

# Considering health, pain and communication in Positive Behaviour Support

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# Learning Outcomes from today:

1. Understand the current research
  - Health needs
  - Intersection of Health, Well-being and Behaviour.
2. Keeping a respectful, balanced approach
3. Gain awareness of tools for assessment.
4. Explore strategies you may include during planning
  - including how the BSP-QEII can inform our practice
5. Be familiar with resources to support implementation.

We'll also map our learning to the Convention on the Rights of People with Disability and the PBS Capability Framework.

You're not you when you're feeling...



# You're not you when you're feeling...

|                         |                         |                  |                 |
|-------------------------|-------------------------|------------------|-----------------|
| Hungry                  | Bloated                 | Tired            | Achy            |
| Thirsty                 | Missed your medication  | Giving up coffee | Your knee hurts |
| Dealing with a migraine | Sore                    | Stomachache      | Exhausted       |
| Constipated             | Heartburn is playing up | Toothache        | Yuck            |

# What the research tells us



**Simply having a cold** is associated with reduced alertness and slower movement.

We are also slower to take on new information and to remember things.

Smith, A.P. (2012). Effects of the common cold on mood, psychomotor performance, the encoding of new information, speed of working memory and semantic processing. [Brain, Behavior, and Immunity](https://doi.org/10.1016/j.bbi.2012.06.012). Accessed on November 4, 2020 at <https://doi.org/10.1016/j.bbi.2012.06.012>

# Current Research – Health needs

"People with intellectual or cognitive disability often have more complex health needs and a higher mortality rate than the general population."

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 systemic advocacy report. The State of Queensland (Department of Justice and Attorney-General)

**42% of adults** with disability rate their health as fair or poor.

Compared to 7% of adults without disability.

accessed at: <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/health/health-status>

# Current Research – Specific risks

People with disability, particularly an intellectual disability, are more likely to experience:

- Dental problems
- Epilepsy
- Chronic constipation
- Respiratory disease
- Gastro-oesophageal reflux disorder (GORD)

# Concurrent Considerations – Mental health

There is a high prevalence of mental health problems for people with disability. These can co-occur with challenging behaviour , however a clear relationship between the two is not clear.

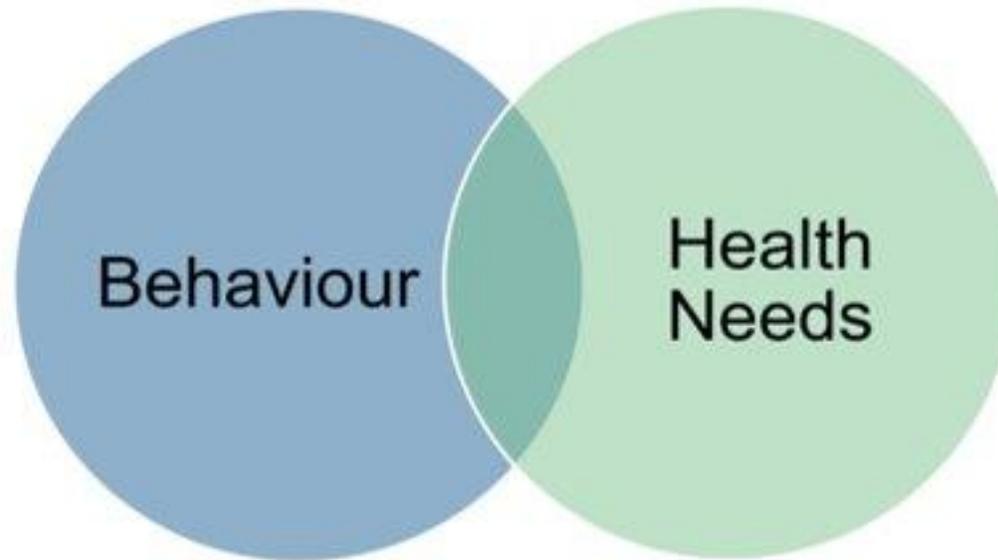
Bowring, D.L., Painter, J. and Hastings, R.P. (2019). Prevalence of Challenging Behavior in Adults with Intellectual Disabilities, Correlates, and Association with Mental Health. *Current Developmental Disorders Reports* 6 (p.173–181). [doi.org/10.1007/s40474-019-00175-9](https://doi.org/10.1007/s40474-019-00175-9)

# Concurrent Considerations - Trauma

**“The possibility of trauma in the lives of all clients/patients/consumers is a central organising principle of trauma-informed care, practice and service provision. This is irrespective of the service provided, and of whether experience of trauma is known to exist in individual cases”**

(ASCA, 2012, p. 88, cited in [Taking Time Literature Review \(berrystreet.org.au\)](http://berrystreet.org.au)).

# Intersection of physical health and behaviour



“Although behavioural change has been well documented as the first symptom of many serious health problems this can be overlooked”. (Evenhuis, 1997)



## Meet 'Lenny'

...a developing health problem might be viewed as just “being difficult.”

*He's up at the toilet ... I believe that it's a boredom thing, not so much boredom because he does a lot of things but coupled with the short-term memory he forgets.*

Bowers B, Webber R, Bigby C. Health issues of older people with intellectual disability in group homes(†) *Journal of Intellectual & Developmental Disability*. 2014;39(3):261-269. DOI: 10.3109/13668250.2014.936083. Accessed at: <http://europepmc.org/article/PMC/4348046>

Photo by [Adam Nieścioruk](#) on [Unsplash](#)

# Meet 'Robbie'



...a developing health problem might be viewed as just “typical behaviour for that person”

*Robbie hit out this week at staff, and last week as well.*

*When younger, Robbie had medication to prevent self harm and hitting out at others. The medication was stopped last year and things have been going really well, till now. We think it is just the same thing again.*

- Anecdotal report

Photo by [Adam Nieścioruk](#) on [Unsplash](#)

# Diagnostic Overshadowing

Diagnostic overshadowing occurs when a health professional makes the assumption that the behaviour of a person with learning disabilities is part of their disability without exploring other factors such as biological determinants.

Royal College of Nursing (2018) All you see isn't all there is: Looking beyond learning disability. Bulletin. Sourced at <https://www.rcn.org.uk/magazines/bulletin/2018/may/overshadowing>

# Tony Vardaro – Social Worker and Disability Health Network member.



# Tools for Assessment

## General

- All functional assessments include a review of the person's health.
- Is there a health plan?
- For adults – [Comprehensive health assessment program\(CHAP\)](#)
- Other health records?
- Is the person currently facing a significant health issue? What is the progress on this being attended to?
- What is the person's health literacy – their understanding of the health issues they may be dealing with or awareness of healthy lifestyle choices?

# (Some) Tools for assessment\*

Paediatric Pain  
Profile

Link:

<http://www.ppprofile.org.uk/>

Abbey Pain Scale

Link:

[https://apsoc.org.au/PDF/Publications/Abbey\\_Pain\\_Scale.pdf](https://apsoc.org.au/PDF/Publications/Abbey_Pain_Scale.pdf)

Intelligent Pain  
Assessment Tool |  
PainChek

DisDAT

Link: St Oswald's  
Hospice | Distress  
and Discomfort  
Assessment Tool  
(DisDAT)  
(stoswaldsuk.org)

## Distress and Discomfort



v21

### Assessment Tool

Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

#### COMMUNICATION LEVEL \*

|  |  |         |
|--|--|---------|
| This individual is unable to show likes or dislikes                                      |  | Level 0 |
| This individual is able to show that they like or don't like something                   |  | Level 1 |
| This individual is able to show that they want more, or have had enough of something     |  | Level 2 |
| This individual is able to show anticipation for their like or dislike of something      |  | Level 3 |
| This individual is able to communicate detail, qualify, specify and/or indicate opinions |  | Level 4 |

\* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association).

#### FACIAL SIGNS

##### Appearance

| What to do   | Appearance when content   |          |       |       | Appearance when distressed |          |       |       |
|--|---------------------------|----------|-------|-------|----------------------------|----------|-------|-------|
| <i>Ring</i> the words that best fit the facial appearance. Add your words if you want. | Passive                   | Laugh    | Smile | Frown | Passive                    | Laugh    | Smile | Frown |
|  | Grimace                   | Startled |       |       | Grimace                    | Startled |       |       |
|  | <b>In your own words:</b> |          |       |       | <b>In your own words:</b>  |          |       |       |

# Specific Assessment Considerations

## Where there is chemical restraint

PRN (as needed medication),

- Does the checklist to provide PRN overlap with observations of physical discomfort for the participant? How is the person's physical discomfort addressed?

## Side effects

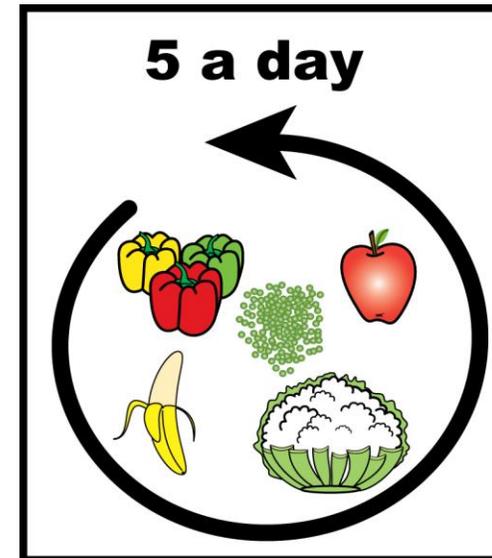
- Are these related to the health issues the person is experiencing?
- Consult with pharmacists regarding side effects.

# Planning guided by the BSP –QEII (extract)

|   | <b>Quality components of behaviour support plans</b>                                | <b>Evaluation guidelines and examples</b>  |
|---|---|--|
| 5 | Environmental supports that addresses the triggers and setting events               | <p>What changes need to be made to address the triggers and setting events (eg. system, communication, materials, interactions etc).</p> <p>Other factors may also need to be considered. - Health, choice, routine, engagement.</p> |
| 6 | Replacement behaviour that meets the same function as behaviour of concern          | Must specify replacement behaviour(s) that serve the same function as the behaviour of concern and must be easily performed.   |
| 7 | What strategies, tools or materials will be used to teach the replacement behaviour | Teaching strategies including at least one detail about how this will be done (eg. Materials, strategy, skill steps are described).  |

# Implementation - Communication needs

[AAC - Introduction to Augmentative and Alternative Communication - YouTube](#)



# Implementation - Communication needs

**WidgitHealth** Easy read and communication support for healthcare and medical professionals

About Widgit Health Products Downloads News & Projects Contact Us

**Patient Easy Read Symbol Sheets**  
My Health | A&E and Hospital | Blood pressure | Diabetes | Eyes | Health Living | Kidneys | Operations | Skin | Teeth | Tests

**My Health**

- My Medication Review**  
Key symbols

**A&E and Hospital**

- How to call an ambulance**  
Full symbols
- A&E communication passport**  
Key symbols
- Going to hospital**  
Full symbols

**For professionals**  
A collection of free PDF's for patients using Widgit Symbols.  
To find out more about a resource, click on the information icon next to the PDF.  
[More materials available](#)

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Health Check

Page 1 of 3

**Health Check**

Your health team will invite you to go to a health check.

They will send you a letter.

The letter will tell you the appointment time.

Your health check will be at your GP practice.

Visual sequence icons: 1. Two people with a plus sign. 2. A hand pointing to a document. 3. A person entering a room. 4. A document with a plus sign and checkmark. 5. Two people with a plus sign. 6. A red envelope. 7. A white envelope with a red stamp. 8. A white envelope with a red stamp. 9. Two people talking. 10. A document with a plus sign and checkmark. 11. A clock. 12. A document with a plus sign and checkmark. 13. A person entering a room. 14. A house with a plus sign and checkmark.

# Overcoming Barriers - access

## Getting there

- extending appointment times ; calendars; drive-by to prepare to go somewhere new

## Successful appointments

- support providers with strategies around behavioural support planning for the best outcome, waiting and/or modifying attendance; provide brief behavioural information if needed.
- supporting the presence of an advocate or someone the person trusts at appointments;

## Accessible Information

- provide written information in an accessible format
- using visual aids when explaining procedures or results

# Implementation – health literacy

**A small selection of resources for the people you work with:**

Health education for teenagers and adults from Centre for Developmental Disability Health Victoria, Monash University

<https://www.healthyactivelife.org/>

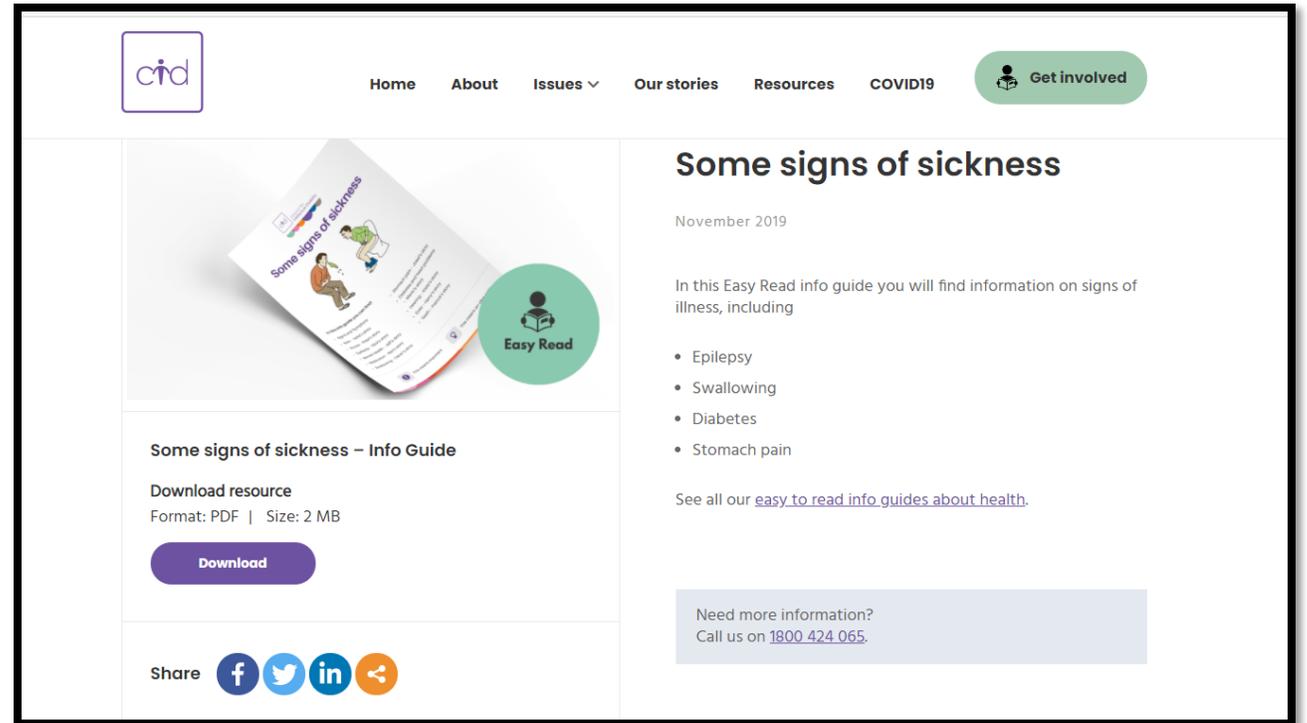
[Your Dental Health - Inclusion Melbourne](#)

[What Is Diabetes - Queensland Centre for Intellectual and Developmental Disability - University of Queensland \(uq.edu.au\)](#)



# Implementation – accessible information about health

## Easy Read Health Guides from the Council for Intellectual Disability [CID]

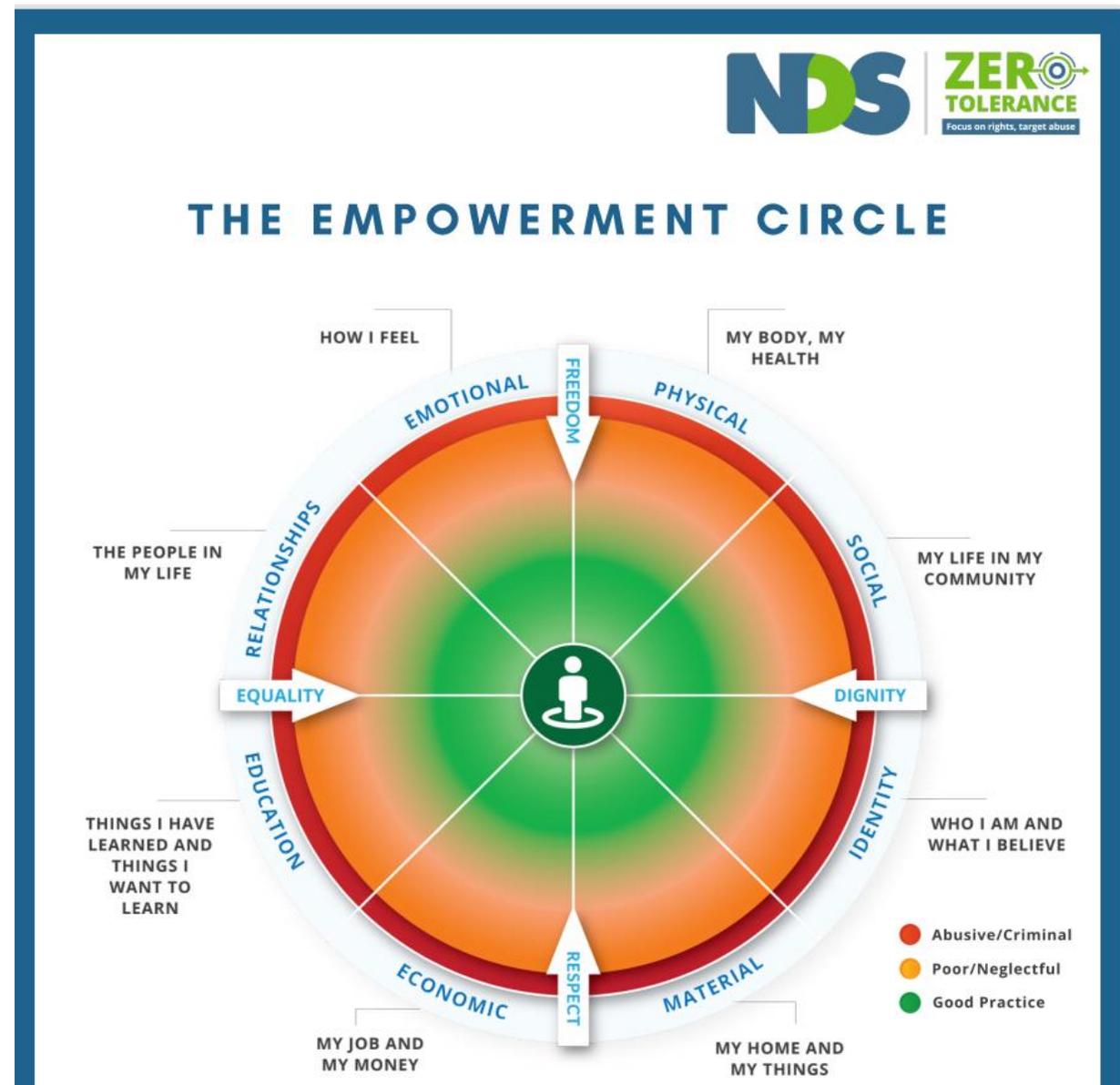


The screenshot displays the CID website interface. At the top left is the CID logo. The navigation menu includes Home, About, Issues (with a dropdown arrow), Our stories, Resources, COVID19, and a green 'Get involved' button with a person icon. The main content area features a large image of a booklet titled 'Some signs of sickness' with an 'Easy Read' icon. Below the image, the text reads 'Some signs of sickness – Info Guide' and 'Download resource' with 'Format: PDF | Size: 2 MB' and a purple 'Download' button. Social sharing icons for Facebook, Twitter, LinkedIn, and a general share icon are present. On the right side, the article title 'Some signs of sickness' is followed by the date 'November 2019' and a paragraph: 'In this Easy Read info guide you will find information on signs of illness, including'. A bulleted list follows: 'Epilepsy', 'Swallowing', 'Diabetes', and 'Stomach pain'. Below the list is a link: 'See all our [easy to read info guides about health](#).' At the bottom right, a grey box contains the text: 'Need more information? Call us on [1800 424 065](tel:1800424065).'

# Quality of Life and good practice

The Empowerment Circle builds on the work of Robert Schalock Quality of Life (QOL) domains and introduces additional life areas.

[Link to Empowerment Circle WORD 42KB \(nds.org.au\)](#)



# Know it Works - Quality of Life\*

## KINDL

A generic Health – Related QOL assessment for children and adolescents.

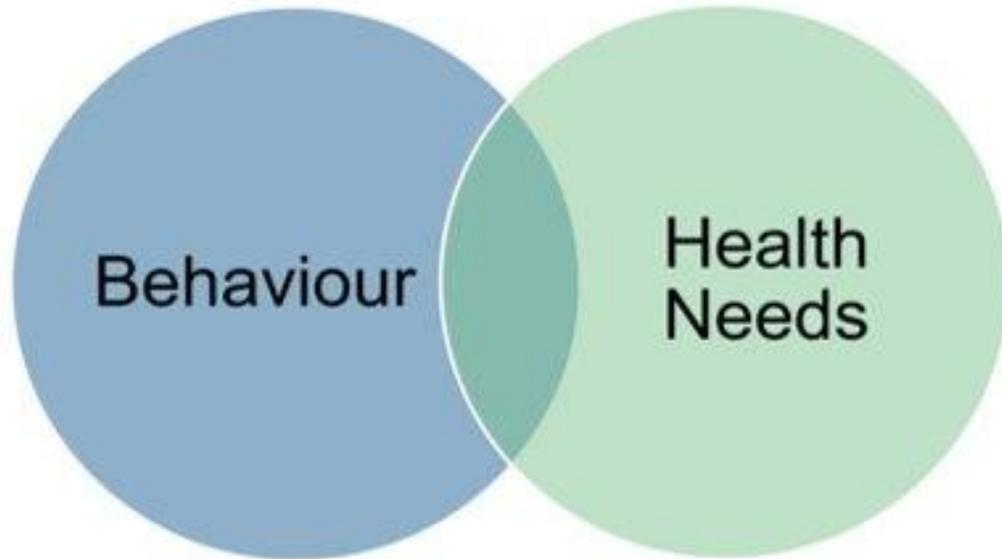
[Questionnaires - kindl.org](http://kindl.org)

## I-CAN

A supports needs assessment (training and certification required)

<https://cgs.org.au/i-can/>

# My role is...my role isn't...



“The disability services sector and disability professionals represent critical players in access to health care and continuity of health care for people with disability.”

- Professor Julian Trollor, Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, page 46. Accessed on 15/12/2020 at [STAT.0049.0001.0001.pdf](https://www.royalcommission.gov.au/STAT.0049.0001.0001.pdf) ([royalcommission.gov.au](https://www.royalcommission.gov.au))



Re-visting 'Lenny'

'Lenny' was supported him to go to a urologist.

Bowers B, Webber R, Bigby C. Health issues of older people with intellectual disability in group homes(†) *Journal of Intellectual & Developmental Disability*. 2014;39(3):261-269. DOI: 10.3109/13668250.2014.936083. Accessed at: <http://europepmc.org/article/PMC/4348046>

Photo by [Adam Nieścioruk](#) on [Unsplash](#)

# Re-visiting 'Robbie'



Robbie was supported to

- *Keep using the communication board*
- *A page was added about pain and discomfort*
- *A social story about being active and healthy was shared with Robbie regularly*

Robbie's team was supported to

- *Improve record keeping*
- *Be able to identify when Robbie's health needed to be reviewed*
- *How to share the communication resources*

Photo by [Adam Nieścioruk](#) on [Unsplash](#)

# Mapping to the Convention on the Rights of People with Disability

**Right to health** - People with disability have the right to the enjoyment of the highest attainable standard of health without discrimination. (Article 25: Health)

**Right to accessible information** - People with disability have the right to express themselves, including the freedom to give and receive information and ideas through all forms of communication, including through accessible formats and technologies...” (Article 21: Accessibility)

**Reducing and eliminating the use of restrictive practices**  
(Article 16: Freedom from exploitation, violence and abuse)

# Mapping to the PBS Capability Framework

## 1. Interim Response

BSP's - identify any existing data that might provide insight into the situation

Providers - Provide support for immediate review by a medical professional if required

## 2. Functional Assessment

BSP's - Understand the importance of obtaining baseline measures (QOL); identify antecedents of the behaviours of concern; consider physical or mental health problems, including the effect of medications and sleep.

Providers – Arrange medical reviews as required

**Always discuss your practice with your supervisor to ensure best practice and meets standards.**

“The inability to communicate pain verbally can be stressful and frightening for any individual”

Johnson, E, Bornman, J. and Tönsing, K.M.(2016). An exploration of pain-related vocabulary: implications for AAC use with children. Journal of Augmentative and Alternative Communication Volume 32,4 (p249-260)

# Meet 'Kim' and 'Penny', actors from the films - Recognising Restrictive Practices



# Resources for considering health, pain and communication in PBS

## Zero Tolerance

Zero Tolerance is an initiative led by NDS in partnership with the disability sector. Built around a national evidence-based framework, **Zero Tolerance is a way for organisations to understand actions they can do to prevent and respond to abuse, neglect and violence of people with disability.** Resources include Recognising Restrictive Practices and Trauma Informed Support can be found here: [Zero Tolerance - National Disability Services \(nds.org.au\)](https://www.nds.org.au)

## Health education

- For teenagers and adults <https://www.healthyactivelife.org/> (Centre for Developmental Disability)
- For practitioners and supporters [Healthcare & People with Intellectual Disability Course \(futurelearn.com\)](https://www.futurelearn.com/courses/healthcare-and-people-with-intellectual-disability)

## Selection of Accessible Information

- [What Is Diabetes - Queensland Centre for Intellectual and Developmental Disability - University of Queensland \(uq.edu.au\)](https://www.uq.edu.au/centre-for-intellectual-and-developmental-disability/what-is-diabetes)
- [Your Dental Health - Inclusion Melbourne](https://www.inclusionmelbourne.org.au/your-dental-health)
- [Health Archives | Council for Intellectual Disability \(cid.org.au\)](https://www.cid.org.au/health-archives)
- <https://widgit-health.com/>

## Pain (See slide 11)

Pain Australia Clinics, research and resources: <https://www.painaustralia.org.au/>

# Resources for considering health, pain and communication in PBS

## Centre for Disability Research

- Inclusive research paper: [Being and Keeping Healthy.docx \(cds.org.au\)](#)

## Centre for Developmental Disability Health – GP education

Dr Paul Nguyen, General Practitioner and Medical Educator: [Presentation - ACT Senior Practitioner Seminar Series](#)

## NDIS Quality and Safeguards Commission - various

- [NDIS Worker Orientation Modules](#)
- [Compendium of Resources for Positive Behaviour Support | NDIS Quality and Safeguards Commission \(ndiscommission.gov.au\)](#)  
(tools shared in the Compendium are noted with a asterisk\* in previous slides)
- [Practice Alerts - Resources | NDIS Quality and Safeguards Commission \(ndiscommission.gov.au\)](#)

## Disability and health video - moving away from the medical model of disability

[Tony Vardaro – YouTube](#) – Department of Health, Western Australia (2015)

# References

Adults Surviving Child Abuse (ASCA, 2012). Practice guidelines for treatment of complex trauma and trauma informed care and service delivery. Kirribilli, Australia: Adults Surviving Child Abuse. p. 88, cited in [Taking Time Literature Review \(berrystreet.org.au\)](http://berrystreet.org.au).

[Australian Human Rights Commission\(2020\) Guidelines on the rights of people with disability in health and disability care during COVID-19](https://humanrights.gov.au/our-work/disability-rights/publications/guidelines-rights-people-disability-health-and-disability). Retrieved from <https://humanrights.gov.au/our-work/disability-rights/publications/guidelines-rights-people-disability-health-and-disability>

Australian Institute of Health and Welfare. (2020). People with disability in Australia. Retrieved from <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

Bauer A, Taggart L, Rasmussen J, Hatton C, Owen L, Knapp M. (2019) Access to health care for older people with intellectual disability: a modelling study to explore the cost-effectiveness of health checks. BMC Public Health. Jun;19(1) 706. doi:10.1186/s12889-019-6912-0. PMID: 31174506; PMCID: PMC6556058.

Bowring, D.L., Painter, J. and Hastings, R.P. (2019). Prevalence of Challenging Behavior in Adults with Intellectual Disabilities, Correlates, and Association with Mental Health. Current Developmental Disorders Reports 6 (p.173–181). doi.org/10.1007/s40474-019-00175-9

Disability Services Commissioner (2019) A review of disability service provision to people who have died 2018–19. (Accessed on 4/11/2020 at [https://www.odsc.vic.gov.au/wp-content/uploads/02\\_DSC-2019-DeathR-4-October-2019.pdf](https://www.odsc.vic.gov.au/wp-content/uploads/02_DSC-2019-DeathR-4-October-2019.pdf) )

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Hunt, A., Goldman, A., Seers, K., Crichton, N., Mastroyannopoulou, K., Moffat, V., ... , & Brady, M. (2004). Clinical validation of the paediatric pain profile. *Developmental Medicine and Child Neurology*, 46, 9-18. doi: 10.1017/S0012162204000039

Johnson, E, Bornman, J. and Tönsing, K.M.(2016). An exploration of pain-related vocabulary: implications for AAC use with children. *Journal of Augmentative and Alternative Communication* Volume 32,4 (p249-260)

Trollor, J. (2020) Statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, p46. Accessed on 15/12/2020 at [STAT.0049.0001.0001.pdf \(royalcommission.gov.au\)](https://www.royalcommission.gov.au/STAT.0049.0001.0001.pdf)

Webber, L.S., Major, K., Condello, C., & Hancox, K. (2017). [Providing positive behaviour support to improve a client's quality of life](#), *Learning Disability Practice*, 20, 4, 36-41 [cited in Victoria Government (2019). Recognising and reducing mechanical restraint: Practice Guide <https://providers.dhhs.vic.gov.au/sites/default/files/2019-07/mechanical-restraint-practice-guide.docx>]

Thank you for watching this webinar.

Wishing you good health and a productive week.

Sarah Nicoll

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NDS is pleased to be able to provide the Behaviour Support Practitioner Workshops as part of a two-year grant from the **NDIS Quality and Safeguards Commission**, for free to the sector.