc)

- In the clinic (such as interaction between people involved)

- Communication, behaviour, and consent

- Management or care at home

Review of current resources – 30 minutes

Review of treatment planning resources:

- Angwin, L, Leighton, D, & Despott, N. 2015a. Your Dental Health: **A Guide for People with a Disability, their Family Carers, Friends and Advocates**. Inclusion Melbourne. https://inclusionmelbourne.org.au/wp-content/uploads/2019/04/IM-Dental-Health-Publication-COMPLETE-2.pdf

- Zylan, R., Despott, N., Tracy, J., Shnider, W. 2019 **Oral Health and Intellectual Disability: A Guide for Dental Practitioners**. Inclusion Melbourne, https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Presentations from experts: Karleen Plunkett and Eva Sifis – 30 minutes

The self-advocates will introduce themselves and describe their life experiences, including interactions with health professionals and dentists.

Eva:

Discussion of the differences she has observed in health care before and after her acquired disability.

Barriers and what people with disability think about before they get to an appointment / service:

- Think about your surroundings

- What information is on your website?

- Is your website accessible?

- Accessible car parks / pathways to the entrance

- Signage – can people find you easily?

- If you invite someone to your office, ask for access requirements

Inclusive communication:

- Don't ask us inappropriate things

- Treat us as adults

- People with disability are at different acceptance levels - be mindful

- We are all individuals and each disability does not mean the same thing for everyone

- Attitude – What we say and how we say it

- Awareness – Know your customer

- Ask – People with disability will know what they need

Karleen:

Discussion of Karleen's experiences finding and using appropriate dental services.

Complex communication:

- Shared experience from a self-advocate about a good, and a bad, visit to a dentist

- What made these good/bad experiences?

- What could be done to make all experiences good experiences

Communicating

- How you can explore the best way to communicate with a patient

Discussion of new content presented and learnt – 30 minutes & Goal setting and wrap-up : 15 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session Plan 2:

Aims:

1. For dental practitioners to understand how the disability sector works and interacts with the dental sector

2. For dental practitioners to have a basic understanding of restrictive practice from a disability perspective

3. For dental practitioners to understand and explore techniques for working with patients with disability

Overview of session 1 and follow up – 10 minutes

Presentation from expert: Nathan Despott, Inclusion Melbourne – 30 minutes

Introduction to the disability sector:

- Introduction to overlapping support plans in the life of a person with disability, and where dental advice 'fits' in with this

- The nature of the disability workforce (i.e. may be long term, may just be there for that shift) and that they often do not have any health training

- Oral health often not prioritised due to competing priorities

- Restrictive practice in the disability sector

  - What is considered restrictive?

  - Understanding the concept of the least restrictive alternative

  - Misuse/overuse of restrictive practices and the impact on the person.

Presentation from expert: Richard Zylan, Dentist and Parent of a person with disability – 30 minutes

Richard will share the experiences of his son, and his own experiences treating people with disability.

Discussion of the experiences of being a parents or carer, and techniques that general dentists can use in the dental surgery.

Review of current resources – 30 minutes

- Dental Health Services Victoria (DHSV), 2007b. **Supporting Every Smile**. https://everysmile.dhsv.org.au/

- Southern Association of Institutional Dentists, 2013. **Special Care Advocates In Dentistry Modules: SAID Professional Modules**. http://saiddent.org/modules.php

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Presentation from expert: Dr Helen Marchant and Dr Kerrie Punshon, Western Special Needs Dentistry : 15 minutes

Overview of special needs dentistry and consideration including registration process and formal guidelines.

Content TBC

Discussion of new content presented and learnt – 30 minutes & Goal setting and wrap-up : 15 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Option Two – 3 CoP Meetings

Session Plan 1:

Aims:

1. For COP participants to understand the 'big picture' and the need for collaboration with people with lived experience and other sectors.

2. For dental practitioners to begin to understand the dental pathway for a person with intellectual disability

3. For dental practitioners understand the difficulties of accessing good dental treatment for a person with complex communication or cognitive disability

Introduction to project – 10 minutes

Presentation from expert: Nathan Despott, Inclusion Melbourne – 30 minutes

Why cross-sector collaboration is key:

- People with disability have poor health and fewer resources
- Good healthcare relies pm respect, communication, and collaboration between the person with intellectual disability, the key worker/family, and the dental practitioner/other health care
- Demystifying communication with patients, key workers/ family and why this is important for successful ongoing oral health

Ideal treatment pathway for a person with intellectual disability:

- Access to services (preparing, accessing, transport, other supports etc)
- In the clinic (such as interaction between people involved)
- Communication, behaviour, and consent
- Management or care at home

Presentation from expert: Nathan Despott, Inclusion Melbourne – 30 minutes

Overview of literature review.

Literature review focuses on existing education/ training interventions related to oral health of people with

intellectual disability among four groups: dental health professionals, non-dental health professionals, people with intellectual disability and their carers.

Review of current resources – 30 minutes

Review of treatment planning resources:

- Angwin, L, Leighton, D, & Despott, N. 2015a. Your Dental Health: A Guide for People with a Disability, their Family Carers, Friends and Advocates. Inclusion Melbourne. https://inclusionmelbourne.org.au/wp-content/uploads/2019/04/IM-Dental-Health-Publication-COMPLETE-2.pdf

- Zylan, R., Despott, N., Tracy, J., Shnider, W. 2019 Oral Health and Intellectual Disability: A Guide for Dental Practitioners. Inclusion Melbourne, https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf

Questions

– What did you think?
– How did you feel?
– How did it respect the rights of people with disability?
– Was it useful?
– What would you keep?
– What would you change?

Review of current resources – 30 minutes

The self-advocates will introduce themselves and describe their life experiences, including interactions with health professionals and dentists.

Eva:

Discussion of the differences she has observed in health care before and after her acquired disability.

Barriers and what people with disability think about before they get to an appointment / service:

- Think about your surroundings
- What information is on your website?
- Is your website accessible?
- Accessible car parks / pathways to the entrance
- Signage – can people find you easily?
- If you invite someone to your office, ask for access requirements

Inclusive communication:

- Don't ask us inappropriate things
- Treat us as adults
- People with disability are at different acceptance levels - be mindful
- We are all individuals and each disability does not mean the same thing for everyone
- Attitude – What we say and how we say it
- Awareness – Know your customer
- Ask – People with disability will know what they need

Karleen:

Discussion of Karleen's experiences finding and using appropriate dental services.

Complex communication:

- Shared experience from a self-advocate about a good, and a bad, visit to a dentist
- What made these good/bad experiences?
- What could be done to make all experiences good experiences

Communicating

- How you can explore the best way to communicate with a patient

Discussion of new content presented and learnt – 30 minutes & Goal setting and wrap-up : 15 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session Plan 2:

Aims:

1. For dental practitioners to understand how the disability sector works and interacts with the dental sector

2. For dental practitioners to have a basic understanding of restrictive practice from a disability perspective

3. For dental practitioners to understand and explore techniques for working with patients with disability

Overview of session 1 and follow up – 10 minutes

Presentation from expert: Nathan Despott, Inclusion Melbourne – 30 minutes

Introduction to the disability sector:

- Introduction to overlapping support plans in the life of a person with disability, and where dental advice 'fits' in with this
  - Positive behaviour support and Behaviour Support Plans
- The nature of the disability workforce (i.e. may be long term, may just be there for that shift) and that they often do not have any health training
  - What is considered restrictive?

- Oral health often not prioritised due to competing priorities
- Restrictive practice in the disability sector
  - What is considered restrictive?
  - Understanding the concept of the least restrictive alternative
  - Misuse/overuse of restrictive practices and the impact on the person.

Review of current resources – 30 minutes

- Dental Health Services Victoria (DHSV), 2007b. **Supporting Every Smile**. https://everysmile.dhsv.org.au/
- Dental Health Services Victoria (DHSV), 2007a. Disability Awareness Guide. https://www.dhsv.org.au/__data/assets/pdf_file/0012/3144/disability-awareness-guide.pdf

Presentation from expert: Richard Zylan, Dentist and Parent of a person with disability – 30 minutes

Richard will share the experiences of his son, and his own experiences treating people with disability.

Discussion of the experiences of being a parents or carer, and techniques that general dentists can use in the dental surgery.

Discussion of new content presented and learnt – 30 minutes & Goal setting and wrap-up : 15 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

Session Plan 3:

Aims:

1. For dental practitioners to understand and explore techniques for working with patients with disability

2. To understand the role of Special Needs Dentistry, and when you do and do not need to refer

3. To be confirmed: Aim to understand about the topic to be chosen from the full CoP plan

Overview of session 2 and follow up – 10 minutes

Presentation from expert:
Dr Helen Marchant and Dr Kerrie Punshon, Western Special Needs Dentistry – 30 minutes

Overview of special needs dentistry and consideration including registration process and formal guidelines.

Content TBC

Review of current resources – 30 minutes

- Southern Association of Institutional Dentists, 2013. S**pecial Care Advocates In Dentistry Modules: SAID Professional Modules**. http://saiddent.org/modules.php

- Dental Health Services Victoria (DHSV), 2010. **Brushing up on oral health for disability residential services**. https://www.youtube.com/playlist?list=PLcAjB30TLQlFEyZCGBjgKktlk7Jsm0dcW

Presentation from expert: TBC – 30 minutes

Presenter and content to be chosen from the full CoP session plans

Discussion of new content presented and learnt – 30 minutes & Goal setting and wrap-up : 15 minutes

Questions

– What were our three take-away points?
– What was missing from today?
– How will you implement what you've learnt? (1 or 2 items.)

budget: pilot project

The following pilot budget is an alternative to the long form project budget. This budget allows for:

- Six-month pilot with three community of practice meetings
- Development of limited number of resources
- Academic evaluation
- Production of literature leading to application for further research funding

Budget Line Item (six month period)	Total
Personnel Expense	
University of Melbourne - Professor Keith McVilly	15,000.00
University of Melbourne - Alana Roy and Tejashree Kangutkar- Project Coordination (0.4 FTE)	20,800.00
Inclusion Melbourne - Nathan Despott and Jenna Hepburn - Project Coordination (0.4 FTE)	20,800.00
Deakin University - Professor Hanny Calache	7,500.00
Dynamic Dentistry - Dr Richard Zylan - Project Advisor	1,950.00
Deakin University - Dr Joanne Watson - Project Advisor	1,950.00
Bayley House - Karen Woods - Project Advisor	1,500.00
Dentists (Allowance 6 dental practitioners per COP meeting - 3 meetings @ $150 per meeting)	2,700.00
Self Advocates with intellectual disability (Allowance 2 people attendance at COP, based on 3 meetings @ $100 per meeting)	600.00
Interdisciplinary Experts (Allowance 4 per COP meeting - 3 meetings @ $150 per meeting)	1,800.00
Subject matter experts (Allowance 3 experts @ $400 each)	1,200.00
ASSCID - Dr Kerrie Punshon - Project Advisor	1,235.00
Western Special Needs Dentistry - Dr Helen Marchant - Project Advisor	1,235.00
North Richmond Community Health - Alyson Bettega - Project Advisor	950.00
Rainbow Rights & Advocacy - Cameron Bloomfield - Co-leader	855.00
Administrative Assistance	1,500.00
Subtotal	**80,075.00**

Activity / Project Operating Expenses (Non Staff)	
Resource Development	3,000.00
Venue Hire	1,800.00
Catering (COP and Advisory)	500.00
Printing	1,500.00
Travel allowance for people with ID	500.00
Subtotal	**7,300.00**

External Party Expenses*	
Graphic Design	3,000.00
Videography	5,000.00
Subtotal	**8,000.00**
Total	**95,375.00**

grant submission activity

Inclusion Designlab has applied for a range of grantsduring 2019/2020. The initial strategy was to apply for a large ILC grant to cover the Community of Practice establishment and implementation. However, the current aim is to apply for arange of large and small grants, allowing for one of two potential pathways:

1. Implementation of a short pilot (tocover the establishment and setup of the Community of Practice and 2 or 3 COP sessions). This would then be followed by an application for a large NHMRC grant (or similar) to run the longer project.

2. Implementation of long project.

We are also exploring the possibility of producing literature based on knowledge gained to date and leveraging this to apply for research grants normally reserved for projects for which a pilot has already occurred.

Date	Funding Group	Title	Amount
Unsuccessful			
23/07/2019	Gandel Philanthropy	Your Dental Health for People with Intellectual Disability	$39,400
13/05/2019	Endeavour Foundation	COP Dental Inclusion for PWID	$69,650
27/06/2019	HCF Foundation	Your Dental Health - Community of Practice	$232,600
27/06/2019	NDIS ILC Economic & Community Participation	Transforming Practice in Oral Health and Intellectual Disability - Interdisciplinary Professional Development and Capacity Building	$682,210
Pending			
23/07/2019	Department of Health	Your Dental Health Materials	$75,000
13/05/2019	Transport Accident Commission	COP Oral Health, Cognitive Impairment, Acquired Brain Injury	$50,000
27/06/2019	William Buckland	Expression of Interest	$ -
Upcoming Grants		**Status / Notes**	
Anytime	Gandel Philanthropy	Inclusion Melbourne unsuccessful in 2019. University of Melbourne will lead grant application in 2020.	$40,000
22/4/2020	NHMRC Synergy		$5M
April 2020	Collier	2020 grant guidelines not yet available	TBC
TBC	Nib Foundation	2020 grant guidelines not yet available	$50,000
TBC	Ian Potter	2020 grant guidelines not yet available	TBC
TBC	Perpetual	2020 grant guidelines not yet available	TBC
1/6/2020	JT Reid	Resubmit in June for November funding	No limit
Mid 2020	Tucker	2020 grant guidelines not yet available	$25,000
TBC	Lord Mayors Charitable Foundation	2020 grant guidelines not yet available	TBC
July 2020	Scanlon Foundation	2020 grant guidelines not yet available	TBC

section B

Plain language statement

Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

This research will address gaps identified in the international literature with respect to increasing the knowledge and confidence of dental practitioners to manage the dental health of people with intellectual disability in general practice settings and minimise reliance on both general anaesthesia and unnecessary (and costly) hospital admissions.

Community of Practice (COP) meetings will be held for two hours every 6-8 weeks over an 18-month period (from February 2020 to August 2021) at a central location in Melbourne, employing a qualitative action research methodology often used in social and disability research.

The COP members will include

- Project leaders
- ~10-15 dental practitioners (at least 6 private practice dentists, 2 oral health therapists and 2 public dentists).
- 2 self-advocates with intellectual disability with dental service consumer knowledge and experience in action research.
- 1 x Support worker and 1 x Residential services supervisor.

What will I be asked to do?

Should you agree to participate you may be asked to share your lived experience of disability and/or density practice.

You may be asked to read, discuss and develop tools and resources that help dentists to work with people with intellectual disabilities.

You may be asked to listen to presentations, read and watch materials which have sensitive information such as the links between sexual assault and dentistry and also various case studies about disabilities, human rights and dentistry.

What are the possible benefits?

The COP will help to increase the knowledge of dentists supporting people with intellectual disabilities and how best to support them during dental treatment.

Dentists will have more positive attitudes towards people with intellectual disabilities.

Dentists will have increased confidence working with people with intellectual disabilities.

Increase number of people with intellectual disabilities going to their general dentist practice and a decrease in hospitalisations.

You will be reimbursed for your time in the form of a voucher?

What are the possible risks?

There is minimal risk, if any, to participants in this program of research.

This project aims to be inclusive of people with intellectualdisabilities and is consistent with the principles of the United Nations Convention on the Rights of Persons with Disabilities (2007), this project will serve to draw attention to and reinforce the inherent rights and abilities of people with disability to direct matters effecting their own lives.

Do I have to take part?

No. Participation is completely voluntary. You are able to withdraw at any time.

Will I hear about the results of this project?

Participants who are known in the disability sector and dentist community will be approached for their skills, knowledge and experiences.

What will happen to information about me?

No identifying information will be released by the University as part of the research report. When writing reports, presenting project findings, or publishing articles, only deidentified data will be reported.

Is there any potential conflict of interest?

It is possible that researchers and project partners may have prior professional relationships with participants (e.g. dentists, people with intellectual disabilities and guest speakers).

The decision to participate or withdraw from study one will not impact on-going professional relationships or service delivery.

People with intellectual disabilities and the dentists will not be required to engage in any therapeutic processes during program of research.

Who is funding this project?

TBC

Where can I get further information?

If you would like more information about the project, please contact the researcher.

Keith R. McVilly PhD MAPS MCCIP |
Professor of Disability & Inclusion
The University of Melbourne |
School of Social & Political Sciences

School Office - Level 4, John Medley Building (191)
The University of Melbourne, Victoria 3010 Australia
T: +61 3 8344 5366 | F: +61 3 8344 7906
E: Keith.McVilly@unimelb.edu.au
Web: http://findanexpert.unimelb.edu.au/display/person754213

Who can I contact if I have any concerns about the project?

This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, University of Melbourne, VIC 3010. Telephone: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number of the research project.

Advisory Group

Terms of Reference and Agreement

1. Project Partners

Inclusion Melbourne

As Victoria's longest-serving intellectual disability support provider, Inclusion Melbourne (IM) is a leader in the development of innovative support solutions. IM brings together people with a disability, community organisations, leading disability researchers, government and peak bodies, to develop cutting-edge models of practice, choice and citizenship that contribute to the continuous development of the disability sector through evidence-based practice, accessible materials, and training for families and organisations.

Disability and Oral Health Collaboration

The Disability and Oral Health Collaboration (DOHC) was initiated in 2018 by Professor Hanny Calache (Deakin University, University of Melbourne), Dr Kerrie Punshon (President, ASSCID), Nathan Despott (Inclusion Melbourne), Professor Susan Balandin (Deakin University), Dr Richard Zylan, and dental and disability academics from Deakin University, University of Melbourne and La Trobe University. Two key outputs of the DOHC have been a systematic literature review (prepared by Dr Tejashree Kangutkar) and several events bringing together members of the DOHC.

The DOHC priorities for action are to:

1. Enhance health literacy (oral health literacy and disability literacy) for dental professionals, non-dental professionals, support workers and carers, and people with disability.
2. Enhance oral health educational programs in the curriculum of health professional courses.
3. Create resources that can be used by groups that teach health professional curricula and can be integrated/ incorporated into what is actually being taught in the curriculum.
4. Develop and deliver continuing professional development programs (e.g. masterclasses) for dental professionals, non-dental health professionals, support professionals and carers.
5. Determine feasibility of innovative models of oral health care for people with disability that include reasonable adjustments to care provision.

University of Melbourne

The University of Melbourne has a strong commitment to research, teaching and community engagement that seeks to understand the issues that concern people with disability, their families and support systems, and to co-produce policies, practices and technologies that address these concerns. The Melbourne Disability Institute (MDI) is one mechanism by which multi-disciplinary activities across the university are brought together. Professor Keith McVilly's team, in the School of Social & Political Sciences and working across the university, focuses on applied research in partnership with community sector organisations to develop and test innovative solutions to real world problems that have potential for upscaling and wider application. His team is also concerned with fostering the next generation of leaders and practitioners, and connecting students with people with lived expertise as part of their university education.

2. The Project

Project Background

The Oral Health and people with Intellectual Disability: A Community of Practice for Effective Intervention Community of Practiceproject, henceforth called the Community of Practice project, represents the expansion of work that commenced with theYour Dental Health project, a collaboration between oral health professionals, other health professionals, disability support professionals, and people with intellectual disability (ID), which was formed to develop high quality oral health resources for people with ID.

The project's resources are available at www. inclusiondesignlab.org.au/dental. Resources include a world-first 'dual read' guide for people with intellectual disability, their supporters and advocates. The site also contains:

- Three live-action videos of dental procedures in plain spoken English
- Four short neurodiversity-friendly plain language animations explaining home care, fillings, and orthodontics
- A message from three dentists to all general dentists discussing the benefits and opportunities for treating patients with ID in the general dental setting rather than referring to other specialists
- A video demonstrating optimal pre-post interaction between dental practice staff and direct support professionals in the patient's life

The project also surveyed 100 dentists at the 2017

Australian Dental Congress regarding enablers and barriers to provision of dental healthcare for people with ID.

One of the barriers identified was a lack of standardised communication between health professionals, disability staff, dental health professionals and allied health professionals. The Oral Health and Intellectual Disability Guidewas developed to address this issue. The Guide has now been endorsed by the ADA and ASSCID and hard copies disseminated to every dentist in Victoria and WA, with an article and links to the Guide published in the Federal ADA journal.

The Your Dental Health team worked with the Disability and Oral Health Collaboration (noted in Section 1, above) to produce a submission to the Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability. This is also available at the Inclusion Designlab website.

The Community of Practice project represents an opportunity to test and trial the pathways, interventions, and interdisciplinary perspectives developed thus far. The project be performed with academic rigour and produce additional high quality, ecologically valid resources for the disability, dentistry and allied health sectors.

Research aim:

To identify, through collective problem solving (ie. a Community of Practice – CoP approach), best practice solutions for Australian dental professionals to more effectively include people with intellectual disability in their clinical practice.

Research questions:

1. What are the enablers and barriers to the provision of effective dental services to people with intellectual disability in regular public and/or private practice dental surgery settings?
2. What resources are currently available to support the inclusion and effective treatment of people with intellectual disability in regular public and/or private practice dental surgery settings; what is the relevance and quality of these resources; and how might these resources be improved and made more accessible?
3. What additional resources are required to support the inclusion and effective treatment of people with intellectual disability in regular public and/or private practice dental surgery settings?
4. How might the content of best-practice resources be communicated to dentists and oral health practitioners, so as to translate knowledge into practice through information dissemination, training and education?

5. How might education and training best be made available to dentists and oral health practitioners at various stages of their professional development, including during pre-service and in-service education?
6. What is the effect on dentists and oral health practitioners as a result of their participation in a CoP with respect to their: (a) professional goals in relation to the inclusion of people with intellectual disability in regular public and/ or private practice dental surgery settings; and (b) their engagement with patients with intellectual disability?

Research objectives:

1. Exposing dentists to a range of self-advocate (patient) and interdisciplinary voices; and subsequently identifying enablers and barriers to the provision of dental services to people with intellectual disability in regular public and/or private practice dental surgery settings;
2. Systemically auditing and reviewing a range of dental health resources in a CoP setting; and subsequently developing new training and educational resources for Australian dental professionals for use beyond the CoP, to more effectively include people with intellectual disability in their regular dental practice, including a training module: (a) for tertiary dentistry and oral health therapy students, and (b) for use in Continuing Professional Development (CPD) for registered dentists and oral health therapists;
3. Developing communication resources relating to the mainstream treatment of people with intellectual disability for the dental profession more broadly;
4. Translating resources and knowledge into practice;
5. Evaluating the CoP approach in effecting a change in the engagement of dental professionals with people with intellectual disability by: (a) setting and reviewing professional goals to be undertaken by participants between CoP meetings; and (b) tracking and reviewing changes in dental professionals' engagement with patients with intellectual disability.

Project outcomes:

The research objectives will contribute to the long-term aims of the overall programme of research:

1. To increase the volume of patients with intellectual disability being treated by regular dental professionals in community dentistry and private practice settings, and reduce hospital admissions
2. To improve the oral health, and therefore the overall health, of Australians with intellectual disability
3. To create innovative, efficient communication and referral pathways between the dentistry and disability support sectors that will drive better outcomes.

Research design

This program of research will be undertaken as Action Research (AR). In AR those involved in the everyday practice of the topic of inquiry under investigation take the lead on investigating that topic.As practitioners with expertise in their own field, they reflect upon questions that arise from their own practice, and question their own beliefs, assumptions, and practices with the goal of understanding, developing, and improving their practice.Furthermore, the practitioner-researchers seek to uncover gaps in both their own knowledge and the literature informing their practice, and in turn generate and test solutions to address these knowledge gaps.

The Communities of Practice (CoP) approach is predominantly a qualitative action research methodology, often employed in social and community research.It is a powerful action research model given it combines aspects of participatory community development, focus groups comprised of experts in the topic of inquiry, peer review, peer mentoring, and a degree of collegiality not often seen in other research models. The CoP approach allows for both robust formative and summative evaluation, and often produces rich data that can be observed and collected in situ. This means that CoPs can achieve both traditional research and applied aims at the same time.

In the current context, the CoP approach will provide an environment conducive to the:

1. Inclusion of numerous interdisciplinary experts spread across the CoP meetings
2. Delivery of evidence-informed training to CoP members at each CoP meeting
3. Effective co-design in the revision of existing resources, and the development of new resources
4. Opportunities for reflection on professional practice, together with the setting and review of professional goals (which could later inform educational resources for other practitioners)
5. Evaluation of both the CoP process and outcomes for participants

Project Governance

The project will be facilitated by two teams and will take the form of a Community of Practice utilising participatory approaches to research. The project participants will guide and direct the content and themes throughout the project, leading to the development of the information resources. The two teams will be:

1. A Project Coordination Group comprised of representatives of Inclusion Melbourne and University of Melbourne
2. An Advisory Group, comprising a range of representatives of University of Melbourne, Deakin University, North Richmond Community Health, Australian Society of Special Care in Dentistry, and people with intellectual disability, ABI and cognitive impairment.

See Appendix for further information about oral health and intellectual disability.

3. Advisory Group

Purpose

The purpose of the Advisory Group is to provide expertise and guidance to the Project Coordinationteam toachieve the project activities and outcomes.

Length of Appointment

The Advisory Group will operate from May 2020 until May 2023 using one of the following potential formats.

Format 1: Pilot project, followed by long form project. There may be a gap of a 2-3 months between pilot and long form project.

Format 2: Long form project only, with no preceding pilot.

Responsibilities of the Advisory Group members

The responsibilities of members are to:

• Attend meetingsevery four months to be held in the central Melbourne area (in person or via online video platform Zoom)
• Actively participate in meetings through attendance, discussion, and review of minutes, papers and other Advisory Group documents.
• Understand the goals, objectives, outcomes and activities of theproject
• Provide advice to the project coordination team to consider appropriate strategies and activities that will meet project objectives
• Actively contribute to the Advisory Groupaccording to knowledge, skills, experience and expertise
• Contribute knowledge of the needs and experiences of people with disability and their affiliated communities

Responsibilities of Project Coordination Group

The ProjectCoordination team will fulfill the following responsibilities:

• Maintain regular and effective communication with Advisory Group members
• Scheduleall Advisory Group meetings
• Develop agenda, compile supporting documents, and disseminatethese in advance of meeting
• Facilitate Advisory Group meetings, and ensure that discussions are focused and productive
• Raise project issues or concerns for discussion and guidance by Advisory Group members
• Take minutes of meetings and disseminate to Advisory Group members after each meeting

Remuneration

An hourly remuneration/honorarium of $65.00 will be paid to Advisory Groupmembers who are not already funded for this work by another organisation to perform the duties required by the Information Project. The hourly remuneration does not include travel time, however expenses for public transport, taxis, rideshare and accommodation will be reimbursed upon case-by-case arrangement with the Project Coordination Group. Reimbursement methods will be discussed in the first Advisory Group meeting.

Resignation

Members can withdraw from the Advisory Group at any time in writing to the Project Coordinators.

Attendance

If a member is unable to attend, it is expected that they tender an apology to the Chair at least two days before the scheduled meeting. If two meetings are missed consecutively, the Project Coordinatorswill contact the member to review continued capacity to participate.

Communication Between Meetings

Communication between meetings will be facilitated via email.Between meetings members may be asked to review documents and provide advice and comment. This will only occur if an item is time sensitive.

Decision-making

The Project Coordinatorswill consider the information and advice provided by the Advisory Group, however the final decision in relation to project implementation will remain with the Project Coordinators with support from the project partners.

Privacy & Confidentiality

Advisory Group members are expected to comply with the provisions of privacy laws with respect to information and activities in connection with their role on the Advisory Group and to use project and confidential information for the sole purpose of the Information Project. For the purposes of this project, this means that:

• Advisory Group members are free to discuss information about the project with colleagues from their representative organisations and with other members of the Advisory Group. However, information about the project should only be shared with individuals or bodies external to the organisations represented by Advisory Group members with permission from the rest of the Advisory Group.
• Materials and resources developed as part of the project represent the labour and creativity of the Community of Practice participants, the researchers, and the Project Coordination Group. Therefore, the external sharing of content from these resources while they are still being drafted should only occur with permission from the Project Coordination Group.
• Personal information shared by or about people involved in the project (COP participants, advisory, coordination, researchers) should be treated as private and therefore only shared with permission of the person/s concerned.

4. Agreement

I understand and agree to the above Advisory Group Terms of Reference and accept the offer to join the Advisory Group.

I understand that the project may be delivered in one of two methods:

- Pilot project followed by long form project
- Long form project only

Signed:

Name:

Date:

Representative organisation:

Witness:

Name of witness:

Date:

5. Appendix

Key foci of the Community of Practice project

a. Oral health and overall health of Australians with intellectual disability

Oral health is central to overall wellbeing. Good oral health is required if people with intellectual disability (ID) are to experience good general health, participate in their communities, and function to the best of their abilities. The consequences of neglecting oral health are serious and include pain, infection and loss of teeth, leading to functional difficulties with diet, speech and behaviour, as well as severe systemic health issues.

Poor oral health has been linked to increased risk of cardiovascular disease, diabetes and other chronic conditions (Bascones-Martinez 2012). For example, diabetes has been linked to the presence of periodontal disease (Bascones-Martinez 2012) with patients having "six times higher risk of worsening glycaemic control and the development of the macro and microvascular complication of diabetes, in particular cardiovascular and kidney disease" (Watanabe 2011).Inflammation constitutes a major mechanism for the observed link between oral diseases, specifically periodontitis, and several particular systemic diseases. There is evidence for an association between periodontal disease and diabetes, as well as emerging evidence for other conditions including: obesity; coronary artery disease; metabolic syndrome; [poor] oral health after menopause; helicobacter pylori; [and] adverse pregnancy outcomes (Sievers et al., 2010:17).

In addition to serious systemic health issues, unrecognised oral health can lead to other complex outcomes. For example, a person with intellectual disability and non-verbal communication may experience severe gum or tooth pain but be unable to communicate this pain to staff, carers or friends in a manner that is immediately understood. It is entirely reasonable to expect this communication to occur through 'behaviours of concern' (where the person's behaviours can cause harm to themselves or others, or damage to property; see discussion below) that are misunderstood and result in the inappropriate use of restrictive practices (i.e. physical, mechanical and chemical restraint, seclusion, or a range of environmental restraints) that can cause further harm and breach people's civil and human rights. The person's poor oral health may go relatively unnoticed other than through bad breath and, eventually, issues related to appearance and behaviour that impact on social engagement. Here it should be noted that these 'behaviours of concern' can be an indicator of poor oral health and a barrier to receiving the oral health care necessary to prevent or address these behaviours.

b. Treatment planning

Planning for quality oral care should be managed through high quality administrative planning led by the primary body that supports the person with disability – this is usually the person's family, guardian, or support accommodation provider. In many ways, the oral health of people with intellectual disability represents the litmus test of disability support systems as it requires the sound interaction of communication, practice and inter-disciplinary collaboration.

People with cognitive impairment often require additional support in order to participate in decision making regarding their dental treatment. Many are reliant on a substitute medical decision maker to provide consent for some or all of their dental treatment. Where communication between clinicians and decision makers is inadequate or inefficient, people with ID are at greater risk of over-treatment, under-treatment, treatment provided without respecting their wishes, delays in management and other forms of unsuitable care.

People with ID can also have difficulties cooperating with oral care, leading to the use of physical and chemical restraint to facilitate their dental treatment. The use of restrictive practices in the delivery of oral care is an area of concern affecting their human rights and access to care. The DOHC has identified a sizeable gap in practice and regulation between disability legislation, disability support practice, and dentistry.

c. Positive Behaviour Support and restrictive practices

The Positive Behaviour Support Capability Framework (developed by the NDIA Quality and Safeguards Commission) does not sufficiently address the considerable intersection of oral health and 'behaviours of concern'. Consequently, oral health is not ordinarily considered as part of the Functional Behavioural Analysis (FBA) of people's behaviour support needs and remains unidentified and poorly treated as part of the person's Behaviour Support Plan (BSP).It is rare for dentists to be well acquainted with the principles of Positive Behaviour Support, much less Person-Centred Active Support and Supported Decision Making. PBS is a scientifically based intervention that emphasises the importance of both functional and clinical assessment, together with the development of interventions that address environmental, clinical and skills-based issues that contribute to the person's behaviours of concern. While PBS has been evident in the disability sector for many years, it does not currently feature in the education and professional development of most health practitioners.

The issue of restrictive practices is a significant one in terms of people's civil and human rights, as well as their access to appropriate health services. It is the opinion of the DOHC and Your Dental Health teams that there is a lack of common understanding and collaboration on this issue between the disability and oral health sectors, leading to gaps in practice and regulation between disability legislation, disability support practice, and health sectors including dentistry.

Across Australia, the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission places increased emphasis on Positive Behaviour Support (PBS) and ensuring that all available strategies are employed so that restrictive practices are minimised and where possible avoided. Restrictive practices (listed in a. above) may only be used by a disability support professional if authorised to do so in a Behaviour Support Plan (BSP) that has been approved by, and registered with, the Commission.

It should be noted that the actions of direct support professionals fall under the guidelines noted above, including in the dental surgery. This means that dental practitioners cannot ask support professionals to implement restrictive practices such as physical restraint during dental appointments.

Dental practitioners are empowered to use oral anxiolysis or sedation to manage the patient in the least invasive manner should they be unable to treat the person in the dental chair. However, behaviour support strategies require time to implement and there are financial disincentives towards providing such care both in the private dental practice business model and in community dental settings, where practices are subject to waiting lists and productivity targets.

d. Referrals

In areas with established SND services, it is very common for dentists working with a person with intellectual disability and related communication barriers to refer them to oral health professionals in other settings should they feel the patient is unable to consent to treatment, communicate clearly, make decisions, tolerate treatment, or behave in a way that enables treatment. People with intellectual disability are frequently referred to specialists in Special Needs Dentistry and/or the hospital dental services for specialist treatment, including treatment under general anaesthetic – essentially a chemical restraint. Practices vary by region. The proportion of referrals involving people with ID has been reported to range from 4.4% of referrals to Special Care Dentistry units in Tasmania (Lim & Borromeo 2017) to 21% of referrals to the Special Needs Dentistry Unit at the Royal Dental Hospital of Melbourne in Victoria (Rohani et. al. 2017), however data is not available from all states.

e. Systemic factors across sectors

Rather than problematising poor oral health as the fault of the individual, a focus on the broader systemic gaps across the oral health and disability sectors is needed. The practices, systems and tools required to support people with intellectual disability to have good oral health – regardless of their self-care skills – already exist in the various practice frameworks in the disability sector, however the effective training and coaching of these frameworks and the inter-disciplinary communication that is required to connect these practices, systems and tools is lacking.

For most, the experience of disability is defined by social exclusion and the disadvantage caused by socioeconomic disadvantage, societal assumptions and a lack of support, rather than medical or functional diagnoses. A lack of dentists with adequate skills in managing people with a disability was the most frequently reported problem in obtaining dental care, followed by cost of dental treatment, and transportation difficulties, especially for wheelchair users (Pradhan et al. 2009). The solutions therefore lie in adopting a bio-psycho-social approach to assessment and intervention, as advanced by the World Health Organisation (WHO).

f. Knowledge gap: Oral health in the disability sector

Oral health is a generally neglected area in the disability support sector, with staff not able to provide comprehensive pre- and post-planning (ref: pages 8 and 9 of Oral Health and Intellectual Disability, https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf).Carers need to be made aware of the negative impacts of oral problems and trained to identify them by observing behavioural changes at an early stage to reduce the suffering caused by advanced disease and to improve OHRQoL (Pradhan 2012).

There are 6 primary units available to students undertaking Vocational Education and Training Courses such as Certificates III and IV in Individual Support (Aged Care and Disability). However, the vast majority of support professionals working in the disability sector have not completed these modules. Regardless of the uptake of accredited training units by direct support professionals, many of these planning, observation and direct support skills are also part of evidence-based direct support practice frameworks, such as Person Centred Active Support (PCAS), that should already be employed by disability support organisations.

There is a small but strategic set of oral health skills is required for the typical support professional working in community or residential settings in order to play a beneficial role in the interdisciplinary oral health care of people with ID. These skills include:

- vVsually identifying oral problems in people with ID

- Discussing oral health with people with ID

- Supporting home preventive care as directed by an Oral Home Care Plan

- Basic planning of regular appointments, including clear communication with administration staff at local dental practices

- Working with people with ID whom they support to prepare for appointments

- Ensuring Oral Care planning documents are used, reviewed, and communicated to relevant allied health professionals

g. Knowledge gap: Disability in the oral health sector

The Your Dental Health project has found that many dentists do not have sufficient understanding of the structure, roles and practices of Australia's disability support sector. Some of these knowledge gaps include:

- Positive Behaviour Support, Behaviour Support Plans and Restrictive Practices

- The difference between supported decision making and substitute decision making

- Decision making hierarchies within supported accommodation providers in the disability sector

- The difference between carers and direct support professionals, whereby the latter are subject to significant disability legislation, decision making structures, and practice coaching, while the former are usually unpaid and/or informal and often not subject to the same legislation and systems of the disability support sector

- The various individual planning documents and communication techniques that may be helpful in supporting dentists to navigate the needs of patients with ID

Any plans to systematically upskill general dentists in skills usually employed by specialists in Special Needs Dentistry (SND) must also include building knowledge in engaging with these disability support sector processes.

The above information has been adapted from the ADA and ASSCID endorsed publication Oral Health and Intellectual Disability (https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf) developed by Inclusion Designlab and the Your Dental Health project team.

h. Special Needs Dentistry

Special Needs Dentistry (SND), also known as Special Care Dentistry (SCD), is one of the newest Australian dental disciplines, defined as dentistry that "supports the oral health care needs of people with an intellectual disability, medical, physical or psychiatric conditions that require special methods or techniques to prevent or treat oral health problems, or where such conditions necessitate special dental treatment plans." (https://www.ada.org.au/Dental-Professionals/Policies/National-Oral-Health/2-5-1-Government/ADAPolicies_2-5-1_Government-_V1.aspx)

With only 17 specialists in Australia, patients referred to public Special Needs Dentistry services in Australia face long waiting times for care. Despite the evident need for more dentists with advanced skills in SND, the barriers to undertaking further education are high, and sharing specialist knowledge with general oral health professionals is difficult due to time constraints. The distribution of SND specialists and experienced dentists is uneven throughout Australia and mainly focused in metropolitan centres. This means that there are some parts of the country where suitable services and resources are lacking and the full range of services is not available or is severely restricted.

Australia's 10-year National Oral Health Plan does not include enough detail regarding upskilling general dentists to work with people with ID. The last three of Australia's 10-year Oral Health Plans have not met stated targets for improving the oral health of people with a disability. These include upskilling general dentists to work with people with ID, and upskilling people with developmental disability and their families, carers and support workers.

The significant over-referral of people with ID who might otherwise be treated in a general dental setting represents a very real threat to the oral and overall health of Australians with intellectual disability (as well as a significant cost to government) and represents gaps in practice, collaboration, planning, and interdisciplinary communication – aided by a gap in language and practice knowledge between dentistry and the disability support sector.

Many people with ID can be seen in general dentistry settings, depending on staff training/experience, adequate processes, suitable facilities, and proficiency in engaging with the relevant disability support systems and inter-disciplinary planning methods.The ability to provide familiarisation and continuity of care with familiar clinical staff and direct support professionals facilitates the provision of regular care, not just episodic relief of pain, and is of utmost importance to enable early identification of oral disease and implementation of early intervention procedures that will reduce the development of advanced oral disease requiring invasive dental treatment under sedation or general anaesthesia for management.

i. Communication

Greater collaboration between the disability and dental sectors will be required in order to overcome these challenges and improve the delivery of oral health services with people with ID. There are many professions intersecting around oral health and people with ID, which has resulted in a number of conceptual and practice gaps:

- **Within dentistry:** Information about treating people with ID is limited to those working in special needs dentistry, dental hospital, and the few general dentists practicing with people with ID.

- **Between dentistry, medicine, psychology, and allied health sectors:** Dentistry is separated from other medical and allied health services due to a lack of education and public funding (such as Medicare). The communication gap between sectors means that many people with intellectual disability whose poor general health has been caused or exacerbated by poor oral health could experience significant improvement if their dentists and GPs were to communicate with each other in a consistent and systematic way.

- **Between dentistry and the disability support sector:** Dentists with strong clinical knowledge of disability will only be able to use this knowledge to affect change if they also have a good working knowledge of the disability support sector. Treatment in the dental surgery must be accompanied by strong planning, communication with the person's supports, and home care. Combined theoretical and practical training and continued support for carers is needed to improve their knowledge and confidence in providing oral care for adults with disabilities (Pradhan et. al. 2016a).

- **Between dental services and people with disability themselves:** Access to dental services for people with disabilities is also an issue as private practice is unaffordable to most people with disabilities and public dental services are limited due to a dental workforce with limited skills in provision of services to people with disabilities, as well as long waiting lists.

Oral health records need to be communicated to family members, non-dental healthcare professionals, and direct support staff who might not have any training in oral health. The difference in frequency between visits to the dentist and doctor can sometimes be 1:20. Communication regarding oral health needs to occur in a documented and/or recorded manner:

1. Between people with intellectual disability and their dentist

2. Between people with intellectual disability and their GP

3. Between supporters and people with intellectual disability

4. Between dentists and GPs

5. Between dentists and supporters, particularly accommodation staff and families

6. Between GPs and supporters

The Oral Health and Intellectual Disability Guide contains two high-quality, succinct ADA-endorsed formsthat can be used to facilitate communication and treatment planning between (a) dentists and GPs and (b) dentists, people with disability, and their supporters. Dental assessment records should be separated from daily 'progress notes' in the person's files as these are often difficult to search and are regularly overlooked or archived.

j. General anaesthesia

There is concern about people with mild disability being offered treatment under general anaesthetic due to a lack of time and resources and training to manage treatment in less restrictive ways. Equally, there are serious access issues for those patients who do require GA for dental treatment. In some cases, the patient may receive most treatment in the dental chair, but require a GA for certain clinical procedures. In other cases, a GA may be the only way to fully examine a patient and provide necessary treatment. The type of patient who needs a general anaesthetic is one who may be less likely to express if they have oral pain, and whose behaviour may be impacted by undiagnosed, or untreated dental problems. Many public lists for dental general anaesthetics are in the order of 1-2 years long. The problem is even more difficult for medically complex patients who are not suitable for day surgery.

There is a lack of equity and common standards regarding the appropriate use of general anaesthetic and restrictive interventions in the treatment of people with intellectual disability, behaviours of concern, and communication limitations. Interdisciplinary collaboration as outlined in this submission can reduce the over-referral to general anaesthesia and allow better access to those for whom this modality is required.

k. Oral care for victims/survivors of abuse

Dental practitioners can be key observers of overall health and wellbeing (including abuse prevention) for people with intellectual disability.

However, dental treatment can be difficult for people with post-traumatic stress disorder (PTSD) arising from physical or sexual abuse or past dental/medical interventions. People with a history of sexual abuse often avoid treatment and general care. Many programs for victim/survivors are not accessible to people with disability.

There are confounding issues which can mask identification of people who have PTSD. These include people with physical disability who may have limited tolerance, postural/seating issues, involuntary movement etc., communication issues, cognitive issues, behavioural issues or sensory issues. All these factors make it difficult to assess why a person may refuse or not cope with dental care, either on a daily basis or during professional visits. Some factors may be identified but others may be missed. Abuse may not always be reported, and some people will have difficulty communicating with others what has happened to them. Therefore, it is important for such patients to be able to access care from the same clinician to build rapport and trust.

Developing confidence, familiarisation and positive experiences around dental visits is important yet is frequently overlooked. Emotional support is often required for people with ID undergoing dental treatment generally, and especially as many patients have histories of sexual abuse and assault.

A number of self-advocates have indicated to the DOHC and Your Dental Health teams that their history of sexual assault has made them wary of health care, particularly dental treatment. Sexual assault of people with disability in group homes and other segregated environments, particularly people with intellectual disability, is extremely prevalent and for some cohorts may represent more than a small minority of patients with an ID.

l. Guardianship

Various types of guardianship and powers of attorney exist throughout Australia, and legislation varies between states. Financial, medical decision maker and legal powers must usually be gained through separate processes. In the past, parents of people with profound intellectual disability have often acted in a de facto guardian capacity for their loved ones, however this is no longer appropriate.

The Australian Law Reform Commission has called for current guardianship and related substitute decision making mechanisms to be replaced by Supported Decision Making. Supported Decision Making practice models empower people to make their own decisions to the maximum extent possible and to have these decisions recognised in law.It champions the power of consistent relationships, progressive exposure to new options, continuity of support, and related concepts in preference to 'substitute decision making'. These reforms are now reflected in the National Disability Insurance Agency Act (2013) and state legislation across Australia (e.g. Powers of Attorney Act [Vic] 2014; Mental Health Act [Vic] 2014; Medical Treatment Planning & Decisions Act [Vic] 2016; and Guardianship & Administration Act [Vic] 2019). The NDIS allows participants to have a Plan Nominee and/or Communication Nominee. A detailed description of these roles is outside the scope of this submission, however it must be noted that being a Nominee in relation to a person's support funding does not equate to legal guardianship.

A key implication of Supported Decision Making is that some people with disability will be able to actively engage in their treatment and treatment planning if they are well supported, while some people may be deemed as unable to consent or engage if they are not supported according to best practice. These issues need to be explored and applied in the context of oral health care.Subsequently, dental professionals and disability professionals need to come together to plan a way forward.

literature review

Dr Tejashree Kangutkar, Prof Hanny Calache, Dr Jo Watson, and Prof Susan Balandin completed a systematic literature review to support the work of the Disability and Oral Health Collaboration. As part of the MDI-funded research design project, it was decided that a summary of the literature review report would be created as part of the 'starting point' of the Community of Practice. In addition to the summary, a brief fact sheet about the findings of the literature review was also developed. Both will be made available to Advisory Group members and Community of Practice participants.

The aim of the literature review was to explore and document the existing education and training interventions related to the oral health of people with intellectual disability among four groups: dental health professionals, non-dental health professionals, people with intellectual disability and their carers.

Citation for Literature Review:Kangutkar T, Calache H, Watson J & Balandin S. (In press). Education and training interventions to improve oral health of people with intellectual disability.

Summary of literature review

Prepared by Dr Tejashree Kangutkar, University of Melbourne

Background

Poor oral health has a significant impact on systemic health and quality of life. People with intellectual disability have poorer health outcomes and experience greater difficulties in accessing dental services as compared to the general population. Education and training programs have been considered as one of the effective interventions in improving knowledge, attitudes and skills. As development and dissemination of adequate educational resources and training modules is one of the aims of the CoP project, it was asserted that exploration of literature of what has already been done in this area would be valuable for further considerations. Asystematic review was conducted by the researchers of this project to document the effectiveness of implementing education/ training programs across multiple disciplines to improve oral health related outcomes among people with intellectual disability. Better holisticsupport can be achieved by enhancing the knowledge, skills and attitudes of everyone involved in health relate decision-making of people with intellectual disability. Various dental health professionals, non-dental health professionals, carers and people with intellectual disability themselves were identified as key stakeholders in oral health related decision-making of people with intellectual disability by the researchers of this project. This report is a summary of the systematic review that was conducted over a period of six months by the research group of the CoP project.

Research aim

The aim of this research was to explore and document the existing education and training interventions related to oral health of people with intellectual disability among four groups; dental health professionals, non-dental health professionals, carers of people with intellectual disability and people with intellectual disability.

Methodology

Major electronic databases were searched using Deakin's online library from 2008 to 2019. Two reviewers were involved in setting the inclusion and exclusion criteria and screening of titles, abstract and fulltext for final inclusion in the review. Twenty-papers were deemed eligible for inclusion, assessed using Crowes Critical Appraisal Tool (CCAT) and key findings were extracted.

Key findings

1. Oral health professionals play a vital role in educating caregivers of people with intellectual disability about oral health.

2. Basic oral healthcare plans for people with intellectual disability must match the prevention strategies that are recommended for the general population.

3. There is a need to revise the current curriculum to better prepare undergraduate dental students for managing people with intellectual disability.

4. Training of everyone involved in supporting the oral health decision making of people with intellectual disability is a key driver of positive outcomes. It also raises the attitudes and expectations of supporters.

5. Training of dentists and dental students improved attitudes, knowledge and skills but there was no improvement in the oral health status of people with intellectual disability from this intervention alone.

6. Training interventions are more costeffective in improving knowledge, skills and attitudes when:
   - Other oral health professionals are prioritised as trainers as dentists' time is expensive.
   - Available resources are adapted when starting a new intervention.
   - Printing resources are replaced by online resources for those who have online access.

7. A high level of interest was expressed by dental students to pursue special needs dentistry but they felt that the quality of education they received at undergraduate level was poor in this area.

8. None of the selected studies included oral health education and training interventions for non-dental health professionals.

9. People with intellectual disability expressed that they should receive information about dental health services in ways that are easy to understand, and oral health professionals must possess adequate communication skills.

10. Studies explored the impact of general anaesthesia on oral health and OHRQoL of people with intellectual disability but did not report on carers' knowledge about (a) the adverse effects of general anaesthetic and (b) alternative treatment options.

11. To promote an interdisciplinary holistic approach to the management of patients with chronic diseases and/or developmental impairments, it is imperative that all health professionals be educated and trained in the following:
    - The importance of oral health for the management of the conditions that they are treating.
    - Oral health preventive messages and basic available procedures.
    - Referral pathways required for smooth transitions of patients from one service to another.
    - Basic information on access to both public and private dental services.

12. Carers and supporters were dissatisfied with dental services during transition from child to adult. This can be mitigated by providing information on easily accessible websites and maintaining consistency of information provided by all staff members involved in this transition.

13. Training resources for carers and supporters should primarily focus on prevention, oral hygiene care and training to identify chronic dental problems.

14. Transdisciplinary training across non-dental health professionals could improve Oral Health Related Quality of Life (OHRQoL) of people with intellectual disability.

15. Non-dental health professionals should be linked with dental representatives and undertake interprofessional training to identify serious dental health issues that require immediate attention by oral health professionals.

Conclusion

Dental health professionals expressed interest in learning about special needs but rated their current undergraduate training as poor which could be the cause of their lack of confidence and skills in managing people with intellectual disability. One of the negative implications related to incorporating education and training modules in SND at undergraduate level to improve knowledge and skills within an already crowded curriculum is insufficiency of time to include any additional teaching. There was no reported evidence on education/ training interventions among non-dental health professionals who are, or could be, potentially involved in oral health decision making for people with intellectual disability. People with intellectual disability strongly supported the idea of their involvement in oral health related decision-making and patient-centred care in dental services. Evidence suggests that education/training interventions for dental health professionals and carers have significantly improved knowledge and attitudes but there has been no improvement in oral health status of people with intellectual disability post intervention. Further randomised controlled trials evaluating long-term effectiveness of education/training related interventions in improving oral health status of people with intellectual disability are necessary to corroborate the findings of this review.

Issues / tasks to be considered by the CoP project:

1. Investigate the efficacy of high quality interdisciplinary support planning, and the adequate preparationof people with intellectual disability prior to treatment, days and weeks in advance.

2. Consider use of multimedia tools to help psychologically prepare patients with intellectual disability for treatment.

3. Promote use of efficient interdisciplinary planning forms.

4. Focus on interdisciplinary training and practice improvement for dentists, GPs and allied health, disability support professionals and family/carers.

5. Investigate the impact of training on attitudes ofinterdisciplinary professionals and supporters.

6. Enable dentists to acknowledge shortcomings of their capacity to manage people with intellectual disability.

7. Consider recommendations suggested by Kupzyk and Allen, 2019:
   - Find dental health professionals who are experienced and comfortable with individuals with intellectual disability.
   - Have supports and carers plan multiple 10+ minute "field trips" to dental clinics prior to treatment to familiarise patients.
   - Have support providers work with dental clinics to support implementation of relaxing and reinforcing activities for patients.
   - Consider requests for pre-exposure to, or non-use of, masks, gowns, gloves and some dental instruments.
   - Have caregivers bring preferred edibles, activities, objects with the person.
   - Emphasise ending visits with relaxation and enjoyment.
   - Have subsequent trips include gradual exposure to stimuli.
   - Develop a fear hierarchy.
   - Progress to the next step when the individual has been compliant with the current step.
   - Plan for how to handle disruptive behaviour.

questionnaires

CoP – Oral Health in Intellectual Disability

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Note: PWID - People with intellectual disability

Pre-intervention (Quantitative)

A. About previous training or professional development in the disability support sector/ system:

Did you receive special needs training at under-graduate level?

- ☐ Yes, extensive training
- ☐ Yes, adequate training
- ☐ Yes, limited training
- ☐ No
- ☐ Don't know

Have you received any training in managing PWID other than under-graduate level?

- ☐ Yes, extensive training
- ☐ Yes, adequate training
- ☐ Yes, limited training
- ☐ No
- ☐ Don't know

If yes, what was then means of training you received?

- ☐ Training resources in form of booklets and brochures
- ☐ Online training course
- ☐ Workshops and seminars
- ☐ CPD points course
- ☐ Short course without CPD points
- ☐ CDs and videos
- ☐ Others

How would you rate the quality of special needs training at under-graduate level?

- ☐ Excellent
- ☐ Good
- ☐ Satisfactory
- ☐ Poor
- ☐ Very poor
- ☐ Did not receive training

Have you received any previous training or professional development on improving attitudes and behaviour towards people with intellectual disability?

- ☐ Yes, extensive training
- ☐ Yes, adequate training
- ☐ Yes, limited training
- ☐ No
- ☐ Don't know

B. Experience:

How often do you see PWID at your dental practice?

- ☐ Very often (more than three PWID every month)
- ☐ Often (at least three PWID every months)
- ☐ Few (at least three to four PWID every year)
- ☐ Very few (less than three PWID every year)
- ☐ Never

How often do you refer PWID to a special needs dentist?

- ☐ Always
- ☐ Sometimes
- ☐ Only for second opinion
- ☐ Never
- ☐ I do not see PWID

To whom do you generally refer PWID ?

- ☐ Special Needs Dentist
- ☐ Paediatric dentists
- ☐ General dentists with experience in managing PWID
- ☐ Other health professionals
- ☐ Do not refer

Do you think your clinic has appropriate accessibility (physical and cognitive) for PWID? Physical accessibility includes elevators, ramps and sidewalks and, cognitive accessibility includes providing easily-understood content, such as text written using plain-language standards; focusing attention on important content; making forms easy complete to complete, easy website authentication, etc

- ☐ Yes, extensive physical and cognitive accessibility
- ☐ Yes, extensive physical accessibility
- ☐ Yes, extensive cognitive accessibility
- ☐ Yes, adequate physical and cognitive accessibility
- ☐ Yes, adequate physical accessibility
- ☐ Yes, adequate cognitive accessibility
- ☐ Yes, limited accessibility physical and cognitive accessibility
- ☐ Yes, limited physical accessibility
- ☐ Yes, limited cognitive accessibility
- ☐ No accessibility

What do you think are the main barriers in managing PWID? You can select more than one answer

- ☐ Poor infrastructure
- ☐ Lack of resources
- ☐ Lack of skills
- ☐ Lack of knowledge/ training
- ☐ Lack of confidence
- ☐ Lack of co-operation from PWID
- ☐ Lack of co-operation from carers
- ☐ Longer treatment time
- ☐ Lack of second opinion
- ☐ Lack of knowledge about their medical condition
- ☐ I do not see any barrier
- ☐ I do not have time to manage PWID
- ☐ Not sure

If you manage PWID, and according to your experience how would you rate the level of rapport/ communication that is achieved with the support workers/carers?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Satisfactory
- ☐ Poor
- ☐ Very poor/ no communication

If you treat PWID, on average, do you think support workers/ carers follow your advice appropriately?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ No contact with carers/ I do not treat PWID

Do you think general anaesthesia is the best option for providing dental treatment to PWID?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Not sure
- ☐ Do not treat PWID

Do you discuss your experience with PWID with other dentists?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ Not currently but I would like to

Do you co-ordinate/ communicate with health professionals of PWID to know about health conditions of PWID?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ Not currently but I would like to

I rate my level of agreement with the following statement "It easy to understand and access information related to the medical needs of PWID" as

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Satisfactory
- ☐ Poor

Do you provide pre and post dental care support to PWID and their carers?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ No contact with carers/ I do not treat PWID

C. Attitudes:

How comfortable are you to manage PWID?

- ☐ Very comfortable
- ☐ Comfortable
- ☐ Somewhat comfortable
- ☐ Not comfortable at all
- ☐ Not sure
- ☐ I do not manage PWID

How often would you refer PWID for a second opinion

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ I do not manage PWID

How confident are you about managing PWID?

- ☐ Very confident
- ☐ Confident
- ☐ Somewhat confident
- ☐ Not confident at all
- ☐ Not sure
- ☐ I do not manage PWID

Do you enjoy managing PWID?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ Not sure
- ☐ I do not manage PWID

D. Expectations:

What form of training would you like to receive regarding management of PWID? You can pick more than one answer.

- ☐ Training resources in form of booklets and brochures
- ☐ Online training course
- ☐ Workshops and seminars
- ☐ CPD points course
- ☐ Short course without CPD points
- ☐ CDs and videos
- ☐ Others

What information would you like to receive regarding management of PWID? You can pick more than one answer.

- ☐ Information about their disability
- ☐ Oral healthcare routine of PWID
- ☐ Oral manifestations of PWID
- ☐ Medical history and drugs
- ☐ Contact details of other non-dental health professionals related to PWID
- ☐ Dental management guidelines
- ☐ Behaviour management strategies
- ☐ Others

Do you have sufficient involvement of non-dental health professionals like GPs, speech therapists, pharmacists, behavioural therapists, nurses etc in planning dental treatment?

- ☐ Always
- ☐ Sometimes
- ☐ Never
- ☐ I do not manage PWID

Could you please rate your level of agreement with the following statement "Involvement of non-dental health professionals in dental care is important"?

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Not sure
- ☐ I do not manage PWID

Could you please rate your level of agreement with the following statement "Non-dental health professionals managing PWID must have some oral healthcare-related knowledge and training"?

- ☐ Strongly agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Not sure
- ☐ I do not manage PWID

Would you like to discuss your experience of managing PWID with other dentists and experts?

- ☐ Yes
- ☐ No
- ☐ Maybe

E. Awareness, knowledge and attitudes of disability rights

Do you know about the Disability Act Victoria 1992?

- ☐ Yes, I am fully aware
- ☐ Yes, I am somewhat aware
- ☐ Not aware but I would like to know
- ☐ Not aware and not interested

In 2008, Australia ratified the United Nations Convention on the Rights of Persons with Disabilities. Do you know about United Nation's Article 12 and Article 25?

- ☐ Yes, I am fully aware of Article 12 and Article 25
- ☐ Yes, I am aware of Article 12
- ☐ Yes, I am aware of Article 25
- ☐ Yes, I am somewhat aware of Article 12 and Article 25
- ☐ Yes, I am somewhat of Article 12
- ☐ Yes, I am somewhat of Article 25
- ☐ Not aware but I would like to know
- ☐ Not aware and not interested

F. Interdisciplinary approach

Do you communicate with other health professionals and support works involved in health-related decision making of PWID?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ Yes, only when required
- ☐ No but I would like to
- ☐ No, I do not wish to/ find it unnecessary
- ☐ I don't treat PWID

How do you communicate with other health professionals involved in health-related decision making of PWID? Paper-based forms

- ☐ Face-to-face
- ☐ Phone
- ☐ E-mails
- ☐ Video call
- ☐ Through the carers
- ☐ Other means (Please specify)
- ☐ I do not communicate with other health professionals
- ☐ I do not treat PWID

Pre-intervention (Qualitative)

1. What are your views on the importance of oral health for PWID?

2. What difficulties do you experience while managing PWID?

3. What are your thoughts about any previous training that you have received in managing PWID?

4. How do you think the training can be improved?

5. What would motivate you to manage more PWID in your practice?

6. What do you think about involvement of non-dental health professionals in oral health related decision making of PWID?

7. What do you think about the role of support workers/carers in managing oral health of PWID?

8. What would you like to learn about PWID?

9. What do you know about the disability rights and specific legislation?

10. What pre and post dental care support do you provide to PWID or their carers?

Post-intervention (Quantitative)

Pre-intervention questions from B, C, D and E will be repeated for post-intervention quantitative data collection
F. About CoP project

How would you rate your overall experience with CoP session?

- ☐ Excellent
- ☐ Very good
- ☐ Satisfactory
- ☐ Poor

Would you be interested in participating in similar sessions in future?

- ☐ Yes, definitely
- ☐ Maybe
- ☐ No, never
- ☐ Not sure

Post-intervention (Qualitative)

Did you find CoP sessions useful for improving the experience of PWID at your dental service? Could you elaborate or highlight the outcome of the CoP session that you think would to be most useful and suitable to be implemented at your practice?

What was the most valuable aspect of CoP, if any? (Hints to be used as prompts only if the interviewee does not come with any valuable aspects of the CoP sessions, for example, sharing information and experience? Dissemination of learning resources? Learning about PWID and their oral health concerns? Involvement of variety of stake holders? Co-design and shared decision making?)

How do you think the CoP sessions can be improved?

consent form

Project:
Oral Health Community of Practice

Responsible Researcher:
Professor Keith R. McVilly

Additional Researchers:
Professor Hanny Calache, Mr Nathan Despott,
Dr Alana Roy and Dr Tejashree Kangutkar

HREC ID:
TBC

Note:
For people with intellectual disability, this Consent Form will be read with them, and discussed with them by a person they already know and trust. They can contact the researchers to ask any questions as required.

Participant Name:

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.

2. I understand that the purpose of this research is to investigate how to improve dentists' practice with people who have intellectual disabilities.

3. I understand that my participation in this project is for research purposes only.

4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.

5. In this project I may be required to present information, read resources, tools and articlesdata, discuss and design resources to help support dentists to work better with people who have disabilities.

6. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice. However, I will be unable to withdraw any data I have already contributed to the project.

7. I understand that the information arising from this research will be stored at the University of Melbourne and may be used in the future for other projects of a similar nature.

8. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.

9. I understand that given the small number of participants involved in the study, it may not be possible to guarantee my anonymity.

10. I understand that after I sign and return this consent form, it will be retained by the researcher.

Please tell us your support needs (e.g., access, communication, food, etc) so that we can make this research assessible for you. My support needs are:

Participant's signature:

Date:

Participant's email:

Participant's telephone number:

Participant's organisation:

Where the Plain Language Statement and Consent Form have been read and explained to a person with intellectual disability, the person providing support is requested to sign the following:

I have explained to the person volunteering to participate the information provide on the Plain Language Statement and I am satisfied that the person participating in this activity or project:

1. Understands the Consent Form and obligations arising from signing the form; and

2. Has provided their consent freely.

I am aware that researchers will rely on my acknowledgement that I have explained the terms of this agreement to the person signing the Consent Form to the best of my ability, and that the person understood the terms of the agreement to the best of his or her ability. I also understand the form and the project brief.

Name of person explaining the form:

Relationship to the person volunteering to participate:

Signature person explaining the form:

Date:

Address or email:

Phone:

Additional resources

This will be separated out into two chapters:

- Oral health units in VET certificates
- Resource exemplars

oral health units in vocational education and training (VET) certificates

At present, the oral health related units in disability certificate courses in Victoria are available under eight titles. These units are mainly offered in Certificate III and Certificate IV courses in disability, ageing support and individual support, with six of the units available as electives to students undertaking disability certificates. The eight units independently focus on topics such as application of fluoride varnish, informing and supporting patients about oral health, assisting with oral hygiene, recognising and responding to oral health issues and use of basic oral health screening tools. Integrating the topics covered independently in separate units into a single comprehensive unit would be valuable for delivering key oral health related training to those enrolled in various disability support related courses. This would enable every aspiring disability support worker to learn about a range of key components of oral healthcare rather than choosing to focus on a single topic.

One output of the Community of Practice project will be the development of a framework for a single unit that includes the core knowledge, skills and competencies synthesised by the Your Dental Health materials and their validation in the COP.

Code	Title	Courses	Additional comments
HLTOHC003	Apply and manage use of basic oral health products	Certificate IV in Disability; Certificate IV in Ageing Support; Certificate III in Individual Support	
HLTOHC408B	Apply fluoride varnish	Not included in disability courses	Not included in disability
HLTOHC006	Apply fluoride varnish	Certificate IV in Disability; Certificate IV in Ageing Support	Not included in individual support
HLTOHC408A	Apply fluoride varnish	Not included in disability courses	Not included in disability
HLTOHC002	Inform and support patients and groups about oral health	Certificate IV in Disability; Certificate IV in Ageing Support; Certificate III in Individual Support	
HLTOHC004	Provide or assist with oral hygiene	Certificate IV in Disability; Certificate IV in Ageing Support; Certificate III in Individual Support	
HLTOHC001	Recognise and respond to oral health issues	Certificate IV in Disability; Certificate IV in Ageing Support; Certificate III in Individual Support	
HLTOHC005	Use basic oral health screening tools	Certificate IV in Disability; Certificate IV in Ageing Support; Certificate III in Individual Support	

Course Title & Year of Release	Application	Settings	Key Tasks	In accordance *	Comments
* In accordance with Commonwealth and State/Territory legislation, Australian/NZ standards for maintaining infection control and industry codes of practice.					
Use basic oral health screening tools August 2015	To describe the skills and knowledge required to prepare for and conduct authorised oral health screening tests within scope of work role to identify the need for referral to an oral health practitioner or for additional education or instruction in oral health care.	Workers in a range of health and community service environments where authorised basic oral health screening is carried out.	Prepare for and participate in basic routine oral health screening services. Follow screening tool questioning, observation and recording requirements. Review screening process and referral outcomes.	No	Requires discussion and collaboration with other health professionals and stakeholders.
Recognise and respond to oral health issues August 2015	To describe the skills and knowledge required to identify variations and recognise oral health issues through a visual check, observation of patient behaviour and habits, signs and symptoms and physical condition of patients. This enables the candidate to respond appropriately to the clinical findings to initiate follow up oral health care.	Workers in a range of health and community services environments where their work role requires them to recognise and respond to oral health issues.	Identify variations in patient behaviour and habits. Undertake basic visual oral check and questioning. Follow up and promote ongoing oral health care.	Yes	Role includes liaising with supervisor in consultation with patient to ensure appropriate referral occurs. Key role involves training patients for self-management.

Course Title & Year of Release	Application	Settings	Key Tasks	In accordance *	Comments
Provide or assist with oral hygiene **August 2015**	To describe the skills and knowledge required to provide or assist a patient with their oral hygiene where the patient is unable to perform all or part of these tasks by themselves.	Workers who provide direct patient care in a range of health and community services environments.	Identify patient's oral hygiene requirements to ensure good oral health. Assist and support patients in an appropriate manner. Assist and support patients in their identified oral hygiene needs. Recognise and report changes in patient oral hygiene requirements.	Yes	Identifying key signs and symptoms of oral diseases.
Inform and support patients and groups about oral health **August 2015**	To describe the skills and knowledge required to provide practical information and instruction to patients and groups to promote and support good oral health care practices.	Workers in a range of health and community services environments whose work roles provide them with an opportunity to promote and support good oral health care.	Develop and maintain understanding of oral health information and issues. Provide information related to oral health using a person-centred approach. Provide specific information and instruction on oral hygiene self-care techniques and appropriate aids. Evaluate effectiveness of oral health information session.	Yes	The skills and knowledge will enable the candidate to provide health promotion and practical demonstration/instruction of oral hygiene practices and techniques.

Course Title & Year of Release	Application	Settings	Key Tasks	In accordance *	Comments
Apply fluoride varnish **August 2015**	To describe the skills and knowledge required by practitioners working specifically in rural, remote and isolated areas and/or facilities that have knowledge and experience in oral health care, to apply fluoride varnish in line with prescribed treatment as outlined in an individualised oral health care plan and in accordance with relevant jurisdictional, legislative and regulatory requirements.	Registered Aboriginal and/or Torres Strait Islander health practitioners, registered nurses and registered enrolled nurses in primary health care settings in rural, remote and isolated areas where the work roles may require the application of fluoride varnish.	Prepare for the application of fluoride varnish. Apply fluoride varnish to teeth. Provide information to patient and/or family/carer about post-application advice and follow up requirements. Record and document information about the application.	Yes	
Apply and manage use of basic oral health products **August 2015**	To describe the skills and knowledge required to apply and manage use of basic oral health products and provide assistance to patients in the use of those products as identified in an individualised oral health care plan.	Workers whose work roles specifically include the application of identified oral health products in line with product guidelines and in compliance with all regulations related to the supply and use of regulated products.	Prepare for and participate in the application of basic oral health care products. Apply basic oral health care products. Support oral health and oral hygiene of patients with special care needs. Complete reporting and documentation and evaluate outcomes.	Yes	Mentions training on dementia and oral health.

resource exemplars for community of practice meetings

Community of Practice participants will be asked to give feedback on a range of existing resources about oral health and intellectual disability. The critique from people with intellectual disability, support professionals, dentists and other oral health professionals will help to inform any final resources produced by the COP and project researchers.

The research design project team searched for exemplar resources using a range of online tools, with a focus on gathering resources that were easy to locate, convenient to use/access, and practical for supporting the desired outcomes of users. Any resources that were designed to be used by a person with intellectual disability, their carer or support professional, or their oral health professional needed to be easily located in order to be deemed an effective public health tool by the research design project team. Primarily, Google and YouTube search tools were used to gather the results listed below, with some additional reliance on the project team members' networks. Australia has produced many resources, as have the UK and US, for oral health professionals and support professionals. Resources were critiqued for the quality of their content about oral health, or intellectual disability, and then were selected for inclusion in the final community of practice session plans.

There are very few resources that are designed for people with intellectual disability, and even fewer that seek to explain the relationship between dentist, supporter, and person with disability or the entitlements of a person receiving oral health care. The lack of high-quality resources that explain how the oral health and disability sectors are able to work together highlights the need for additional support and training in both sectors to improve the health and wellbeing of people with intellectual disability.

Written Resources:

The following resources, publications, webpages, and reports provide written content about the intersection of oral health and disability, with particular reference to intellectual disability.

Resource	Summary	Target Audience	Author	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Disability Awareness Guide	Information about respectful and appropriate communication with people with disability. Some information about decision making power of carers.	Oral health professionals	Dental Health Services Victoria (DHSV), 2007a.	Victoria, Australia	✗	✗	✓
Supporting Every Smile	Webpage information about oral health for disability support professionals who undertake person care tasks. Particularly focused at supported accommodation staff.	Support professionals	Dental Health Services Victoria (DHSV), 2007b.	Victoria, Australia	✗	✓	✓
Dental Care Every Day: A Caregiver's guide	'How to' guide for everyday oral health and visiting the dentist.	Support professionals	National Institute of Dental and Craniofacial Research (NIDCR). 2012.	USA	✓	✗	✗
Practical Oral Care for People with (Series) Autism Cerebral Palsy Down Syndrome Intellectual Disability	This series of fact sheets focus on how an oral health professional can treat their patient with disability. The focus is on treatment in a dental surgery.	Oral health professionals	National Institute of Dental and Craniofacial Research (NIDCR). 2012.	USA	✓	✗	✓
Oral care for people with disabilities	Background information about disability generally, and common oral health concerns. Generalised information about treating people with disability.	Oral health professionals	Dental Practice Education Research Unit, 2012a	South Australia, Australia	✗	✗	✗
Dental care for people with disabilities	Information for carers of people with disability. Overview of oral health with some signs to look for.	Carers and support professionals	Dental Practice Education Research Unit, 2012b	South Australia, Australia	✗	✓	✗

Resource	Summary	Target Audience	Author	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Oral Health Services forChildren and Adolescents with Special Health Care Needs	A resource guide of useful tools for anyone working with oral health and people with disabilities. Lists policy, program, education, and organisation options.	Carers and Support Professionals	Holt K, Barzel R, eds. 2020.	USA	✗	✓	✓
Oral health for people with special needs	Information on the practical techniques and tips for brushing and flossing a person's teeth.	Carers and Support Professionals	Queensland Government, 2017	Queensland, Australia	✗	✓	✗
Promoting oral health for people living in disability accommodation services	Toolkit for facilitating oral health training for supported accommodation staff. Discusses oral health care plan and assessments, as well as when to make dental appointments for a person with disability.	Support Professionals	Dental Health Services Victoria (DHSV), 2008.	Victoria, Australia	✓	✗	✓
Clinical Guidelines and Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities	Comprehensive explanatory guidelines for treating a person with intellectual disability. Discusses barriers to oral health care, practical tips, and restrictive practice.	Oral health professionals	The Royal College of Surgeons of England, 2012	UK	✓	✓	✓
Oral health and people with intellectual disability	Newsletter submission discussing concerns of the oral health of people with intellectual disability, and barriers to treatment.	Support professionals	Queensland centre for intellectual and developmental disability (QCIDD), 2010	Queensland, Australia	✗	✗	✗

Resource	Summary	Target Audience	Author	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Dental advice for people with disabilities	Easy English information about eating healthy, brushing teeth, and when to visit a dentist. Website as a hole is not cognitively accessible, this information was difficult to find.	Person with intellectual disability	Dental Health Services Victoria (DHSV), Unknown	Victoria, Australia	✗	✓	✗
Oral health and physical disabilities	Tips for transport and physical support with oral health practices	Carers and Support Professionals	Oral Health Foundation, Unknown a	UK	✗	✓	✓
Dental care for people with special needs	Information about Special Needs Dentistry and treatment	Carers and Support Professionals	Oral Health Foundation, Unknown b	UK	✗	✗	✗
Your Dental Health	Webpage with resources, videos, and forms to support with the oral health of people with intellectual disability	Carers, Support Professionals and Oral Health Professionals	Inclusion Melbourne, 2019	Victoria, Australia	✓	✓	✓
Your Dental Health: A Guide for People with a Disability, their Family Carers, Friends and Advocates	Guide for people with intellectual disability about oral health, signs of poor oral health, risk factors, and what happens at the dentist.	Carers, Support Professionals and Oral Health Professionals	Angwin, Leighton, & Despott, 2015a	Victoria, Australia	✓	✓	✓
Your Dental Health: A Guide for People with a Disability, their Family Carers, Friends and Advocates (Western Australia Edition)	Guide for people with intellectual disability about oral health, signs of poor oral health, risk factors, and what happens at the dentist. Tailored for Western Australia	Carers, Support Professionals and Oral Health Professionals	Angwin, Leighton, & Despott, 2015b	Victoria, Australia	✓	✓	✗

Resource	Summary	Target Audience	Author	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Oral Health and Intellectual Disability	Treatment pathway for people with intellectual disability, including common oral health concerns, and barriers such as working within the disability sector	Oral Health Professionals	Zylan, Despott, Tracy, Shnider (2019)	Victoria, Australia	✔	✔	✔
Healthy Smiles for Children with Autism	Simple information and tips about caring for the oral health of a young person with Autism.	Carers and Support Professionals	Anderson Center for Dental Care, Unknown a	USA	✘	✘	✘
Healthy Smiles for Children with Autism (2)	Information and tips about caring for the oral health of a young person with Autism	Carers and Support Professionals	Anderson Center for Dental Care, Unknown b	USA	✘	✘	✘
Healthy Smiles for Children with Down Syndrome	Simple information and tips about caring for the oral health of a young person with Down Syndrome	Carers and Support Professionals	Anderson Center for Dental Care, Unknown c	USA	✘	✘	✘
Healthy Smiles for Children with Down Syndrome (2)	Information and tips about caring for the oral health of a young person with Down Syndrome	Carers and Support Professionals	Anderson Center for Dental Care, Unknown d	USA	✘	✘	✘
Special Care Advocates in Dentistry Modules: SAID Professional Modules	Range of training modules on a variety of disabilities including Intellectual Disability. Includes clinical concerns, sedation, restrictive practice. There are basic strategies for working with patients with disability and how oral health professionals can successfully treat their patient	Oral Health Professionals	Southern Association of Institutional Dentists, 2013	USA	✔	✘	✔

Resource	Summary	Target Audience	Author	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Oral Health & Disability: The Way Forward	Overview of Irelands policy, research, and support service suggestions for disability organisations. Emphasis on family or carer support for oral health, rather than oral health professional considerations. Includes recommendations for disability providers and carers.	Carers and Support Professionals	Elliott, Nunn, and Sadlier, 2005	Ireland	✔	✘	✔
Oral and Dental Problems in Scleroderma and Sjögren's Syndrome	General and Oral health information of people with Scleroderma and Sjögren's Syndrome	Oral Health Professionals	Aldred and Talacko, 2009	Victoria, Australia	✘	✔	✔

Video Resources:

The following video resources include demonstrations, first person accounts, lectures, and new pieces about oral health and disability, with particular focus to intellectual disability.

Resource	Summary	Target Audience	Producer	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Home Dental Care for People with Disabilities	Demonstration on mouth model of oral hygiene practices. Discusses modifications to equipment and craniofacial anomalies.	Carers and Support Professionals	Children's Hospital of Pittsburgh, 2012	USA	✕	✓	✓
Dentistry and Disability	Addresses the barriers that occur pre, during, and post dental treatment. Includes tips on how to make treatment as accessible and successful as possible.	Oral Health Professionals and Support Professionals	Inclusion Melbourne and Monash Health, 2017	Victoria, Australia	✓	✕	✓
Visiting the Eastman dental hospital	A step by step guide to visiting the dental hospital for treatment.	Person with intellectual disability	University College London Hospitals, 2016	UK	✓	✕	✕
NYU Dentistry Oral Health Center for People with Disabilities	Information about special care dentistry and the university clinic.	Carers and Support Professionals	NYU College of Dentistry, 2019	USA	✕	✓	✕
Treating Patients with Disabilities	Information about disability, attitudes to disability, and providing care. Discusses the importance of communication with carers and supporters who can help with tips on how to work with an individual.	Oral Health Professionals	Royal College of Dental Surgeons Ontario, 2015	Canada	✓	✕	✓

Resource	Summary	Target Audience	Producer	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Periodontal Disease in Adults with Developmental Disabilities	Description of periodontitis and medicalised information about why this may be higher for people with disability. Focus on chronic health conditions	Carers and Support Professionals	Children's Hospital of Pittsburgh, 2012	USA	✕	✕	✕
Periodontal Disease in Adults with Developmental Disabilities	Description of periodontitis and medicalised information about why this may be higher for people with disability. Focus on chronic health conditions	Oral Health Professionals	May, P. 2013	USA	✕	✓	✓
People with disabilities	Information about oral information form (care plan), and some direction for cleaning a person's teeth, including familiarising the person with disability to equipment	Carers and Support Professionals	Embæt-tilandlæknis (Directorate of Health) 2012	Iceland	✓	✕	✕
Dental Care for Children with Special Health Care Needs - Boston Children's Hospital	Demonstrates the process of visiting the dental hospital, starting with finding the clinic. Focus on children with disability	Person with intellectual disability and carers	Boston Children's Hospital, 2013	USA	✓	✕	✓
Sally's visit to the dentist	Demonstrates the process of dental care, includes some pre-dental visit care and the relationship between person with disability and supporter	Person with intellectual disability and carers	Dental Health Services Victoria (DHSV), 2015	Victoria, Australia	✓	✕	✓

Resource	Summary	Target Audience	Producer	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Brushing up on oral health for disability residential services	Series of 9 videos on the oral health care of people with disability living in residential services. Practical tips with brushing, flossing and dentures.	Support Professionals	Dental Health Services Victoria (DHSV), 2010	Victoria, Australia	✗	✓	✓
Dentists train for special needs patients	News segment highlighting the need for additional training for people with intellectual disability	Oral Health Professionals	13WHAM ABC News, 2015	USA	✓	✗	✓

Additional Resources being used in the COP:

The following written and video resources are supplementary content for the Community of Practice that demonstrate themes that intersect with oral health and disability.

Resource	Summary	Target Audience	Author / Producer	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Social Model of Disability	Introductory video to the differences between the medical model, and social model of disability.	Oral Health Professionals, Carers and Support Professionals	Shape Arts, 2017	UK	✓	✗	✓
Accessible Information	Introduction to accessible information for people with a range of disability including intellectual disability	Oral Health Professionals and Support Professionals	You Me Us, 2017a	Victoria, Australia	✓	✗	✓
Don't DIS my ABILITY – Day in the life	A day in the life of Graeme Innes, and his guide dog Arrow. An amusing narrative of the interactions that can occur during the day of a vision impaired person.	Oral Health Professionals, Carers and Support Professionals	NSW Government, 2017	New South Wales, Australia	✗	✗	✓
Customer Service	Introduction to good customer service for people with disability and different communication.	Oral Health Professionals and Support Professionals	You Me Us, 2017b	Victoria, Australia	✗	✗	✓
Amanda's Story	Discussion of the attitudes and culture to accessibility and disability	Oral Health Professionals, Carers and Support Professionals	You Me Us, 2018	Victoria, Australia	✗	✗	✓
Sexual Assault	Introductory definitions to sexual assault	Oral Health Professionals, Carers and Support Professionals	Victoria Legal Aid, 2016	Victoria Australia	✗	✗	✓

Resource	Summary	Target Audience	Author / Producer	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
What is sexual assault?	Fact sheet outlining the definition of and types of sexual assault. Discusses consent and lack of consent in a legal framework	Oral Health Professionals, Carers and Support Professionals	SECASA, 2013a	Victoria, Australia	✗	✗	✓
Legal definitions of rape and indecent assault	Fact sheet outlining the definition of rape and indecent assault	Oral Health Professionals, Carers and Support Professionals	SECASA, 2013b	Victoria, Australia	✗	✗	✓
What are the myths and facts about sexual assault?	Fact sheet disproving many myths about sexual assault in Australian society	Oral Health Professionals, Carers and Support Professionals	SECASA, 2013c	Victoria, Australia	✗	✗	✓
CASA Dental Survey Results and Analysis 2018	Report discussing the findings of an oral health survey of survivors	Oral Health Professionals, Carers and Support Professionals	SECASA, 2013c	Victoria, Australia	✗	✓	✓
Trauma informed dental care: Dentist Lecture (Series)	Series of 3 videos of SharonneZaks lecturing to dentists about trauma and survivors experiences of the dentist and what can be done to support patients	Oral Health Professionals	Zaks, 2018 a, b, & c	Victoria, Australia	✗	✓	✓
Videos for survivors	Series of 10 videos for survivors of sexual assault on oral health and visiting the dentists. Survivors and dentist discussing their experiences	Carers, Support Workers and Oral Health Professionals.	Zaks, 2018 d, e, f, g, h, I, j, k, l & m	Victoria, Australia	✗	✓	✓

Resource	Summary	Target Audience	Author / Producer	Location	Suitable Intellectual Disability Content	Suitable Oral Health Content	Final COP Inclusion
Considering Additional Risks	Webpage of resources to help understand and implement good practice and the use of restrictive practice. Considers personal and service risks, trauma informed, restrictive practice, and family violence films, and a range of state specific resources	Support Professionals	NDS, 2017	Australia	✓	✗	✓
Every Moment Has Potential	Online modules for active support training of support professionals, targeted at residential accommodation services	Support Professionals	Greystanes Disability Services and La Trobe University, 2015	Australia	✓	✗	✓
Representing the rights of persons with disabilities	Video of Jo Watson challenging the assumptions that people with severe or profound cognitive disability are unable to lead self-determined lives	Carers, Support Workers and Oral Health Professionals.	Watson, 2016	Australia	✓	✗	✓

references for resource exemplars

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67 Sutherland Road, Armadale, VIC 3143
T. 03 9509 4266
E. projects@inclusiondesignlab.org.au
W. inclusiondesignlab.org.au