

Time for a vaccine injury compensation scheme?

One of the tests for this seminar is to hear a consumer perspective that may challenge the orthodoxy in public health about the benign nature of immunisation programs. From an ordinary person's perspective, there is an effusive benevolence associated with immunisation as an intervention for the public good. Immunisation *would* be entirely benign if it did not also hide the dark reality that immunisation can, in rare cases cause harm, and the harm in some of these cases can be catastrophic. So, the orthodoxy I question is the one that says that the greater good justifies some harm to some, and also that this greater good justifies the systematic denial of the links between the harm and the intervention.

The fact that we are here today reflects that it is acknowledged immunisation can cause harm. The people who have organised this seminar are clearly those in favour of progressing this debate about a compensation scheme for vaccine injuries. Despite this favourable environment, there is a need to put onto the public record, a perspective from consumers that arises from the *historical* failure to acknowledge that vaccines can cause harm. For some in our community, this recognition is long overdue. People who believe that their children have experienced harm as a result of immunisation have faced enormous opposition to having this view validated in any way. The validation of this link between immunisation and an adverse outcome forms the basis for any claims for compensation. Critically, this compensation is usually sought to assist the affected individual or child and their carers, with supports needed to cope with the effects of the loss of function that may have been linked to the vaccination injury.

I do not seek to frame my argument for no fault compensation in terms of the practical purposes of the compensation itself. I think that the purposes of compensation in terms of quality of life of affected individuals are fairly self-evident.

I pose an argument based on the correction of the historical injustice that we have permitted in the name of immunisation. There is a moral and civic imperative for no fault compensation related to immunisation. This imperative dictates that such a scheme should have existed in parallel to immunisation programs since their introduction. We must now face righting this situation and proceeding in a just way for all those who may face these experiences into the future.

It is my view that the essential things that make us human are the capacity for love, the capacity to create music and art, the capacity for grace and the capacity to sense justice and injustice. It is this latter capacity, to intuit at a deep, almost sub-rational level, that something is just 'not right' that is commonly expressed by people who believe that their child has been harmed by a vaccination.

There is a unique element to these adverse events related to immunisation. This unique element is the systematic denial of a link between the injury and the intervention and the effects of this denial on the person fighting for this recognition. It is this systematic denial that is the cause of the most profound affront to the humanity of the people concerned. It is another feature of human make-up that we can be reconciled to physical injury far more easily

than we can to an injury to our sense of justice, our sense of self and our rights and entitlements as a citizen. In the case of adverse events from vaccination, the physical injury is caused by a medically sanctioned intervention. The affront to the person is inflicted by the State that denies responsibility for this.

Case examples

Mother gave consent for immunisation booster to her school age child, as part of a national campaign when Michael Woolridge was Fed Minister for Health. The information for parents stressed the benefits to individuals and the community and according to the mother, made only slight reference to risks. We checked the information given to parents and agreed with her on the scant reference to risks. After the immunisation, the daughter was diagnosed with blood disorder, Thrombocytopenic purpura which is a known risk of the vaccine, sufficient to draw an association between the two, not a causal link. We tried to secure assistance or the mother and the child; counselling, support, medical treatment, but could not do so. The mother was not in any position to take any sort of legal action.

A father of a now 30 year old woman, is certain she suffered severe and irreversible brain damage within 48 hours of immunisation as a toddler. Requests for information, explanation, support and advice were continually ignored. He has been identified and dismissed as a trouble-maker. According to him, no-one would even take responsibility to investigate his claims.

Denial of the adverse events from immunisation has a poisonous effect on the people caught in the middle of this tragic consequence. We expect people to immunise their children for the benefit of the child and the broader community. This compliance rests in the individual's sense of obligation to both their off-spring and society. We must off-set this obligation with protections for these individuals when injuries occur as a result of this compliance. The historical failure to provide a system of redress is unreasonable. The conspiracy to deny links between adverse events and immunisation interventions has been a travesty of justice for all those people affected since the introduction of wholesale immunisation schemes. This systematic denial of the possibility of adverse events from immunisation is what I would call a **civic and social injustice**.

Civic and social injustice.

From my work as an advocate I have come to understand that there are some grievances that arise from what is felt to be a breach in the mutual obligations that exist between a citizen and the State. For some people, it is only through having to face a vaccine injury that they become aware of the nature of this relationship between themselves as citizens and the State and its agencies.

There are very particular grievances that bring into sharp relief the citizen's sense of what is just and fair in the civic realm, where they have complied with an obligation imposed by the State and the consequences for them have been profoundly negative. There is nothing more crushing for an individual citizen than to feel themselves to be alone in a battle with the State for recognition of an event or association that is systematically denied. This is how it feels for some people whose children have been in that rare and unfortunate group to experience a

vaccine injury and faced denial of the association between the vaccine and an adverse outcome. People in this sort of battle with the State or agents of the State, experience a rage and a frustration that could be argued to have its own unique colour on the spectrum of emotions. I have met people through my work who seem to have been so transformed by this rage and the struggle for recognition that they almost no longer recognise themselves, but cannot stop the fight. Unfortunately, by this time, they can appear rabidly anti-immunisation, completely alienated from conventional medicine and suspicious of State authorities and public service systems. They are easy to dismiss as unreasonable and this dismissal compounds the problem. The anti-immunisation lobby may not disappear entirely with the introduction of a no-fault compensation scheme. However, it is fairly easy to argue that the existence of this lobby may be a legacy of the historical denial of adverse events from immunisation.

Some lessons from our recent past – other civic and social injustices

I would like to illustrate my position that failure to compensate for vaccine injury is a civic and social injustice, with two exemplars.

Relinquishing Mothers and their children

At one time in recent decades, there was a societal pressure for young unmarried mothers to relinquish their babies to couples unable to carry their own child or who were prepared to raise the child of another. The primary rationale supporting this was that of the best interests of the child, with a secondary benefit returning to the woman herself. Beliefs at the time about a broader social good arising from preventing single mothers and single parent families, as well as preventing the appearance of illegitimate children, allowed for this process to be supported in the civic realm as well. Policies and legislation were established that allowed for adoption of the children and their absolute separation from their biological roots. For these relinquishing mothers and some of the children, we now know that these social and civic policies in support of relinquishment came at a great cost.

So-called ‘child migrants’

Another group of people who have suffered greatly from a civic and social injustice is the children whose forced transportation from England was based on rationalisations about individual benefit in the context of a wider social good. Churches, the State, community organisations and individuals all worked in concert to bring these children to Australia and place them in various institutions. Many of the children suffered terribly and continue to do so as adults as a consequence of these policies that were seen at the time as reasonable.

When the consequences of relinquishment and child transportation caused excruciating harm to the individuals concerned, our society struggled to cope with how to deal with issues that this raised. These people, by virtue of society’s paralysis in response, were consigned to their own private journeys of pain and adjustment. The myriad of so-called ‘benefits’ of their experience jostle with the paradoxical consequences for them personally. These battles to rationalise the benefits and contradictions can take decades, sometimes never being resolved in that person’s lifetime. Both groups are pressured to see the benefits of the situation they are in and are even expected to be grateful for what has been provided to them. For relinquishing mothers, they are pressed to see that the adoptive parents will be able to give

their child opportunities that they couldn't. For the child 'migrants', there is a pressure to acknowledge that they faced few opportunities in their country of origin and are better off as a result of the actions taken on their behalf.

The parallels between these two examples and people adversely affected by childhood immunisation programs are considerable. The State, supported by the scientific and health care communities, is a considerable force to challenge, just as the church and State were impenetrable for young mothers and transported children. Gratitude for the illnesses avoided is a main plank of immunisation campaigns, just as gratitude for better life opportunities was a selling point in the other programs. The powerful deciding what is best for the individual, with no room for dissent, is another shared theme.

We have grown as a society to help both of these groups of relinquishing mothers and child 'migrants' to express and declare their struggles. We have validated their pains, and to some degree expressed regret that these unintended consequences occurred as a result of social and civic policies and practices.

A no-fault compensation scheme for vaccine injury will reflect a 'coming of age' of public health practice in respect to childhood immunisation programs. Immunisation is an imposition on individuals by society of an intervention that has some risks for the individual concerned. It is grossly unjust to deny that immunisation is the cause when this could be so. We must correct this historical injustice and I hope that tonight's program contributes to progress on this issue.

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November 2005