

1st February 2011 - 357

Can. Res
Wr

Dear [REDACTED]

I am a grandfather of a child with Down Syndrome, and I am writing to express concerns about, and to provide feedback into, the public consultation upon Disability Living Allowance (DLA) reform.

We wish to raise general points about the proposals, as well as a specific concern about proposal item 40 *"whether or not we should take into account a child's support needs if they are being met from public funds by another institution, such as a school"*.

Regarding proposal item 40, regardless of funds used to support children with Down Syndrome in school their families incur large number of unavoidable specific costs associated with the children's care. These are costs that are also each over and above costs for a non-disabled child. Hence, when the phrase 'for older' children' is used below it refers to the fact that children with Down Syndrome typically require additional care and equipment, incurring additional costs, to a much later age than is the case for a non-disabled child.

Families of children with Down Syndrome incur additional expenses, over and above those incurred with a non-disabled child, in the following areas:

- Mobility – our children are less mobile, tire more easily and lack road safety awareness:
 - Transport to appointments & parking;
 - Specialist buggies for older children;
 - Road safety equipment for older children;
- General Health and Safety – our children lack safety awareness:
 - Road safety equipment for older children;;
 - Locks, stair gates and similar for older children
 - Night safety equipment for older children;
 - Need for constant supervision in each room in the house, which will often involve extra paid for childcare;
- Night and sleep issues – our children are impacted by a wide range of night and sleep issues, including refusal to go to bed, highly disturbed nights going on up to 16 years of age, bed wetting, vomiting and night disturbance. This incurs additional costs such as:
 - Sleep Apnia alarms – for breathing problems affecting sleep;
 - Decongestants;
 - Additional night laundry – up to 6, 7 times a night;
 - Bed rails for longer than children of the same age;
 - Greater breakages;
 - Restless Leg Syndrome / night disturbance incur the need for extra massage or physical activities such as dance or swimming, each provided by a trained specialist, incurring additional cost;
 - Shocks and scares can provoke cessation of breathing, this can involve admission to hospital;
- Additional laundry and cleaning costs:
 - Greater electricity use;
 - Greater washing machine use, more frequent replacement;

- Need to have more much bedding and clothing than for another child;
 - Much greater use of baby wipes beyond the age of three;
- Specialist correspondence in relation to medical appointments, a child's Statement of Special Educational Needs, or communication with schools:
 - Incurs additional PC, printing and writing material costs;
- Specialist food and feeding equipment – since so many of our children are impacted by significant sensory issues and / or allergies;
- Specialist clothes, because of our children's low muscle tone:
 - Shoes;
 - Body support corsets;
- Specialist therapy equipment – this is always expensive since it need to be purchased through specialist agencies and, like toys, sustains higher level of breakage than for other children:
 - Specialist putty;
 - Chewy Tubes;
 - Computer programs;
 - SLT resource books and materials;
 - Adapted bikes;
 - Adapted swimming kit;
 - Trampolines;
 - Specialist chairs / tables / pens / writing slant;
 - Specialist classes such as music, dance, swimming needed as Occupational Therapy;
- Specialist training and courses for parents (and carers);
- Specialist childcare such as Little Angels, an agency employing staff specially trained to look after children with special needs;
- Additional holiday related costs:
 - Specialist holiday centres such as Symbol (Symbol UK, a specialist speech and language therapy agency) camp, which incur direct charges and indirect additional transport costs;
 - Higher rates of travel insurance, especially if heart condition;
 - Need to ensure disabled child friendly, safe accommodation, which usually means more expensive accommodation.

This listing of these costs for families of children with Down Syndrome does not mean that every family always incurs every single cost. However, all such families unavoidably incur the great majority of these additional costs.

To repeat, these costs are not only unavoidable, but they are also each over and above costs for a non-disabled child. They also represent costs incurred outside of school. In addition, school holiday periods are not covered by provision in school, so that holiday respite or childcare would need to be by a paid trained specialist, or by specialist play centres manned by trained staff – there are already too few of the latter, and many are currently closing.

A further specific concern relates to the proposal to introduce eligibility for support only 6 months after diagnosis. In the case of Down Syndrome, diagnosis is at birth, while children with Down Syndrome typically require often intensive medical intervention within their first 6 months of life. This incurs significant additional costs. A three month delay in eligibility for financial support is already damaging, extending

this to 6 months would represent further damage to families at their time of greatest vulnerability, and would additionally risk the long-term health of children.

We are also concerned about the proposal to assess need through face-to-face meetings with an independent healthcare professional who may have little understanding of the impact, nature and complexities of Down Syndrome, which would be necessary to allow an in-depth analysis of an individual's circumstances to be carried out. We would like to know who the DWP are working in collaboration with while they develop an objective assessment of individual need for people with disabilities. We would further like to understand which independent specialists in health, social care and disability are contributing to the process to develop an objective assessment. Do any of these specialists have considerable experience of Down Syndrome in particular?

In a more general sense, we have wider concerns about aspects of the proposed DLA reform, as follows:

- Costs associated with Down Syndrome are not only about healthcare, but reflect a range of support and care needs, which must be taken into account;
- It is exceptionally rare for a person with Down Syndrome not to have expensive additional support needs as an adult;
- Finally, families with children with Down Syndrome are already placed under significant and measurably damaging financial pressure. Families of children with Down Syndrome have been shown to suffer:
 - Reduced earnings – diminished by 1/3 with a child with disability;
 - Greater incidence of marital break up and divorce;
 - Negative impacts upon siblings, often necessitating additional sibling childcare, if a principal carer has to attend additional appointments.

The consequences of taking away some of the already inadequate levels of DLA financial support, many of which will incur additional costs to the State, include:

- Children with Down Syndrome becoming adults with less independence, needing more expensive care, since they will be more socially isolated and physically dependent;
- Greater financial stress upon families, in particular restricting the capacity of both parents to attain full time employment, thus reducing family earnings and tax and NI contribution;
- An increase in the numbers of children needing greater, and more expensive, institutional care;
- An increase in rates of separation and divorce among families of children with Down Syndrome.

We would welcome a simpler assessment process for families, who have so many difficulties and pressures, but urge you to take the above specific costs and general concerns into account as this public consultation feeds into the reform process.

Yours faithfully,

