



Joint Position Statement on Carers with Learning Disabilities

From The Princess Royal Trust for Carers, Crossroads Care, Mencap, The National Family Carer Network, Who Cares For Us? and Respond.

Why do we need a statement?



- To help organisations who help carers with learning disabilities, to work better together.



- To help other people understand about the lives of carers with learning disabilities.

What is a carer with a learning disability?



Carers with learning disabilities look after a partner, family member or friend. They don't get paid for this. Many carers with learning disabilities care for people who also care for them. This is called mutual caring.



Some of the caring jobs that carers with learning disabilities do are:

- cooking and cleaning,
- helping with personal care and medication,
- lifting and carrying,
- or helping with benefits and forms.



Sometimes it is difficult to see when a person with a learning disability starts to help more. This means that they might not get all the help that they need.

How many carers with learning disabilities are there?



We don't know how many carers with learning disabilities there are. Mencap thinks there are a lot, and there will be more in the future¹.

But many of these carers don't know they are carers. Organisations who help sometimes don't know when a person with a learning disability has become a carer. This means that carers with learning disabilities don't get the benefits that are available to carers or the support to help them.



Carers with learning disabilities aren't easy to find. There isn't much information about them, so it's hard for organisations to get money to help. There isn't much support for workers who are trying to help these carers.



People with learning disabilities may still be discriminated against. Sometimes it's hard for others to understand that they can be carers too.

Carers with learning disabilities sometimes don't have many friends because they spend a lot of time helping the person they care for.



Older people's services, learning disability services and carers' services often don't work together to support families where there is mutual caring. This means that these families don't get support.

What do carers with learning disabilities want?



- To be recognised as carers, to have a good carers assessment and to have good help and support



- To have good, easy to understand information, about what is available locally

¹ Mencap, *Housing Timebomb* (2002)



- To have a life of their own, including short breaks and good emergency planning



- To have choice and control over their own lives, including having a say in planning meetings.



- To have a health check every year

How could carers with learning disabilities be better supported?

There will be more carers with learning disabilities in the future, and we know that there will be less money to pay for services.

We would like to see organisations that work with people with learning disabilities, carers and older families, offer:



- Services for carers with learning disabilities, with people working together



- A choice of support, including support that's just for carers with learning disabilities and support that's for all carers



- Access to mainstream carers' support services and concessions



- A chance to have a say and help to make things better for carers with learning disabilities



- A chance to be involved in workforce development



- Personalisation and direct payments that work for all



- Help for people with learning disabilities to understand that they are carers



- Involvement with future and emergency planning

Who is supporting us?



This statement is supported by:



- The Princess Royal Trust for Carers www.carers.org



- Crossroads Care www.crossroads.org.uk



- Mencap www.mencap.org.uk



- The National Family Carer Network www.familycarers.org.uk



- Who Cares For Us? www.inspiredservices.co.uk

- Respond www.respond.org.uk

This statement is also supported by The National Valuing Families Forum, The Foundation for People with Learning Disabilities, Sharing Caring Project (Sheffield Mencap), Bromley Mencap, The Standing Commission on Carers and Hft's Family Carer Support Service.

For information contact the Policy and Development Officer (Learning Disabilities), The Princess Royal Trust for Carers; tel 0844 800 4361; email cbaker@carers.org.

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