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Whole life disability strategy





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Foreword

We are proud to present, Leicestershire County Council's, first whole life disability strategy that sets out an initial plan for how disabled people can live happy, independent, and successful lives.

Joining together Children and Adult health and social care services, Leicestershire demonstrates how important we feel this agenda is and how we believe, by working together, we can achieve more for disabled people and their families.

An estimated 210,000 (20%) of residents in Leicester, Leicestershire, and Rutland have some form of disability or long term health problem¹: each and every one of those people deserves to be able to access support, develop their skills and to meet life's challenges, and make the most of their opportunities.

We want disabled people to be independent and equal in society, have choice and control over their own lives. Disability should never be a barrier to live a happy, independent, and successful life. Our aim for this strategy is to support removing barriers for all types of disability through challenging and changing attitudes and understanding that this is everyone's responsibility.



Richard Blunt

Cabinet lead member for Adults and Communities



Ivan Ould

Cabinet lead member for Children and Family Services

¹ Source: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/692771/family-resources-survey-2016-17.pdf.

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The purpose of the strategy

The whole life disability strategy supports the integration of health and social care services for disabled people within Leicestershire.

This strategy has been co-produced with disabled people and statutory health and social care services. Building on the best practice in the statutory services the strategy establishes that co-production will be adopted as the way in which services will work with disabled people, their parents and carers going forward.

The strategy identifies the key concerns disabled people have around the support they receive from health and social care services and details the initial response from these services in addressing the concerns raised.

This document does not provide a comprehensive list of all the services available for disabled people, but responds to the themes clearly expressed by disabled people as we have engaged with them in the development of this work.

Our strategy is about everyone: disabled children and adults; family members; carers; friends; neighbours; employers; educators; decision makers; funders and planners. It aims to challenge thinking, change attitudes, and recognises that disability and removing barriers is everyone's responsibility and everyone has an important part to play.

We want disabled people to be independent and equal in society, and have choice and control over their own lives.

Throughout this strategy there are a number of direct quotes from disabled people and members of their support networks that were provided through the engagement process.



Jon Wilson

Director of Adults and Communities



Paul Meredith

Interim Director, Children and Family Services

Introduction

Our Vision

Leicestershire County Council's Strategic Plan 2018-22: Working together for the benefit of everyone includes its vision for Leicestershire. We want to have a strong economy that creates the best life chances for all. A place where people are well and safe, living as part of great communities where people enjoy life with maximum independence in quality homes that are affordable. The Whole Life Disability Strategy focuses on how we will deliver these outcomes for disabled people throughout their lives.

The vision starts with the moral imperative that we make sure disabled people living, working, studying, and visiting our communities are supported, empowered, and enabled to live their lives to the full.

Within Leicestershire our aim is to take a whole life approach to ensure that disabled people of any age can live healthy, safe, independent, and fulfilling lives in their own communities. They'll have greater employment opportunities, better health and community relationships, and increasing independence and control over what they want to do and how they wish to be supported.

To deliver our vision, we will:

- Take a Whole Life Approach - We will aim to reduce the impact of transition between different ages and stages of life by working with individuals, their families and others who support them, to create a seamless experience.
- Focus on early help, intervention, integration, and prevention – Starting at birth we will aim to ensure that disabled people and their families will have access to the right information and support to enable them to be actively included within their local communities. We aim to ensure they are supported to start developing the skills they will need to lead a more independent life.

- Promote Personalisation and Progression – Services will demonstrate how they are responding to meeting the identified outcomes of everyone they support, and how they can demonstrate when they are met.
- Champion increased independence and employment – People should be able to live, work and be active contributors in their community, making the best use of their own and other available resources and opportunities.
- Promoting Choice and Control with shared responsibility and community resilience – People should be able to exercise choice and control over as many matters as they can, but with these rights goes responsibility. We will be adopting a strengths-based approach that takes account of informal as well as formal networks of support to link people into their own community capacity rather, than wrap services around them.
- This strategy sets out, initially, how the statutory agencies will work together with disabled people, their families and others who support them to make the vision a reality.



The context for Leicestershire's strategy

Our strategy is aligned with the many forms of legislation and policy relating to disability, equality and improving the quality of life for disabled people.

We have been keen to establish foundations for the work that are relevant to disabled people, parents, carers, and professionals working within the field. The elements considered below now form foundations for the final strategy as they have been widely accepted in the engagement process by disabled people.

Definition of disability

The definition of disability adopted and agreed with people through the initial engagement workshops is from the Equality Act 2010. It states:

You are classed as disabled if you have a mental or physical impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

'Substantial' is more than minor or trivial, e.g. it takes much longer than it usually would to complete a daily task like getting dressed.

'Long term' means 12 months or more, e.g. breathing condition developed because of a lung infection.

People with progressive conditions (ones that get worse over time) can be classed as disabled.

Social model of disability

Through the engagement, we explored with people the Social model of disability, a concept which says it is not a person's condition or impairments that disable them, but environmental and societal conventions and the way society is organised that creates barriers and do not accommodate difference and therefore disable people. This model has been widely accepted as positive by people who have participated in the engagement workshops, whilst we adopt this model as a positive statement way of reshaping services, we acknowledge that disabled people have physical, medical, and emotional needs that needs that should never be disregarded

"A whole life disability strategy makes sense, as disability is for life... I need help to know what is going to happen next..." *Teenager*





12 pillars of independence

The initial engagement process was established in a way that allowed us to hear the voice of disabled people and their parents and carers. A very clear message that has influenced all conversations is the desire of people to have greater independence, choice, and control over their lives. To focus thinking around this area we are adopting the 12 pillars of independence, often referred to as the 12 basic rights of disabled people, which state disabled people should have:

1. **Appropriate and Accessible Information**
2. **An adequate income**
3. **Appropriate and accessible health and social care provisions**
4. **A fully-accessible transport system**
5. **Full access to the environment**
6. **Adequate provision of technical aids and equipment**
7. **Availability of accessible and adapted housing**
8. **Adequate provision of personal assistance**
9. **Availability of inclusive education and training**
10. **Equal opportunities for employment**
11. **Availability of independent advocacy and self-advocacy**
12. **Availability of peer counselling**

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We expect

All disabled people will need access to good quality, accessible information, advice, and universal services to help **Prevent** need.

Many disabled people benefit from early help or targeted support to **Reduce** need later in life.

Some disabled people will need help and support quickly, doing this well can **Delay** increased need.

A **Few** people will have need for ongoing support to **Meet** their needs.

Equality Act 2010

The Equality Act 2010 is a major piece of legislation that brings together and strengthens the various existing pieces of anti-discrimination legislation that have been passed since the 1970s.

Under the Act, disability is one of nine protected characteristics that all public bodies must have due regard to in their policies, procedures and when carrying out activities so as to eliminate discrimination, advance equality of opportunity and foster good relations between different people.

Leicestershire County Council does this through its Equality Strategy which is supported by annual delivery plans setting out specific actions and timescales for completing them.

The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities is an international human rights treaty of the United Nations intended to protect the rights and dignity of disabled people. Parties to the Convention are required to promote, protect and ensure the full enjoyment of human rights by disabled people, and ensure that they enjoy full equality under the law. The Convention has served as the major catalyst for viewing disabled people as full and equal members of society with human rights, rather than as objects of charity, medical treatment, and social protection.

“I am autistic, I create computer games, I want to make a computer game that changes the world for me and my friends – can you help me? *Teenage boy*”



What we know about people with a disability

In 2018 there are 65.6m people living in the UK, of these it is estimated that 14.4m people 22% report a disability or long term health problem (8% children, 19% working age adults and 45% pension age adults), an increase from 18.6% in 2011/2².

In Leicester, Leicestershire, and Rutland (LLR) at the time of the 2011 Census, there were 168,000 usual residents reporting a long-term health problem or disability, which is 16.5% of the population, compared with 18.6% for England³. Aligning with 3.5 percentage point increase in national trends it is estimated there are now 210,000 disabled people in LLR, 20% of the 1.1m population.

“We need to work together creatively to ensure existing resources meet the increasing needs presented to us.”

Frontline practitioner

Learning Disability

Medical estimates of learning disability prevalence indicate there are nearly 15,000 people with a learning disability in the County⁴.

The no. of children with Education, Health and Care Plans (EHCPs) has risen by nearly 1000 since 2015, with a total of 3703 children and young people (0-25yrs) with EHC Plans in the County as at March 2018 (SEN 2 Data).

GPs are asked annually how many of the adults on their practice list have a learning disability. The 2016/17 Quality Outcomes Framework shows that 2.1% of Leicestershire’s GP registered population had a learning disability. This is significantly lower than the England average of 2.6%⁵.

People with learning disabilities are more likely to have co-morbid conditions such as autism, mental health conditions, physical and sensory impairments. At the most complex end of the scale of learning disabilities are people who are described as having a “profound and multiple learning disability” (PMLD) or a profound and multiple intellectual disability (PMID).

Government figures in 2017 suggest that 6,655 of school aged pupils with an Education and Health Care Plan in state maintained schools in Leicestershire are identified as having specific, moderate, severe, profound, or multiple learning disabilities. This compares to the East Midlands at 5.5% and England average of 5.2%. In Leicestershire the figure increases to approximately 7,000 with the inclusion of pupils in Independent provision and Further Education⁶.

2 Source: DWP, 2017. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/692771/family-resources-survey-2016-17.pdf

3 Source: 2011 Census, ONS. Available at: <https://www.nomisweb.co.uk/census/2011/qs303ew>

4 Based upon CCG GP populations 2018- NHS East Leicestershire and Rutland (326713) and NHS West Midlands (391237) at a rate of 2.1%

5 Source: Fingertips, PHE, 2017. Available at : <https://fingertips.phe.org.uk/search/learning%20disability>

6 Source: Department of Education. SFR37/2017 tables 15, 16,17,18. Available at: <https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2017>

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Carers

At the time of the 2011 Census, 10.4% of the usual resident population of LLR (105,000 people) provided some kind of unpaid care. This is compared with 10.8% in the East Midlands and 10.2% in England. Of these, 2.2% (23,000 people) in LLR provided 50 or more hours per week. This is compared with 2.5% in the East Midlands and 2.4% in England⁷.

Many carers do not think of themselves as a carer and so do not know about the services and support which is available to them highlighted by the fact that just 12,190 people (all ages) were in receipt of Carers Allowance in LLR in 2017⁸. The rising older people population highlights the importance of carers and the services they provide - given that the majority of carers care for older people.

The median age of death of people with learning disabilities in Leicestershire is 57 which is comparable to the population of people with learning disabilities in England, but is significantly worse than the average age of death (75.5) for the general population in the most deprived areas of Leicestershire.

Mental health

In 2015, 8.7% of children in Leicestershire aged 5-16 were estimated to have a mental health disorder. This is compared to 9.2% for England and 9.4% for East Midlands⁹. The most common problems across the region were conduct disorders, emotional disorders and hyperkinetic disorders.

Data on adult mental health is reported at Clinical Commissioning Group (CCG) level. In 2014/15, 12.2% of the adult population of East Leicestershire and Rutland CCG were estimated to have a common mental health disorder. In West Leicestershire CCG the figure was 11.6% and in Leicester City CCG the figure was 14.8%. In comparison, the rate was 15.6% for England and 14.2% for Central Midlands NHS Region¹⁰.

People with a long term health problem or disability are two to three times more likely to develop mental health problems, particularly anxiety and depression. The 2015/16 GP Patient survey found 4.8% of Leicestershire's population report long term mental health problems. In 2016/17, almost 60,000 patients in Leicestershire were recorded with depression on GP practice disease registers. This accounts for 10.6% of the practice population which is significantly higher than England's average of 9.1%¹¹.

“Everybody is different, how we communicate and understand is different but we all have a voice – please listen!” *Young disabled woman*

7 Source: 2011 Census, ONS. Available at: <https://www.nomisweb.co.uk/census/2011/qs301ew>

8 Source: NOMIS, ONS, 2017. Available at: <https://www.nomisweb.co.uk/query/construct/summary.asp?mode=construct&version=0&dataset=116>

9 Source: Fingertips, Public Health England, 2017. Available at: <https://fingertips.phe.org.uk/profile-group/mental-health/profile/cypmh/data#page/0/gid/1938133090/pat/6/par/E12000004/ati/102/are/E10000018>

10 Source: Fingertips, Public Health England, 2017. Available at: <https://fingertips.phe.org.uk/profile-group/mental-health/profile/common-mental-disorders/data#page/3/gid/1938132720/pat/46/par/E39000030/ati/153/are/E38000010/iid/90853/age/240/sex/4>

11 Public Health England. Mental Health Dementia and Neurology. Common Mental Health Disorders (2018). Available at: <https://fingertips.phe.org.uk/profile-group/mental-health/profile/common-mental-disorders>

Engagement

Between January and September 2017, we carried out extensive engagement with disabled people, their parents and carers and with professionals working in this field.

We ran workshops, attended existing groups, and met with bodies set up to represent the views of disabled people.

During this engagement work we spoke to and took the views of over 1,000 people.

The engagement with disabled people was all carried out through face to face contact, often using card systems to ensure understanding, backed up by 'easy read' documents to help people assimilate the messages.

The voice of disabled people, being central to our thinking, planning, and delivery of services has driven the priorities for the strategy.

This strategy has also been developed in consultation with health and social care professionals, a range of public, private, voluntary and community sector organisations, including care and support providers.

What disabled people told us

- Disabled people are telling us they are frustrated at having to repeatedly tell their story to different professionals, sometimes workers from the same teams. People with Mental health conditions have spoken about the stress they experience when reliving traumatic experiences through this process.
- Disabled people have described, in many of the forums, their desire for greater independence and to gain choice and control over their own lives.
- Many disabled people and parents/carers told us they find it difficult to navigate health and social care systems and feel they would benefit from a named individual to be able to call on at their time of need. They also described the many wasted hours for themselves and the many professionals trying to gain an understanding of their specific needs to provide the correct support.

- Disabled people and Parent/carers told us they experience difficult transitions, particularly from children's services to adult services. Many people described the anxiety they felt during this phase.
- Across the region duplication of services was highlighted by disabled people, parents and carers, and professionals as frustrating and wasteful. It was agreed that ensuring services and agencies work better together will make life easier for disabled people and their families.
- Disabled people expressed a desire to see better transport policies. Many felt the outlying districts of Leicestershire were not well served by public transport which meant they had to use more expensive transport options on a regular basis. Disabled people felt the current restriction on the use of bus passes before 9.30am impacted on their ability to take up work and volunteering opportunities. Also, making it difficult to take part in morning activities. The transport services across Leicester City were generally viewed as meeting people's needs.
- It is essential to involve disabled people, their families and disabled people's organisations and groups in decision making about services and access to places using their expertise from experience.
- To challenge thinking, support change in attitudes and inform that disability and making places accessible is everyone's responsibility and everyone has an important part to play.



What are we doing about the concerns raised by disabled people?

We are committed to addressing the concerns raised, in many instances, as concerns have been raised, staff have been deployed to consider how to take a response forward and action has already commenced, which further underlines a strategy of this nature has to be constantly evolving to truly reflect the needs of disabled people.

Partners have acknowledged how disabled people are concerned about the lack of integration and how that creates confusion for them. To start to address this concern a high-level workshop was organised for all the partners of the strategy to work together to address the specific concerns raised.

The outcomes of the workshop will form a high-level action plan and associated detailed action plans. Key elements of the work are captured below.

“We are tired of fighting for our children’s care, please work with us, we can identify where there is wasted time and energy, we want to help to shape the services now and for the future.” *Mother of child with PMLD*



You said

Disabled people and parents/carers tell us they find it difficult to navigate health and social care systems



We will

- Work with disabled people and their families to explore what good care navigation could look like
- Work with partners to explore the training needs for primary care staff in relation to supporting disabled people



Required outcomes

- People will experience improved navigation of services through developing lead professional roles
- Front line workers will have a good awareness of the legal framework regarding Special Educational needs (SEN and Disability and have in place effective mechanisms to support the Education, Health and care assessment, review and transition process.
- We are developing a “Pathway to Adulthood” protocol to support effective transition from 14yrs onwards

**You said**

Disabled people desire greater independence

**We will**

- Work with all partners to promote and extend opportunities for supported employment for disabled people
- Through the Learning Disability transforming care programme target the reduction in hospital admission by providing greater levels of community care
- Increase the number of opportunities for disabled people to have a home of their own through investing in more supported accommodation
- Continue to roll out local area co-ordination across the County to support disabled people to be active members of their communities
- Increase the numbers of people who are supported to manage their own care through increasing access to personal budgets, including personal health budgets and the development of Individual Service Funds
- There are various potential travel options available for disabled people across the county ranging from the commercial and County Council supported bus networks to Community Transport and Demand Responsive Transport etc. We will seek to ensure that disabled people are aware of the range of travel options that are available to them and what of these options the County Council is able to cost effectively provide within the resources available

**Required outcomes**

- More disabled people will feel that they are being supported to have choice and control over their own lives through having increased independence and being part of the community in which they live

**You said**

Disabled people are frustrated at having to tell their story many times.

**We will**

- Work together to improve the way we share information particularly between children's and adult services
- Ensure that disabled people have copies of their assessment and support plans so that they can control who their information is shared with

**Required outcomes**

- Disabled people and their parents/carers will have greater control over their own information



Disabled people and parents/carers experience difficult transitions, mainly from children to adult services



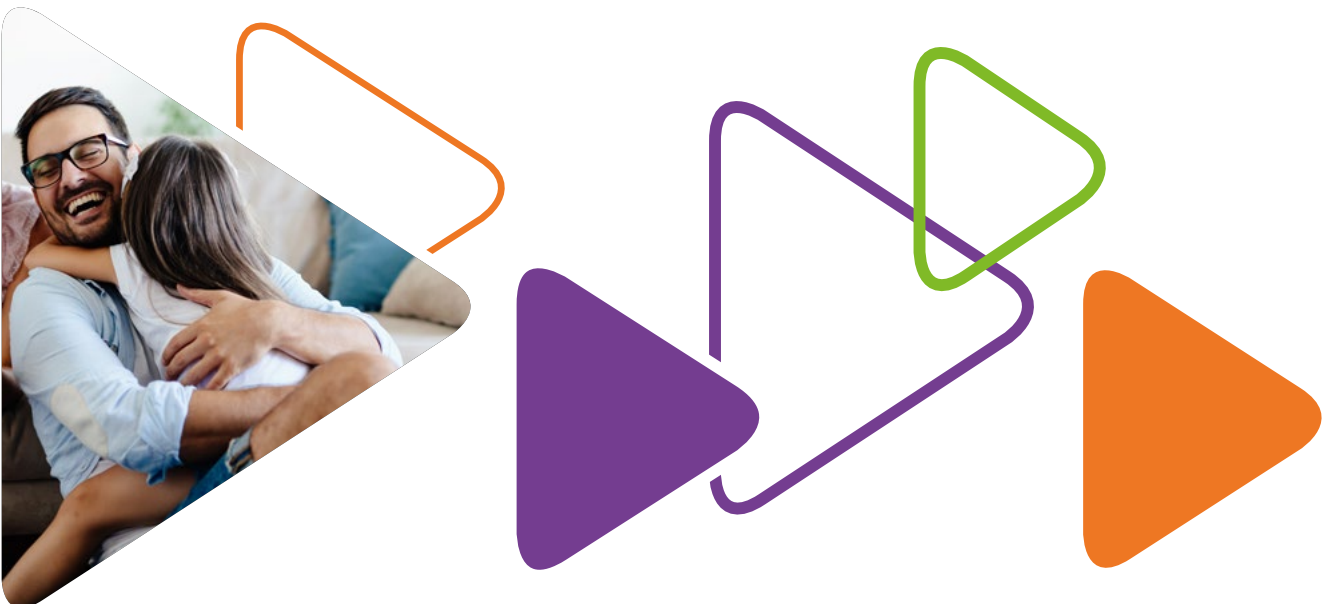
We will

- Establish a 'Pathway to Adulthood' document that sets out how services will work together, from when a young person is 14yrs of age, through to adulthood.
- Work closely with young people and their parents/carers to ensure that the pathway is accessible and easy to navigate, with the views and aspirations of young people being central to decision making.
- Develop a clear 'offer' so that young people and their parents/carers have the information that they need to make an informed choice.
- Develop better joined up working between Children and Families Services and Adult Services so that changes and transitions can be managed carefully and at a pace that suits the young person.
- Work with Colleges, employers and other organisations to develop the range of education and employment opportunities, including supported internships.
- Take into account all aspects of the young person's life, including steps towards employment, independent living, community inclusion and health in the pathway to adulthood.
- Ensure we investigate the key issues for disabled people as they transition into their old age
- We are reviewing our 'School Readiness Strategy' to ensure that parents of a disabled child experience a joined up approach to early identification and support. (Children and Families Plan, Priority One "Ensure the Best Start in Life")



Required outcomes

- A person-centred process to support navigation through transition, from child to adulthood and on to older age



What next ?

This Strategy document supports the Council's ambitions as established the Strategic Plan, "Working together for the benefit of everyone: Leicestershire County Council's Strategic Plan 2018-22". The delivery of the strategy will contribute to all 5 strategic outcomes, however the implementation of the strategy will be overseen through the governance of the Wellbeing and Opportunity Outcome led by the Director of Adults and Communities.

We will review the strategy annually and a reference group will be developed to ensure that disabled people are partners in developing the detailed action plans and can hold us to account if we do not deliver on the things we have said we will do.

