



HERTFORDSHIRE MATTERS

# LEARNING DISABILITIES

**HCF**  
Hertfordshire Community Foundation

## Introduction

In 2016 we launched Hertfordshire Matters, pledging our commitment to understanding the needs, challenges and opportunities in our county. We have been using both the main and interim reports to help guide our grant making and inform our donors. We are also very pleased to see that they are being used by grant applicants to help evidence the need for their projects.

For this year's report we decided to focus on Learning Disabilities. We thought it significant that over the last three years nearly 20% of our grants have been awarded to community and voluntary groups which support or work with people who have learning disabilities. We wanted to find out more about the needs of those with learning disabilities in the county, and in particular how HCF can best support the groups who help to meet them.

The needs of those with learning disabilities for a fulfilling life are exactly the same as for everyone else – good health, housing, satisfying work and education, leisure and good relationships in a supportive community environment. We know from our earlier work that thriving communities are a result of everyone having a voice and influence in the community,

a feeling of belonging and a channel through which to communicate but we are also aware that people with learning disabilities have more barriers to achieving this than those without.

Equal rights are now enshrined in legislation, nationally and internationally and Government and local authority intentions are working towards enacting those rights and improving the quality of life for those with learning disabilities. Against a backdrop of a growing and ageing population and national public sector funding cuts, Hertfordshire County Council (HCC) will have fewer resources per person to fund social care and support so there will be a greater reliance on voluntary and community groups to help provide the equality of opportunity Hertfordshire strives for. This is where HCF comes in – working to best support those smaller groups.

This report highlights some of the issues and shares information from groups we have worked with. We hope it will start conversations. For those who would like to look at the issues in more detail we have included links to relevant references and a reading list on the last page.

## What is a Learning Disability?

Over the years the description has changed but the current 'most recognised' definition in the UK is that:

*A person with learning disabilities will have the following characteristics prior to adulthood which have a lasting impact on development:*

- *A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence); typically identified as an IQ of 70 or less, together with*

- *A reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development<sup>1</sup>*

Whilst the definition is currently agreed upon, the labels will continue to change, especially as those experiencing the conditions may prefer to be referred to differently.

<sup>1</sup> Valuing People, Department of Health 2001

# LEARNING DISABILITY - THE CHALLENGES

## About Learning Disabilities

Learning disabilities are usually grouped into four main levels: mild, moderate, severe or profound which broadly reflect the level of support an individual may need. Mild learning disabilities can be difficult to diagnose as individuals may be able to cope with most everyday tasks, but may need support with such things as filling out forms or finding a job. People with a severe learning disability or profound and multiple learning disability (PMLD) will need more care and support with areas such as mobility, personal care and communication. Many also have physical disabilities.

Individuals' needs can change according to their stage of life, for example when moving from a well-resourced specialist school to a college or supported living and whether they have behaviour that presents challenges.

Learning disability is often confused with dyslexia and mental health problems. Mencap describes dyslexia as a "learning difficulty" because, unlike learning disability, it does not affect intellect. Mental health problems can affect anyone at any time and may be overcome with treatment, which is not true of learning disability.

### The number of people in Hertfordshire with a Learning Disability is growing

Public Health England estimates that about 2% of the population of Hertfordshire (c 23,500) has a learning disability although only one in five is known to GPs (around 5,000 people). Due to an increase in life expectancy, including more children surviving beyond birth, the number of people with learning disabilities in the county is predicted to grow by 9% by 2025.<sup>2</sup>

### Life expectancy is increasing but inequality remains

Although the number of people with learning disabilities is relatively small it is clear that people with learning disabilities, and often their families experience a range of health and social inequalities. They are also disadvantaged across every element of life. National research shows:

#### Life Expectancy

In spite of increased life expectancy there remains significant inequality. On average, females with learning disabilities live for 18 years less than the general population, and for males it is 14 years less.

(NHS Digital, 2017).

#### Mental Health

40% suffer with mental health problems at some point – more than twice the rate of the general population.

(McManus et al. 2009)

#### Strong Communities

Loneliness for young people is high with 85% of those aged 18-34 saying they are lonely compared with 25% of the general population.

(Scope.org.uk. 2018)

#### Work

Only 6% of those adults with a learning disability, known to their local authority, are in paid employment. This is despite more than 60% wanting to and being able to be in work.

(HSCIC 2015)

#### Education

Ofsted's 2017 Local Area SEND inspections indicate that children and young people who have SEND are having a poorer experience of the education system than their peers.

#### Fairness

Children of families where someone has a disability are twice as likely to live with low income and material deprivation as those in non disabled families.

17% families of children with learning disabilities say they are going without food, 21% without heating.

(Contact a Family 2012)

<sup>2</sup> Public Health England 2016

# HERTFORDSHIRE

## Hertfordshire's Learning Disability Partnership Board

### What is it?

Learning Disability Partnership Boards were originally set up across the country to help deliver the aims of the 2001 Valuing People White Paper which emphasised that people with learning disabilities are people first. Their aims were to improve the lives of people with learning disabilities and their families by focusing on what people can do rather than what they can't, and to give a voice to those affected by learning disabilities. The boards are no longer a statutory requirement but Hertfordshire's has continued to develop.

### Who's involved?

There are 30 members. The board has adopted the 'Think Local Act Personal' approach to co-production which aims to develop more equal partnerships between people who use services, carer and professionals. Half of their voting members are people with learning disabilities or family carers. The current co-chairs include a family carer and a senior manager from Adult Care Services. Other members include representatives from health and social care, education, commissioning and community organisations providing support to meet the needs of those with learning disabilities. The Herts Self Advocacy Network and the Carers forum both present reports to the board.

### What do they do and what difference does it make?

The board has been influential in improving lives locally, ensuring that people with learning disabilities and family carers play an active role in planning, developing and checking services. They feed into all the relevant health and care boards and strategies relating to learning disabilities including:

- Transforming Care which aims to increase the number of people able to live in the community rather than in hospital
- Co-Production board which aims to help shape social care services together and has produced an employer toolkit to encourage businesses to employ people with disabilities

As well as a number of local networks and forums, they have dedicated working groups focused on meeting

the aims of the Learning Disability Strategy. These include Lifelong Learning, Transport (they have worked with bus companies to streamline bus passes and to try and make travel safer and easier), Feeling/Keeping safe and Meaningful Life in the community.

They also sign off on the Hertfordshire Learning Disability Self-Assessment Framework which is an annual process which has been going on since 2007 to check how well services are meeting the needs of people with learning disabilities, their families and carers. The Self Assessment Framework working group designs the annual survey which helps inform future plans and work areas. The most recent survey<sup>3</sup> highlights continuing concerns around:

- o Loneliness – nearly one third of people said they were lonely
- o Employment – only 9% of those surveyed were in paid employment
- o Social isolation - only one in five were in a relationship

HCF would like to thank the board. Attending meetings has been a very valuable way to understand the current local issues and to connect with groups working in this area.

To find out more about Hertfordshire's Learning Disability Partnership Board and the local forums go to: [www.hertfordshire.gov.uk](http://www.hertfordshire.gov.uk)



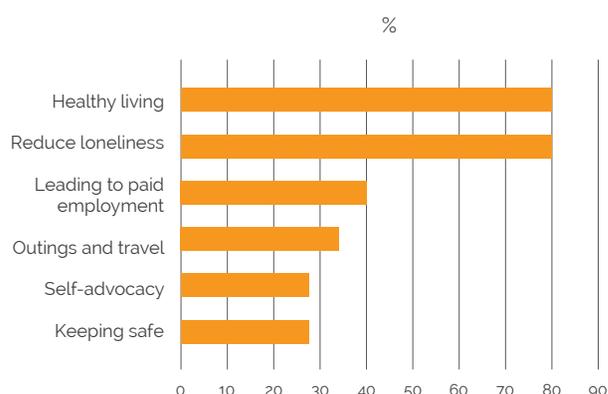
<sup>3</sup> Improving Health and Lives 2017 which 217 people with learning disabilities completed

# WHAT WE'VE FOUND OUT

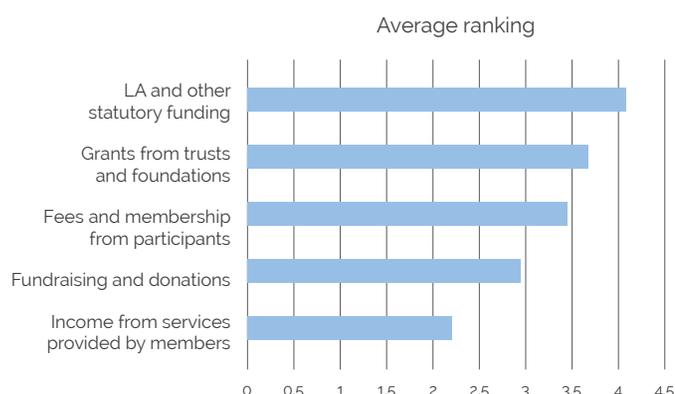
## Our survey

We surveyed the groups we've funded who work with those with learning disabilities to find out a bit more about what they're doing and how they're doing it. Here's what they said...

### What types of support do you offer to people with learning disabilities?



### Where does your funding come from, in order of importance?



### What are the top three challenges for the year ahead?

90% of those surveyed said

**'FUNDING, RESOURCES AND FUNDING!'**



Other challenges included:

**'Finding suitable employers for our volunteers to work with after courses'**

**'Recruitment of volunteers especially for Trustee positions'**

**'Horses staying sound'**

### What are you looking forward to over the next year?

Answers included:

**'Wider acknowledgement of the capabilities people with learning disabilities have'**

**'Increased awareness of hate crime against those who have a learning disability'**

**'To see the two trustee positions filled that will be vacant at the AGM'**

# INTERVIEW



**Vic Hobson set up Mudlarks in Hertford** to give young adults with learning disabilities a chance to benefit from the therapeutic power of gardening. Their first grant came from HCF. We spoke to Vic as the charity approached its 10th birthday to see how things have changed and what the future holds...

## What inspired you to start Mudlarks?

'I worked for VSO (Voluntary Service Overseas) for two years in Nepal helping to set up village schools. In my first year I stayed with a family who had a delightful little boy who was deaf and did not go to the school. Disability was thought to be a reward for sin and so he was hidden away. I got on well with the boy and asked his mother, 'would you like him to be able to go out to work one day, or stay home for the rest of his life?' When I went back for my second year the little boy arrived with his mother on the first day of school. Then, one by one, other mothers appeared, bringing their disabled children too. It was very emotional. That inspired me, after VSO, to teach at a special school in Stevenage for children with learning disabilities and that is where I saw how well young people responded to horticulture. In 2008 I started Mudlarks.

## What changes have you seen in the ten years since you started?

'Apart from our numbers rising to 160, the scale of need has changed. On our first day four boys came to volunteer from Mencap House and were able to walk unaided. Now the people who come to us are more severely learning disabled and often in wheelchairs. The MLD schools (supporting those with Moderate Learning Disabilities) now include many young people with Severe Learning Disabilities and the SLD schools include young people with more complex needs than before.

'We've seen funding change for us and small groups like us. When we started, 90% of our funding came via statutory funding and we raised the remaining 10% to pay for wheelbarrows and seeds. Now 30% is centrally

funded and the rest we raise ourselves from grants and fundraising.'

'About three years ago some of the people who'd been here for a while were keen to get some paid work, because of course everybody aspires to have a paid job whether they have learning difficulties or not. Paid work is really hard to come by if you have learning disabilities, so that's how the café got set up.'

## What do you see as the challenges ahead for Mudlarks and people with Learning Disabilities?

'Transition from school to college to work is still a challenge for young people going from special schools with good resources. Some of the colleges are very good but there is still a gap and finding work or meaningful activities is always hard. Also respite care is getting more difficult to find for families of people with complex needs.

For Mudlarks, the end of the European Social Funding which has supported our training programmes which help people into work is our biggest challenge next year. And winter! We could do with some big greenhouses!'

## What are the opportunities? What are you looking forward to next year?

'I'm excited about our forest school. We've been working with school children with severe and profound learning disabilities outside in a forest area and it has been brilliant. We want to develop our own forest school outdoor centre run together with learning disabled people so that a wide range of people can join in.'

# HOW HCF IS HELPING

## Hertfordshire Hospice Education Consortium

### Training for End of Life Care

People with learning disabilities should have access to quality care – at every stage of life. They are more likely to develop conditions such as dementia, have complex needs and require additional care. They may also find it more difficult to understand what is happening to them so it's essential that those caring for them are able to understand their needs, identify the best approaches and be confident in delivering them.

HCF recently helped to fund an innovative collaborative pilot project to educate, train and support staff from residential care settings and hospice staff to ensure that everyone caring for individuals with learning disabilities has the knowledge, skills and confidence to provide high quality palliative end of life care.

The programme has been recognised at a national level and, thanks to further funding from HCF, it is being rolled out to another 10 care homes; the training is being expanded to include staff from day care settings and the team is looking to introduce end of life care for people with learning disabilities into higher education courses at the University of Hertfordshire.



## Grove Cottage

### Developing Potential

Grove Cottage (Bishop's Stortford Mencap) has provided social and educational activities for people of all ages with a learning disability for more than 50 years. Over 150 members can access groups ranging from youth clubs to speech and language therapy but all the activities have the same aims - to help develop potential, improve quality of life, reduce social isolation and provide respite and support for the families.

HCF has not only been able to provide a grant towards their Café project which provides work experience and life skills training for their members, but Grove Cottage was one of the first cohort on our Building Effectiveness Programme. This provided access to tailored workshops and a professional mentor to empower the organisation to run more effectively and face the future with renewed confidence and enthusiasm.



# HOW HCF IS HELPING

## Trinity Community Project

### Developing choice and Reducing Social Isolation



For many people with learning disabilities, being independent can be a challenge but supporting them to be able to make their own choices, access activities that interest them and spend time with other people, whether they have learning disabilities or not, can help to reduce the social isolation that so many experience.

HCF has been delighted to be able to support a number of organisations who are doing just that including the Trinity Community Project who provide a range of social and skills-based activities and have recently started a Community Engagement programme using trained volunteers to support their members to access other community activities.

## Electric Umbrella/Music 24/ActOne Arts Base

### Self Expression

When the traditional methods of communication such as reading, writing or speech are difficult for you, finding another outlet that allows you to express yourself and connect with those around you can be life changing.

For those with learning disabilities, music can provide a means of communication, self-expression and interaction. It improves motivation, encourages and stimulates physical movement and communication but perhaps, most importantly, brings joy.

HCF has supported a number of music-based projects including Electric Umbrella whose members meet weekly to write and record songs, play instruments and sing karaoke, Music 24 who provides interactive music therapy sessions to groups with learning disabilities or dementia and ActOne Arts Base whose UV nightclub, designed and run by young people with learning disabilities, enables learning disabled and non-learning disabled young people to enjoy music and dance together.



# WHAT NEXT

## Grant Making

Applying what we know to our grant making, it's clear that support is valuable across a wide range of learning disability related issues but some of the priorities identified include: helping people access paid work, activities which help reduce social isolation and projects which help to promote good health and address health inequalities. In particular it is good to ensure that the groups and projects have a high degree of co-production. For details of current funding opportunities visit the Grants page on our website.

## Capacity Building

We know that many of the groups we work with are concerned about future funding. In addition to providing grants for running costs and projects, we recognise the importance of helping groups to develop and build their capacity to support their communities. Through HCF Training and Development we provide organisational support including 1:1 advice, a range of training courses and the tailored, supported development programme "Building Effectiveness" which last year supported ten organisations.

**Building Effectiveness Programme** The 2018/2019 cohort includes Hertsmere Mencap, Watford Mencap and the Watford Sheltered Workshop who all specifically support people with learning difficulties. A further three groups selected have a significant number of learning disabled beneficiaries. As before, each organisation will be supported through a development planning process to help them achieve their strategic goals. To find out more about the programme and other training and organisational development opportunities visit [www.hcftraining.org.uk](http://www.hcftraining.org.uk)

## HCF's 30th Anniversary Fund 'Building Potential'

To mark HCF's 30th Anniversary we are delighted to launch a new grants programme giving smaller groups and organisations an opportunity to apply for funding to help develop their organisation's potential. Successful applicants will be allocated a professional Advisor who will conduct a face to face organisational needs analysis. Following this process, where relevant, a Mentor will be assigned to enable the organisation to meet its strategic objectives. Visit [www.hertscf.org.uk/grant-making](http://www.hertscf.org.uk/grant-making) for further information.

## Reading list and References

For more information and useful links related to learning disabilities, our reading and reference list can be found at [www.hertscf.org.uk/hertfordshire-matters](http://www.hertscf.org.uk/hertfordshire-matters)

## Love Herts - Give Where you Live

The Love Herts appeal enhances our ability to help vulnerable people in Hertfordshire by making it easy to effectively give to your community. Donations to the appeal are used to help and support a wide range of deserving causes and community initiatives across Hertfordshire which may otherwise go unsupported. By using our extensive knowledge of the county and its voluntary sector, supported by our Hertfordshire Matters project, we are able to identify and target the areas and issues most in need of support. To find out more visit [www.hertscf.org.uk/give-to-your-community](http://www.hertscf.org.uk/give-to-your-community)



Sign up for our newsletters to keep up to date with our work on our website ([www.hertscf.org.uk](http://www.hertscf.org.uk)) and don't forget to follow us on Facebook and Twitter!

### Hertfordshire Community Foundation

Foundation House, 2-4 Forum Place, Fiddlebridge Lane, Hatfield, Hertfordshire AL10 0RN  
Tel 01707 251351 [www.hertscf.org.uk](http://www.hertscf.org.uk)

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