

# **Friends of Independent Lives**

Membership study  
2023





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Other people have to choose between heating and eating. We're having to choose between heating, eating and care.



# Welcome

## Welcome to our 2023 Friends of Independent Lives membership study.

Independent Lives was set up more than twenty years ago by a group of disabled people who wanted to help others to better manage their Direct Payments.

At the beginning of 2022 we were incredibly proud to launch Friends of Independent Lives, a free membership programme for those with lived experience of disability or caring responsibilities who wanted to help shape our community and grow the charity.

Since that time we have been working with members to find out what really matters to them, what their frustrations are and where we should be focussing our efforts.

Thank you to everyone who took part in the creation of this study, and I am looking forward to the impact it will have on people's ability to live independent lives.

**Rebecca Smicle**

Chief executive



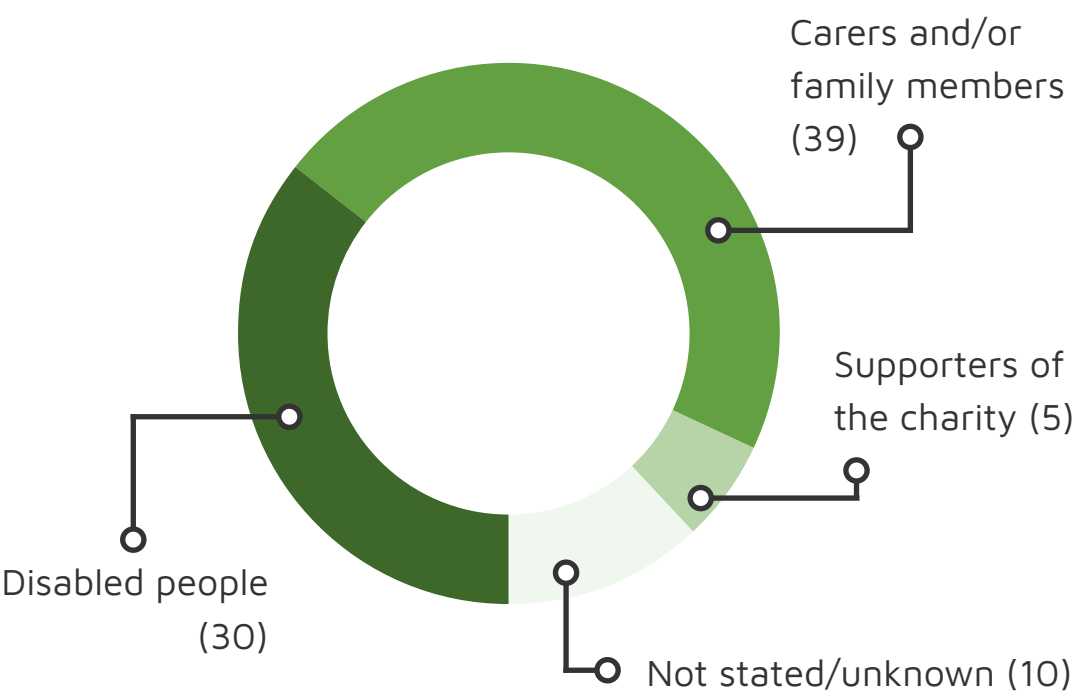


# Executive summary

Between August 2022 and March 2023, Independent Lives has been offering its Friends of Independent Lives members the chance for a one-to-one conversation with a member of staff to discuss any issues they are currently facing as a disabled person or carer.

Of the 84 people signed up to Friends of Independent Lives, 52 engaged in meaningful interactions with the Independent Lives engagement officer. They were given an open-ended opportunity to discuss their views, with conversations ranging from five minutes to two hours.

The 84 members of Friends of Independent Lives are comprised of the following groups of people:



Of the 52 people who took part in the study, 17 were disabled themselves, 30 were a carer or family member and 5 were supporters of the charity.

Disabled people	Carers	Supporters
17	30	5

The Friends of Independent Lives members are spread across a wide geographical base (as shown below). Location data was not available for 20 members.

Area	Carers	Disabled people
Arundel and South Downs	5	4
Adur and Worthing	12	9
Bognor and Littlehampton	4	3
Chichester	0	3
Crawley	5	3
Horsham	2	2
Mid Sussex	5	2
Other (including Hampshire, Norfolk and Kent)	2	1
Croydon	1	1





**Don't underestimate the stress involved in continually having to justify yourself and your existence.**

# Key findings

Through discussions with the engagement officer, a number of key themes were identified.

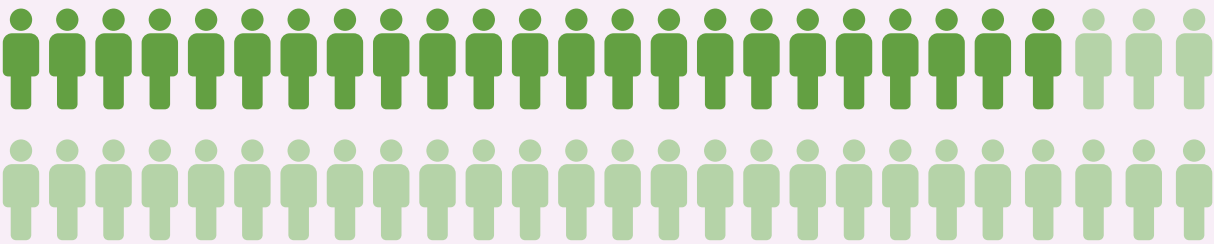
Although Friends of Independent Lives members commented on a wide range of subjects, there were key themes that were repeated throughout conversations. These were:

Theme	No. of people	% of people
Frustration with the system	23	44%
Lack of social opportunities (especially for working age adults)	22	42%
Isolation and poor mental health	22	42%
Frustration with not being treated as an individual	15	29%
Difficulties recruiting and retaining personal assistants	11	21%

Friends of Independent Lives members also commented on other topics with a number of concerns around rising prices and cost of living.



Number of respondents to identify theme: 23



Comments from respondents:

Comment	
1	The Councils don't have a joined-up approach, departments don't talk to each other, and I end up having to repeat our story over and over again.
2	Don't underestimate the stress involved in continually having to justify yourself and your existence, just to make ends meet.
3	They don't give us the opportunity to use our Direct Payment funding in the way we want, that would be of most help.
4	When you call out for more support, they make you feel like you are the only one asking. From talking to other carers, I know this isn't the case.
5	You've given them pots of money and then tied their hands. (In relation to restrictions on Direct Payment spending).
6	We're on a waiting list for re-assessment and can't use the Direct Payment until we hear back, so thousands of pounds is just stacking up in the account. We can't use it for what we need. Why can't they be made more flexible when creating plans in the first place, and take the pressure off social workers?
7	We get bounced back and forth between services.

1

Frustration with the system.

Many of those included in the study spoke of their frustration with the system. People spoke about social care and benefit reviews, the stress and worry involved with preparing for such reviews, and the impact that had on their mental health.

Members spoke of their frustration having to repeat themselves to multiple departments and services. One member told us about having provided evidence of their disability to one department only to be asked to do the same again for another department in the same building a fortnight later.

Others spoke of the challenges faced by carers and felt that services didn't always appreciate the pressure they were under or the time constraints being a carer created.

Respondents highlighted difficulties in using their Direct Payments in a way that was most useful to them. While they acknowledged the challenges faced by services themselves, they felt that if social workers took a more flexible approach to their funding needs earlier it would decrease the need for contact further down the line.



Number of respondents to identify theme: 22



Comments from respondents:

Comment	
1	I'm not going out as much since the pandemic. I'd like to meet new people.
2	It seems as though there is almost nothing there for physically disabled people.
3	He just wants to be able to go out and socialise without his dad being there.
4	I couldn't find anything. (When asked about services for working age adult).
5	Outings for (working age adult) would make such a difference to their independence and confidence. I cannot join them on these things, and they don't want me (parent) there! (They) would like to get out with others the same sort of age with support staff.
6	It's very tricky to find something for (working age adults). There seems to be a cut-off after teen years.
7	Adults seem to get a bit forgotten.
8	What they really want is the opportunity to meet a partner.
9	There's nowhere for them to go.

2. Lack of social opportunities.

Many people commented that they felt there was little support for working age disabled people, and that support tails off after teenage years, with minimal provision until services for older people become applicable.

Working age adults would like to have the opportunity to socialise without a parent or family member present. This was the single most commonly raised issue throughout this study.

“ He just wants to be able to go out and socialise without his dad being there.

The activities this group would like to participate in should be relevant to their age group. Many suggested having bespoke services, where support staff and transportation could be booked for independent activities, while others liked the idea of group environments.

Diversity of carer groups also factored into this. Some carers felt that support groups were often attended by carers supporting people of a particular demographic (e.g. older people or people with dementia). This meant that they felt out of place, and they missed out on the benefit of peer support.



Number of respondents to identify theme: 22



Comments from respondents:

Comment	
1	I need some support to be able to talk to other parents in a similar situation.
2	I sometimes feel alone. It's nice to meet other people using services.
3	We're both very lonely and very depressed. (Carer and cared for).
4	You either get a lot of support from family and friends or you get nothing.
5	I used to get out and about with friends but there's been nothing for years now.
6	I feel very isolated and very alone.
7	I'm struggling, I have no opportunity to share.
8	It's been really tough; my mental health is suffering. More support is needed.
9	I feel very isolated as a carer.
10	Sharing issues together makes you feel less alone.
11	I need other people to talk to, others going through the same thing, or professionals.
12	I'm stuck at home 24/7 with my caring responsibilities, and I'm not good online.

# 3

## Isolation and poor mental health.

Many of those involved in the study talked openly about experiencing isolation or poor mental health as a result of their disability or responsibilities as a carer.

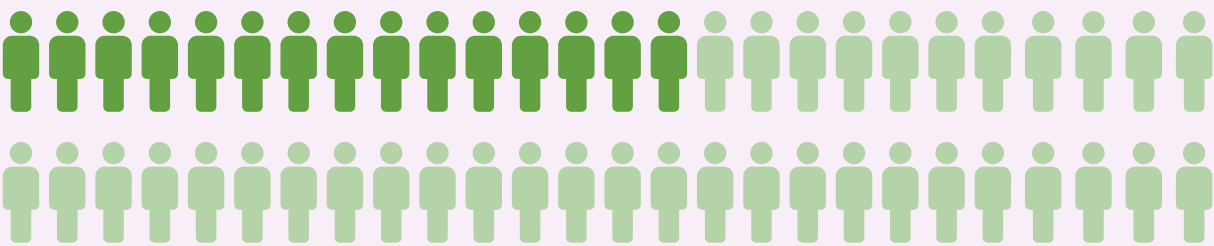
Many carers and family members are simply too busy to engage with support groups that may be of help to them. Some people were managing full time work alongside their caring responsibilities. Others had given up work because their caring responsibilities were too substantial for them to continue. This means that many have little opportunity to socialise or to share experiences with others in a similar situation.

“ It’s been really tough; my mental health is suffering. More support is needed.

The previously identified lack of social opportunities confounded people’s isolation and poor mental health with many highlighting a lack of opportunities that were appropriate to their needs and circumstances.



Number of respondents to identify theme: 15



Comments from respondents:

Comment	
1	People treat disabled people badly.
2	People try to baby them and think they are an idiot.
3	There's a real lack of inclusivity in society and understanding of people's needs.
4	A lot of people feel awkward about my disability. I don't mind talking about it.
5	People with physical disabilities and learning disabilities sometimes get lumped into the same boat. We don't necessarily have anything in common.
6	The person I care for has a rare condition, and when I've tried going to support groups in the past, people just haven't understood.
7	There's nobody locally with the same condition. I feel lonely.

4. Frustration with not being treated as an individual.

Many people expressed frustration towards stereotypes about disabled people, and the way that society treats them.

Respondents to the study felt that they were often grouped together with other disabled people despite disability being a term which covers a wide range of people with a wide range of individual needs and experiences. People felt frustrated that they were often treated as a 'disabled person' rather than an individual with unique circumstances.

“ People with physical disabilities and learning disabilities sometimes get lumped into the same boat. We don't necessarily have anything in common.

Others expressed how lonely it can be having, or supporting someone with, a more unusual condition, and the difficulty in finding people who can identify with what they are going through.



Number of respondents to identify theme: 11



Comments from respondents:

Comment	
1	We're having to get by with no personal assistant currently. We just can't find anybody.
2	It's so difficult to find personal assistants, even though we have been advertising heavily.
3	There aren't the people out there willing to do the job for the price we are funded to offer.

5

Difficulties recruiting and retaining personal assistants.

Many people spoke about the difficulties in recruiting and retaining personal assistants and the impact this had on their ability to live independent lives.

Most felt that these issues were caused by the rates of pay their Direct Payments allowed them to offer potential employees. Many spoke of the lack of people who were willing to do the work for the pay being offered and compared the pay rates to those offered by supermarkets, questioning why anyone would take on the increased responsibility of being a personal assistant where you could earn more elsewhere.

“ There aren't the people out there willing to do the job for the price we are funded to offer.

Without personal assistants in place, respondents felt more at risk of experiencing the other challenges highlighted within this report. They needed proper care and support in place before they could tackle issues including isolation or poor mental health.





# Additional findings

## Respondents to the study covered a wide range of subjects.

A common thread among respondents were concerns related to the cost-of-living crisis. Many felt that the impact on recruiting personal assistants against a background of increased living costs was substantial. Many were also concerned about their own finances and the increased burden they would be facing while already juggling complicated and demanding personal circumstances.

“ Other people have to choose between heating and eating. We’re having to choose between heating, eating and care.

Respondents were pleased with the support and services provided to them by charities like Independent Lives and although expressed frustration at the wider system, they understood the extreme pressure many services were under.

# Comments about Independent Lives

The feedback on Independent Lives was overwhelmingly good, with only one participant offering negative feedback, which has been passed to the relevant departments for consideration and response.

Comment	
1	I am extremely grateful for the payroll service, which is superb.
2	I use Independent Lives for payroll. Staff get the figures to me straight away, it’s really good.
3	Independent Lives have been so helpful. You run an amazing service.
4	Independent Lives are really helpful.
5	PA Pages is extremely good.
6	Tyler’s Story is such an honest and articulate film. They are not their disability, they are a person, and the film shows this so well.
7	Independent Lives helped me when I didn’t know what to do. I was very upset and distressed. It has made such a difference. They are amazing, they are always at the other end of the phone.
8	It’s absolutely marvellous. Payroll are ever so nice and helpful.
9	Independent Lives is best placed to offer support.
10	Payroll reply to me quickly and they know what they are talking about.
11	I’m very impressed with PA Pages. It’s easy to use and follow.



# Thank you

## Thank you to everyone who has helped us to put together this study.

It has been an enlightening experience to talk to so many Friends of Independent Lives members. The open and honest nature of the responses we have received will really help Independent Lives to understand what matters most to disabled people and carers and target support toward the areas where there will be the most impact.

In response to the feedback we have received, we have developed two work streams through which all our engagement, communications and fundraising will flow in 2023:

- ✓ **Improved community access**
- ✓ **Increased disability awareness**

On the next page you will see some of the things which we have started working on and are planning to deliver this year. This is just a flavour of some of the work to be delivered by Friends of Independent Lives. There is plenty of room for members to shape the work we do and if that sounds interesting to you then please sign up.

If you would like to discuss any of the issues we have highlighted or would like to find out more about our membership programme then please don't hesitate to get in touch, you can email us at [friends@independentlives.org](mailto:friends@independentlives.org).



**Polly Bishop**  
Engagement officer



## 2023 work streams:

### Improved community access

We will identify and tackle issues that stop disabled people from being included in their communities, promoting the social model of disability and developing campaigns which help people to live independent lives.

### Increased disability awareness

We will provide a platform from which disabled people can shape the world they want to see. We will work to ensure that the experiences of disabled people are recognised by those most able to enact change.





# Looking forward

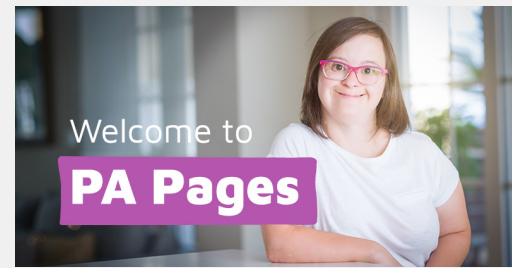
**We are always looking for new ways to create a fair society where everyone can participate and has the opportunity to fulfil their potential.**

Take a look at some of the projects that Friends of Independent Lives is involved with at the moment.



## Media training

We will be providing some of the Friends of Independent Lives members with specialist media training. This will help them to share their experiences and stories and help to shape people's views of disability. Working together, we can reduce the stigma and misunderstanding surround disability.



## PA Pages

Independent Lives has been developing a digital resource for recipients of Direct Payments. PA Pages is designed to help support recruitment of personal assistants and help with things like getting advice or booking training. You can access PA Pages at [www.pa-pages.org](http://www.pa-pages.org).



## Fundraising

We are looking to expand our fundraising activities as a charity. Donations help us to respond to specific needs in flexible and creative ways.



## Accessibility

Recently we have been involved in supporting beach accessibility in Worthing with the purchase of a new beach accessible wheelchair. Funds for the wheelchair were raised by a Friends of Independent Lives member. We're hoping to build on this work with future projects.



## Awareness raising

We are looking at opportunities to raise awareness of disability and have recently received funding to deliver a creative project called Postcards from Disability Pride. More news on this soon.



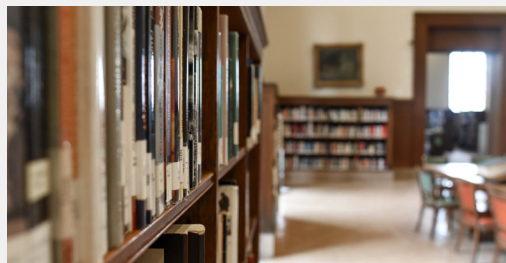
## Our services

Independent Lives continually works to improve the services we provide and membership feedback plays a big part in that.



## Volunteering

We are exploring how we can use volunteering at Independent Lives to increase the amount of support we are able to provide.



## Community research

We will be working with the NHS over the coming months to further our understanding of the issues that disabled people and their carers face and to not just report on them but to create lasting change.

# Join Friends of Independent Lives

**By working together  
we can create a better  
future for everyone.**

We welcome people with lived experience of disabilities or health care needs who want a chance to have their voices heard and want to help shape a society that works for everyone.

Visit our website where you can find out more about becoming a Friend of Independent Lives and where you can complete a short form to register your interest.

You can also speak to us directly by giving us a call or dropping us an email.

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