Dear Sir or Madam

Thank you for the opportunity to make a submission to the proposed disability reform.

My wife and I and our eldest daughter had the care of a child with severe disabilities who died in September 2011 at 23 years of age. I would like to make a few comments on the proposed reform in the light of that experience.

1. I would like firstly to commend and support your proposed reform. It is an excellent one and sorely needed. Much of the ground has been well covered in your work to date and I will restrict myself to comments where I hope they will be of some use.

2. It might be more useful to have a distinction between existing and new/acquired disability/health issue rather than between disability and new injury. It would be a simpler way of keeping the focus on need rather than the cause of need which seems to be an odd way of developing a new system. The message should be the care and support you need 24 hours per day, 365 days per year.

3. I think it is important not to cap the total amount of assistance for an individual or to set eligibility limits for particular forms of assistance. The need for assistance will be determined by a range of factors: the nature of the disability/health issue, the extent of informal assistance by relative and friends and the level of expectation of what the person should be able to do. To take one example, the need for respite for carers can be anywhere from nil to full-time.

The scheme should set the level of expectations high and with the purpose of maximising independence and individual capacity to contribute to the society (through paid work and other means). This is particularly important as some families will 'set the bar' much lower than what the individual is capable of. The other factors influencing the need for assistance are so variable that to set a limit would be to deny some individuals the optimum level of assistance. I expect that in such an approach the need for assistance will average out in a flexible system of support and not require a different quantum of support, particularly if the type of assistance is geared to the individual (eg, not putting people in higher care facilities than is needed because that is all that is available).

4. There needs to be a major provision of assistance at the point of diagnosis of the disability or the acquisition of the disability or health problem. This is the most difficult time for carers and loved ones. Help to sort through the best system of care and intervention is essential during a period where grief and emotional upset are often at a high level and where family members may want 'to do it all' in ways that are not sustainable.

5. The timely provision of first class and ongoing access to information on the nature of the disability/health problem, likely prognosis and what are useful interventions

(and how to get them) needs to be first class. The provision of assistance and information are two sides of the coin - both essential and strong related.

6. There appears to me to be major potential savings in reform in this area, giving the confusing, costly to administer and archaic systems currently in place,
including income support and workers compensation arrangements. Is the work being done on this?

Yours sincerely

Tim Gilley