



Faculty of Medicine, The Department of
Developmental Disability Neuropsychiatry 3DN

A scoping review of causes and contributors to deaths of people with disability in Australia

SUMMARY OF RECOMMENDATIONS

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Executive Summary

The establishment of the National Disability Insurance Scheme's Quality and Safeguards Commission presents a unique opportunity to develop Australia's first nationally consistent arrangement for reviewing deaths of people with disability. In preparation for this national death review process the Commission requested the Department of Developmental Disability Neuropsychiatry at UNSW Sydney to conduct an Australia-wide scoping review focused on mortality trends and factors relating to the deaths of people with disability.

The scoping review was the first of its kind to provide a national baseline picture of death trends and related factors by drawing on published state and territory level disability death review data. It considered the death reviews of 901 people with disability across the states of Vic, QLD and NSW. Details of the scoping review methodology and findings are available in the full report, "Salomon, C & Trollor, J (2019). A scoping review of causes and contributors to deaths of people with disability in Australia (2013-2019): Findings"

This report presents the Commission with a series of recommendations based on findings from the scoping review. It includes:

- **Methodological recommendations related to how deaths of people with disability are tracked and analysed**
- **Practice improvement recommendations to address specific types of deaths as well as overarching areas of problematic practice that contributed to the deaths of people with disability**
- **Links to resources that may prove useful when implementing a practice improvement agenda**

ABOUT THE SOURCES

VIC:

Disability Services Commissioner (DSC). A review of disability service provision to people who have died 2017-18. Melbourne: Disability Services Commissioner **VIC 17-18**

Parliament of Victoria, Family and Community Development Committee 2016, Inquiry into abuse in disability services: final report, State Government of Victoria, Melbourne **VIC 07-16**

N=95

NSW

NSW Ombudsman (2015). Report of reviewable deaths in 2012 and 2013. Volume 2: Deaths of people with disability in residential care **NSW 12-13**

Ombudsman NSW (2018). Report of reviewable deaths in: 2014 and 2015 & 2016 and 2017: Deaths of people with disability in residential care **NSW 14-17**

N=733

QLD

Office of the Public Advocate (QLD). 2016. Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland. A systematic advocacy report **QLD 09-14**

N=73

For the remainder of the report these sources are referenced as:
VIC 17-18; VIC 07-16; QLD 09-14; NSW 12-13; NSW 14-17

Methodological recommendations

The following methodological recommendations are presented for consideration by the Commission when planning its investigations into deaths of NDIS recipients:

1.1. Regular reporting, using standard definitions and statistical analysis techniques is required and will aid tracking of changes in mortality data over-time:

The vastly different time frames and terms of reference between existing jurisdictional reports hinders detection of national trends related to deaths of people with disability. With the exception of NSW, no jurisdiction had a mechanism for regularly reporting and mapping changes in deaths over time. We recommend the commission commit to publishing public annual reports.

1.2. Death investigations are time- and labour- intensive and must be adequately resourced to ensure timely investigation and reporting:

The Victorian Disability Services Commissioner (VIC 17-18) highlighted the considerable time and resource commitment required to conduct a comprehensive investigation into a person's death. This is particularly the case for people with disabilities who may have complex and multiple health conditions, and those who receive care across different sectors. The Commission should ensure that their team is adequately resourced to conduct labour-intensive investigations in a timely manner.

1.3. Consideration should be given into how category and cause of deaths will be determined in cases not reported to the state coroner:

Not all in-scope deaths of people with disabilities are 'reportable' deaths to the relevant state coroner. For example, 33% of in-scope deaths in the VIC 17-18 report had no category of death available to analyse. This occurred because the deaths fell outside of state coroner's scope of investigation. In Victoria, specifically, this may assume increased importance, as government-run disability accommodation and respite services (where deaths are considered 'reportable') are tendered out to the non-government sector (in settings where deaths will no longer be 'reportable' to the state coroner), as part of the NDIS transition. The Commission should give consideration to how it will determine cause of death in cases where no coroner's report is available.

1.4. Consider measures to address under-reporting of 'reportable' deaths:

The QLD Office of the Public Advocate (QLD 09-14) has highlighted the common issue of under-reporting of deaths of people with disabilities, even in cases where the deaths are, by law, 'reportable' to the state coroner. Research suggests that health staff and disability staff may lack awareness of reporting obligations¹. Variation in reporting requirements and different penalties for non-reporting across jurisdictions contribute to confusion^{2 3}.

¹ Charles, A., Ranson, D., Bohensky, M., & Ibrahim, J. E. (2007). Under-reporting of deaths to the coroner by doctors: a retrospective review of deaths in two hospitals in Melbourne, Australia. *International Journal for Quality in Health Care*, 19(4), 232-236.

² Neate, S. L., Bugeja, L. C., Jelinek, G. A., Spooner, H. M., Ding, L., & Ranson, D. L. (2013). Non-reporting of reportable deaths to the coroner: when in doubt, report. *Medical journal of Australia*, 199(6), 402-405.

³ Middleton, S., & Buist, M. T. (2014). The coronial reporting of medical setting deaths: a legal analysis of the

Under-reporting can negatively impact the extent to which data can be used to draw conclusions about the prevalence of certain deaths in populations with disabilities. Attention should be given to developing clear policies around reporting obligations. Education about reporting obligations should be provided to health staff as well as disability staff, given it is likely that a considerable proportion of NDIS recipients will die in a hospital setting.

1.5. The Commission should advocate for robust coronial investigations of relevant deaths of people with disabilities:

The QLD Office of the Public Advocate (QLD 07-14) raised concerns in their report about the brevity of many available coronial reports. They note that while all deaths in care in QLD must be reported to the Coroner's office and investigated, not all investigations will result in an inquest and/or published findings/comments. Between 2009 and 2014, they note that there was only one inquest into a death in care of a person with disability in QLD: "Overall the Advisory Panel felt there could have been further scrutiny and examination of the circumstances surrounding the deaths of many of the people who died in care in this sample. In particular, the Panel commented on the lack of advocacy in the coronial system for people who have died in care." There is potential for the committee to work in partnership with state and territory coroners' courts to better understand the types of deaths of people with disability that may warrant further investigation.

1.6. Consideration should be given regarding how deaths of people with disabilities could be better flagged within the National Coronial Information System (NCIS) database:

Authors of the VIC 07-16 report highlighted limitations in NCIS database functionality that made it difficult to isolate deaths involving clients of disability services. We approached the NCIS administrators to enquire whether their coding had changed since the publication of this report, however, they highlighted that there is still no explicit code for disability status within the database. Identification of relevant cases is therefore still reliant on conducting keyword searches of the attached searchable PDF reports (coronial finding, autopsy report and police notification of death form), and manually reviewing their contents to ascertain relevance. Additionally, terminology used in these reports is not standardised. These reports may refer to a specific type of disability (for example, 'vision impaired', 'autism spectrum disorder' or 'acquired brain injury') without mention of the term 'disability' itself. Persons receiving a disability pension may be identified through searches of the 'Employment Status' and 'Occupation Text' fields; however, this would not identify all persons with a disability. Identifying relevant cases through such a manual review would be time- and labour- intensive. We recommend that the Commission liaise with the NCIS administrators with the view of developing an explicit code for disability status within their database. Additionally, the Commission will need to establish information sharing arrangements with each jurisdiction's peak coronial body so that deaths of NDIS recipients will be referred back to the Commission in a timely manner.

1.7. Consideration should be given as to how data about the deaths of people with disability who fall outside the scope of the Commission's terms of reference will be captured:

Vastly differing inclusion criteria across the reviewed reports has highlighted the difficulty of determining prevalence of death trends among Australians with disabilities. In order for the Commission to comment on how deaths of NDIS participants compare to deaths of other Australians with disabilities who are not NDIS recipients, or to understand the deaths of people with disabilities as a whole, attention will need to be given to collecting data from currently excluded groups. The deaths of NDIS participants whose deaths are not considered 'in connection' with the provision of NDIS supports, people with disability who do not receive NDIS funding, people with disabilities in custody, or elderly people with disability in aged care facilities, for example, are all at risk of being excluded from monitoring requirements at present.

variation in Australian jurisdictions. Melbourne University Law Review, 37, 699-735.

1.8. Consideration should be given to routinely eliciting family perspectives as part of the death review process:

We note that across the five reviewed reports, no investigative processes were established to routinely seek input from family members regarding the quality of care the person received or how the level of care may have impacted on the person's death. Research has established that disability service providers and family members do not always share the same perspectives about care provision and can each offer unique perspectives⁴. Ensuring that death reviews routinely elicit information from family members may improve the comprehensiveness of our understanding of causes and contributors to deaths. We encourage the committee to develop a feedback tool that would be routinely sent out to family members of the deceased (where relevant) to allow them to provide comment on the circumstances surrounding the person's death.

⁴ Bossink, L. W., van der Putten, A. A., & Vlaskamp, C. (2017). Understanding low levels of physical activity in people with intellectual disabilities: A systematic review to identify barriers and facilitators. *Research in Developmental Disabilities*, 68, 95-110.

Understanding the core characteristics of those that died

The following recommendations related to understanding the core characteristics of people who die are presented for consideration by the Commission when planning its investigations into deaths of NDIS recipients:

2.1. Our review of death reporting across jurisdictions has highlighted considerable variance both in the *type* of core characteristics data collected, and the *methods* used to analyse these data. In order to collect the most robust data set and to identify patterns in the data based on cohort characteristics we recommend that the Commission collect:

- Basic demographics: age, gender, cultural status (i.e. ATSI, CALD)
- Service-related data: accommodation type, type and intensity of service provision/s
- Preventive health care data:
 - Influenza and pneumococcal vaccine status
 - Date of last comprehensive health exam
 - Date of last dental review
 - Evidence of specialist referral and follow-up for identified risks (weight, hypertension, re-occurring infections, etc.)
- Medication data:
 - name, class of medication, indications for use, total number of medications, total number of medications per medication class, date of last medication review.
 - for psychotropic medications, data on diagnosis of mental illness should be collected. For 'off-label' use of psychotropics for behavior management- record presence of challenging behaviour, use of restrictive practices (type, indications, RP authorization), behaviour support plan
- Decision-making data: Information about the persons capacity to consent to treatment or who is their substitute decision maker
- Disability-related data:
 - *Causes of disability* (meaning of 'primary' and 'additional' disabilities should be clearly laid out for reporting purposes. Primary and additional causes of disability should also be combined to provide a picture of the persons overall number and types of disabilities)
 - *Level of functioning/severity of disability* - map areas in which the person needs support to presence and adequacy of support for needs (i.e. communications, mobility)
- Health data:
 - Co-occurring physical and mental health issues (number per person and type)
 - Weight, BMI, smoking status, and level of physical activity (and evidence of specialist assessments as relevant to identified risks)
 - Nutrition, swallowing and mealtime support needs AND presence of mealtime support plan AND adequacy of mealtime support plan AND date of last specialist visits as indicated by risk
 - Communication needs AND presence of communication plan
 - Mobility needs AND presence of mobility plan



2.2. Where possible, analysis should be stratified to develop a more nuanced understanding of demographic patterns in different sub-populations of people with disability.

For example: age of death by gender, type of disabilities by age of death, diagnosis by medication prescription, and so forth. We commend the work undertaken by the NSW Ombudsman in stratifying findings by whether or not the person resided in disability services or an assisted boarding house, and highlight the considerable differences in demographic patterns that emerged based on this division. Stratifying analysis will support the development of increasingly targeted and potentially effective interventions to address risk for different groups.

Analysing cause of death

This review identified considerable variation in how different jurisdictions analyse cause of death for people with disability. In order to maximise the utility of cause of death data, we recommend the following:

3.1. Data on both the underlying cause of death (at ICD-10 Chapter and sub-chapter level) as well as contributing and direct causes of death should be collected for all cases:

These data are essential to building up a complete picture of how the death occurred and will help the Commission to identify core target areas for practice improvement. We note that only NSW analysed direct and contributing causes of death in addition to underlying causes. This approach provided a more complete picture of the contribution of different disease systems to the person's death and highlighted patterns that were missed in the analyses conducted in other jurisdictions. For example, the significant contribution of mental and behavioural disorders as an associated cause of death was only highlighted as a result of the NSW analysis.

3.2. Underlying causes of death attributed to the aetiology of the disability should be recoded prior to analysis:

Unlike Trollor and colleagues' analysis of mortality data⁵, no report included in this scoping review, described if or how it attempted to recode deaths attributed to the aetiology of the disability. Concern has been raised in the literature that use of aetiology of disability as an underlying cause of death obscures insight into actual causes of death that could help direct preventive care efforts to reduce premature mortality⁶. The ICD-10⁷ variously classifies disabilities as 'mental and behavioural disorders' (i.e. intellectual disability, cerebral palsy, autism) or as, 'chromosomal or congenital abnormalities' (i.e. Down syndrome, spina bifida). Using these codes to classify underlying cause of death, however, has been noted to obscure the effect of other contributors to mortality, some of which may be potentially avoidable or amenable to intervention. For example, in a cross-sectional analysis of cause of mortality data in the United States⁸, it was noted that such coding obscured high rates of choking deaths among people with developmental disabilities. The contribution of dementia and Alzheimer's disease to deaths of people with Down syndrome was also obscured. Respiratory deaths have also been shown to increase significantly in populations with Down syndrome⁹ and intellectual disability (5) once these categories are recoded.

A significant number of deaths in-scope for this review (14%, n=122), were attributed to the disability itself: 63 people in the NSW 14-17 sample, 25 people in the 12-13 sample, 1 person in the VIC 17-18 sample and 1 person in the QLD 09-14 sample had 'congenital and chromosomal conditions' listed as their underlying cause of death. Thirty-one people in the NSW 14-17 sample and 1 person in their 13-14 sample had 'mental and behavioral disorders' listed as the underlying cause of death. It is thus possible that cause of death data reported in this scoping review may under-represent deaths from external and respiratory causes. We recommend that the Commission consider

⁵ Trollor, J., Srasuebku, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open*, 7(2), e013489.

⁶ Foreman KJ, Naghavi M, & Ezzati, M. (2016). Improving the usefulness of US mortality data: new methods for reclassification of underlying cause of death. *Population Health Metrics*, 14(14), 14.

⁷ World Health Organization (WHO). (2013). International statistical classification of diseases and related health problems-10th revision. Geneva: World Health Organization.

⁸ Landes, S. D., Stevens, J. D., & Turk, M. A. (2019). Obscuring effect of coding developmental disability as the underlying cause of death on mortality trends for adults with developmental disability: a cross-sectional study using US Mortality Data from 2012 to 2016. *BMJ Open*, 9(2), e026614.

⁹ Baird, P., & Sadovnick, A. (1990). Underlying causes of death in Down syndrome: accuracy of British Columbia death certificate data. *Canadian Journal of Public Health*, 81, 456-461.

the recoding process used in the Trollor study⁵, which involved recoding the underlying cause of death to the cause of death that appeared immediately adjacent to the coded disability-related aetiology in reported sequence leading to death. We anticipate that such recoding will assist in revealing the extent of potentially avoidable causes of death in people with disability. Consideration should be given to hiring someone with medical and technical expertise to support this recoding process.

3.3. Analysis of causes of death should be in keeping with routine reporting of deaths by AIHW, and directly comparable to the general population.

For each major disability type, this will include underlying (sometimes referred to as leading) cause of death, associated causes of death and multiple causes of death, standardised mortality ratio by sex and cause, and age-specific causes of death. Potentially avoidable causes of death and deaths amenable to treatment should also be defined and reported by disability type.

Identification and analysis of such deaths is essential given our previous work⁵ demonstrating that people with intellectual disability in NSW had much higher proportions of potentially avoidable deaths (38%) than people without intellectual disability (17%), including deaths due to infections, diseases of the circulatory system, cancer and other external causes. External causes of death should also be reported in detail as our research¹⁰ shows that these are of salience for some groups including people on the autism spectrum.

Previous jurisdictional reports include rates of expected and unexpected deaths, and natural and unnatural causes; however, a lack of definitional clarity around some of these terms was evident in some reports. The Commission should carefully consider if and how they plan to define and operationalise each term. We note that only QLD systematically defined and analysed potentially 'avoidable', 'treatable' and 'preventable' death rates.

3.4. Data collection systems should enable causes of death to be stratified for different demographic groups.

As the NSW ombudsman's stratified analysis of deaths by accommodation type ('disability service' or assisted boarding house') has highlighted, risk profiles and causes of death can differ significantly between different groups of people with disability. Recipients of NDIS funding will have varied demographic, health and risk profiles. We therefore recommend that the Commission consider data collection that would enable cause of death and risk stratification by factors such as: age, gender, indigenous status, accommodation type, disability type and severity, number and type of co-morbidities, number and type of medications, communication needs, mobility needs, influenza and pneumococcal vaccination status, date of last comprehensive annual check-up, weight status, smoking status, and level of physical activity. For specific causes of death such as choking and aspiration pneumonia, stratified analysis could also be considered for known risk factors such as swallowing difficulties, presence of a mealtime plan, involvement of specialists, psychotropic medication and so forth.

3.5. All standard metrics used for reporting rates of death in the general population and other vulnerable groups, should be included in future reports produced by the Commission.

Stratified by primary disability type, the Commission should report on: life expectancy at birth, deaths by age and gender, age specific death rates per 100,000 by gender, comparative mortality ratios by age, sex and disability status. The AIHW report¹¹ on life expectancy and death rates in indigenous populations provides an illustration of comprehensive reporting using standard metrics.

¹⁰ Hwang, Y. I., Srasuebku, P., Foley, K. R., Arnold, S., & Trollor, J. N. (2019). Mortality and cause of death of Australians on the autism spectrum. *Autism Research*, 12(5), 806-815.

¹¹ Australian Institute of Health and Welfare (AIHW). (2011). *Life expectancy and mortality of Aboriginal and Torres Strait Islander people*. Canberra: AIHW.

Reducing respiratory related deaths

Authors of the NSW, QLD and VIC death reviews make a number of valuable practice improvement recommendations to address avoidable respiratory deaths and decrease the risk of aspiration pneumonia among people with disability. Some of these provide potential points of compliance monitoring for the Commission:

- All people with disability should be routinely screened for vulnerability to aspiration and/or pneumonia. All clients should be screened for risks such as swallowing problems, reoccurring chest infections, mobility limitations, GORD, poor oral health, diagnosis of cerebral palsy, epilepsy or Down syndrome, prescription of multiple medications, including psychotropics.
- All people with identified risks should be referred for specialist assessments and support. Eating and swallowing assessments should be conducted by qualified specialists on all at risk individuals. People with recurrent respiratory infections should be referred to specialist respiratory clinicians.
- Recommendations regarding mealtime safety made by specialists should be embedded into mealtime management plans and followed exactly.
- Disability and health care staff as well as family members should be provided with additional education and training with the view of promoting awareness of:
 - Why and how people with disability are vulnerable to respiratory conditions and aspiration.
 - The importance of safe feeding techniques and precisely following all mealtime recommendations relating to feeding, food consistency and supervision while eating.
 - Signs and symptoms of pneumonia, and the need to seek immediate medical assistance when they occur (irrespective of whether the person has seen a doctor recently or not). Education should stress that often there is only a short window of time between the infection developing and potential death.
- Regular medication reviews should occur with the view of reducing psychotropic use and polypharmacy where appropriate in order to minimise risk of aspiration.
- People with epilepsy should have regular access to specialist support and medication reviews to decrease risk of aspiration.
- People who are potentially vulnerable to pneumonia should be vaccinated against pneumococcal pneumonia as well as influenza in a timely manner.
- All people should be supported to maintain good oral hygiene and have regular access to dental care.
- Staff should closely monitor people receiving enteral feeding (including PEG feeding) for signs that aspiration could be occurring, and for early signs of respiratory infection and seek medical care immediately.
- Organisations should put guidelines and policies in place to mandate the above recommendations to ensure that they are implemented and monitored and that action is taken when breaches occur.
- Additional education, training and resources should be provided to health staff regarding conducting swallowing assessments and providing written guidance to people with disabilities and disability organisations. We note the concerns raised by the NSW Ombudsman in their 2014-17 report that in transitioning to the NDIS people would only be able to access funded speech pathology services through the health care system. Mainstream health care staff may also require additional training to tailor their practice to the needs of people with disabilities. While we understand that interim funding for swallowing therapies is now being considered within the NDIS, a permanent funding solution is yet to be finalised.

Reducing deaths related to choking

Authors of the NSW, QLD and VIC death reviews make a number of valuable practice improvement recommendations to reduce rates of choking among people with disability. Some of these provide potential points of compliance monitoring for the Commission:

- Disability and health care staff as well as family members should be provided additional education and training with the view of promoting awareness of:
- How to identify potential eating, drinking and swallowing problems and the importance of seeking prompt specialist assessment if noted.
- How to prepare food and beverages to the correct consistency.
- Safe positioning, prompting and pacing during meals
- The importance of following mealtime plans precisely, including the need for constant supervision where indicated. Staff should be made aware that only very minor gaps in supervision are needed for choking to occur.
- How to respond if a choking occurs. This includes first aid training with annual refresher courses.
- The importance of staff education as a protective factor for choking has been highlighted in research findings. For example, improved carer knowledge of choking risk and vulnerabilities has been shown to improve the extent to which carers adhere to mealtime guidelines¹².
- All people with disability should be screened for choking risks.
- People with identified choking risks should be assessed by a qualified health professional and an appropriate mealtime plan should be implemented accordingly.
- Health professionals who develop mealtime management plans should work with service organisations to ensure that they understand the resource and rostering requirements needed to implement the plans.
- People with disabilities subject to mealtime management plans should be provided with accessible information about their plan to increase compliance.
- Channels of communication between the person's family, disability provider, health care team and other support staff, should be improved to ensure that mealtime management plans are known and followed consistently across settings.
- Staff and services should be made aware that measures such as locking cupboards, fridges and freezers are not always failsafe, and do not replace effective supervision.

¹² Chadwick, D., Jolliffe, J., & Goldbart, J. (2002). Carer knowledge of dysphagia management strategies. *International Journal of Language and Communication Disorders*, 37, 345- 358.

Improving epilepsy management

The QLD (09-14) report authors make several important recommendations for managing epilepsy among people with disability, and potentially reducing avoidable epilepsy related deaths. Some of these provide potential points of compliance monitoring for the Commission:

- *"Adults with a suspected seizure should be seen by a specialist in the diagnosis and management of epilepsy within two weeks. All adults diagnosed with epilepsy should have an agreed and comprehensive written care plan.*
Adults with a history of prolonged or repeated seizures should have an agreed written emergency care plan that provides guidance for support staff, carers or family members on how to administer emergency treatment.
All adults with epilepsy should have an accessible point of contact with specialist services.
All adults with epilepsy should have at least yearly reviews (or more regularly depending on how well their epilepsy is controlled).
If seizures are not controlled in adults with epilepsy, or if there is treatment failure or side effects from their medication, they should be referred within 4 weeks to tertiary services for further assessment." (QLD 09-14)"
- Their work also highlights the importance of educating disability and health care staff as well as the person's family about appropriate seizure recognition and monitoring. Staff should additionally receive training regarding appropriate administration of anti-seizure medication, and emergency response pathways and care for people who are having a seizure. Staff should be made aware that, in general, anti-epileptic medication should be continued even when the person is admitted to hospital. They also recommend that care providers use seizure detection smart watches and pressure mattresses overnight for at risk residents to reduce the risk of sudden death from epilepsy.

Reducing lifestyle risks

Authors of the NSW, QLD and VIC death reviews offer valuable strategies for reducing lifestyle risks. Some of these provide potential points of compliance monitoring for the Commission:

- People with disabilities should be provided with information about healthy lifestyles (including information about healthy eating, weight management, physical activity, and drug, alcohol and smoking reduction) in formats that are accessible to them.
- Health care and disability staff, along with family members, should be provided with topical training so they can more effectively support clients to meet healthy lifestyle goals.
- Disability services should ensure that metrics related to lifestyle risk (i.e. levels of physical activity, diet, BMI, smoking, drinking and other drug use, blood pressure, and blood glucose levels) are regularly monitored. Any abnormal results should trigger referral to specialists.
- Prescriptions of psychotropic medications should be carefully rationalised and monitored. Specialist medication review should be sought where appropriate.
- Specifically in relation to cardiovascular risk in people with congenital heart disease, the QLD Office of the Public Advocate (QLD 09-14) notes: *“Even those people whose heart defects were corrected as children should have access to specialist cardiologist treatment. Regular medication reviews are also essential, particularly when being administered psychotropic medications given that this can also be a risk factor for cardiovascular disease.”*
- The NSW Ombudsman (NSW 12-13 & 14-17) notes that people should have access to healthy support both within and outside of their care environments. This includes service organisations developing internal programs focused on exercise and healthy eating and so forth, as well as linkage to mainstream supports. The *Get Healthy Information and Coaching Service* is one such mainstream service available in NSW (see <http://www.gethealthynsw.com.au>), although additional work is needed to ensure such population level health strategies are made accessible to people with disability.

Resources to support practice improvement

Below we highlight a subset of resources that may support practice improvement around topical areas identified in the scoping review. This list is not exhaustive.



Aspiration and respiratory infection

A number of valuable resources have been compiled to decrease risks associated with aspirations and respiratory infections, for example:

The ID Health Network has produced seven short videos about health and people with intellectual disability: one is for clinicians and support staff about common respiratory concerns, including aspiration pneumonia; another deals with mental health issues in people with intellectual disability, including challenging behaviour (see NSW 12-13)

Easyhealth.org.uk has a number of accessible resources related to respiratory risks including the video, "Cold or Flu" <http://www.easyhealth.org.uk/content/cold-or-flu>

Massachusetts DDS, have produced a Quality and Risk Management Brief for Dysphagia, Aspiration, and Choking

https://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/documents/QINA_aspiration_final2.pdf



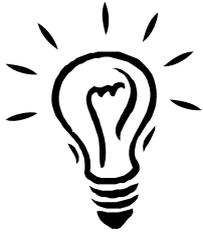
Choking

Resources have been compiled to decrease risks associated with choking. These include:

An audit tool developed by FACS in NSW to review the quality of mealtime plans and related support across ADHC accommodation services in relation to identifying and managing choking and other risks to residents (see NSW 12-13)

The NSW Ombudsman developed a factsheet to raise awareness of the risks that many people with disability face that make them highly susceptible to death from respiratory diseases and from choking on food. It is titled *Preventing deaths of people with disabilities in care: Breathing, swallowing and choking risks*, and can be downloaded via this link:

<https://www.ombo.nsw.gov.au/news-and-publications/publications/factsheets/community-and-disability-services/preventing-deaths-of-people-with-disabilities-in-care-breathing,-swallowing-and-choking-risk>



Epilepsy

A number of valuable resources and seizure tracking devices have been developed, including:

Evidence-based checklists for the risks of SUDEP (i.e. Rohit Shankar et al. *“Sudden Unexpected death in epilepsy (SUDEP): Development of a safety checklist”* (2013) 22 (10), Seizure, 812)

A Marriot, S Turner et.al., *Making Reasonable Adjustments to epilepsy services for people with learning disabilities* (Public Health England, 2014) available at www.improvinghealthandlives.org.uk/gsf.php5?f=313318&fv=20779

National Institute for Health and Care Excellence (NICE) *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care* (CG137. London, NICE, 2012).

Robertson and colleagues’ review of service user response to epilepsy management for cohorts with intellectual disability provides a useful international snapshot of tools and initiatives currently being implemented Robertson, J., Baines, S., Emerson, E., & Hatton, C. (2017). Service responses to people with intellectual disabilities and epilepsy: a systematic review. *Journal of Applied Research in Intellectual Disabilities*, 30(1), 1-32)



Lifestyle risks

Many resources have been developed for people with disability to reduce lifestyle related risks. These include:

The Department of Developmental Disability Neuropsychiatry (3DN) has developed a suite of lifestyle related resources to support people with intellectual disability. These include podcasts, cardiometabolic monitoring frameworks (youth and adult versions are available) and easy read and other fact sheets. Resources can be accessed here: <https://3dn.unsw.edu.au/positive-cardiometabolic-health-ID>

3DN has also developed on-line training modules for health, allied health and disability staff to support them to reduce lifestyle risks in populations with intellectual disability. Modules can be accessed here: <http://www.idhealtheducation.edu.au/>

ADHC, NSW physical activity checklist (in health care policy and procedures)

NSW Ombudsman factsheet on *Smoking, obesity and other lifestyle risks*



Supporting people with disabilities who are dying

A number of valuable resources have been developed to support end of life decision making for people disability. These include:

The Talking End of Life project (TEL): This website resource educates disability support professionals how to teach people with intellectual disability about end of life. It may also be helpful for families, health professionals, and educators. TEL comprises 12 modules. Modules include activities, case studies, videos, resources and links to the research. TEL also offers a set of additional website resources. <https://www.caresearch.com.au/TEL/>

Videos from the “**Dying to Talk**” research project give extra information (Wiese, M. Y., Stancliffe, R. J., Wagstaff, S., Tieman, J., Jeltos, G., & Clayton, J. (2018). TEL Talking End of Life [website]. <https://www.caresearch.com.au/TEL>

Scope (2007). **Supporting people with disabilities coping with grief and loss: an easy-to-read booklet.** This booklet was developed in Victoria, Australia. It can be freely downloaded from: <http://www.easyhealth.org.uk/sites/default/files/SUPPORTING%20PEOPLE%20WITH%20DISABILITIES%20COPING%20WITH%20GRIEF%20AND%20LOSS.pdf>

Tuffrey-Wijne, I. (2017). **Palliative care and intellectual disabilities.** University of Hertfordshire. <http://www.intellectualdisability.info/physical-health/articles/cancer,-palliative-care-and-intellectual-disabilities>

The Robert Wood Johnson Medical School has developed a list of **resources to support people with intellectual and developmental disabilities and their caregivers cope with grief, death and dying.** It can be accessed here: http://rwjms.rutgers.edu/departments_institutes/boggscenter/documents/EndofLifeResources12013.pdf

The Vanderbilt Kennedy Center has compiled a brochure to educate caregivers about how to **support a person with intellectual disability who is grieving** (not palliative care specific). See: <https://vkc.mc.vanderbilt.edu/assets/files/tipsheets/copinglosstips.pdf>

Books Beyond Words (“Am I going to die” and “When someone dies” and “When dad died” and mum died”— now available online <https://www.booksbeyondwords.co.uk/>)