



Letters to the Editor

6 March 2012

Dear Editor,

PUBLIC SERVICES FOR CHILDREN WITH SPECIAL NEEDS: DISCRIMINATION BY DIAGNOSIS

McDowell and O'Keefe's¹ timely viewpoint draws attention to some very important issues related to the long-awaited expansion of early intervention services by the Australian Federal Government. I agree that using diagnostic categories for funding eligibility has inadvertent (and hopefully unintended consequences) of excluding children who would also benefit from early intervention but do not have one of the selected diagnoses for inclusion in early intervention funding. I also agree that this may push clinicians into stretching the diagnostic truth or firm up an early diagnosis to help desperate families obtain necessary funding. Although Cerebral Palsy Alliance has been a strong advocate of early diagnosis of Cerebral Palsy (within the first weeks of life) rather than over an 18-month time frame, this has been done, not to enable inclusion into funding programs for Better Start but to allow earlier identification and inclusion in intervention services that will make a significant impact on the future development of these children. We also know that families are often seeking a diagnosis for their child's delayed development for many months going from one health professional to another. Furthermore, having a diagnosis (where possible) can be extremely helpful for evidence based decision making and prognostication. This can ultimately lead to better outcomes and potentially cost savings, which could be used to help others in need.

Cerebral Palsy Alliance is an advocate for the National Disability Insurance Scheme and supports the inclusion of those with moderate and severe disabilities within the eligibility criteria based on functional need and not on diagnosis-based access. Having the AMA behind this platform addresses some of the legal, moral and ethical dilemmas that the authors point on in their article.

Our plans for the cerebral palsy registers to collect and measure functional impairments through the CP Follow-Up Program^{2,3} (aimed at prevention of secondary complications of cerebral palsy) is one way of ensuring that assessments can be used for a broader functional profiling of patient need and therefore can be used for counting by politicians when deciding on allocations.

Professor Nadia Badawi
Macquarie Group Foundation Professor of Cerebral Palsy
CP Alliance
Notre Dame University, Sydney University
Sydney, Australia

References

- 1 McDowell M, O'Keefe M. Public services for children with special needs: discrimination by diagnosis? *J. Paediatr. Child Health* 2012; **48**: 2–5.

- 2 Häggglund G, Andersson S, Düppe H, Lauge-Pedersen H, Nordmark E, Westbom L. Prevention of hip dislocation in children with cerebral palsy. The first ten years experience of a population-based prevention programme. *Bone Joint Surg.* 2005; **87-B**: 95–101.
- 3 Häggglund G, Andersson S, Düppe H, Lauge-Pedersen H, Nordmark E, Westbom L. Prevention of severe contractures might replace multi-level surgery in CP. Results of a population based health care program and new techniques to reduce spasticity. *Pediatr. Orthop.* 2005; **14**: 268–72.

10 April 2012

Dear Editor,

Thank you for the opportunity to reply to Professor Nadia Badawi's letter. The primary purpose of our article,¹ to which she responded, was to generate discussion on what we see as an important issue of how public resources for children who have special needs may be distributed fairly and effectively.

Professor Badawi reiterates the importance of early identification of cerebral palsy (CP) and the benefit of early intervention. She further notes the challenge where diagnosis may take some time. We would suggest that the answer to this challenge is less about increasing capacity to make a categorical diagnosis (such as CP) in very early childhood, and more around provision of early intervention systems to respond to functional struggles in child development while the underlying diagnosis is being clarified.

We would argue that any system reliant on establishing a categorical diagnosis prior to services will influence the diagnostic process. Professor Badawi advocates a CP register to assist with longitudinal research informing treatment outcomes and cost savings. If some of those CP diagnoses are made 'in order to get services', in clinical cases where there continue to be diagnostic uncertainty, the set of data within this register will become more heterogeneous and less reliable. It is possible this has already occurred with autistic disorders.

We support the work of organisations, such as the CP alliance, that focus on a single diagnostic area of special need. As paediatricians in clinical practice, seeing the full range of referred children, we advocate for equity of care across the population. There may be opportunity as Professor Badawi points out for this to occur within the National Disability Insurance Scheme. We hope that our article, and the discussion it may provoke, will contribute to the considerations around how this scheme is most equitably managed.

Reference

- 1 McDowell M, O'Keefe M. Public services for children with special needs: discrimination by diagnosis. *J. Paed. Child Health* 2012; **48**: 2–5.

Dr Michael McDowell
Dr Mick O'Keefe
Child Development Network
South Brisbane, Queensland
Australia