



*Jack & Jill went up the hill,  
To fetch a pail of water,  
Jack fell down,  
& broke his crown,  
& Jill came tumbling after.*

*Then up Jack got & home did trot,  
as fast as he could caper,  
to old Dame Boggin,  
who patched his noggin,  
with vinegar & brown paper.*

Dear Friend

It really saddens and angers me to see this debate about the domiciliary care allowance (DCA) continuing today. I know from our nurses that the 288 families under our wing have been adversely affected by delays of up to 8 months in their applications for DCA which is intertwined with the granting of carer's allowance.

What is also shocking to me is that the HSE continues to ask our families to fill in review forms for the DCA, knowing that the children under Jack & Jill care will not get better. But what's really appalling is that for some of our families as soon as they get that letter stating their DCA is being reviewed, that same DCA payment is stopped throughout the whole review process. That's just bureaucracy gone mad and totally unfair. They are effectively treating the parents of severely disabled children with contempt and increasing stress levels.

When my son Jack Irwin was born in February 1996 there was no domiciliary care allowance until the child reached the age of 2 years old. Why? Because civil servants expected that children like Jack would not survive beyond 2 years old – shocking but true. After much debate with the then Minister for Health Brian Cowen and with the help of Charlie McCreevy we had a breakthrough and the DCA for children from diagnosis was introduced between 1996 and 1997. But now as a society we're going backwards when it comes to the healthcare of the most vulnerable in society.

These precious children and their parents must be treated with dignity and as a society we must not let this type of shabby treatment continue. I don't mind whose feathers I've got to ruffle in the HSE, but ruffle I will continue to do.

The economic model for caring for sick children at home is a 'no brainer' a phrase repeated again and again when we met 40 TDs and Senators recently to urge them to do something about the fact that Ireland doesn't have a National Paediatric Home Nursing Care Budget. We could paper the walls of Leinster House with all the policies supporting home nursing care for severely disabled children. And the economic model proves that it is nine times less expensive to care for a child at home at €16,422 per annum, compared to €147,365 for hospital care (Trinity Report 'No place like home' February 2010). But what do we have in Ireland today? Delays, cuts and incompetence from the HSE at the top.

I'm calling on the Minister for Health, the Minister for Children, the Minister for Social Welfare and the Ministers for Finance to sort this DCA crisis out and to sort the delays in carer's allowance and



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medical cards in the process. Our children and their parents deserve better and no politician can hide behind the 'no money' excuse because sorting it out won't cost money - it will actually save money. If parents are to care for their sick child at home they must be supported by the State to do so. Bottom line.

I also want to repeat our call (a joint call with the Irish Hospice Foundation) for a National Paediatric Home Nursing Care Budget to meet the needs of the 1,400 children in Ireland today with life-limiting conditions. A case we argued in Leinster House to lots of nodding heads. Having no National Paediatric Home Nursing Care Budget in Ireland today is causing major challenges as funding is ad hoc and difficult to track while tremendous resources are being spent chasing up scarce resources. There are inconsistent practices between regions, hidden costs to the taxpayer and a greater burden on acute services, as well as greater stresses to parents who want their children at home, but need good support to do so. We can start by ringfencing a budget. Our initial calculations suggest that a minimum of €14.5 million should be ringfenced in year one.

And what can you do today to help make this necessary change? Email this letter onto your local politicians or better still give them a call. Tell them you support the Jack & Jill call for action and together we can raise the volume of these issues.

Yours sincerely

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Jonathan Irwin