

COMMENTARY

Could we care for Amillia in rural Australia?

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Submitted: 14 April 2007; **Resubmitted:** 15 August 2007; **Published:** 10 October 2007

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Rural and Remote Health 7: 768. (Online), 2007

Available from: <http://www.rrh.org.au>

ABSTRACT

Extremely premature and very low birth weight infants have multiple, costly and complex health and developmental issues. After the neonatal period, the best chance for these children to avoid extreme disability and dependence, and thereby reach their potential, is with timely and intensive early intervention by appropriate allied health services, such as speech, occupational and physiotherapy. However, currently in rural Australia, such children are further disadvantaged by their relative lack of access to appropriate types and levels of services, compared with their urban counterparts.

Key words: access, allied health services, low birth weight infants, premature infants.

One of the latest medical frontiers to be pushed back came with the recent news of discharge from hospital in the USA of baby Amillia Taylor. Amillia made it home after being born at less than 22 weeks of gestation. The popular press has reported this good news story widely, but there has been an over simplification of the fate of Amillia.

Extreme prematurity and very low birth weight (VLBW) infants have multiple complex issues. At 24 weeks, survival

rates are poor. The estimated costs of keeping a single child alive at that gestation to hospital discharge is approximately \$250 000¹. If these children survive to discharge, multiple other barriers confront them and their parents. The complications of prematurity are extensive, and include developmental delay, chronic lung disease, vision and hearing problems, heart disease and cerebral palsy. Are very premature babies being saved, at great expense, to live a life of extreme disability and dependence?



A Canadian study found that VLBW babies, who survived the 'neonatal storm', could have excellent outcomes². This study found that such children could achieve the same educational and vocational outcomes as normal birth weight children if they received intensive early intervention. Depending on the health system, this is a big 'if' and less optimistic outcomes have been reported in the US system³.

Early intervention broadly consists of two strategies: education and health. Key features of early intervention in health include speech, occupational and physiotherapy. In VLBW children and in children with disabilities, developmental milestones are delayed or not achieved without therapy input. Intervention needs to be timely, because delays in one area often result in delays across many areas. As one example, a child who is unable to hold its head up may be delayed in reaching and rolling, milestones that are essential in order to explore their environment and subsequently to purposely grasp objects that are in turn explored. The essence of such intervention is that it needs to be early and intensive.

The Canadian health system is known for its universal healthcare policies. A recent editorial⁴ notes that, apart from preventing complications in the first place, one way to maximize the potential of these children is by 'uniformly implementing post discharge health and psychosocial family interventions and monitoring'. How would the Australian health system meet the needs of baby Amillia in rural Australia?

Tamworth in north-west New South Wales (NSW), Australia is a large regional center with a township population of 35 000⁵. Armidale, 110km to the north, has a population of 20 000⁵. Based on the Commonwealth Department of Health and Aged Care measure of accessibility to services, both these regional centers have very good access to health services. The Accessibility/Remoteness Index of Australia (ARIA) arose to facilitate the tailoring of '...services to meet the needs of Australians living in regional Australia'⁶; p.3. Tamworth receives a rating 1.78⁶; Appendix F; p.78 meaning it is defined as 'highly accessible' and has 'relatively unrestricted

accessibility to a wide range of goods and services'⁶; Appendix A p. 22. Armidale is rated 2.12⁶; Appendix F; p.75, defined as 'accessible' with 'some restrictions to accessibility of some goods and services'.

In NSW, children with mild disability or isolated conditions amenable to allied health therapy are cared for under the umbrella of NSW Health and generally seen in community health clinics. Those with moderate or severe disability come under the umbrella of the Department of Ageing, Disability and Home Care (DADHC). However access to allied health for disadvantaged children in our region is not equitable, and rural children with disabilities are at a significant disadvantage, compared with their metropolitan counterparts.

Several years ago access to early intervention therapy was raised as a clinical governance issue in the northern sector of Hunter New England Area Health. Views from paediatricians, allied therapists, parents and teachers were sought to better understand the problem.

To cite but a few examples:

1. A toddler who required a cochlear implant, having never spoken a word in his life by age 18 months, could access speech therapy once every 6 months.
2. Children with moderate-severe disability were unable to access therapy through community health (because this manages children with mild disability only) and also unable to receive therapy through DADHC because of a lack of services and staff.
3. Children with significant speech deficits received group therapy as little as four times per year, prompting one mother to ask why the 'government has given up on children like (our daughter)'.
4. Experts in childhood early intervention expressed 'deep concerns about the lack of allied health therapists available for young children with disability in this area,' and that children may be deprived of their '...social, educational and moral rights'.



5. A therapist wrote that the system is ‘...hugely detrimental and discriminatory’.
6. A paediatrician wrote that, ‘... the way the system works at present is disadvantaging all children...and urgently needs to be addressed’.

There are more examples but they all highlight difficulties with access to early intervention. The issue is not with the quality of the therapists - many correspondents have nothing but praise for the healthcare workers - but is about access to and quantity of therapy.

The Area Health Service funded its own review of paediatric allied health services⁷ ‘in response to concerns raised by parents regarding the provision of therapy services to children with a disability in the New England region’. In this review, families identified difficulties in navigating the myriad of services, were confused about eligibility for services, experienced delays in accessing services, and experienced a lack of coordination between services. Significantly, seven families were identified as having recently left the region to improve their access to services.

This review also found that NSW Health had to provide a realistic allocation of hours for allied health services, and that DADHC needed to substantially increase resources.

The provision of adequate allied health services for disabled children has been raised through the clinical governance structure, with the Area Executive, through the relevant clinical streams and through local politicians, but there is no capacity to solve this problem, even at those levels.

There are several barriers to providing adequate allied health services in rural NSW. The first is the unnecessary and arbitrary division between degrees of disability. One paediatrician in north-west NSW has written that we now have, ‘...the absurd situation of trying to differentiate if a child belongs with DADHC or with health, based on a bureaucratic set of guidelines that are totally out of touch with reality’ (K Power, pers. comm., 2006). Because DADHC has minimal staff for a large number of children

(and adults) and in many areas no staff, children with the greatest need receive the least services. Allied health professionals provide therapy knowing that many others are missing out or receiving less than is reasonable. The division in services hinders the team approach so vital in early intervention, minimizes professional interaction and hinders continuing education. Collectively, these contribute to recruitment and retention problems⁷.

The second problem is the historical and ongoing under-resourcing of preventative programs, such as early intervention. The reality of this situation is best summarised by an allied health therapist who writes:

...the greatest sadness in all of this is what is experienced by families themselves....If we believe we are committed to the benefits of intervention how can we not work to improve access to therapy services for children with disabilities? Their needs are high and the cost of not providing adequate intervention is even higher. By not providing adequate services we deny these children of their basic right to have an improved quality of life, to enjoy good health, to gain the best mobility, to be able to communicate in their environment, to achieve their optimal learning potential and work towards contributing to society in a profound and inspiring way. We simply do not have the right to deny them this.

And so, back to Amillia. She has many struggles ahead of her. If lucky, she will have access to appropriate early intervention to maximize her chances to reach her potential, whatever that may be. If she were to be discharged to north-west NSW we know that she would be discharged to fail to reach her potential.

There is an ingrained flaw in the system that works against disabled children who live in rural areas. Doctors, allied health therapists, teachers and parents know what the problem is, but governments and health administrators lack the resolve to address it.



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