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**YOU AND YOURS – NEEDS OF DISABLED CHILDREN AND THEIR FAMILIES -
03.02.03**

ROBINSON

They'll be a debate in the House of Lords tonight on the needs of disabled children. It's in response to a question from a Labour peer. Baroness Doreen Massey has asked how the Government plans to respond to a report from the charity Barnados on the hardships faced by the parents of children with disabilities. The report - Still missing out - drew on in depth studies with 17 families. It found parents struggling to make ends meet and having to fight for basic services. I'll be talking to Baroness Massey in a moment. First, here are two of the mothers who took part in the Barnado's research. Tania Smith lives in Bristol, her son, Jack, who's 7 is profoundly autistic, she says both of them have been trapped in their home since May 2001 because their garden doesn't have a fence.

TANIA SMITH

Jack will escape, any opportunity he can, he doesn't understand danger. There was one incident where I had, because of the lack of fencing, he actually managed to get out the garden and I had to chase him down the road. I fortunately got injured not Jack. It needed me to lobby - intense lobbying, writing letters - and in the end I had to go to my MP to get a response. Now this has been going on since May 2001 and as I speak my actual fence is now being built, now this is going to be a huge, huge difference to my lifestyle and my child's lifestyle because it means that we can actually have windows open, doors opened - we can be part of the community.

ROBINSON

Tania Smith. Angela Jones from Gateshead has a daughter Bronwen, who has a severe learning disability, she says she's finding it increasingly hard to make ends meet.

ANGELA JONES

It's quite hard work, in fact it's treble the work you do in an ordinary job. I mean even though I love looking after my daughter I'm physically and mentally exhausted and I don't see a lot of people outside because I've got to stay in to catch up or try and catch up on sleep but I mean I've not even had a lie in for six years. Sometimes I'm terrified to go to sleep in case I sleep in when she does get up through the night. For instance, say, if I put her to bed an hour too early I'll bet your life she'll get us up one, two, three or four in the morning and she can really scream and why she scream is she's very frustrated and can't tell me why she's up in the first place, maybe she'll have a soiled nappy and I've got to get in before she goes shuffling on the floor, otherwise it'll be soiled all over the carpets and oh what can I say? I get very little from benefit and they might give us £40 to be a carer but I find that very insulting anyway. I've found I've got to cut down maybe on a little bit of shopping, like today I was looking for bleach and things and not realising that I couldn't get everything in. Like I say I need an awful lot of cleaning stuff to clean the soil from the carpets and struggling with clothes because she slavers a lot or maybe they're too soiled and I've got to replace them. I think I would need at least £3 or 400 a week to look after a child with disability.

ROBINSON

Angela Jones. Baroness Massey's in our Westminster studio and the author of the Barnado's report, Neera Sharma, is here. Neera, why are families with disabled children more likely to be worse off financially than other families?

SHARMA

Well there are a number of reasons. Firstly, as we just heard from Angela, it costs a lot more to bring up a child who's disabled than an able bodied child, in fact it costs three times as much.

ROBINSON

Where does that figure come from - three times as much?

SHARMA

That comes from government research - so that's a government figure. And it's also borne out by the studies in our report that families are spending a lot more money on basic necessities - fuel, heating, transport, leisure facilities. Families are also more likely to be living in poverty because they cannot access work. Government has stated that the main route out of poverty for these families is work. If you're poor it helps to get to work. However, the national childcare strategy is not catering for the needs of disabled children. Specialist day care is very, very expensive and the Government early years partnership, Sure Start and all the other initiatives, are not adequately funded to make provision for disabled children.

ROBINSON

These are all the nursery provision which is starting in the inner cities?

SHARMA

That's right, yes, it's mostly that but it's also leisure facilities and community facilities, so for most parents they will use after school play clubs, they will use holiday play schemes, so that they can go to work, for disabled children that is not possible.

ROBINSON

Baroness Massey, these must surely be issues that ministers know all about, do you know whether there are any new initiatives planned?

MASSEY

What I can say is that the Government has actually put in place some initiatives to help, such as the childcare credit and the income support. What we, as the All Party Parliamentary Group for Children want to do is to make sure that two things happen. One is that services are better coordinated at a local level for parents with disabled children. And secondly it's very important that they have support, not just financial, but they have support from other parents and from local groups.

ROBINSON

But the point that Neera Sharma's making that if you have a really profoundly disabled child you cannot get childcare and therefore you cannot return to work.

MASSEY

I'm aware of that and I take that point absolutely.

ROBINSON

Are ministers aware of it though?

MASSEY

I think they are and I think that we are - what the ministers are trying to do is to put together many packages that will impinge on disabled - children in disabled families. What we as a group are saying in Parliament is that we must have better coordination of services. There are many initiatives but somehow disabled children seem to fall between the net in many cases, as we've heard.

ROBINSON

Neera Sharma, if we could coordinate services better how much difference would that make?

SHARMA

That would make a tremendous amount of difference. It's not just childcare services, it's education, it's health services and social services and the services that social workers provide which are not well coordinated at present. So what it means is that families sort of spend their whole time and their whole energy telling their story to different professionals. If they didn't have to do that and professional workers spoke to each other or families had a key worker then that would take the strain off families, they'd have more time to pursue employment or they'd have more time to care for their child instead of trying to spend time constantly trying to get services for themselves and for their child.

ROBINSON

Do sufficient services exist because there is an argument that we under-count anyway the number of disabled children in this country and therefore we're just not planning services for them?

SHARMA

Services are very scarce. So, for example ...

ROBINSON

So I mean in that sense coordinating them wouldn't make any difference would it?

SHARMA

It would help - it would go some way so that - because there's a lot of wastage of resources at the moment, so if there was better coordination - so, for example, if in the case of families claiming benefits the different agencies don't speak to each other so families have to claim housing benefit from one department, benefits from another department, so if that was rationalised it would assist but the scarce resourcing would have to be addressed as well.

ROBINSON

What about Baroness Massey's point that there are new benefits that can be claimed - are people claiming what they're entitled to?

SHARMA

No, our report shows and research shows that families under-claim, so that only 40-60 per cent of families who are entitled to disability living allowance, for example, for their child, claim it. So there's vast under-claiming. And the Government has put up benefits for disabled children, that's very welcome, and it helps, but if families then don't get what they're entitled to obviously that negates the whole point of a good policy, if resources are not then put into take up and targets are not set for take up.

ROBINSON

Baroness Massey, what if anything do you think this debate in the Lord's tonight will really achieve?

MASSEY

I think it will, first of all, raise awareness of the issue and we are concerned that parents are not

taking advantage in many cases of the disability allowance and of the invalid care allowance. So it will raise awareness. I think it will also - what I shall be asking for is that we have a separate debate or discussion after the debate tonight where we can involve ministers and interested parties to look at the whole situation and try to get better coordination and better awareness of the benefits that people are entitled to.

ROBINSON

Baroness Doreen Massey, Neera Sharma from Barnado's thank you both.