



Health Matters

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Good health matters to us all. Feeling unwell or in discomfort or pain focuses us inwards and reduces our ability to engage with and enjoy the world around us. Achieving and maintaining optimal health and function is therefore an important foundation for a good life.

This paper highlights the role disability support practitioners and health professionals can play in monitoring the health of, and providing timely and appropriate healthcare to, people with intellectual disability. The paper follows a workshop run by ASID in July 2017 which Professor Nick Lennox and I had the privilege and pleasure of discussing how best to improve the health of people with intellectual disability with a room full of committed and thoughtful disability and health practitioners.

The focus of this particular paper focuses on the health of and healthcare for those who do not use speech or other formal systems to communicate.

Health inequity

People with intellectual disability have poor health when compared to the general population and have unique health vulnerabilities throughout their lives. Many of these health inequities are not directly related to the disability or its cause, but rather are the result of social and economic disadvantage (Kavanagh et al 2012, Emerson et al 2011). The consequent health outcomes are manifest in the increased morbidity and rates of premature death among people with intellectual and associated developmental disabilities (Troller et al 2017, Kavanagh et al 2012, Department of Health 2011, Lennox & Taylor 2008,).

Complex health needs

For children with disabilities the complexity of their health and social issues and the importance and interplay of health and disability are generally understood and addressed through the provision of multidisciplinary healthcare. The allied health team and general practitioner work with appropriate medical generalist physicians (paediatricians) and specialists according to the person's particular health issues and needs (cardiologists, gastroenterologists, neurologists etc),

When children become adults, the expectation is that their health needs can be met by mainstream health services. In Australia there is, however, no specialist generalist physician equivalent to the paediatrician (until people reach old age and a geriatrician is involved) and so the responsibility for monitoring, assessing and coordinating healthcare rests with the general practitioner. Many general practitioners feel ill equipped and resourced for this task. Similarly, specialized allied health teams support children and their families through childhood, but when people reach adulthood such teams are scarce and those in community health feel inadequately trained and resourced to meet the needs of people with complex disabilities.

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Health, communication and behaviour

When people become unwell or are in pain, their focus turns inward and they are less able to engage with the external world. For those not able to express their symptoms with words, or other formal communication systems, a change in behaviour may be the only way they express their illness or discomfort. Their behaviour may communicate important information about their symptoms. Refusing food, for example, may be a sign that the person is experiencing nausea; someone refusing to walk may have a broken toe, arthritic hip or pressure injury; someone not wanting to join in previously enjoyed group activities may be depressed.

A change in behaviour therefore becomes important information for disability support practitioners to notice, monitor, document and share with health professionals. Likewise, health professionals can ask targeted questions about behaviours that may indicate particular symptoms in order to make a diagnosis. Information about common medication side effects should be provided by health professionals to disability support practitioners so they can recognise the ways these may be demonstrated through behaviour change. For example, a medication may cause dizziness and if this information is given to the disability support practitioner it alerts them to watch for the person being unsteady on their feet; a medication likely to cause a dry mouth can explain a person's increased interest in asking for drinks.

Symptoms of illness may also lead to confusion or fear in those not able to understand what is happening to them. This is also the case in the general population when someone, for instance, develops psychosis or a delirium. For people with cognitive impairments, the onset of distressing symptoms may likewise provoke an emotive as well as a physical response. For instance, someone with pain may feel confused and fearful and, not understanding the

need for health professionals to examine them, may lash out when approached.

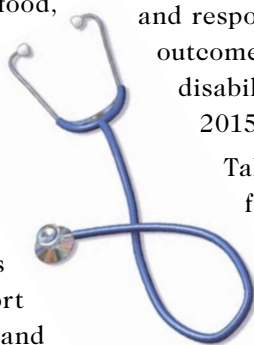
Healthcare is a partnership

The healthcare of many adults with intellectual disability depends on effective communication and collaboration between disability support practitioners, who have had little training in health, and medical practitioners who have had little training in disability. Gaps in knowledge, understanding and responsibility can contribute to the poor health outcomes currently experienced by people with disabilities (Troller 2017, Tracy & McDonald 2015).

Taking a proactive approach to healthcare is fundamentally important, particularly for people who have difficulty clearly describing their symptoms and concerns. A comprehensive annual health assessment by the GP, supported by a tool such as the CHAP (Lennox 2007) completed by someone who knows the person well, is an essential part of healthcare. The assessment is supported by Medicare and enables the GP to spend the time in the consultation ensuring a complete understanding of the person's health needs, including a focus on health promotion (including diet and exercise) and disease prevention (including immunisation and cancer screening). Hearing and vision assessment can also be undertaken in this appointment.

Working together, disability practitioners and health professionals can support people with intellectual disability to maintain good health. Just as disability practitioners learn about the person they support over time, so medical practitioners learn about the person's health needs and the way they look and behave when well and when unwell. The doctor builds the medical understanding and history over time, and learns how to best work meet the needs of the person. This is valuable knowledge and the benefit that comes with continuity

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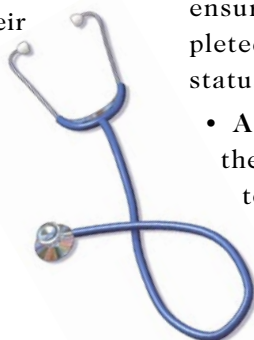


of care. It is therefore important to support and encourage the ongoing relationship between the person and their own individual GP whenever possible.

Better health means better lives

Disability support practitioners play a central role in ensuring people receive the healthcare they need to achieve and maintain optimal health and wellbeing.

Tips for support practitioners to improve healthcare for people with intellectual disability not able to describe their symptoms and manage their own healthcare. The tips below focus on the partnership between the disability support professional and the person's general practitioner (GP); most also apply to partnerships with other health professionals.



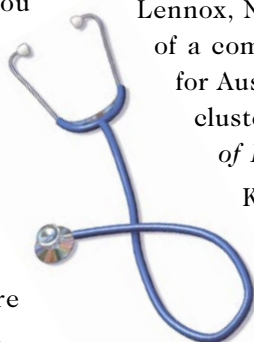
- **Be alert to change:** Changes in a person's behaviour, communication, sleeping or eating patterns, weight or mood could indicate physical or mental illness.
- **Record changes seen:** Charting behaviour, sleep, weight, mood, etc provides valuable clues to the person's health status.
- **If concerned act:** Don't be hesitant. If you think there is something wrong get it checked out. There is no harm done if there is nothing wrong – but there can be great harm done if physical or mental illness remains undetected.
- **Book a long appointment with the GP:** It usually takes more time for the doctor to work out what might be going on and making sure there is enough time reduces time pressure.
- **Support the person to tell their own story as much as is possible:** Be ready to model communication strategies and provide additional detail and information as required.

- **Accurate diagnosis depends on good information:** Ensure you have all the person's health information at the consultation, including the health file. Information about past physical or mental illness, the results of previous tests, health professionals involved (present and past), medications (both current and past), allergies and immunisations, previous surgery, family history may all be relevant. For the annual health assessment ensure the CHAP or a similar tool is completed to collect information about health status prior to the appointment.
 - **Ask questions:** If you don't understand then you can't help the person concerned to understand or convey the information accurately to other staff - so ask questions until you do. Ask for written information - doctors use electronic record systems and will print out a copy of the outcomes of the consultation if asked.
- **Ensure management strategies are implemented:** Ensure the diagnosis and management strategies are recorded in the file and that all staff know the outcome of the appointment and what they need to do - new medication, tests/ referrals arranged.
- **Effective management strategies depend on accurate diagnosis:** The doctor depends on you to monitor whether the treatment or other interventions strategies are effective. If not, let the doctor know. Different treatments may be more effective, or perhaps the diagnosis needs to be reviewed.
- **Arrange follow up:** It is very important for the doctor to review the person to make sure the interventions have achieved the expected result and that medication side effects are detected. Medications may need to be changed, new tests ordered, progress of symptoms and signs

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monitored. Follow up provides a 'feedback safety loop' to check the original diagnosis was correct and the management strategies appropriate and effective.

- **If the person remains unwell act:** Sometimes things go wrong. The diagnosis may be incorrect. Medications can have side effects. A new problem may arise. If you feel the person has not responded as expected, then take the person back to the health professional again and again until the problem is resolved.
- **If not satisfied complain:** Don't give up! If you feel the person you are supporting is not receiving the care they need let your line manager know. The Disability Services Commissioner, the Health Services Commissioner and the Mental Health Complaints Commissioner all investigate complaints in their particular jurisdictions. Complaints are an important mechanism to drive service improvement.
- **Ensure the person has an annual comprehensive assessment by their GP supported by a tool such as the CHAP.**



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In summary

The health and healthcare of people with intellectual disabilities can be greatly improved through an effective partnership between the disability practitioners and health professionals working with the person concerned. Respecting and valuing the contribution of all concerned establishes a solid foundation for this partnership.

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