

Learning Disability Report: Older People with a Learning Disability

What help do we need to give Older People with a Learning Disability who live in Lothian?



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What is this report ?

This report is part of a bigger project looking at the type of help given to **all** people with a learning disability, who live in the Lothian area.

This report is only about **older people with a learning disability** who live in Lothian.

It is about the help that people may need to stay **healthy**.

- It tells you about help that older people can get **at this time** in Lothian.
- It also tells you the **extra** help we think older people with a learning disability need in the **future**.



Who wrote this report ?

This report was written by a group of people called the '**Older Adults with Learning Disability Group**'.

This is a group of people who think it is important that older people with a learning disability get the help they need.

Some people in the Older Adult with Learning Disability Group **work** in the health and social and voluntary services. They want to make sure they are helping people as well as they can.

One member of the group **has a learning disability**. He wants to make sure everyone understands the needs.



Why do we need this report ?

Help comes from different **services**.

We want to make sure that people are getting the **right** services, when they need them.

If not, we may need to develop **new services** to give people the right help.

This report will help people decide if we need new services for older people with a learning disability in Lothian.



The Three Big Things

There is a lot that we want for older people with a learning disability (50 years or older) or people with Down's Syndrome (40 years or older). To make it simpler, there are three big things that we want to have in Lothian.

These are:

1. A **new group** to be set up. This group will make sure the right services are planned for older people. Members of the group will be from health, social work, housing, community education, users and carers.

The group can also give advice and training to other people, who do not know as much about older people with learning disabilities.

2. Set up **new kinds of care** for older people with learning disabilities. This care includes:

In patients: People who need to stay in hospital or who need permanent nursing.

Day patients: People who come into hospital for an appointment in the day.

Terminal care: For people who are dying.

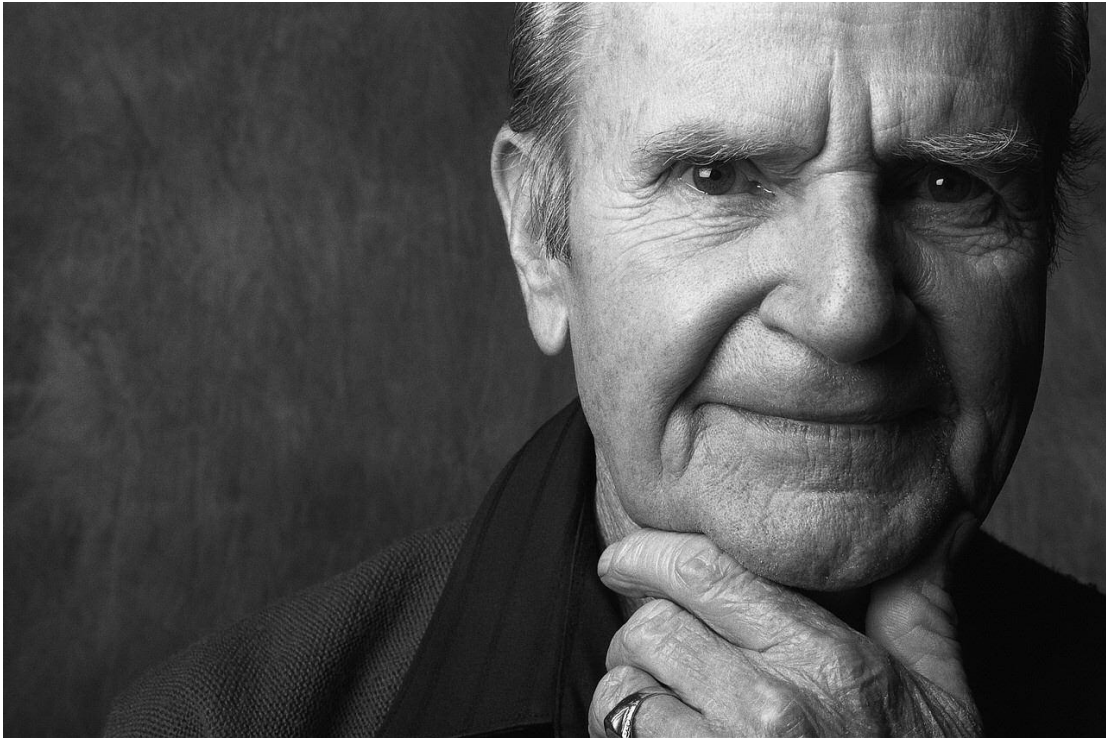
Day service & respite: Care for people during the day to give them, and their carers, a break. This is very important for people with dementia and with other physical health problems.

It is important to think what help each person **wants**, not just what help we can give them.

3. There needs to be a **new programme** set up. This will involve all the different people who work in health, social care and education.

This programme will help people to be healthy and happy. It will teach people about health. It will support people in coping with change in their life. It will help people to see their friends and do things they want to do. It will also make sure that older people with a learning disability can get to any local services that they want to.

About Older People with Learning Disabilities



Some Important things to know.

- ❖ People with learning disabilities may start to need extra help when they are **50 years old** or older. People with **Down's syndrome** may have problems to do with older age at **40 years** or older.
- ❖ We think there are up to **1500 people** in Lothian who have a learning disability and are over the age of 50.
- ❖ We are all living to an older age. There are now **more** older people with a learning disability than in the past.
- ❖ People who have a lot of physical and mental health needs are also living longer. The **needs** of older people with a learning disability are now **different** than in the past.
- ❖ We think that the number of older people with a learning disability is going to get **bigger**.
- ❖ Many people with a learning disability are still living with their family. Family members are also getting older and may need extra help.

Why do they need special help?

Older people with learning disabilities may have a number of problems as they get older. They have **different needs** to other older people **without** a learning disability. They also have different needs to **younger** people with a learning disability.

- ❖ They may have **more** physical health problems, which makes it harder to see, hear or walk around.
- ❖ They may also have **more** mental health problems, which make it harder for them to feel happy or to make sense of things going on around them.
- ❖ Some people with a learning disability have Down's Syndrome. These people are more likely to develop **dementia** – especially once they are over 50 years old.
- ❖ People who have Down's Syndrome and dementia may be a lot **younger** than other people with dementia. They will have **different needs** to other people with dementia.

Dementia.

Dementia is a disease. People with dementia can find it harder to remember or understand things. They may find it harder to do all the things they used to in their life.

A person with dementia and a learning disability does **not** have the same problems as other people with dementia.

- ❖ Dementia does not affect everyone in the same way. In people with Down's Syndrome, dementia can have a **big effect** very quickly. It can also cause other problems like epilepsy.
- ❖ People with a learning disability may already find some things confusing. Dementia can make the world even more **confusing**. It can also make it hard for other people to know how someone is feeling.
- ❖ Each person with a learning disability is **different**. They find some things easy and other things hard. If someone also has dementia, their needs are **not the same** as other older people with dementia.

Other Important Needs.



❖ Friends and Activities

Many older people still want to see their friends and to do things they enjoy. It is important that they can still do this as they get older.

Many older people with a learning disability find it difficult to meet people and to see friends as much as they want to.

There may be nowhere for them to go to meet friends. They may find it hard to travel to places if they live a long way away.

❖ Coping with Change

When we leave school there is lots of change in our lives. When we are older there is also lots of change. Our bodies change and we may not be able to do all the things we used to do.

Older people with learning disabilities may need help to get used to these changes.

They may also need help to do new things which make them happy as they get older.

❖ Death

We all get older and eventually die.



It is important that older people with a learning disability are given help if someone they love dies.

It is also important that they are given help during the last part of their own lives, before they die.

❖ Family carers

Carers who look after people with learning disabilities may also need some help.



They may be getting older and may find it harder to look after somebody else.

Carers are more likely to have certain physical health problems. They may also get very tired, sad and feel worn out.

Many carers do not ask for help. They may not know who to ask for help.

It is important that we think about family carers needs in this report, as well as the people they care for.

Services for Older People with a Learning Disability in Lothian



Things we should be doing.

The **National Health Service** in Scotland has said what things they think are important for older adult services.

These important things are called **NHS Quality Indicators**.

These Quality Indicators say:

- ✓ As we get older, we may need **different** types of help.
- ✗ This does **not** mean that older people should have to '**stop and start**' services. This could be very confusing for people.
- ✓ Health services should **work together** to help people with the **changes** that happen to them as they get older.
- ✓ It is very important that people with a **learning disability and dementia** get the right sort of help.

These Quality Indicators were checked in 2005. This is what the Inspectors found :

Things we are doing now in Lothian

- ✓ There is a **doctor** in Lothian who knows a lot about older people with learning disabilities. This doctor helps other doctors and Community Learning Disability teams who help look after people with learning disabilities.
- ✓ There is a **guide** for carers called the '**Older People's Health Checklist**'. This reminds carers of things to check about older people with a learning disability.
- ✓ Nurses called '**Hospital Liaison Nurses**' help people with a learning disability if they need to go into hospital, or be moved from one hospital to another. These nurses work with Medicine of the Elderly services if the person is over 65 years old.
- ✓ It is important to know if somebody has **dementia**. People with dementia may need extra help. Psychologists in Lothian help to check if people have dementia.

What else do we do in Lothian ?

- ✓ People with learning disabilities and dementia can sometimes get medicine that helps for a while.
- ✓ An older person with learning disabilities in the Learning Disability Inpatient Services can get an advocate, to help them tell other people what they think.
- ✓ There is a project in Edinburgh called **Caring for Older People in Edinburgh (COPE)**. This provides a day service for people with a learning disability and dementia.
- ✓ There is also the **Older People with Learning Disability Group** in Lothian. This group looks for ways to help older people with a learning disability.
- ✓ There are also teams called the '**Community Learning Disability Teams**'. These teams help people with learning disabilities to get on with their lives. They help them feel healthy and happy. These teams help people of all ages with learning disabilities.



What else do we do in Lothian ?

- ✓ People who look after older adults with learning disabilities are called **carers**. Carers can sometimes be a family member or a friend. It can be tiring to look after somebody. There are some services in Lothian which help to give carers a rest. These are called **respite services**.
- ✓ There are a few people in Lothian called '**Local Area Co-ordinators**'. Their job is to help people get the right help from services in their area.



What we are not doing in Lothian

- ✘ Older people with learning disabilities may not get the **same type** of help all over Lothian.
- ✘ There are no special inpatient services for people with learning disabilities over 65 years of age.
- ✘ There is **not enough help** for people with dementia and learning disabilities. The COPE project can only look after a small number of people. Other people must wait to get help.
- ✘ The COPE project can only help some people with dementia. If people's **needs change**, COPE may no longer be able to help them. They may need a different **type of care**.

What we are not doing in Lothian

- ✘ It is difficult in Lothian to get **respite care** for somebody with learning disability and dementia if they have never used it before.
- ✘ A lot of the health workers in Lothian help **all** people with learning disabilities. There is not a lot of **special help** for **older** people with learning disabilities.
- ✘ There is not enough **training** about learning disabilities and dementia.



What services do we need in Lothian ?



What should an older person expect from a service ?

We think that there are some things that older people with a learning disability should **expect** from their services.

- ☑ They should be **well designed** and **right** for people of that age.
- ☑ The same **amount of choice** as other older people with **no** learning disability.
- ☑ The same amount of choice as **younger** people **with** a learning disability.
- ☑ A service which **suits** the person.
- ☑ Support from people who **understand** their needs.
- ☑ To be treated with **respect**.



What help should we be giving ?

Person Centred Plans

We are all different. People should be able to choose what kind of help they need throughout their lives. This is called **person centred planning**.



We think person centred plans are important. They make sure people get the help they want and need. We would like to see person centred planning in place with regular reviews for older people with learning disabilities across Lothian.

Staying Healthy & Happy

It is important that we do not wait until people are ill before they get help. There are things which can help people to stay healthy. Seeing our friends, exercising and being able to go out and do things that we enjoy, can all help us feel happy and healthy.

It is not always easy for older people with learning disabilities to do these things. We think it is important that someone can help them with this.

It is important to think about how people can get to useful services. If people live away from the towns, they may not be able to use services that they need.

Day Services

We think there needs to be more good day services for older people with a learning disability.



COPE is a good service for older people with a learning disability who have dementia. Some may want to be in a place they know well. They also may not like change.

Help for Carers

We think that help is needed for older family carers. They may need extra help quickly.

There needs to be enough services to help give carers a break. Some people with dementia do not sleep very well. Their family carers can get very tired and need help.

Housing Planning



A lot of people do not like moving house. It is harder to cope with moving house when you are older.

We think it is important that people with a learning disability have a house that they can still live in as they get older and if their needs change.

It is also important to think about the people that are sharing a house with someone. If someone gets dementia, they may not be able to share a house with people who have very different needs.

Health Needs

Older people with a learning disability may have **special health needs**.

It is important that carers understand how older people with a learning disability can **stay healthy**.

Nurses, health care workers and family carers need to learn about these special health needs. They can then know if someone is not healthy and arrange treatments.

Mental and Physical Health Needs.

Older people with a learning disability have health needs of the body.

They also have mental health needs to do with the health of their mind.

It is important that any health services help with both of these types of need.



Help with getting older.

We think it would be useful for people with learning disabilities to learn about some of the problems they may face as they get older.

They may need help to solve these problems.

Getting the right help

It is important that older people with learning disabilities get the right help. This means staff need to be trained. We also need to make sure their skills are maintained in the long term. Care packages need to be flexible, including day services.

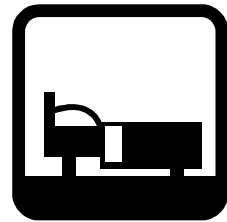
Dementia Testing

It is important that we know if someone is getting dementia.

We can get this information by doing some tests to see what people can do when they are younger. We do the same tests again when people get older.

It is important that we do these tests on people with Down's Syndrome who are aged between 30 and 40 years of age.

Inpatient beds and day services



There are some services available for younger people with a learning disability, such as inpatient beds and day services.

We think that people with a learning disability who are older than 65 should also be able to use these services.

There needs to be a place where older people with a learning disability can come and stay, if we do not yet know what help they need. This would be an inpatient service for older people.

This is very important for older people who may have dementia but no one is sure yet.

An inpatient service would mean that nurses and other health workers can tell what problems a person has. They can then make sure they get the right help.

Support for Dying

It is important that older people with a learning disability who are dying are receiving the right care.



Care for people who are dying is called **palliative care**.

Older people with a learning disability should get the same kinds of palliative care as other people. This should include the choice of staying in their own home with care provided there.

It is important to make sure that palliative services in Lothian can help older people with a learning disability. We think someone should be given a job to do this.

Residential / Nursing Homes

Some older people with learning disabilities will need a lot of help for the rest of their lives. It is important that all the services think about what someone may need **now**, and in the **future**. If someone has dementia or a serious illness their needs may change.

Older people should not have to switch services as they change. We think there is a **big need** for nursing care which helps someone as they change.

There needs to be a special nursing home where nurses and other health workers understand how best to help each person as they change.



Specialist Learning Disability Team

We think it would be very helpful to have an extra team of people who know a lot about older people with a learning disability.

This team could help to teach and support staff in the community learning disability teams. This would be called a **specialist learning disability team**.

Bigger Community Teams



As people get older they may need more help to walk, to speak and to eat. Different types of people with different jobs can help with all of these things.

These people work in ‘community learning disability teams’. They help people of all ages with a learning disability.

The community learning disability teams are already busy helping lots of people. There needs to be more staff in the community teams to help older people with a learning disability.

Managed Care Network

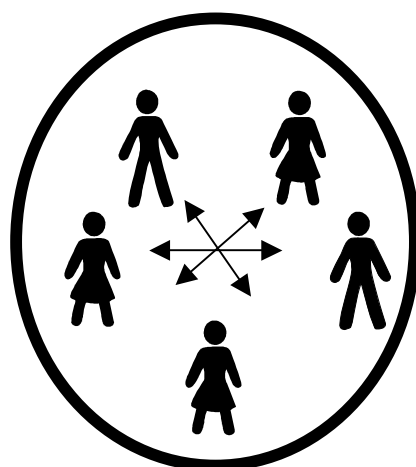
Another idea is to set up something called a 'Managed Care Network'.

A Managed Care Network is a group of people who do not work in the same place, but they all understand about older people with learning disabilities.

These people could help to train people in their area to help them understand about older people with learning disabilities.

To set up a Managed Care Network we would need more money and at least one more job.

This job would be to help to set up and run the Managed Care Network.



What services should we offer ?

This is a summary of what we want:

- ❖ **Planning for the future.** Making sure we think properly about somebody's needs – now and in the future. We need to make sure we think about health, home, education and social needs together. One thing can affect the other thing.
- ❖ **Understanding health.** We need to make sure older people with learning disabilities and their carers understand about health and are doing everything they can to stay healthy.
- ❖ **Types of services.** We need to make sure that we can help people in inpatients, outpatients or day services. We should be helping all the people who need our help.
- ❖ **Friends and Fun.** We need to make sure people can keep in touch with friends and can still do the things they like doing as they get older.

What services should we offer ?

- ❖ **Day Care.** It is important that there is a good day service for older people with learning disabilities. This needs to be able to help as many people as possible. Staff who work in this service must understand the special problems that older people with learning disabilities have.
- ❖ **Help for Carers.** There is a need to help family carers. They may not always know who to come to ask for help. We need to make sure carers know who can help them and how they can help. They also should be able to have a break if they need it.
- ❖ **Dying.** There is a need to help older people who are in the last stage of their life and may soon die.
- ❖ **Specialists.** We need to have staff who know a lot about older people with a learning disability. These staff can share what they know and make sure we are giving people the best care and help possible.