

**INQUIRY INTO THE PROVISION OF EDUCATION TO
STUDENTS WITH A DISABILITY OR SPECIAL NEEDS**

Organisation: Arthritis NSW

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**ARTHRITIS NSW SUBMISSION TO THE INQUIRY INTO THE PROVISION OF
EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS**

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Arthritis NSW Summary

Arthritis NSW is a member based charity whose aim is to support people of all ages living with arthritis. We assist children in many ways including:

- Juvenile Arthritis Camps
- Children's magazine
- Parents Support Branch
- Information books
- Advocacy and education for the general community
- Teachers resources

Through our work with parents and children we have heard about many experiences both positive and negative, with the NSW Education Department.

Juvenile Idiopathic Arthritis (JIA)

JIA has a prevalence of 1-4 in 1000 children. (*Manners P, Diepeveen DA: Prevalence of juvenile chronic arthritis in a population of 12-year-old children in urban Australia. Pediatrics 1996, 98(1):84-90.*)

This makes JIA one of the most prevalent chronic conditions in children, however there remains great ignorance and misinformation regarding this condition in the community and this is also evident within the NSW Education System.

Each child with JIA is affected to varying degrees and their abilities can change, not just from day to day, but also during the day. Many children with JIA experience morning stiffness, which means they are less mobile and have greater pain upon rising. This means that a child will find it difficult to get ready for school and less able to carry out more physical tasks early in the day. However by afternoon they may be able to function at a relatively normal level. This can lead to the mistaken belief that the child is over exaggerating their condition or "faking it" completely.

There are no allowances in the *NSW Department of Education Disability Criteria (School Sector) May 2003* for such a variable disease. Whilst it is understandable that it is difficult for a school to make applications for funding based on this, parents have expressed frustration at the implication that they are trying to get support or assistance for their child, which they do not deserve.

The amount of funding available to support the education of a child with a disability is not readily disclosed to those outside the Education System, so it is difficult to comment on its adequacy

In principle the processes are in place to ensure that children with disabilities or special needs receive equal opportunities in the provision of education. However in reality these provisions are not easy to find as an outsider, be it parent or service provider wishing to assist children with disabilities.

The focus of most health care practitioners in the modern holistic model is on functional ability rather than disability and allocation of funding and support within the education system should align with this.

There have been occasions where parents have reported that a health expert's report, such as an Occupational Therapist, has been rejected by a teacher who feels they have over stated the child's disability. Even to the extreme where a request for the child to use a pen built up with foam and be given extra time in hand written activities, was rejected because the teacher felt that the child was just being lazy.

Another similar example involves a physiotherapist who was concerned that a child was being excluded from all physical activity and wrote an exercise routine that the child and the rest of the class could do together. This was rejected by the teacher.

We advocate that it is better management to supply the necessary equipment to help a child function at the best of their ability, rather than wait until incorrect equipment has further reduced their functional capacity. The current support criteria appears to be an "all or nothing" approach based on criteria which parents are unaware about.

The guidelines set out in "Who's going to teach my Child - A guide for parents of children with special needs" produced by the NSW Department of Education and Training are straightforward, however very few parents of children with JIA are aware of this guideline. One of the main points it emphasises is that schools and parents should be working together with the input of other specialist personnel to put together a support plan. However this rarely happens in the case of a child with JIA and if there is a learning support plan in place, it is done without parent consultation.

Many parents feel there has been an increase in support given to children with behavioural or learning difficulties, as they tend to be more obvious and may cause disruption in the class. Parents feel that those children who sit quietly (often because they are in extreme pain) do not get noticed until their leaning has fallen behind.

Very few parents have reported that they have ever been referred to support services such as occupational therapy or physiotherapy. The contact with school counsellors is varied, some finding them the most supportive member of the team

and others feeling they are so over loaded, that their child slips through the cracks in the service. As previously mentioned, on many occasions the allied health reports are not taken into consideration when assessing the child's needs.

Many of the gaps in services and much of the frustration of children and parents could be addressed by increasing teachers' knowledge about JIA.

The education sessions run by Arthritis NSW in schools are always very well received and in most cases help improve the child's experience within the school. However this can only occur at the invitation from the school, usually at the parents' request.

JIA is not always mentioned in teacher training and is often overlooked when general disability in-services are conducted. On the whole the support services for children with a disability or special needs are stretched beyond capacity and urgently need a further injection of funding.

Arthritis NSW is happy to participate in professional development in-services for teachers and counsellors to promote better management of children with JIA in the school environment. This can be arranged by contacting us on 02 9857 3300 and asking for the Manager of Education & Member Services.