

**“Concentrate on what I can
do, not what I can’t”**

The experience of people with
learning disabilities in the North East

Serving Tyne & Wear and Northumberland
communityfoundation.org.uk

A report by:



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Contents

Easy read summary	2
Introduction	3
Growing up	3
Being healthy	4
Living independently	5
Having good relationships.....	6
Learning disabilities and COVID-19.....	7
Support for people in the community	8
Conclusion	8
Appendix: Voluntary sector organisations specialising in supporting people with learning disabilities.....	9

Easy read summary

This is a report that describes the day to day living experiences of people with learning disabilities and autism in the North East of England.

It is written for a funder (someone who gives out money to charities) called Community Foundation Tyne & Wear and Northumberland. They want to know more, to help them decide projects they should fund. Christopher, a researcher from Newcastle, wrote the report with the help of Sunderland People First and their self-advocates. The report says that lots of people with learning disabilities and autism lead really happy lives. It also says that life can be really difficult for some, for reasons like:

- Some people think we cannot do things and this can hold us back.
- We experience bullying.
- Sometimes we get sick more often than other people, and a lot of people die earlier than others too.
- There are some people with learning disabilities who have been put in places, like hospitals, where they should not be living.

We have decided that the most important thing that this report should say is that everybody has a right to a home. People with learning disabilities and autism need help to have a home, but everybody should have the choice to have their own home.

Our experiences of the COVID-19 and the lockdown have been difficult, like other people, but we have coped. With the help of Sunderland People First we stayed connected to our friends. Sometimes it has been difficult to know which instructions to follow, but our friends have helped us. We also know that you are more likely to die from catching the virus if you have a learning disability, which can be very scary. We think that rich people who give money to other people who are not as lucky as they, are very kind. We think that even though they cannot give us millions, even small amounts are really helpful, especially if they can help us get a home of our own and carry on living there.

Introduction

This diversity and inclusion report captures the lived experience of people with learning disabilities in our region.

We are defining the group on whom we are concentrating as those who would identify with having a learning disability and this incorporates people who may have downs syndrome or cerebral palsy and also some who are autistic¹. We are not using a medical model definition which bases its identification marker on IQ score. The report is written with a focus on Sunderland People First, a self-advocacy group, and their members, and it is their quotes and comments which are presented anonymously (their names have been changed) throughout this report.

Many people with learning disabilities live happy and supported lives throughout our communities, some in the context of families, some alone with external support and others alone. As we are all dependent on one another, a major determinant of quality of life is the quality of relationships which underpin and support those with learning disabilities; where the more and stronger the relationships are, the more resilient and fulfilled livelihoods tend to be. There are others for whom the daily experiences are much more difficult to navigate, especially those who live on their own or have no family/allies/community support. People with learning disabilities have varying degrees of dependency, from total, to none and therefore their associated needs for both care and assistance varies across that range. As Chris from Sunderland says:

We all need each other ... some a lot, some a little.

This is especially true for people with learning disabilities who may need assistance or support to overcome the many of life’s difficulties and barriers, which we look at in this report. We also look at how the current pandemic has affected the learning disabled community.

¹ See <https://www.mencap.org.uk/learning-disability-explained> for a further discussion.

Growing up

Living a good life is often achieved against all odds for people with learning disabilities.

Early years medical interventions and the experiences growing up can be very difficult: socio-cultural expectations of normality; expectations; disappointments; verbal and physical abuse (bullying); depression. Living in disadvantaged areas can mean families may lack the resources to be able to access the necessary means to overcome some of these barriers and certain disadvantage, e.g. bullying, may become worse. Davey says:

My childhood was very hard, I don’t like to think about it, I did not like school.

He and his friends talk about being segregated, isolated and given inappropriate learning opportunities in the schools in the community where they went. For example, He says:

I was put in a nurture group when I went to school, it was the lowest set but they never took any time to ask me how much I knew.

Angela said:

I wasn’t allowed out at playtimes, I had to sit at a table next to a teacher, every day.

Mitigating these negative experiences are family and other key adults in people’s lives. Families and allies use their own strong entitlements and capabilities to access alternative provision and services on behalf of people with learning disabilities. [NB: children with learning disabilities as a thematic area receives the most funding compared to other disability service area in the North East²].

² Hartworth, C. 2015. Mapping disability organisations in the North East and what it means for disability rights in the region. Community foundation Northumberland and Tyne and Wear

Relationships are referred to as a key determinant of happiness and quality of life and Important ones are referred to and their role, i.e. whether a caring, support or friendship. Their importance to their livelihoods is also recognised, for example, as Mary says:

My family and friends are the most important to me. I like people here, the self-advocates.

In the absence of other structural foundations, such as good educational background, opportunities in business or other platforms required for people to make their way in the world, relationships, the quality, number and function of, are perhaps the most important factor in a good life.

Being healthy

It is generally much more difficult for people with learning disabilities to stay healthy.

People with learning disabilities experience worse health outcomes than non-learning disabled people, which has been made significantly worse by COVID-19 (discussed later) including mortality rates that are 18 years shorter for women and 14 years shorter for men, relative to the general population³. At the beginning of the most recent NHS England report which examines the mortality issues in detail, stated:

[It is not fair that] people with a learning disability die younger than other people⁴.

This comment from a learning disabled professional immediately and succinctly located the issue as belonging to both elements of justice and health, which itself is reinforced by the fact that almost 40% of those deaths were avoidable, for example, in 2019, 12 people died as a result of constipation⁵. Donnie, a self-advocate talking about the mortality review report, says;

There is a difference about what should happen and what does happen ... when we hear that 3 out of 10 people receive the best care, it means 7 out of 10 people didn't receive the best care ... our lives are not valued the same as yours.



Donnie from Sunderland People First asked “What does it mean that people are dying younger?”

Other health inequalities include a high prevalence of obesity and respiratory conditions and more likely to have mental health conditions, dementia and have epilepsy. Not only is there higher prevalence of certain conditions among people with learning disabilities, the access of existing health services is poor. For example, regular screening for conditions such as cancers are often missed.

The UK Government has placed the responsibility on Clinical Commissioning Groups to improve the quality of the health and social care services provided to people with a learning disability, and to address the persistent health inequalities. They are expected to work with their local partners including people with a learning disability, families and carers, local authorities and NHS trusts to achieve that. Unfortunately, the level of deaths from COVID-19 has demonstrated that interventions and efforts need to improve.

³ NHS Digital 2017.

⁴ NHS England. 2019. Learning Disability Mortality Review (LeDeR) Programme: Action from Learning, NHS England and NHS Improvement.

⁵ Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Bristol: Norah Fry Research Centre..

Other barriers to good quality healthcare include⁶:

- a lack of accessible transport links.
- patients not being identified as having a learning disability.
- staff having little understanding about learning disability.
- failure to recognise that a person with a learning disability is unwell.
- failure to make a correct diagnosis.
- anxiety or a lack of confidence for people with a learning disability.
- lack of joint working from different care providers.
- not enough involvement allowed from carers.
- inadequate aftercare or follow-up care.

Living independently

The right to live independently is a core human right and an aim for most people, and the United Nations says it is a responsibility of the state to facilitate and support that aim.

Despite these seemingly straightforward arrangements, there are many contemporary issues which demonstrate the difficulty in achieving this. May 22nd 2019 became a significant date in the life of people with learning disabilities in the North East and across the UK. It was the day that the BBC panorama documentary revealed abuse and mistreatment of people with learning disabilities and autism at the Assessment and Treatment Units at Whorlton Hall, County Durham from staff. The 17-bed hospital was one of a similar number of units in England that provide care for around 2,300 adults with learning disabilities and autism.



Paul from Newcastle: "Home is where I feel safe, and I have friendly people around me."

The documentary showed people with learning disabilities and autism were being held in hospitals or psychiatric wards despite being well and the reason for this was that there was no appropriate accommodation/care available in the community (as John illustrates with the following comment, this applies not just to those with complex care packages)⁷.

When my dad died and I couldn't cope, they put me in Prudhoe hospital, I was there for years

The documentary brought into sharp focus the situation of those confined to institutions, the residential need that exists and infringements of their human rights. This led to collaboration between three advocacy groups (Skills For People, Your Voice Counts and Sunderland People First) and the creation of #Right2Home, which became a national and local campaign, incorporating influential national organisations such as Scope and Key Change.

⁶ <https://www.mencap.org.uk>; Op. Cit. 2013; Tuffrey-Wijne, I., Giatras, N., Goulding, L., Abraham, E. and Fenwick, L. (2013) 'Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study,' Health Services and Delivery Research, 1(13); Allerton, L. and Emerson, E. (2012)

'British adults with chronic health conditions or impairments face significant barriers to accessing health services,' Public Health, 126: 920- 927.

⁷ The following YouTube clip is from the campaign's response to Whorlton Hall in Newcastle upon Tyne: https://www.youtube.com/watch?v=Fjz8EBW_vfQ

The subject of a home was chosen as a campaign focus as it brought into sharp relief and clear focus, the need everybody has a home where they feel safe and loved, which was the opposite to that shown in the documentary, which was characterised by fear and abuse. Also, many issues and barriers experienced by people with learning disabilities were expressed/united behind or underneath realising a good home, such as such as access to health care and ongoing support needs.

The issue of people with learning disabilities being trapped in institutions continues, with a recent report from Mencap identifying that currently (at the time of writing) 140 people with a learning disability or autism, who are capable of independent living, are in hospital due to a lack of appropriate accommodation⁸. Self-advocates feel very strongly about this for many reasons, from distress caused by witnessing abuse to members of their communities and the fears associated with that to the importance of living/maintaining as much independence as possible. The value and appreciation of home and independent living is strongly expressed by self-advocates. For example, Ellie says:

I found the best place ever, I've never felt safe in my whole life, but I feel safe now, I never wanna leave this place. It's giving me determination to want to help more people, to find a home, because there are some homes out there that are really nice.



Ellie talking about her home with a support worker

Having good relationships

Relationships are foundational and underpin everything that we do in our lives. Indeed, without good quality relationships, people with learning disabilities would find it difficult to live independently. Michael links the quality of relationships directly with the standard of somebody's living when he says;

If we do not have friends, family or advocates speaking up for us, we are likely to receive care that is far from good enough.

Ellie also connects relationships with independent living when she says:

I need help with money, with budgeting ... but they're always there if you need them ... They said I could go to the shop on my own, but I said the staff could follow behind me for the few first few times, until I get used to it. I couldn't do it without them at first at least.

Creating strong relationships is an important outcome of the work of self-advocacy support groups. Sometimes this ends up in life partnerships as is the case with Lizzie and David who met at a friendship group and have been together for seven years.

I never thought I would be engaged and have a partner that I could share my life with ... it's totally different from when I was younger I've got that person to do everything with.

Other support elements focus on the position of people within society and improving key capabilities such as decision-making. For example, Sunderland People First run We Are All Citizens, a series of workshops on citizenship incorporating: purpose - your own direction in life; freedom - taking charge of your own life; money - having enough to live on; home - having a place where you belong; help - getting help from other people; life - getting stuck in and making a difference; and love - finding friendship, love and family. Such foundational work helps people build good relationships and avoid

⁸ <https://www.disabilityrightsuk.org/news/2020/march/140-disabled-people-'incarcerated'-hospitals-due-lack-accessible-housing>

risky situations (there have been some local campaigns on hate crime, specifically ‘mate’ crime⁹). Ellie says this about the workshops:

It has helped me make better choices, live a better life



Lizzie and Family

Learning disabilities and COVID-19

People with learning disabilities have been hit particularly hard by the COVID-19 pandemic as a result of a number of risk factors making people more vulnerable.

These include living in a residential care home care, pre-existing respiratory conditions, high prevalence of obesity and difficulties of social distancing leading to high infection rate. These have been exacerbated by late/inappropriate/inaccessible communications from NHS/Government which has left people concerned and scared. Examples of disproportionate impact include:

- Approximately 22,500 disabled people of all ages died due to COVID-19 between 2 March and 15 May, compared with about 15,500 non-disabled

people¹⁰; representing 60% of total fatalities have been of people with disabilities¹¹.

- A total of 134% more people with learning disabilities or autism have died during the COVID-19 crisis than is statistically normal, (compared to 34% in the general population¹²) according to data published by the Care Quality Commission¹³.
- Younger disabled males (those “limited a lot” in daily life and aged between nine and 64) were 6.5 times more likely to have died due to COVID-19 than non-disabled males, while disabled females between nine and 64 were even more at risk, with a rate of death 11.3 times higher than non-disabled females in the same age group¹⁴.

The self-advocates of Sunderland People First report that it was difficult during the lockdown, as people with learning disabilities can experience difficulty with social isolation and those living alone can sometimes rely upon support organisations for social contact. The organisation reports and a resilience within the group and despite living alone, many have had no problem with the lockdown. People with all disabilities have enjoyed elements of the lockdown as it brought a freedom from the need to engage in public life which can be exhausting and often negative. Self-advocates have engaged well with online technology, such as Zoom and they have company to hold regular meetings.

⁹ Follow this link to read about a South Tyneside mate crime campaign <https://www.whorya.co.uk/about/>

¹⁰ Office for National Statistics: <https://www.ons.gov.uk/releases/coronaviruscovid19relatedmortalitybyreligionethnicityanddisabilityenglandandwales2march2020to15may2020>

¹¹ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/>

[articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto15may2020?fbclid=IwAR0osaJyCU6bJfnIGL11mIAiJT7d4r_-8E7caGF5bWOeO1z7RYe8ovOncWU](https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/)

¹² Office for National Statistics

¹³ <https://www.disabilityrightsuk.org/news/2020/june/134-increase-deaths-people-learning-disabilities-during-pandemic>

¹⁴ <https://www.disabilitynewsservice.com/coronavirus-call-for-inquiry-and-urgent-action-after-shocking-disability-death-stats/>

Support for people in the community

Voluntary sector agencies play an important role for people with learning disabilities in our region, and there are approximately 34 different organisations which provide services for children and adults.

These include local theatre groups, such as Lawnmowers, national organisations like Key Change who work locally with volunteers to support people with learning disabilities to live in their own homes; activity groups such as Integrating Children and Young People, organised and operated by the family and allies of young people with learning disabilities and Percy Hedley Foundation with an annual turnover of over £30 million (examples of other regional organisations that work with people with learning disabilities are presented in appendix 1). Many of these groups have been set up by parents and carers and the majority of these groups focus the work on development of relationships and ‘social capital’¹⁵. Self-advocacy groups such as Skills For People in Newcastle or Your Voice Counts in Gateshead play an important role in the landscape as they work using user-led principles. It is through groups where people can become involved in supporting themselves and their peers in areas as diverse as family relationships to finding a home and living independently.

Sunderland People First has a group of 12 self-advocates, who are people with learning disabilities that support others to support themselves. Jamie says this about his experience with them:

People can give support and get support here ...
I’ve been on lots of training, I make tea, do technology things, contribute my ideas.

Support organisations have played an important role reaching out to continue to engage and providing support people with learning disabilities. These organisations have ensured that their service users have understood what is happening, what the government guidance says, that they have sufficient food and other Basic needs. The self-advocates at Sunderland People First have adapted well and hold weekly team meeting by Zoom.

Conclusion

There is an investment disparity between children and adult services in the learning disabilities world, with the former receiving the majority.

As is the case with a number of vulnerable groups, transition time when a child becomes an adult, can be very difficult because there are scant services to cater for adults, in transition or not. Voluntary sector organisations working with adults report that they are often a victim of expectation; i.e. people assume another organisation must be responding to the young adults needs, but nobody is. Funding for them is always difficult for similar reasons and also as they often feel that they are not “*sexy enough*”¹⁶, despite having transformational impacts on individual’s lives. This leaves those organisations that do exist either working beyond capacity or people simply not receiving services that they need and this contributes to poor outcomes, e.g. earlier mortality or frequent use of emergency services¹⁷.

¹⁵ This refers to a person’s totality of social resources at their disposal and include things such as existing links with people, means to make new relationships, knowledge and capability of how to make new links, et cetera.

¹⁶ Lisa Clarke, Pers.Com., 16.7.20.

¹⁷ Glover, G. & Evison, F. 2013. Hospital admissions that should not happen: admissions for ambulatory care sensitive conditions for people with learning disability in England, Improving Health and Lives. Learning Disabilities Observatory.

Appendix: Voluntary sector organisations specialising in supporting people with learning disabilities*

Organisation	Location
Better Days	Newcastle
Daybreak	County Durham, Newcastle, Northumberland
Down’s Syndrome North East	North East
Durham Otters Swim Club	County Durham
Gateshead Autism Group	Gateshead
Gateshead People Self-Advocacy Group	Gateshead
Gateshead Mencap	Gateshead
Gateshead Autism Group	Gateshead
Gateway Wheelers	Chester-Le-Street
Grenfell Club	Redcar
Haswell & District Mencap	County Durham
Integrating Children and Young People	County Durham
Key Change	Gateshead, Newcastle and Darlington
Larchfield Community	Middlesbrough
Lawnmowers Independent Theatre Company	Gateshead
LD: North East	North Tyneside
MENCAP	North East
New Prospects	North Tyneside
North East Autism Society	North East
North Tyneside Disability Forum	North Tyneside
Percy Hedley Foundation	Newcastle & North East
Skills for People	Newcastle
Sunderland People First	Sunderland
Wear Mencap	County Durham
Your Voice Counts	Gateshead, Newcastle, South Tyneside

*There are other organisations that support people with learning disabilities amongst their general caseload of disabled people, such as Darlington Association on Disability.

Let's talk

We hope that this report will inspire more of you to give to causes that address diversity and equality issues.

If you would like to discuss this report and what you could do to help, please contact us:

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