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Byrne, J. H. , Lennox, N. G. , & Ware, R. S. (2016). **Systematic review and meta-analysis of primary healthcare interventions on health actions in people with intellectual disability.**

Journal of Intellectual & Developmental Disability, 41(1), 66-74. doi:10. 3109/13668250. 2015. 1105939

Background: People with intellectual disability have substantially more unidentified health needs than the general population. We systematically reviewed the effectiveness of primary healthcare interventions intended to increase health actions for people with intellectual disability. **Methods:** Electronic databases were searched on 16 September 2014. Randomised and non-randomised studies with a concurrent control group were identified. Study quality was assessed and, where possible, meta-analysis was undertaken. **Results:** Five studies (3 randomised controlled trials, 1 matched cohort study, and 1 cohort study) with a total of 1,570 participants were included. General practitioner-led health checks were the most effective intervention and resulted in significantly more clinical activities, such as vision testing (risk ratio [RR]=3. 3, 95% CI [2. 3, 4. 7]) and hepatitis B vaccinations (RR=2. 4, 95% CI [1. 7, 3. 4]). **Conclusions:** Health checks were the only intervention to significantly increase short-term health promotion and disease prevention activity. The long-term effect of any intervention remains unknown.

Cocks, E. , Thomson, A. , Thoresen, S. , Parsons, R. , & Rosenwax, L. (2017).

Factors that affect the perceived health of adults with intellectual disability: A Western Australian study.

Journal of Intellectual & Developmental Disability, 1-12. doi:10. 3109/13668250. 2017. 1310816

Background: Adults with intellectual disability (ID) experience poorer overall health than the wider population. Identification of personal, support service and lifestyle factors affecting health status will provide opportunities to improve health outcomes. **Methods:** The study was a cross-sectional survey of adults with ID. Interviews were conducted between January and July 2013. Univariate and multivariate analyses were performed using self- or proxy-reported general health as the dependent variable. **Results:** Not good health was independently associated with increasing age, financial hardship, smoking, and living in a home of their own. Physical exercise was inversely associated with not good health. **Conclusions:** Subjective health may be improved by attention to the factors identified in this study. This could include closer monitoring of the health of people with ID as they age and if they live in a home of their own. Similarly, targeted programs promoting physical activity and smoking reduction could improve general health for adults with ID.

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Hemsley, B. , McCarthy, S. , Adams, N. , Georgiou, A. , Hill, S. , & Balandin, S. (2017).

Legal, ethical, and rights issues in the adoption and use of the “My Health Record” by people with communication disability in Australia.

Journal of Intellectual & Developmental Disability, 1-9. doi:10. 3109/13668250. 2017. 1294249

Background: The aim of this review was to explore the legal, ethical, and rights issues surrounding use of the Australian My Health Record (MyHR) by people with communication disability. **Method:** We undertook a narrative review of the legislation and research affecting the implementation of MyHR in populations with communication disability. **Results:** Use of MyHR by people with communication disability will require careful consideration in relation to (a) capacity and consent; (b) roles of nominated or authorised representatives in the system; and (c) the way decisions are made in relation to the use of MyHR, including supported decision-making for people with intellectual disability. **Conclusion:** Legal and ethical issues in the use of MyHR by people with communication disability centre on legal rights and equal access. These issues must be addressed if people with communication disability are to have full access to their legal rights and access in exercising personal choice and control in the use of MyHR.

Hussain, R. , Janicki, M. P. , Knox, M. , Wark, S. , & Parmenter, T. (2017).

Perspectives about support challenges facing health workers assisting older adults with and without intellectual disability in rural versus urban settings in Australia.

Journal of Intellectual & Developmental Disability, 1-10. doi:10. 3109/13668250. 2017. 1326589

Aims: Life expectancy for both sexes in Australia exceeds 80 years, with individuals with intellectual disability also increasingly living into older age. This research aimed to comparatively examine perceptions of staff supporting either older adults or age peers with lifelong intellectual disability. **Methods:** This project asked 420 medical, health, and support workers about training adequacy, health services access, and trigger points for premature institutionalisation. This paper is based on a subsample of 196 respondents who provided quantitative and qualitative responses. **Results:** There was considerable variation in confidence in supporting ageing individuals, while only 23. 7% of doctors reported their training was adequate to support adults ageing with intellectual disability. A lack of services and poor carer health were identified as triggers for premature institutionalisation. **Conclusions:** The study revealed key differences in staff perceptions of support provision and training adequacy when comparing ageing individuals with intellectual disability to the general ageing population.

Milne, J. , Johnson, J. K. , Lord, B. , Ong, N. , Tomsic, G. , & Silove, N. (2016).

Assessing health needs of children with intellectual disabilities: a formative evaluation of a pilot service.

Research and Practice in Intellectual and Developmental Disabilities, 1-11. doi:10. 1080/23297018. 2016. 1168712

Background: Children and adolescents with intellectual disabilities commonly have unmet complex health needs. Their parents often experience barriers in locating and accessing services to assist in diagnosing and managing those needs. **Method:** In response to this service gap, a pilot Paediatric Assessment Clinic was established under the auspices of a large paediatric hospital, to offer a comprehensive disability health service for children aged 6 to 18 years with intellectual

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disabilities and complex health needs. A formative evaluation used observations and a survey of key stakeholders, including 13 parents of children with intellectual disabilities, 6 referring clinicians, and 6 specialists to whom cases were referred post-assessment to understand early outcomes of the pilot service. **Results:** Findings highlighted the benefits of a multidisciplinary, staged approach to health assessment, coupled with a thorough understanding of family, cultural, and psycho-social issues, in providing interdisciplinary and inter-agency service for children with intellectual disabilities. Coordinated management plans between the clinic and disability and specialist health service providers supported parents access to services. **Conclusion:** The evaluation demonstrated the importance of clinical pathways between primary and tertiary health services providers. While demonstrating the intensive resources and engagement processes required to provide an effective multidisciplinary assessment model of care, the evaluation identified limits of the assessment and referral model in ensuring access to needed services.

Newton, D. C. , & McGillivray, J. A. (2017).

Perspectives of carers of people with intellectual disability accessing general practice: “I’d travel to the ends of the earth for the right person”.

Journal of Intellectual & Developmental Disability, 1-9. doi:10. 3109/13668250. 2017. 1310821

Background: Informal carers often play an integral role in the lives of people with intellectual disability (ID) residing in the community. In this study, we explored the extent to which carers of people with ID believe that the health care needs of the person they care for are being accommodated by general practice. **Method:** Semi-structured interviews were conducted with 25 informal carers to people with ID living in Australia. **Results:** Carers of people with

ID report that they experience considerable barriers to accessing general practice care on behalf of the people they care for. **Conclusions:** Given the ever-increasing number of people with ID now living in the community and their vulnerability to health problems, it is imperative that future research focuses on the development of strategies to overcome the barriers identified in this study

Ong, N. , McCleod, E. , Nicholls, L. E. , Fairbairn, N. , Tomsic, G. , Lord, B. , & Eapen, V. (2017).

Attitudes of healthcare staff in the treatment of children and adolescents with intellectual disability: A brief report.

Journal of Intellectual & Developmental Disability, 42(3), 295-300. doi:10. 3109/13668250. 2016. 1236368

Background: Children with an intellectual disability (ID) have complex health needs that extend beyond the expected cognitive deficits, affecting a myriad of developmental domains. These children frequently receive inadequate health care such that their needs remain poorly managed. **Methods:** Staff from the Sydney Children’s Hospital Network (N=160) completed a survey on attitudes, experiences, and training satisfaction when working with patients with ID. The 48 question needs analysis survey was distributed electronically to staff from a variety of disciplines and experience levels. **Results:** Although staff considered themselves broadly competent in caring for children with ID, they were less confident in specific skills, such as managing associated challenging behaviours in the clinic. As confidence in skills such as these decreased, the desire for further training increased. **Conclusion:** This study emphasises the importance of providing accessible, high-quality professional development resources to further develop these skills.

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Webber, R. , Bowers, B. , & Bigby, C. (2016).
Confidence of group home staff in supporting the health needs of older residents with intellectual disability.

Journal of Intellectual & Developmental Disability, 41(2), 107-114. doi:10.3109/13668250.2015.1130218

Background: Increased life expectancy for people with intellectual disability is accompanied by increased age-related health concerns. People ageing with intellectual disability experience more health conditions and are relocated to aged care earlier than their age peers. **Method:** Group home staff were surveyed about their (a) training and confidence in 11 health conditions and 7 health procedures, and (b) attitude to relocating residents with health needs to aged care. **Results:** Staff training in each of 10 health conditions and 7 health procedures was positively associated with increased confidence in supporting residents with those health issues. Higher staff confidence in caring for residents with 9 conditions and requiring 4 procedures was negatively associated with a likelihood of recommending that a person with those health needs should relocate to aged care. **Conclusions:** Targeted training of staff in age-related health issues may contribute to better health care and delay residents relocating to aged care.

Weise, J. , Pollack, A. J. , Britt, H. , & Trollor, J. N. (2016).

Who provides primary health care for people with an intellectual disability: General practitioner and general practice characteristics from the BEACH dataset.

Journal of Intellectual & Developmental Disability, 1-6. doi:10.3109/13668250.2016.1250252

Background: People with an intellectual disability (ID) have complex healthcare needs yet experience barriers to participation in primary care. Further

research is required to examine if the characteristics of general practitioners (GPs) and their practices influence their delivery of care to people with ID. **Methods:** Data from the Bettering the Evaluation and Care of Health program was used to determine if there are significant differences in the ID-GP and Non ID-GP group. Analysis included characteristic-specific rates, chi-square, and odds ratios. **Results:** This study found that GPs who were Australian medical graduates, practising in rural areas, in accredited practices, and in some states of Australia were significantly more likely to be classified to the ID-GP than the Non ID-GP group. **Conclusions:** This research suggests that certain GP and practice characteristics may present barriers to primary care participation for people with ID and supports the need for a comprehensive national action framework. ●

