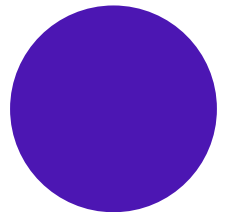
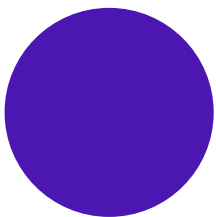
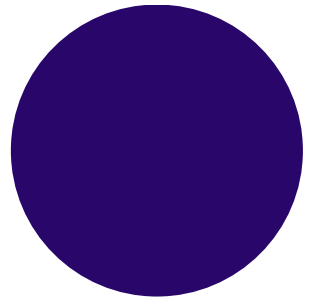
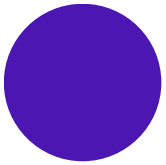


# RIGHTS NOW

POWERED BY ENABLE



A report by



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## Snapshot Survey Results

**97%** think there should be a commissioner role created to make sure people have their rights upheld.

**54%** found it hard to access social care support they needed

**52%** found it hard to access health services.

**49%** have had problems finding out what benefits they are entitled to.

**42%** have experienced money problems in the last year.

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# Forewords

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Enable members have campaigned for decades for a society where they have equal rights and opportunities in Scotland. As a member of Enable for over twenty years, I know how much this means to our members, but the results of this survey - which so many of them took part in - show how far we have to go. Too many people with learning disabilities still don't get fair chances at school or in work, and too many feel isolated and not truly included in their community. We need to change this, and that is why I'm proud to be Convener of Enable's Scottish Council as we launch this important campaign for our **Rights Now!**



**Ivan Cohen**  
Convener,  
Enable Scottish Council

Enable believes in an equal society where everyone has the right to live, work and participate as active and respected citizens. This mission inspired the families who founded the charity in 1954, and today drives our provision of social care, employability and community support. Every day we support people with learning disabilities to secure their rights.

We know our campaign for rights needs to go further. Too many people with learning disabilities still do not receive the social care in their community which should be their entitlement; employability services which could give them the opportunity to contribute to successful, inclusive workplaces; or the support they need at school for fair chances in education.

We are pleased the Scottish Government shares our view that new legislation is needed to protect and promote the rights of people with learning disabilities. We are pleased to support Enable members as they lead the **Rights Now!** campaign. We will work with them for a Bill which secures meaningful progress towards a Scotland where the rights of people with learning disabilities are recognised, respected and made real.



**Theresa Shearer**  
CEO  
Enable

We are pleased to be able to support Enable in launching the **Rights Now!** campaign for a more inclusive society for people with learning disabilities in Scotland. Our mission at Acorns To Trees is to help make community vision a reality. We believe an important aspect of that vision is to support the integration of Adults with Learning Disabilities within the community, so they are truly included, have the opportunity to lead fulfilling lives and make their own contribution to our society.

We're delighted to be supporting Enable in their work to mobilise the learning disability community to make change happen, with an important focus on the Scottish Government's proposal for new legislation to protect their rights. We hope this will make a real, positive difference for people with learning disabilities in Scotland.



**Bill & Fiona Gordon**  
Founders  
Acorns to Trees

# Rights Now!

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**Enable members have been campaigning for decades for new laws to protect and promote their rights.**

Ahead of the Scottish Parliament elections in 2021, Enable, National Autistic Society Scotland and Scottish Autism joined in the Our Voice, Our Rights campaign calling on political parties to commit to a commissioner for people with a learning disability and autistic people.

We are pleased the Scottish Government has committed to introducing a Learning Disability, Autism and Neurodiversity Bill in this Parliament. We believe this Bill needs to set out sufficient powers to protect rights and establish a Commissioner role to work with public bodies to promote the human rights of people with learning disabilities. This should include powers of investigation when these rights are not being respected and fulfilled, the power to take legal action when people's rights are breached and the power to make recommendations to the Scottish Parliament on what actions are needed so these rights are always upheld.

**Rights Now!** has been launched to ensure the new Bill really does make a difference to the lives of people with learning disabilities, and addresses the issues they believe are most important. That is why we have asked for their views in this survey, as well as their families and people who support them, on what needs to be included in the Bill.

**Rights Now! is powered by Enable and led by people with learning disabilities.**



# Facts and Figures

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Research from the Fraser of Allander Institute shows that people in Scotland with a learning disability live on average 20 years less than people who do not have a learning disability

**20**  
**years**

**2 x**

Research from the Scottish Learning Disability Observatory shows that adults with a learning disability are twice as likely to die from preventable illness.

There are an estimated **175,000** people with a learning disability in Scotland



**7%**

The percentage of people with a learning disability in Scotland who are in employment is 7%. The percentage for people without a learning disability in employment is 76%.

Enable was founded in 1954. Our charity has been campaigning for the rights of people with learning disabilities and their families for almost 70 years.

**1954**

**11,000**

Enable Communities, Enable Works and Enable Cares support over 11,000 people every year in Scotland.

# A Bill to Make Rights Real

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**Scotland has a proud record of establishing human rights in our laws, and we know the Scottish Government want to do even more to enshrine rights in Scots Law.**

Enable welcomes this commitment, but too often the rights set out in law are not being made real for people with learning disabilities. The findings of our survey show that we have much to do to ensure our social care, our public services, our education and employment systems, and our communities are genuinely inclusive for people with learning disabilities.

We are pleased that the Scottish Government is involving people with learning disabilities and autistic people as it develops its proposals for the Bill. Enable is determined the Rights Now! campaign will be led by people with learning disabilities and based on their views and experiences. That is why we carried out this survey.

We have found a wide range of ideas and opinions about what should be in the Bill. People have told us that they want the Bill to:

- **Protect their rights and ensure they have the support they need, nationally and locally.**
- **Provide a route to challenge public bodies when this doesn't happen.**
- **Ensure they have accessible information and advocacy, so they can be their own champions for their rights.**
- **Encourage the provision of local services and activities which enable them to be included in their communities - not isolated or lonely.**

There was strong support for a Commissioner role. People wanted the Bill to set out what support they should have so the barriers they face to their rights being fulfilled are overcome. They wanted this role to be a strong national voice which will be heard.

This Bill provides a once in a lifetime opportunity to protect and enhance the rights of those with a learning disability. People with learning disabilities have waited too long for equality and are now calling for action to achieve their **Rights Now!**

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## What should the Bill give people?



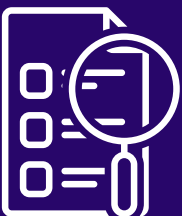
**The right to self-directed care and support**



**The right to inclusive education and employment.**



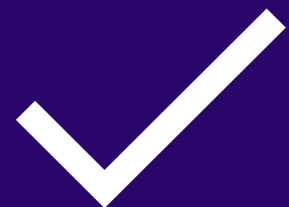
**The right to be included and respected in the community.**



**A Commissioner role to hold public bodies accountable to these rights.**



**RIGHTS  
NOW**  
POWERED BY ENABLE



# Peter's Story

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## **My name is Peter McMahon.**

I am an ENABLE Scotland member from Glasgow and I have been an active campaigner for people with learning disabilities for over 40 years.

I have been campaigning for so long because it is important to me, that people like me, with learning disabilities are able to live their lives how they chose, just like anyone else.

No one should be disadvantaged just because they are different.

I am passionate about making sure people with learning disabilities are included in communities and aren't excluded. That things are accessible for people with learning disabilities, and no one is left behind!

I have produced campaign videos called my Life and My Life 2 on anti-bullying. This is something I am passionate about and I want to share my own experiences to hopefully help others. No one should ever be bullied just because they have a learning disability.

I don't think anyone should be treated differently just because they have a learning disability! I have done a lot, but I feel like not enough has changed over the years.

The Bill is our chance to make sure people like me with a learning disability are able to live their lives how they want.

## **My experience**

I have experienced difficulties in my life just because I have a learning disability!

I have experienced bullying because I have a learning disability.

When I was born you were known as uneducable just because you had a learning disability. You were seen as unacceptable in school.

People are mean because they don't understand that it is okay to be different. More can be done to educate people on what it means to have a learning disability.

I think things need to be more accessible for people with a learning disability. We should be able to do all the things anyone else does with the right support.

No one should be treated unfairly just because they have a learning disability. Now is the time for change.



# Why I think a Bill is Needed

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## Heather Gilchrist, Enable Ambassador

Life for people with a learning disability will be better if we have a strong learning disability, autism and neurodiversity Bill. For those of us who have been campaigning for change for so long, we are pleased to have this chance to make a real difference for our rights.

### **It is our big opportunity to make this a reality.**

Our members got involved with the Our Voice Our Rights campaign because we wanted to make sure that everything we had campaigned for, the things we had been part of achieving, were protected by law. It is so important that our rights are protected by law, as this means it cannot be taken away!

The Bill is an opportunity to secure our rights to make sure that we are treated as equals within society.

We have campaigned for this for decades because it is the only way we can make real progress and achieve an equal society for everyone.

The Bill is an opportunity to change lives for people with a learning disability and autistic people.

It can provide support for people with learning disabilities and others to:

- **Access self-directed care and support.**
  - It is important that people have the right to choice and control over the support they need.
- **Enter the workplace.**
  - We should have a right to the support we need to get into work and to stay in work, and employers should be required and supported to offer inclusive workplaces.
- **Be included and respected in the community:**
  - People with a learning disability should be able to choose where they live, and have a right to be active, connected and engaged citizens in their community. No-one should be moved away from their friends and family.

**"My rights, my friends' rights and the rights of every person with a learning disability in Scotland must be protected in law. We need to make sure we get this Bill in place to do that."**



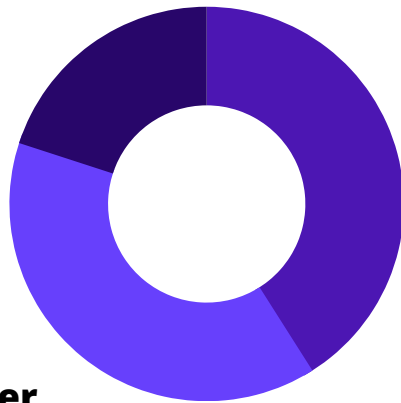
# Our Survey

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# 629 survey responses



**Supporter**  
**20%**



**People with learning disabilities**  
**41%**

**Parent / Carer**  
**39%**

**People could choose to answer as many questions as they wanted to. The figures in this report are based on the responses to each question.**

We wanted as many people as possible to take part in our research for this survey. We used a variety of methods of consulting people so that our survey was accessible and we reached people across Scotland.

We held four focus groups for people with learning disabilities and their families. Our focus groups met in:

- **Edinburgh**
- **Glasgow**
- **Ayr**
- **Elgin**



We promoted the survey by emailing Enable members and supporters and giving them the opportunity to fill in the survey online.

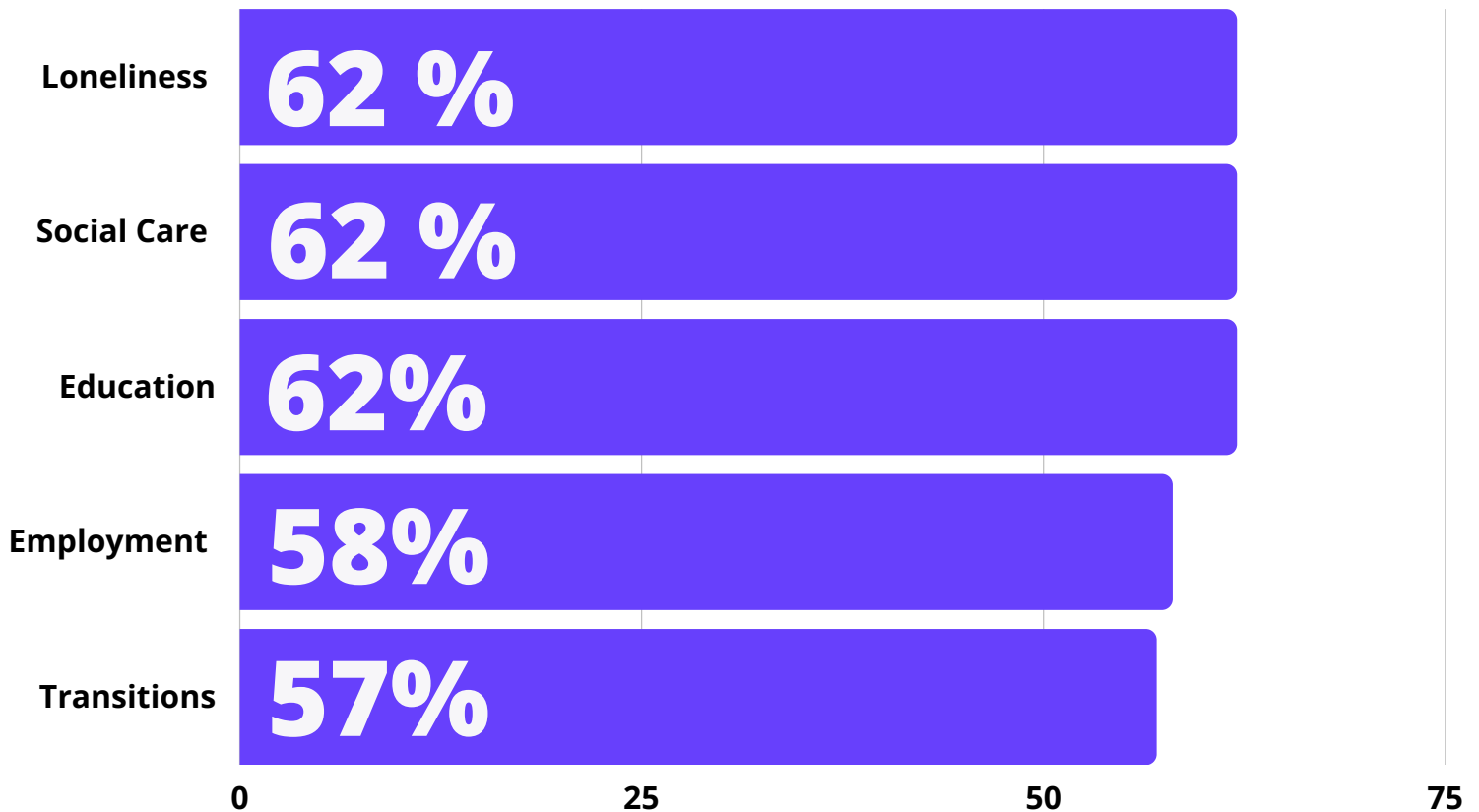
Enable activists made surveys available at local meetings and group events. We had hundreds of conversations to involve as many people as possible. Some of the comments we received are included throughout the report.





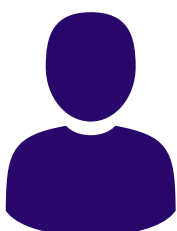
## Access to Support

We asked people about the areas of life where they, or someone they care for have had problems getting access to the support they needed.

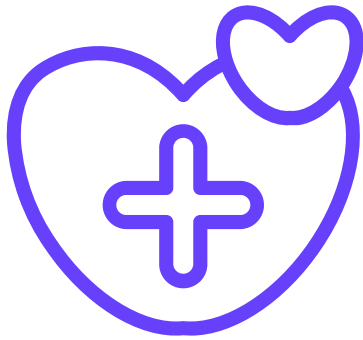


People could choose more than one issue where they had faced challenges in their life..

These results indicate that, in important areas of people's lives, action is required so they have the support they need and fair chances in our society. We believe the new Bill can be an important step forward in addressing these challenges - for example investigating where there is a lack of community support and making recommendations to Government, Parliament and local authorities on what should be done to create positive change.



**"No transition from school ... No budget for social care services ... No inclusion in local community ... home every day for 3 years."**



## Social Care & Health

We asked people if the Bill should be used as an opportunity to ensure that people with a learning disability have access to the social care support they need.

Should the Bill make sure people have access to Self-Directed support?

88%

Should the Bill make sure people have a right to choose the community they live in?

97%

Have you ever found it difficult to get the social care support you need?

54%

0 25 50 75 100

There were also concerns that too many people with learning disabilities are still in hospital or far from home when they should be in their own community.



**"In 2017 due to lack of staff my son's independent living package collapsed. He now lives in a care home 80 miles from his home town."**

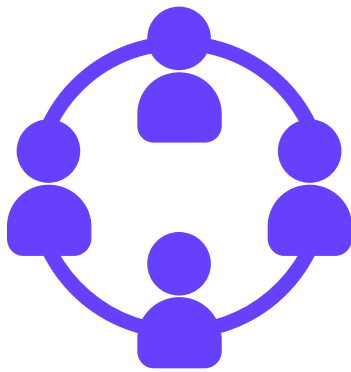
**"I would like to see a move away from hospitalisation of people with learning disabilities and autistic people in psychiatric hospital."**



Enable believes too many people are in inpatient settings who could receive social care in the community. Currently being a person with a learning disability or an autistic person can be a reason for someone to be subject to mental health legislation. Enable believes this should no longer be the case. This Bill could strengthen the rights of people with learning disabilities currently in hospitals who could receive self-directed social care in the community.

**"I have had no support for my disabled son since the start of the pandemic. I have contacted, no pleaded with social work to give some support, it is falling on deaf ears! I am the main carer for my son."**





## Community Support

The issue most identified by respondents as a problem faced by people who have learning disabilities was loneliness. In the responses only from people with learning disabilities, an even higher proportion of respondents identified it as an issue.

The Bill should help ensure people can live in the community of their choice?

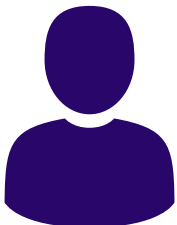
91%

The Bill should help people access community based support?

88%

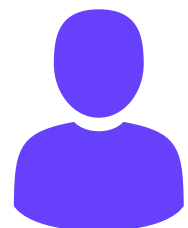
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We heard from a number of people about the problems they faced with isolation and a lack of support in their community.



**"Loneliness is a big problem for young people with learning disabilities as they can be everyone's friend on an acquaintance level, but also no-one's friend and the only child not to be invited to birthday parties."**

**"When I'm off work and my parents are at work I do get very bored; I only have my dog for company."**



People we spoke to believe that problems of isolation faced by people with learning disabilities could be made better by the Bill promoting the importance of community activities and support.



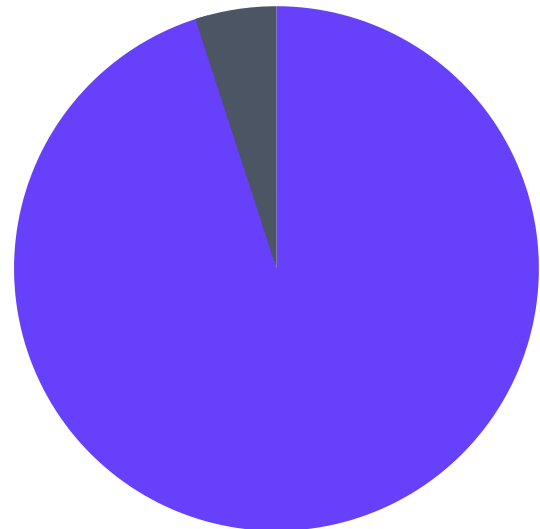
**"I would like more opportunities to make friends in my local area. More ways to find out about what is happening in my local community."**



## Education & Employment

We asked people if they thought that the Bill should make sure that people with learning disabilities have access to education which supports them to have a good life.

No  
5%



Yes  
95%

We know how important education is to a good life.

Our survey told us that education is one of the main areas where people with a learning disability feel there is a lack of support.

### Restraint and Seclusion

For many years, Enable has campaigned to highlight the impact of restraint and seclusion in schools on young people with learning disabilities. Our **Included in the Main?** campaign in 2017 shone a light on this issue, and 2019's **In Safe Hands?** report called for mandatory guidance on the use of restraint and seclusion, mandatory recording of incidents, training for staff and national monitoring.

257 respondents to our survey supported a new law to address restraint and seclusion. Daniel Johnson MSP is proposing a Member's Bill to introduce "Calum's Law".

**"Restraint and seclusion in schools and other services needs to end. The human, education and physical resources need to be in place for this to happen."**

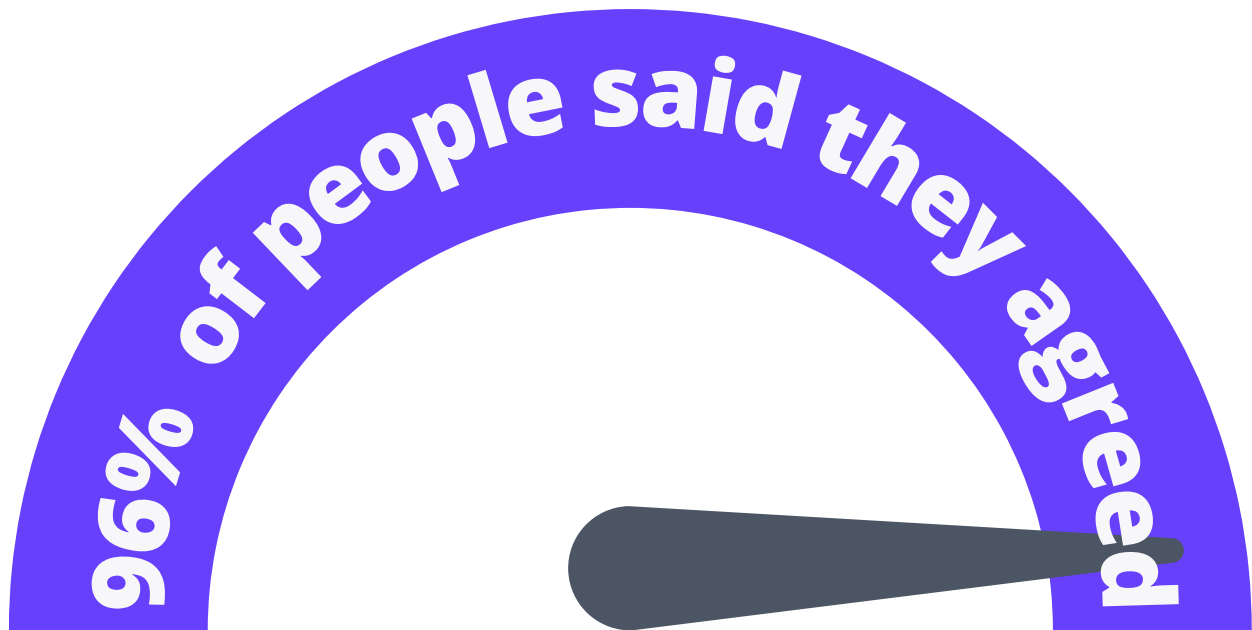


**"School was hard for me because out of all of my classes I only received support in 1 class, the rest of them I struggled with. I moved school 3 times because of bullying."**

# The Results

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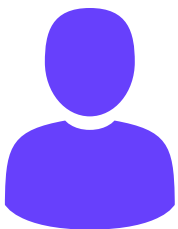
We asked people if they thought that the Bill should ensure people with a learning disability have support to get a meaningful, paid job.



From our conversations with people, it is clear many think there should be more support to help them into employment, and more support to sustain their job and progress at work.

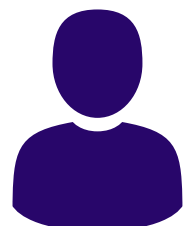


When asked what support the Bill should ensure access to, **320** people said support to get a job.



**"I found it a bit of a struggle getting paid employment, I had to jump through a lot of hoops to get my placement, I spent a lot of time on Job Seekers."**

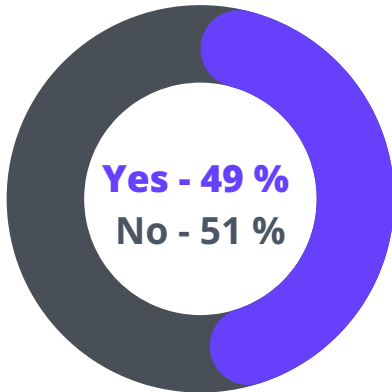
**"I had real problems in my previous job because they didn't understand me and I didn't understand them. I was placed in jobs that were not suitable or in tune with my needs and interests."**





## Benefits & Money

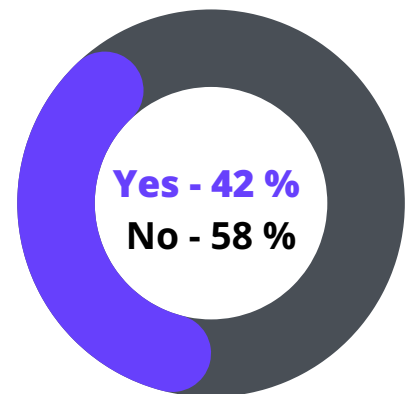
We asked people if they had ever had issues getting access to benefits they were entitled to.



Around half the people we spoke to said that they had issues getting the benefits they were entitled to.

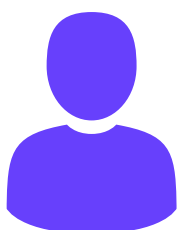
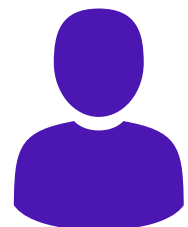
This means people with a learning disability and their families could be missing out on thousands of pounds of support they are entitled to.

Also, 42 % of people said they had experienced money problems in the last 12 months.



Where people have been able to find advice on claiming benefits, including from Enable, this has made a big difference to them, but our survey found more advice and information needs to be available.

**"The cost of living increase has meant we have had to go without and isolation has increased dramatically ... Luckily Enable has a benefits expert who is amazing."**



**"Access to Work grant was a big problem. I did not know I was entitled to this until I got my job. It is not promoted enough and it is not an easy process to apply."**





## National & Local Advocacy

We asked people whether they think there should be a commissioner role and local advocacy to help people assert their rights.

**97 % of people said they supported a Commissioner role being established.**

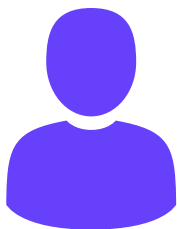
The reasons people gave us for this included:

- Providing a point of contact to raise concerns.
- Assistance in seeking support from public bodies.
- Highlighting problems faced by people with learning disabilities.
- A recognised advocate who would be listened to by local and national government.

The survey also found that people wanted more access to local independent advocacy as well

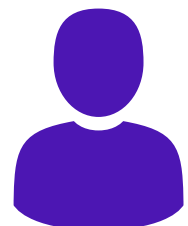
**92%** of people highlighted this as an issue the Bill should address.

**87%** of people also said that the Bill should ensure public bodies provide accessible information.



**"I just feel I am not listened to. And I feel that everyone should get support that they need"**

**"Access to supported decision making for all aspects of your life should be a right."**

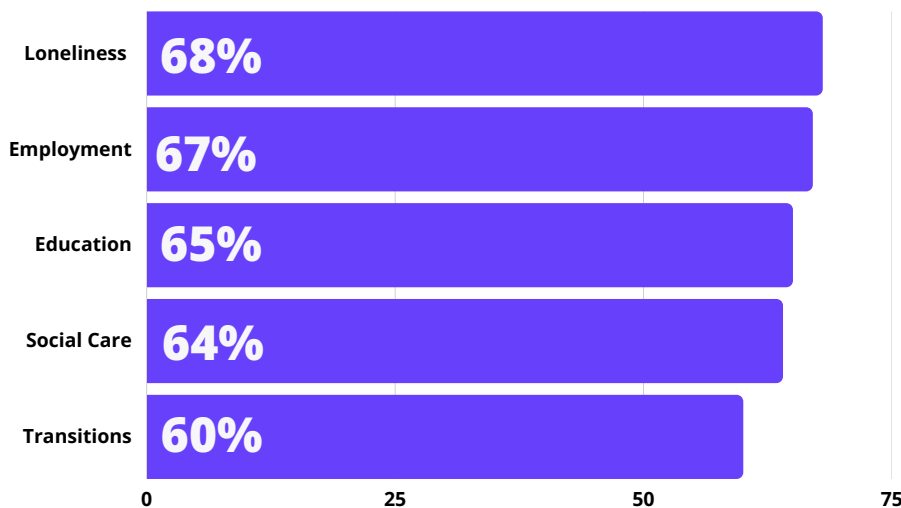




## Learning Disability Survey Results

We took some time to break down the results of our survey for only people who have learning disabilities.

We were keen to reach people with learning disabilities, their families and people who provide support for them to learn their views for this survey. Rights Now! is a campaign which will be led by people with learning disabilities as their own champions for change, so it was also important for us to understand what their responses told us should be the priorities for the campaign.



**97 % of people with a learning disability said they supported a Commissioner role being established.**

**49 % of people with a learning disability said they had issues accessing health care services.**

**44 % of people with a learning disability said they had issues finding out what benefits they were entitled to.**

**45 % of people with a learning disability said they had issues accessing social care services.**

**44 % of people with a learning disability said they had money problems in the last year**

# Support Rights Now!

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Today, we are launching our RightsNow! website.

Go to [rightsnow.org.uk](https://rightsnow.org.uk) to find out more about our campaign and how you can get involved.

You can also call us on

**0300 0200 101**



# RIGHTS NOW

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Do you have a learning disability?

Join your local Enable Ace Group

## enable ace



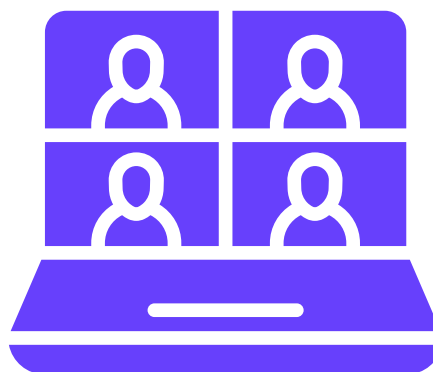
E-mail [aceconnect@enable.org.uk](mailto:aceconnect@enable.org.uk) to find out about your local group

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Are you a parent or carer?

Join Family Connect

## enable family connect

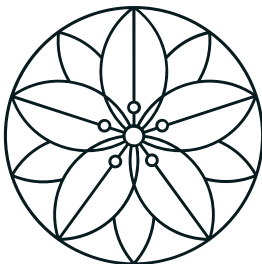


E-mail [familyconnect@enable.org.uk](mailto:familyconnect@enable.org.uk) to ask for monthly schedule of online events and seminars.

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# RIGHTS NOW

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## ACORNS TO TREES

ENABLING COMMUNITY DEVELOPMENT

SUPPORTING THE MEANINGFUL INTEGRATION OF ADULTS  
WITH LEARNING DISABILITIES INTO MAINSTREAM SOCIETY