



# Your right to independent living

What you said about our plan for supporting disabled people to live an independent life.



This is an easy read version of Welsh Government's **Action on Disability: The Right to Independent Living Consultation - Summary of Responses**

September 2019

# How to use this document



This is an easy read version. The words and their meaning are easy to read and understand.

You may need support to read and understand this document. Ask someone you know to help you.

Some words may be hard to understand. These are in **bold blue writing** and have been explained in a box beneath the word. If the hard word is used again it is in **normal blue writing**. You can check what it means on page 31.



Llywodraeth Cymru  
Welsh Government

Where the document says **we**, this means the **Welsh Government**. For more information contact:

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This document was made into easy read by **Easy Read Wales** using **Photosymbols**.

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# Introduction



In 2018 we asked people what they think about our plan called:

## Action on Disability: The Right to Independent Living Framework and Action Plan.



You can read this plan here: [gov.wales/action-disability-right-independent-living](https://gov.wales/action-disability-right-independent-living)



We want this plan to help us support disabled people to live an independent life.



We held meetings and events to find out what people thought. And we asked people to read our plan and answer questions in a response form.



We got 67 response forms. This document is about people's answers to the questions in the response form.



There is a long list of other comments that people gave us. You can read these on pages 55 to 74 of the main report:

**Welsh Government Consultation - Summary of Responses. Action on Disability: The Right to Independent Living.**



You can read the main report here: [gov.wales/  
action-disability-right-independent-living](https://gov.wales/action-disability-right-independent-living)

# What people said

In reply to almost every question, people told us that:



- We need to work **co-productively** with disabled people when we carry out the plan.



**Co-production** means people who use services are included in all decisions. They are seen as equal partners with professionals.



- All our services should work together to make the plan happen. For example, health services should work with social care and housing. We should include the **third sector** in this too.



The **third sector** is the name for all organisations that are:

- set up to help people and places
- not part of the government
- not businesses.

Like charities, community groups and social enterprises.



- The plan should do more to make sure we meet people's different needs. For example, people with mental health problems will have very different needs to people with physical disabilities.



- We should think about how to share the new plan with everyone. So they can have a say and make it happen.

## Question 1

**Do you agree with our plan for supporting disabled people to live an independent life?**

**People said:**



- It is not clear what the plan means by independent living. For lots of people it means somewhere to live and support to live there. But the plan is about more than that.



- The actions in the plan need to be clearer. They should say:
  - › What should be done.
  - › Who is in charge of making sure it is done.
  - › How long it should take to get each action done.
  - › How we can tell if an action has worked or not.



- We should have written a children and young people's version of the plan. So they could have more of a say. And we should have a plan especially for children and young people. Because their issues are not fully covered in this plan.



- It is good that we are basing this plan on the **social model of disability**. But 1 person said that we have made it sound like this is a new idea. The model is over 40 years old and it has been used in our laws for 13 years. It is not ok that we are still talking about how to use it.



The **social model of disability** says that people are disabled by barriers in society. And not by their health condition or difference. Barriers are things like not being able to get into buildings or get information in a way you can understand.



- We should think about whether the **social model of disability** needs updating. We should change it a little so it becomes more based on human rights.



## Question 2

**How do we get organisations and communities across Wales to support the plan and work on the plan?**

**People said:**



- We must think about how we share the new plan with everyone. We need to make sure people have a say in the plan. And also know about it so they can make it happen.



- We must make sure everyone understands the **social model of disability**. And that everyone understands their rights and responsibilities.



- We must make sure there is money for charities and groups led by disabled people. So they can be involved and help deliver the actions from the plan.



- All plans written by **public bodies** should include the actions from this plan.

**Public bodies** are organisations that get money from Welsh Government to run services for people in Wales.

## Question 3

**How can we help disabled people to lead a healthy and full life where they participate in their communities?**

**People said:**



- There is less money for support now. We must make sure we can carry out this plan with the money we have.



- There is no information in the plan about where the money will come from to carry out the actions. This is worrying.



- We should promote the **Access to Work Mental Health Support Service** along with the **Access to Work in Wales** programme.



- This plan works well with the **Employability Plan**. Together both plans will help disabled people get and keep paid work.



- Having a Welsh disability award scheme for employers is a good idea. It would help to make work places more inclusive. But we need to make sure this really works.
- We should keep on supporting disabled people to find paid work by doing things like:



- › Carrying on funding the **Engage to Change** model of supported employment.



- › Making sure disabled people have a fair chance to get training and paid work.



- › Supporting disabled people to use the job centre.



- › Thinking about topping up people's wages with benefits. So people are not better off not working.



- The action plan should focus more on how **assistive technology** can help disabled people live independent lives.

**Assistive technology** is equipment to help you do things for yourself. For example a hoist to lift you out of bed or a computer to help you speak.



- The plan should say that people miss out on things when they do not have the information they need.

## Question 4

**How can we help disabled people learn the skills they need through their life to get a job?**

**People said:**



- Education is very important. The action plan needs to say more about schools.



- We could have an action about **inclusive schools**. And about the information and advice we give learners about education after the age of 16.

**Inclusive schools** are schools where everyone can go to learn, whatever their needs are.



- We need to be clearer about what we will do to support disabled people to get education after the age of 16.



- The new **Additional Learning Needs** law will help everyone get education and skills. Especially because **Individual Development Plans** will last up to the age of 25.



- There needs to be better options for adults to learn part-time. And we need to make sure disabled people can easily use buildings where part-time courses happen.



- We need to support disabled children to have bigger dreams for their future. And give better support to help them get the qualifications they need to do it.



- We should make sure there is money for learning aids. For example tablets, computers and courses. There should also be money for career advice and advice for employers.



- **Apprenticeships** are very important. We need to do more work to support disabled people to get **apprenticeships**.

An **apprenticeship** is when a person learns the skills of a job whilst working.



- It would be good to include actions from **Apprenticeships: Disability Action Plan 2018-2021** in this plan.



- We must make sure that we include people with learning disabilities in the **Disability Champions network**.



- We should set targets for how many disabled people should be in paid work and how many should get **apprenticeships**.



- Employers need training about hiring disabled people. And about what support is available.



- We need to do more to support young disabled people who are about to become adults. We should support them to have big goals, to be confident and to gain skills.



- We need better information for disabled people and for employers.

## Question 5

**How can we help disabled people to live in a home that suits their needs?**

**People said:**



- The plan should say something about what we will do to get more **accessible** housing.

**Accessible** means easy to find, get to and use.



- In 2013 we said we would keep a list of **accessible** housing. But this is missing from the action plan.



- There is not enough affordable housing. More needs to be done on this. People do not have enough choice at the moment and this causes lots of problems.



- More money should be given to organisations so they can give disabled people information and advice on housing and benefits. This information needs to be up to date. And easy for people to get and use.



- We also need to provide better information about how housing affects people's **well-being**.

**Well-being** is anything to do with your health and happiness.



- We need to work with housing providers and councils to make the system for improving homes better. We should be able to tell them what problems people are having.





- The bedroom tax needs to be clearer. Or gotten rid of.



- Disabled people and their carers need to be involved in the design of changes to housing. From start to finish.



- And we need to think about the needs of people with mental health problems in plans to adapt homes.



- We should have an action that supports disabled people to make a complaint about their landlord. Landlords should be held responsible for the homes they provide.

## Question 6

**How can we get social services and health services to support disabled people to lead an independent life?**

**People said:**



- The money we have to provide health and social care should come from 1 place. There are too many arguments about who should pay for what support. And this sometimes means money is not spent as well as it could be.



- We need to help disabled people, families and support staff to learn about **assistive technology** so they can use it more. We need to do this in a way that gives people choice and control. We should give more money to support this.



- It is hard to get money for ongoing needs. The plan should say how we will make sure disabled people keep getting the support they need to live independently in the community. Especially now that we have stopped the **Welsh Independent Living Grant**.



- We should support the use of **advocacy** more. **Advocacy** should empower and support people.

**Advocacy** is when someone speaks up for you and helps you say what you want to say and get your needs met.



- We should do work to get more people working in social care.



- We need to change attitudes towards people who support disabled people in paid work. At the moment they are not paid well or valued.



- We should join up health and social care training courses. And make sure all health staff learn the **social model of disability**.



- We should add an action to the plan to check NHS staff are still doing the **Treat Me Fairly** training.

## Question 7

**What more can we do to improve accessibility of transport and meeting places for disabled people?**

**People said:**



- We should encourage people who work on public transport in Wales to do disability equality training. This training must include all types of disability. Including learning disability and autism.



- We need to work with the public to help make public transport more **accessible**. And to stop **discrimination** of disabled people on public transport. We could run an awareness raising campaign.



**Discrimination** is when you are treated badly or unfairly because of something like disability.



- We should do more to hold transport providers responsible for how **accessible** their services are. And we could do more to encourage transport providers to be more **accessible**.



- We should keep the lower bus prices scheme for disabled people. And work with councils on the way they decide who gets a free disabled bus pass. All councils should be working in the same way. It would be good if free bus passes could also be used on trains.



- Often there are not enough buses and trains running in the countryside. This means disabled people living there cannot fully take part in their communities. **Community Transport** is really important in these places. We must keep supporting it.



- We would like all new buses to be able to give information using sight and sound. For example videos and recorded voice messages.



- Bus and train stations should have information in Braille and other **accessible** formats. Any changes to services should be told to people in an **accessible** way.

## Question 8

**Is there anything else you think we should be doing to help disabled people?**

**People said:**



- Loneliness and **social isolation** is a big issue for disabled people. We should have an action that links to the plan: **Connected Communities: Tackling Loneliness and Social Isolation.**



**Social isolation** is when people find it difficult to meet other people. This might be because of where they live or because they have difficulty getting out and meeting people.



- Disability organisations should try to hire staff with experience of the issues they are working on.



- In school we should learn about respect and stopping abuse and **discrimination**. Parents should learn about these things too.



- UK Government should make the **Equality Act** better at protecting the rights of disabled people and people with mental health problems in paid work.



- There should be more done for **Deaf British Sign Language** users. It would be good to have a **British Sign Language Law**. Like in Scotland.



- We have lost many **advocacy** services because of cuts to money. This has meant that councils are paying for general **advocacy** services that do not know enough about the issues that affect disabled people.



- This plan should include the right to good **advocacy**. Especially for parents with learning disabilities who need **advocates** who know about learning disabilities and about child protection laws.



- Disabled people cannot keep getting **Direct Payments** when they start getting **Continuing Healthcare**. We need to work with Health Boards to think about how disabled people can keep control over their care.



**Direct Payment** is money you can be given instead of a service. You can use it to buy your own support and services.



**Continuing Healthcare** means the NHS will pay for your ongoing care and support. The care and support is free.



- We must make eye care services better. They must be easy to find and use. And we should find out if people have eye conditions quicker. Otherwise people are at risk of losing their sight.

## Question 9

How do you think our plan helps or stops people to be able to use Welsh? What more can we do?

People said:



- There is nothing in the plan about the Welsh language. And it does not link with the plan: **More than Just Words** for giving services in Welsh and English. We must make links to this plan throughout all our actions.



- All information must be in Welsh and English. People should not have to ask specially to get information in Welsh. We should think about the cost of this.



- We need to make sure there is support for disabled people to learn Welsh. The courses should be accessible. And the buildings they are in should be too.



- There should be support for disabled parents who want to send their children to Welsh language school. But who find it difficult to get to because it is far away.



- We should help service staff to learn Welsh so they can give services in Welsh and English. There are no actions in this plan to help with this.



## Question 10

Do you want to say anything else that we have not asked about?

People said:



- We must show we understand all different types of disabilities. Including disabilities or serious illnesses that you cannot see.



- We must treat people with learning disabilities as active and equal members of our society.



- There is nothing in the plan to support adults with autism. Often adults with autism go without support.



- This plan does not show an understanding for the issues faced by **Deaf British Sign Language** users. Many **Deaf British Sign Language** users miss out on information. And find it hard to get services and the knowledge they need to be independent.



- The plan does not talk about the stress and fear caused by cuts to money.



- People are worried that their benefits will be stopped or changed because of volunteering or other types of work. This is stopping people from doing these things. And lots of people find it very stressful to claim benefits in the first place. We need to do more to support these people.



- There should be 1 person who plans healthcare for people who have complex health needs.



- Pathways to getting health and social care should be made clearer for everyone.



- We should look into the cost of different therapies like massage, acupuncture and yoga. These types of therapies may help save money long term. It would be good to have a system like [Direct Payments](#) for health care.



- There should be more money to have school nurses.



- There should be **menstrual well-being** classes in schools. They should be taught by someone with experience who is comfortable teaching it.



**Menstrual well-being** is about periods – this is when girls bleed each month. It covers what to expect and how to tell if something might be wrong.



- Disabled people and people with different health conditions should be invited into schools to talk about their lives. Pupils must see and know about different types of people. These people should be paid for their time.



- Money is a big issue. We should look at how we give charities money to support disabled people. Lack of money should not be used as an excuse by services for not giving disabled people the support they need.

# What has happened since our last plan for independent living in 2013

In the main response form people were asked what has happened since 2013 that should be included in the plan.

People said:



- There have been improvements to public transport.



- The law for additional learning needs has changed.



- The **Social Services and Well-being (Wales) Act** has been important for disabled people. But we need to check if it is making a difference.



- **NHS England** started the **Accessible Information Standard**. Health services in England must follow this. We should have the same.



- There have been changes to money. The **Welsh Independent Living Grant** has been stopped. More people are using **Direct Payments**.



- The **Welsh Government Learning Disability - Improving Lives Programme** started in 2018.



- Services for adults who are **diagnosed** with autism late in life are not what was promised.



**Diagnosed** means a doctor looks at a person's health and behaviour and decides if they have a condition or not.



- Welsh Government gave money to start the **Engage to Change** project. To help 16-25 years old with learning disabilities and autism find paid work.

## Next steps



Thank you to everyone who gave us your views.



We have made changes to our plan and actions thanks to what you have said.



We will keep working on our action plan. And keep thinking about all the things people have told us.



The final version of **Action on Disability: The Right to Independent Living and Action Plan** will be out in September 2019.

# Hard Words

## Accessible

Accessible means easy to find, get to and use.

## Advocacy

Advocacy is when someone speaks up for you and helps you say what you want to say and get your needs met.

## Assistive technology

Assistive technology is equipment to help you do things for yourself. For example a hoist to lift you out of bed or a computer to help you speak.

## Apprenticeship

An apprenticeship is when a person learns the skills of a job whilst working.

## Continuing Healthcare

Continuing Healthcare means the NHS will pay for your ongoing care and support. The care and support is free.

## Coproduction

Coproduction means people who use services are included in all decisions. They are seen as equal partners with professionals.

## Diagnosed

Diagnosed mean a doctor looks at a person's health and behaviour and decides if they have a condition or not.

## Direct Payment

Direct Payment is money you can be given instead of a service. You can use it to buy your own support and services.

## Discrimination

Discrimination is when you are treated badly or unfairly because of something like your disability.

## **Inclusive schools**

Inclusive schools are schools where everyone can go to learn, whatever their needs are.

## **Menstrual well-being**

Menstrual well-being is about periods – this is when girls bleed each month. It covers what to expect and how to tell if something might be wrong.

## **Public bodies**

Public bodies are organisations that get money from Welsh Government to run services for people in Wales.

## **Social isolation**

Social isolation is when people find it difficult to meet other people. This might be because of where they live or because they have difficulty getting out and meeting people.

## **Social model of disability**

The social model of disability says that people are disabled by barriers in society. And not by their health condition or difference. Barriers are things like not being able to get into buildings or get information in a way you can understand.

## **Third sector**

The third sector is the name for all organisations that are:

- set up to help people and places
- not part of the government
- not businesses.

Like charities, community groups and social enterprises.

## **Well-being**

Well-being is anything to do with your health and happiness.