An innovative model of care for meeting the health and social needs of children and young people with intellectual disability

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**Introduction:** People with intellectual disability (ID) often face additional challenges in accessing health care compared with the general population. In 2012, a pilot multidisciplinary service for children and adolescents (6-18 years of age) with ID was set up by the New South Wales Department of Health in partnership with disability services.

**Description of practice change implemented:** Establishment of a multidisciplinary health team comprising medical, nursing and social work support in a disadvantaged area with a high population of refugees in Sydney.

**Aim and theory of change:** The aim of the pilot service was to test if a multidisciplinary service located in the community improves access to health services and improves the integration and coordination of health and disability services.

**Targeted population and stakeholders:** The target population is school-aged children and adolescents who have a diagnosis of ID and have complex health needs. Stakeholders include the children and their families, the health team staff, specialist and general practice providers, members of the disability and special education sectors, and key staff working for the Intellectual Disability Clinical Network (a government organisation).

**Timeline:** The initial funding was for 3 years commencing mid-2012. Further funding has been granted for the service to continue until 30th December 2019.

**Innovation, impact and outcomes:** A survey was completed in 2015 with 18 health practitioners, which included general practitioners, allied health professionals and case managers. Those who referred individuals to the service found that the service improved their knowledge of the health needs of children, enhanced hospital and community linkages and improved collaboration. The specialists who had patients referred to them also expressed satisfaction and valued receiving comprehensive information about clients. Other benefits reported included better discussion of management plans, collaboration between disciplines, and management of adolescents in transition from paediatric to adult care. A repeat survey done in 2018 with stakeholders confirmed the earlier findings. The major challenges reported lie in the realistic expectation of each other’s roles.

**Comments on sustainability:** This model of care has been working for the past 6 years and is likely to be enhanced with more such teams across the age range within the state.

**Comments on transferability:** This model of care can be replicated in other localities with changes in the processes used to suit population needs.
Discussion: The positive gains were achieved with a service model that involved collaboration between public-funded health and disability services. However, in 2017 the model of disability service provision changed to an insurance-based model of non-governmental organisations. This has impacted on the way the team functions and requires ongoing work.

Conclusions: A multidisciplinary health team for children and adolescents with ID enhances access and the provision of integrated care with disability services, schools and local health providers working together. It also enhances pathways for children to hospitals.

Lessons learned: An integrated multidisciplinary team with a flexible model of care is needed to manage the care of these complex patients and families with psychosocial vulnerabilities. The focus should be on both unmet health and social needs.

Keywords: intellectual disability; children; adolescents; multidisciplinary; interagency approach