Submission

No 77

INQUIRY INTO CHILDREN AND YOUNG PEOPLE 9-14 YEARS IN NSW

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Legislative Council, Parliament of New South Wales

Inquiry the health of young children 9-14 years

Submission from

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Signed...............................

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This submission was endorsed by the AFRM Council and its Policy and Advocacy Committee.

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Legislative Committee, Parliament of New South Wales

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Outline of key issues in the context of Paediatric Rehabilitation

We wish to raise the following key issues. Should the Committee have particular interest in the areas identified we would be glad to provide further evidence and documentation.

Key issues for children 9-14 years which have particular impact on children with disabilities

1. **Growth and Puberty**
2. **Developing independence**
3. **Education – transition to high school**
4. **Physical activity**
5. **Sexuality and psychological development**
6. **Respite**
7. **Access to health services**

1. Growth and Puberty – this is a period of rapid physical growth and significant body changes

While children of all age groups are continually experiencing physical growth, during this period individual awareness of their growth, and that of their peers, is heightened. Puberty is commencing earlier for children compared to previous generations bringing with it significant psychological and social challenges as well as physical changes. During periods of rapid growth (puberty) those children with physical disabilities may increase their muscle and bony deformities.

Children with chronic illness and/or disability may face additional issues and problems due to:

- Frequent hospitalisation
- Delayed puberty due to medical conditions and treatment regimes
- Precocious puberty due to brain injury.
- Impaired or compromised functioning in the areas of cognition including: memory, attention, concentration, planning and organisation, reasoning and logic which impact of the ability to understand pubertal changes and cope with their impact.
- Disabilities where physical impairments exist i.e. cerebral palsy, neuromuscular conditions and spina bifida. For these children and young people rapid growth may result in a mismatch between a child's size and their strength. They may become permanent wheelchair users at this time creating new adjustment issues for them, their peer group and their families. For children and young people with cerebral palsy this move to <u>permanent</u> wheelchair use may happen sooner if they are unable to increase or maintain their muscle strength. The significant lack of community physical therapy programmes in to assist in maintaining or increasing strength in the cerebral palsy group reduces the potential for these children to maintain standing and walking abilities.
- Orthopaedic surgery for conditions such as scoliosis or single event multilevel orthopaedic surgery is usually undertaken at this developmental stage to achieve optimal results for the child. The limited physical therapy available in the community may impede the child in maximising the outcomes of these procedures.

2. Developing independence

There are a range of activities where we would expect children and young people to be increasing their levels of independence depending on social, family, cultural and community expectations i.e. use of public transport, managing activities of daily living and expanding social activities with peers. However, for children and young people with acquired brain injury, cerebral palsy and spina bifida, to achieve levels of independence commensurate with their age peers may be compromised by poor social skills and poor planning and organisation skills. Their limited success and/or delayed independence impacts on other areas of development.

3. Educational issues

Children with learning difficulties (due to a range of disabilities such as ABI, spina bifida and cerebral palsy) are provided with very limited additional assistance in the classroom. Furthermore, at the time of transition to high school these learning difficulties may have a significant impact on the child's ability to keep up in the classroom thus widening the gap between them and their peers as demands for age-appropriate self management, organisation of homework and assignments increase.

4. Physical activity

The need to increase and maintain optimal levels of physical activity to achieve optimal health and to prevent a range of problems associated with obesity is well documented. Levels of obesity are higher in the population of young persons with disabilities. The obesity has a negative impact on their body image, physical participation in the community and associated morbidity i.e. high cholesterol and type II diabetes.

Children and young people with disabilities may require additional resources to access recreational and sporting activities that accommodate their cognitive and/or physical impairments. Opportunities for the younger children (primary school age) are greater but competitiveness increases in high school and thus the children with limited abilities are often excluded from team based sporting activities. In this age group playing team sports provides opportunities to develop abilities that have positive implications for other domains of well being i.e. team skills, understanding the implications of winning and losing and coping with this.

Young people with cerebral palsy can significantly improve their mobility and function with strengthening programs. Access to community physiotherapists, personal trainers and accessible gyms is often limited for this age group and more limited for those with disabilities.

5. Emerging sexuality, peer relationships and psychological adjustment

While issues of sexuality impact on a child from the time of birth to adulthood, it is during the transition period of adolescence that the impact of sexual development and disability can become a concern for children, families, school and community.

Parents and teachers may be concerned that the child or young person's disability may impact on normal sexual development and behaviour. For some young people their disability will have no effect or little impact and will not cause physical changes or interfere with the child's ability to learn about sexuality or to make friends and develop relationships. However, for some children physical, cognitive, psychological, emotional and behavioural changes or difficulties may impact on sexual development or behaviour and their families, peers, school and community may require information and specialist support to help the young person make positive adjustments to these changes.

Children and young people with brain injury may have greater difficulty coping with the mood changes of puberty increasing their risk of disinhibition, aggressiveness and possibly, criminal activities. Depending on their levels of cognitive impairment they may be vulnerable to peer pressure promoting inappropriate behaviour or activities and highly suggestible with a lack of insight that puts them at risk of becoming involved in the criminal justice system, being sexually inappropriate or at risk of abuse.

Additionally, increasing insight into their physical, cognitive, social and environmental difficulties or limitations may diminish their participation in the community and put them at risk of depression and/or greater isolation from the community.

6. Respite issues

The further development and need for increased funding to provide an appropriate range of respite options is a crucial issue for children, young people and their families in this age range. The provision of optimal respite options for children and young people with challenging behaviour requires lateral thinking and creativity in policy development so that both children and families have choices about the types of respite available. Frequently families with children with high levels of physical dependency or psychological need are unable to tap into support from extended family as grandparents and other friends and family may actively avoid these more ‘challenging’ children. However, it is these families who often most assistance to maximise their ability to cope.

7. Access to appropriate health services

Equity of access to appropriate health related services is an issue for all children, including those in the 9-14 year age group. Children with disabilities and chronic conditions have increased need for tertiary health services including rehabilitation medicine. Many of these services are based in hospitals in major cities. The need to travel to access such services significantly impacts on children and their families. School attendance and participation in activities may be affected when multiple hospital visits are necessary. Exploring methods of health care delivery such as “ telehealth” and “Outreach Clinic” models may help to improve access to health care for this group of children.