

**Disability Care and Support**  
**Public inquiry**

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**Submission from:**

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Our Institute (Telethon Institute for Child Health Research) has done research on perinatal and paediatric epidemiology with a special interest in cerebral palsy, birth defects, intellectual disabilities and other developmental disorders for many years. We research the causes and prevention of disabilities and of course our interests also cover the kinds of problems that families with disabilities face as the child is diagnosed, treated, supported and cared for and how these needs change over the whole life span. Professor Helen Leonard has conducted surveys on the needs of families with a range of intellectual and other disabilities (eg Down Syndrome, Rett Syndrome) and may well be submitting in addition to this letter. However all of the researchers in this Institute who are conducting research here strongly support the concept of a national insurance for disability as has been proposed by Bruce Bonyhady. In fact, as you can see from the list of attached papers it is something that both Professor Eve Blair and I have been suggesting for many years.

I am sure that you will be inundated with support for this proposal from those who have disability in their family and from those groups which help to care for them. We strongly support their arguments and do not need to repeat them here. Our main additional reasons may not be widely appreciated which is the main reason for this letter.

**1. LITIGATION HAS HAD A VERY NEGATIVE EFFECT ON SOCIETY AND IS NOT GOOD FOR FAMILIES EITHER**

As outlined in several of the papers below we make the case that litigation as the major way for families to seek compensation and funding for disability has been a disaster. It has been shown to be a bad way to get money to support (the very small number of eligible) families, to have had a devastating impact on obstetric care and other health care provision as well as a range of other community activities such as adventure playgrounds and facilities which can no longer afford the insurance premiums.

The list of papers below spell some of this out in greater depth – specifically my paper “Litigation versus Science”; Eve Blair’s “where does and where should the money come from?”; and then the series of papers about cerebral palsy, birth asphyxia and the impact of obstetric litigation for cerebral palsy on obstetric care. We make the case with strong and compelling data that it is impossible to prove that “poor” obstetric care resulted in the brain damage seen in cerebral palsy cases and yet time and time again, so-called expert witnesses give evidence to

show that it was likely (even in cases later shown to be genetic). The impact of obstetric litigation on both the practice of obstetrics and on the costs of insurance premiums for obstetricians and midwives (and hence the costs to the health services and the consumer) have escalated alarmingly. These costs, added to the fear of being sued, has resulted in many obstetricians leaving the discipline and fewer being available to deliver babies. It has also resulted in a dramatic increase in obstetric interventions like caesarean sections (now up to 30% of all deliveries in Western Australia) – so called “defensive obstetrics” - in spite of our (and others) data showing that these increases have had NO impact on reducing the chances of disabled children such as those with cerebral palsy, and has detrimental effects on both mother and child. Cerebral palsy rates have not fallen as the caesarean section rates have risen.

We called repeatedly for a separation of – a) a scheme (such as national insurance as proposed) to adequately fund the cost of a disabled person over their lives which is totally separated from b) a method of ascertaining the cause of the disability and apportioning blame and punishment if poor care, negligence or malicious intent led to the person becoming disabled.

We believe from the literature and from talking to families and their advocates that the process of litigation is not good for families either - few are eligible (see causes of childhood disability below) and even fewer seem to win their cases, the process is prolonged with many taking years to come to some conclusion, of the money eventually paid out, much goes in legal fees and the time spent fighting the case takes a huge toll in time and energy on a family needing to come to terms with how they cope with a disabled child.

## **2. THE CAUSES OF DISABILITY IN CHILDHOOD**

Most causes of physical and intellectual disability in children are unknown or due to factors beyond the control of any group or health professional to influence such as genetic factors, biological risks (brain developmental disorders, haemorrhage or clots in the brain during pregnancy), infections in pregnancy, substance abuse, toxic environmental factors (mercury, lead, PCBs etc), early delivery or poor growth in-utero. After birth some genetic risks are still diagnosed quite late in childhood (eg intellectual disability, Rett Syndrome), neonatal complications of early births (brain haemorrhage, infections) and after the first year of life accidents and injuries start to play a major role. Many causes are associated with poor social circumstance with a variety of possible risk factors. The main message here is that even in those which may seem to the public to have a clear cause – such as “birth asphyxia or lack of oxygen” in labour – when we research it properly we can see that the majority of the pathways commenced well before labour.

Hence due to the challenges of ascertaining causes of disability in all but the most obvious (eg accidents) it would seem best, most humane and fair if there was a scheme that paid for all disability rather than a scheme that depended on suing those we think caused the problem. For all the reasons we outline above and in our published work, a national insurance scheme is the best and most sure way to give disabled people and their carers the support they need to live in our society with dignity and capacity.

We strongly support the proposal for national insurance for disability for its equitable, logical and humane approach. I am happy to give more information or to be contacted to answer any questions as are the other researchers in the Institute.

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