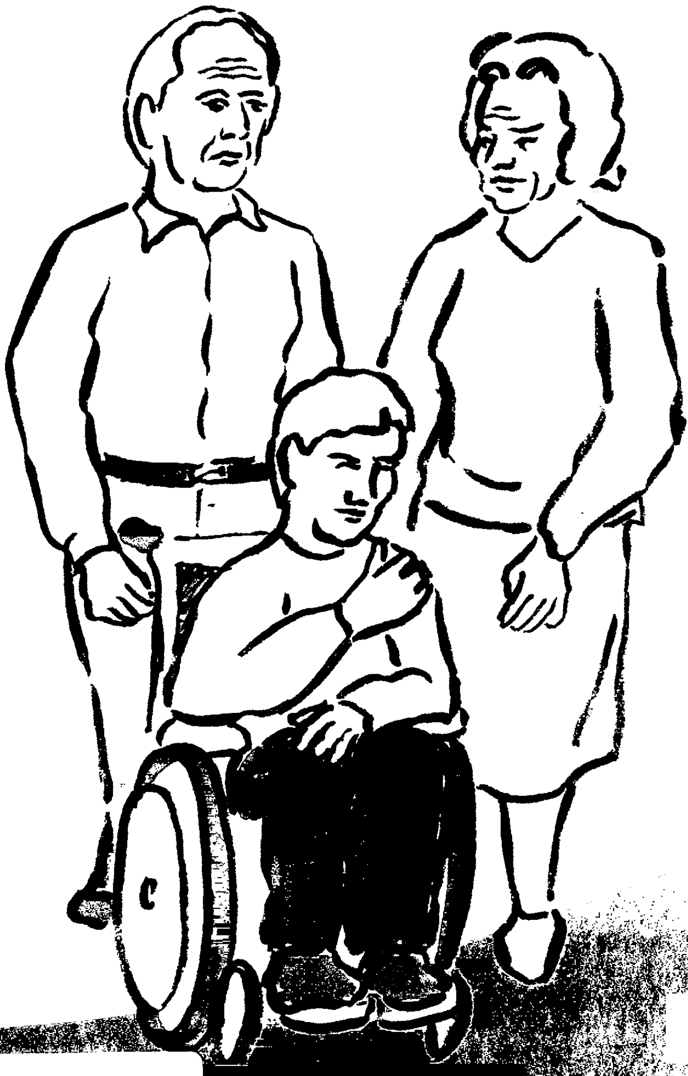
Department of Health



Family Matters

Counting Families In

Family Matters

Produced for the Department of Health
by Community Living, 0870 740 4887.

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Counting Families In

Family Matters is one part in helping make the new National Strategy for people with learning disabilities.

This accessible version is a summary of the main issues for Family Carers. We want Family Carers to get better services and their relatives to have more opportunities in their lives.

This report also looks at how important it is for services and families to work together.

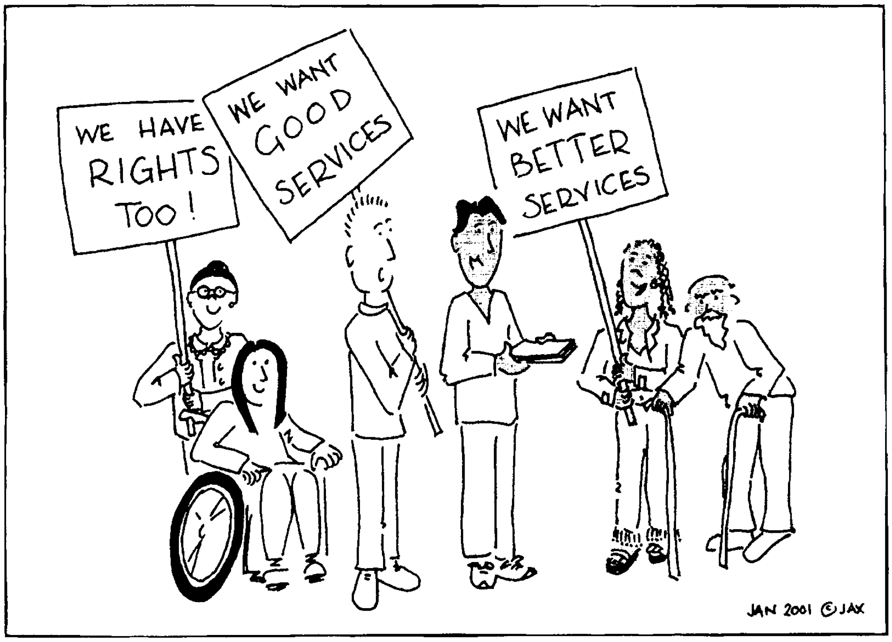
Contents

What Family Carers believe.

The Family Carers Group believes that people with learning disabilities have the same rights as other people in this country.

People with learning disabilities have the right to get the support they need to make the most of their lives.

Family Carers also have rights. Family Carers should be able to get the support they need in their own right.



"...families in campaigning role..."

Groups that need special support

- Families of people with learning disabilities who have older carers.
- Families from minority ethnic communities.
- Families with a young person moving from children's to adult services.

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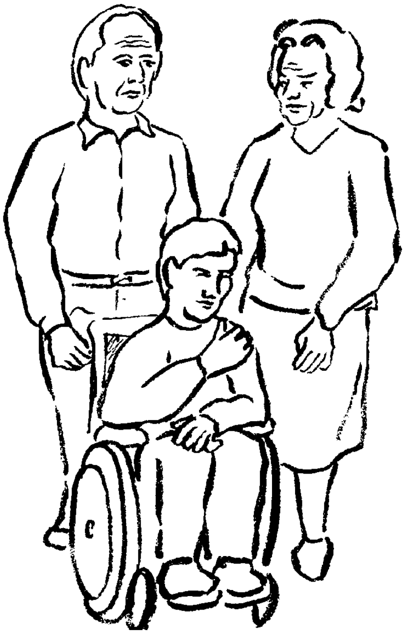
The part played by Family Carers in the National Strategy

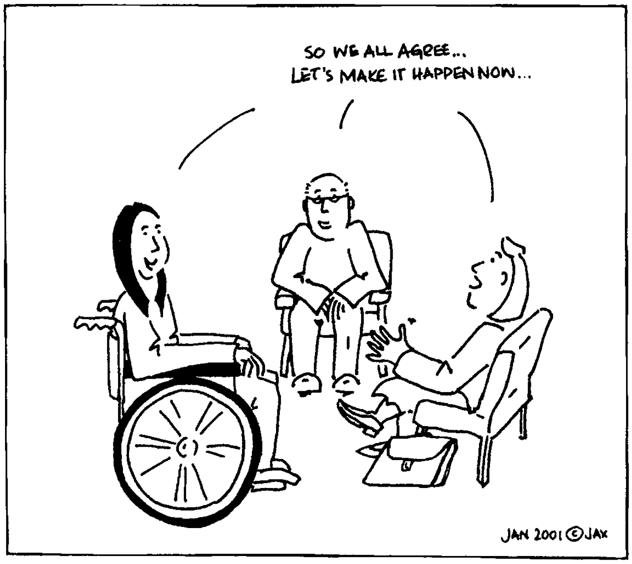


The Family Carers Group said that families do most of the support for people with learning disabilities. They are very important in keeping people in the community.

The group said the Strategy must make a real difference to people with learning disabilities.

Many families have been seen by services as just trying to stop their relative from becoming independent. Services need to understand families' concerns and work with them to find the best answer for the person with learning disabilities.

Many families have worked hard to bring about improvements in the lives of people with learning disabilities. Some have started new and exciting kinds of service.



"...working in partnership with families..."

Who are Family Carers?

A Family Carer is not paid to be with a person with learning disabilities.

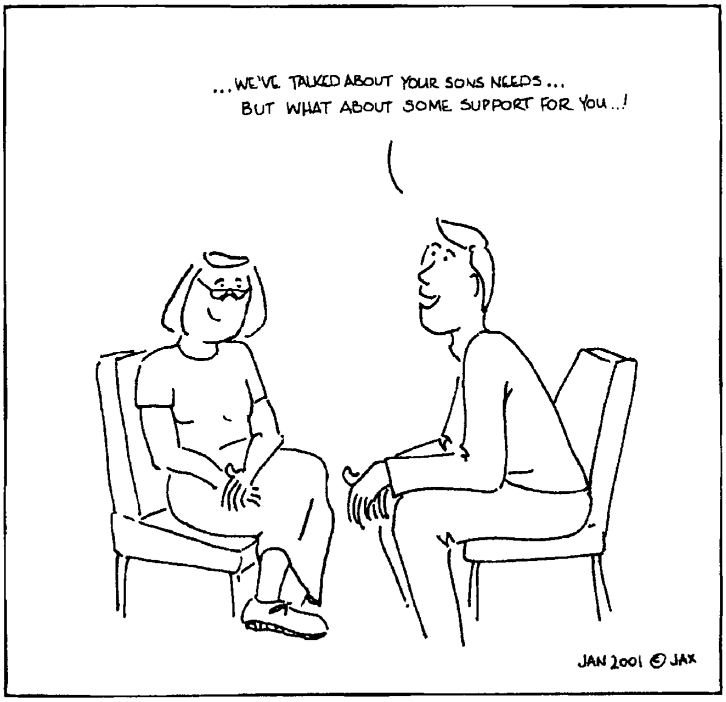
The Family Carer might be looking after one or more people for a long time, even if they move away from home. Some Family Carers are still caring when they are into their 80s and even 90s.

Not all carers will want to join a 'Carers Group'. This does not mean their views should be ignored.

How many Family Carers are there?

Nobody knows exactly how many Family Carers there are.

It is very important to find out about Family Carers if services are to be properly planned and people's needs met.



"...we want dedicated family carer support..."

3

The problems Family Carers have to face.

The rights of carers are not clear. Families are upset when they find they have very few legal rights when it comes to making decisions about their relative.

Family Carers don't always get a carer's assessment.

As well as the many good things about caring, Family Carers have some problems.

These include:

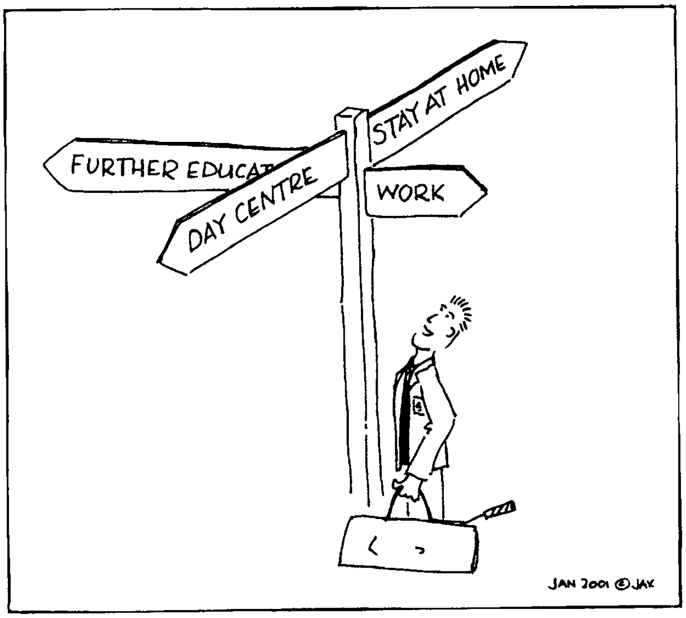
- Stress caused by a lot of worries.
- Not a lot of money.
- Worries about health.
- Having to deal with problems alone.
- Poor housing.
- Marriages going wrong.

These problems are even worse for minority ethnic families because of a lack of information and services to meet cultural needs.

As people get older.

Carers have to cope with several difficulties as their son or daughter grows up, such as:

- Being told your child has a learning disability.
- Making choices about their education.I
- Teenage years and the move from children's to adult services.
- When your son or daughter leaves home.
- Growing older together.
- When illness or death makes it no longer possible to care.



"...Leaving school - what next?..."

All these changes can be difficult for Family Carers to manage. Services can help people to cope better, especially if they plan ahead for these changes that we know are going to happen.

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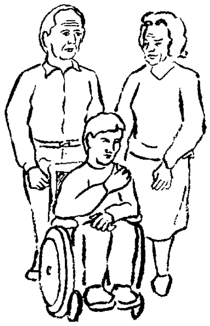
The two most difficult times are the change from children's to adult services and the problems of older family carers.

Some of the needs of older carers are different from younger family carers:



- They continue to care, as they get older.
- They are more likely to be caring alone.
- They lose support when a husband or wife and friends die.
- They form strong bonds with their son or daughter and each becomes dependent on the other.
- They have had a different experience of services than younger Family Carers.
- They are less likely to ask for help at times when they need it most.

Family Carers have a lot of difficulties getting access to proper health care. These include:

- Unhelpful attitudes and communication problems in the GP's surgery.
- The closing of specialist services.
- The lack of support to use ordinary services.

Carers said their relatives were often treated badly in hospital.

Left alone to cope.

Family Carers are often left alone to cope and can feel bad about themselves.

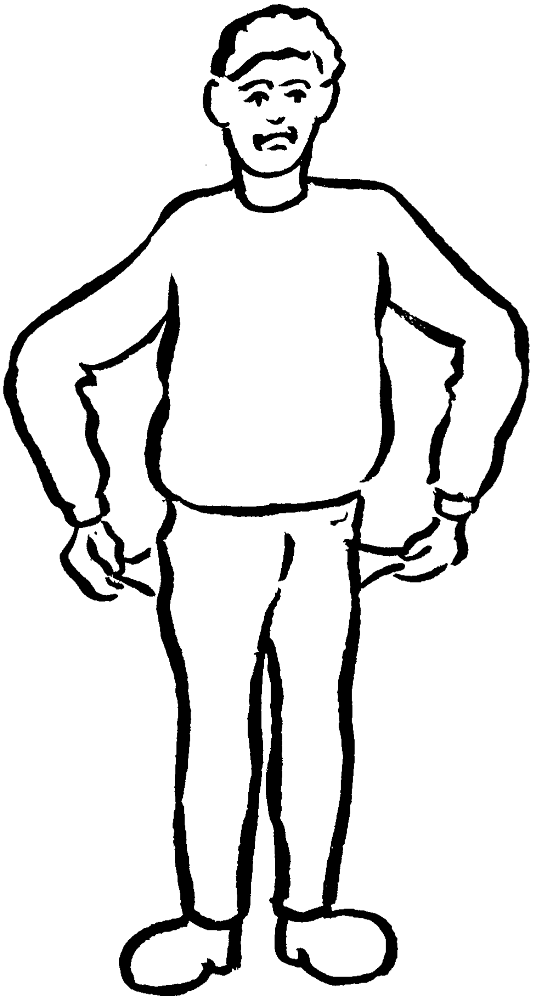
This problem is worse for minority ethnic families as they can get less support from family and friends than is often believed.

Family Carers like the support they get from carer support groups but not everyone wants to or can join a group.

Being short of money

Because of their long-term caring role, Family Carers are often short of money. They have low paid work and they cannot save money or build up a pension.

Family Carers often buy aids or do house alterations themselves because they have to wait so long for the Local Authority to provide them.



What do Family Carers want from services?

The kind of services Family Carers find most helpful are services that:

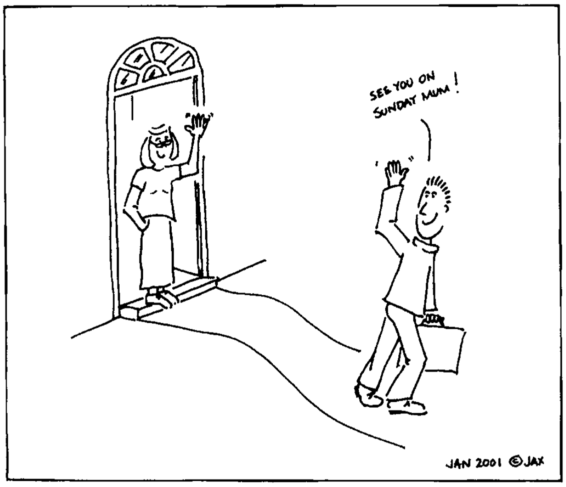
- Are active.
- Think of individual needs.
- Do not keep changing.
- Are easy to get.
- Are there when you need them.

Sadly, carers say it is more difficult dealing with the services than it is caring for their son or daughter.

It is said that many families 'hang on' to people rather than letting them leave home. Although this may be true of some families, most would like their son or daughter to have more independence but say there is not enough good supported housing.

A break from caring.

Family Carers do not get a break. The chance for a break away from caring is something Family Carers value most. A break is good for the carer and gives their son or daughter the chance to meet other people. Breaks need to meet the cultural and religious needs of minority ethnic Family Carers.



"Just because people leave home doesn't mean they leave the family..."

The services Family Carers need are:

- Services in the home.
- More services outside working hours.
- Services that fit people's particular needs.
- Breaks of less than three hours.

Direct Payments were seen as important but people felt they wanted more information first.

Family Carers who have to go to work need to arrange care for their relative.

A voice to be heard.

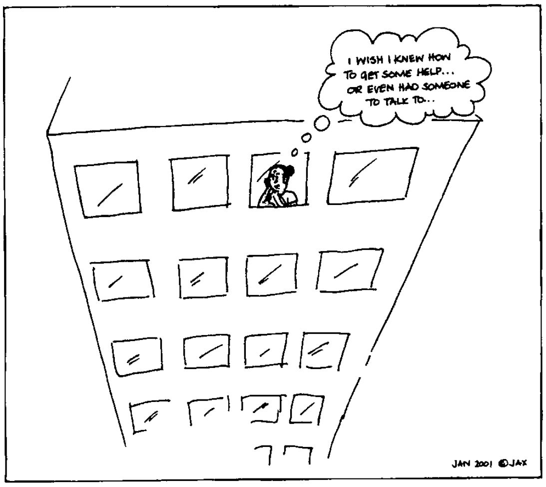
Family Carers say: "Listen to what families have to say, be there when we need help, and don't promise what you can't deliver."

Family Carers want their views and skills valued. They want to be involved in making decisions about their relative and have what they say written down in the services' plans for their relative.

They know how well the services work and should be asked what they think of them. They worry that changes in services can mean more caring duties for them.

Local authorities have to find ways of hearing the voice of 'hidden carers' - those who do not join groups or organisations. This might mean more one-to-one talks, questionnaires, use of newspapers, radio or TV and the telephone.

Authorities should tell families what they have done after talking to them.



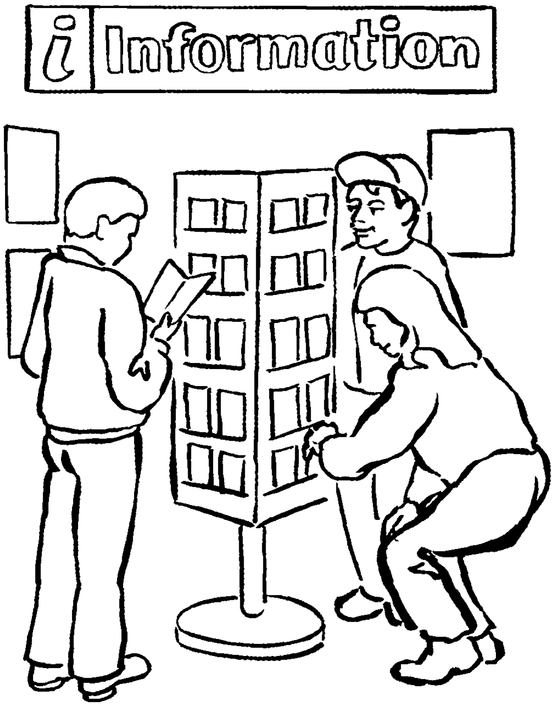
"Disadvantages of black & ethnic minority families..."

Information about rights

Family carers like having expert advice from a key worker; such staff need to be up to date.

They have problems finding out about benefits and services. They need to know how to access them and understand the rules authorities use.

Family Carers say they need one place where they can find out everything they need to know - a 'one-stop shop'.



Information should be easy to obtain. It should be available at libraries, GP surgeries, the local newspaper and through charities likely to be in contact with 'hidden carers'.

As well as leaflets, other ways of giving out information should be used such as tapes, videos and CDs - in different languages.

Assessing the needs of Family Carers

Carers often do not realise they are entitled to have their own needs assessed, some are not offered an assessment, others are refused one.

Even when an assessment is carried out, the services talked about are not then provided.

"… assessment… let's get beyond 'tick this, tick that…'"

To make sure carers' needs are included they could be linked in with the annual review of the person with learning disabilities.

GPs could help by telling Family Carers about their right to an assessment.

Assessments should include the carer's work, their many caring roles and the part they play in the whole family.

Authorities should have a system for making sure assessments are done properly and for looking at the information they provide to help them plan local services.

What should be done to help Family Carers?

More than anything else, Family Carers want better services for their son or daughter. There should be more opportunities and more choice.

Everybody with learning disabilities should have the right to an individual plan that includes what families have to say.

Family Carers want people to be supported by well-trained staff.

Services should see Family Carers as partners.

Family Carers want:

- Rights as carers.
- To get better support.
- To have their own needs recognised in new policies.
- To have one place to go to for support and information.

There should be carer support staff and services especially for the Family Carers of people with learning disabilities.

Make services better

Local Authorities should:

- Offer services giving people a real choice and clear information.
- Have a good Learning Disability Plan.

People with learning disabilities and their Family Carers should take an active part in making the Plan.

Agencies should be able to show how they include people with learning disabilities in planning their services.

Information should be collected about local needs. Standards should be agreed for the whole country to help in planning services.

There should be more contact between services and GPs.

Ways should be found to get more information to 'hidden carers'.

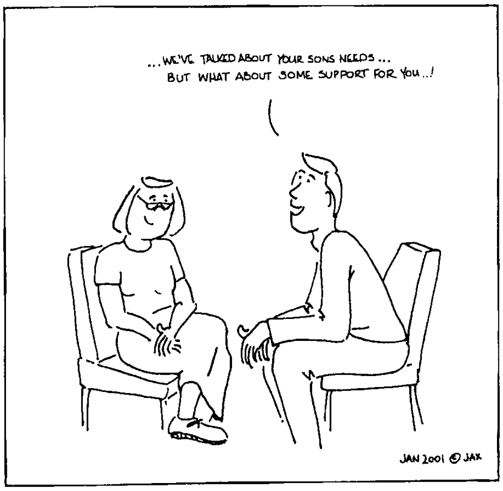
Staff should be properly trained and qualified.

Workshops should be run to look at the problems people have moving from children's to adult services, for older Family Carers and minority ethnic families.

Training courses should be open to Family Carers and people with learning disabilities.

More money should be available for advocates.

There should be more Direct Payments and voucher schemes.



"... we want dedicated family carer support..."

Involving Family Carers in plans

There should be more chances for staff to work with Family Carers as partners.

Services should set standards for good ways of involving Family Carers in their plans.

What Family Carers say should be written down in the services' records.

There should be better management of the services for people with learning disabilities.

Services should have a system to make sure people's needs are met before a crisis develops.

Review meetings, questionnaires, one-to-one meetings and group meetings could all be used to make sure 'hidden carers' are not forgotten.

Services should be able to show how they involve Family Carers and people with learning disabilities in their reviews.

People with learning disabilities who live in residential accommodation should have their needs covered by standards agreed with Family Carers.

Family Carers who take part in talks on plans and policies should be told what action is taken as a result.

As part of the local Learning Disability Plan, there should be a standard way for people with learning disabilities and Family Carers to be asked what they think about the authority's plans.

A senior manager should be specially appointed to develop and put the Learning Disability Plan into practice.

Support for Family Carers.

Family Carers should be told about their right to a Carers Assessment.

Carers' needs could be reviewed at the same time as the person with learning disabilities.

Carer support groups should be funded and supported.

Breaks from care should be available for more carers and be suitable for people with different needs. Voucher schemes, which give people more control, should be developed.

Government should make sure that:

Local Authorities do make changes. They should have to make a good Learning Disability Plan.

One agency should be responsible for making the plan and what happens as a result.

Local Authorities should find out about older carers and carers from minority ethnic communities.

We need information about services and how they are managed across the whole country.

Charges should be the same in all areas.

Local Authorities should be able to show how they are changing services.

"... multiple caring roles in the family..."

Other information

'Valuing People: A New Strategy for Learning Disability for the 21st Century.'

The Full White Paper.

Accessible version Ref 23587

Audio version on tape Ref 24543

Audio/digital CD Ref 24542

'Nothing About Us Without Us'.

The Service Users Advisory Group report to the Government.

Accessible version Ref 24485

'Family Matters, Counting Us In' by Cally Ward.

Family Carers Report to the Government.

Full version Ref 24487

'Learning Difficulties and Ethnicity' by Waqar Ahmad.

Full version Ref 24488

Accessible version Ref 24489

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