

## **Mencap- Programme For Government 2016- Consultation response**

### **About Mencap**

Mencap is the charity for children and adults with a learning disability. Our vision is a world where people with a learning disability are valued equally, listened to and included.

In order to enable Mencap to achieve its vision we have five strategic priorities:

1. Raising awareness and changing attitudes
2. Making a difference to the lives of people with a learning disability here and now.
3. Supporting friendships and relationships.
4. Improving health for people with a learning disability.
5. Giving children the best start in life.

### **About Learning Disability**

A learning disability is a reduced intellectual ability and difficulty with everyday activities, for example: household tasks, socialising or managing money all of which affects someone for their whole life. The level of support someone needs depends on individual factors, including the severity of their learning disability. The Bamford Review of Mental Health and Learning Disability defined learning disability as the “presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development”.<sup>1</sup>

There are an estimated 36,000 adults with a learning disability in NI. Too many of our children and adults with a learning disability face significant challenges and barriers that exclude them from reaching their full potential and participating fully in society. To have a fully inclusive society means ensuring those who are most vulnerable and marginalised are included; this without doubt is those with a learning disability. The Programme for Government must ensure that the lived experience of children and adults with a learning disability significantly improves over the Assembly term and that this can be clearly evidenced and measured.

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<sup>1</sup> Equal Lives Bamford Review of Mental Health and Learning Disability, DHSSPS 2005

## Key acknowledgements and recommendations

Having participated in the initial stage of the ‘Programme For Government’ consultation, Mencap is keen to offer sector focused expertise as a means of positively influencing government policy and strategy, for the betterment of people with learning disabilities across Northern Ireland.

Mencap would like to acknowledge and thank the ‘Programme For Government’ team for several inclusions in the second phase (consultation) document, notably;

- Addressing the needs of children and young people including improving transition
- More influence (for people with disabilities) over their own lives
- More opportunities to allow (people with disabilities) to exploit and maximise their full potential
- A greater sense of belonging for people with disabilities within their own communities, where they feel valued and respected as others are and have more opportunities to participate in community life.
- Raising awareness and changing attitudes towards disability
- Strengthening disability discrimination legislation

Whilst we appreciate that the consultation process is ongoing, we would like to take this opportunity (at the outset) to clearly outline some key areas where we feel that plans could be improved, to ensure improvements in the quality of life for people with disabilities are realised;

1. The measurement for monitoring ‘the quality of life for people with disabilities’ is derived from ‘Life Satisfaction’ data from within the Labour Force Survey (LFS). This survey collects data for ages of 16 and above, thus excluding children. This measurement will not provide a holistic picture of progress across all ages, and therefore must be extended or amended. In addition, we support calls from Disability Action that this indicator must be underpinned by the UNCRPD, in particular, Articles 4.3, 5, 6, 7, 19 and 28. *\*It is worth noting, through the consultation ‘analysis of responses’ document, that the indicator ‘increase quality of life for people with disabilities’ received the highest positive % in terms of maintaining the indicator (78%). However, in terms of the measurement, only 67% supported keeping the ‘average life satisfaction score’ as the sole measure.*
2. If the recommendation above is not to be introduced (to adequately cater for the needs of children), then we at Mencap strongly recommend (as per our previous response) the introduction of a new indicator to specifically support disabled children and their families. As it stands, there is little strategic focus in this area, and with the sole indicator/measurement based within the Labour Force survey, the progress of children (with a learning disability) will be excluded from monitoring essential processes.

3. We would welcome the application of early intervention to all plans relating to people/children with disabilities. Early intervention is key in ensuring children with learning disabilities maximise their potential in life. Various research studies provide a strong evidence base to show how focusing on familial centred early intervention is a successful model for reducing challenging behaviours and mental health later in life. We are firmly of the belief that all plans for early intervention must set out actions for children with a disability.

### **Consultation response**

Whilst Mencap welcome the indicator which commits to '*improving the quality of life for people with disabilities and their families*', we would welcome some clarity around the specific age brackets to be included. As a service deliverer for children and adults we feel it essential that quantitative targets are set for young children and adults at the outset of this Programme For Government.

In our previous response we highlighted that '*the lived experience of children and adults*' must significantly improve over the course of the next Assembly term, and moreover, that this should be clearly evidenced and measured. However, in using the LFS as a sole measure, children are immediately excluded, as the survey is only offered to people aged 16 and above. We would recommend that consideration is given to expanding or amending this measure in order to support the monitoring/evidencing of progress for children with a disability.

Also, as noted in our previous response, 2 children are born very week in Northern Ireland with a learning disability, for whom, early intervention is widely recognised as essential to improve their early development and reduce the inequalities they face. We would welcome a more specific, focused and targeted approach to early intervention for children living with a disability.

Having strongly recommended a further indicator centred on 'support for disabled children and their families' (in the previous tranche of consultation) we are disappointed that no efforts have been made to include this important commitment as an indicator. As the consultation document, and associated delivery plans currently sit, Mencap is not satisfied with the strategic vision for the progression of children with a learning disability in Northern Ireland.

We support comments from organisations such as 'Children in Northern Ireland', who highlight disappointment that children and young people (who have a disability) are largely invisible within this delivery plan.

## Delivery Plan

Mencap welcomes the 6 key areas of focus found within the delivery plan for improving the quality of life for people living with a disability;

1. Raising awareness and changing attitudes towards disability
2. Address the needs of children and young people including improving transition
3. Enhancing opportunities for employment and/or lifelong learning
4. Improving independent living and the provision of suitable homes
5. Improving participation in public and community life
6. Improving access to information and better data collection

In addition, Mencap welcomes the acknowledgement of constraints for people (living with a disability) in relation to being economically inactive, facing problems with housing, education qualifications and participation in public and community life including the arts and sport.

As a means of addressing the constraints (as noted above) Mencap recommends that 'early intervention' is applied to the delivery plan for 'increasing the quality of life for people with disabilities'. Early intervention is noted several times throughout the consultation document, but not in relation to indicator 42. Once again, the inclusion of early intervention should be bolstered with evidence based measures designed to engender progress and transparency.

We welcome the commitment to 'improving transition from post primary to adulthood' and the collaborative cross-departmental approach. Mencap also welcomed the former Employment and Learning Committee's Inquiry into post-SEN provision for people with a learning disability and agree with most of its findings. We would encourage the Executive to follow through on this extensive piece of work and ensure it is delivered through PfG Delivery Plans. However, as with many of the strategic objectives found within the delivery plan, affording the public the chance to monitor progress and engagement will be key. In addition, targeted actions are required to monitor the progress of young people who access transition services. Actions and monitoring processes should analyse rates of young people with disabilities who gain work (either paid or unpaid) through transition services and who progress to mainstream college provision. Only through the monitoring and collation of data can the effectiveness of transition services be clearly evaluated and reviewed.

## **Older carers**

Carers NI warned earlier this year that government was not doing enough to support unpaid older carers whose dedication allows thousands of seriously ill people to retain their independence and continue to live in their local community. Currently more than 15,000 Northern Ireland pensioners aged 70 and over are providing a minimum of 35 hours' unpaid care every week – the equivalent of a full-time job. In addition, over 400 of the carers are 90 years of age or older.

We are concerned that there are no plans in place to add further support to the needs of older carers, we echo the sentiments of the Commissioner for Older People who clearly note that “older carers must not be taken for granted.” We would welcome the creation and delivery of plans which will redress the current chasm in support for our much needed older carers across Northern Ireland.

## **Employment**

Whilst we welcome ‘enhancing opportunities for employment and lifelong learning’- we would like to see a greater means of evidencing and measuring progress in this area. Tangible year on year targets should be created as a means of addressing current economic disadvantages for people living with disabilities. Around two thirds of people with a learning disability want to work (Mencap 2008; also NHS surveys 2010) – however only 17% of people with a learning disability are in any form of paid work (Centre for Disability Research 2008), compared with 46% of disabled people as a whole (Office of Disability Issues 2012) and around 70% of the general population. The Westminster government has committed to halving the disability employment gap by 2020 and, more recently, the Scottish executive has announced plans to follow suit. Mencap would ask that the NI Executive follows the example of its mainland counterparts by committing to a similar outcome which we believe would also benefit many people with a learning disability, as well as the rest of society, here. This is all the more important as, according to Joseph Rowntree Foundation report (March 2016) the employment rate for disabled people in Northern Ireland is 15% lower than it is in Great Britain.

As is the case currently, too many adults with a learning disability want to work but are either unable to find suitable paid employment or find themselves in an unpaid work environment. This is, in part, illustrated by the current 2015-18 European Social Fund which aims to support 7,266 disabled people over the 3 years, most of whom will be supported in work placements - compared with just 692 disabled people who are currently supported to retain paid employment through Workable NI programme. Many of those who have gained paid work are at minimum wage level with very little opportunity for career progression. Clear economic strategic aims, linked to the new Employment Strategy for People with Disabilities, should be applied to the delivery plan for indicator 42.

As noted elsewhere in the consultation document within the indicator ‘increase proportion of people working in better jobs’, we would welcome a robust and equity based approach to employment for people living with disabilities. We would welcome targeted inclusions into priority sectors such as telecommunications and ICT; life and health sciences; agri-food; financial and professional services; and, advanced materials and manufacturing for people seeking jobs whilst living with a disability.

### **Education**

At Mencap we welcome the acknowledgement that ‘there are children who face particular educational and personal challenges to attainment thus there is a need to address these barriers with tailored support so that each child reaches their full potential.’

For many children living with a disability who cannot reach level 2 (SEN focus) there needs to be a suitable alternative in place. We would recommend that Social Clause Contracts be created, with an emphasis on moving away from GCSE attainment. For example, OCN, skills and work experience are more attainable for an adult with a learning disability than GCSE. This current system (measured on 3 GCSE’s) is a system which excludes anyone who cannot possibly attain this and therefore diminishes their accomplishments and potential.

### **Housing**

As noted in the delivery plan, ‘disabled people are more likely to face problems with housing’, and whilst a commitment to build an additional 9,600 social homes could provide a welcome boost, it is imperative that houses are adapted to the needs of people living with a disability. Streamlining the Adaptations and Disabled grants process is a welcome move and must be met with a determination to build more houses with bespoke adaptations from the outset.

It is currently the case that too many adults with a learning disability are unable to live independently in their communities due to housing constraints. Recent statistics from the review conducted by RQIA suggest:

- The current available figures underestimate the need. It is estimated in Northern Ireland 9,200 adults with a severe learning disability (ASLD) are known to social services. This is recognised as an underestimation and does not include adults with a moderate learning disability (AMLD).
- 7,000 (76%) of these ASLD live at home with their parents. A much higher percentage than in Britain or in Rep. of Ireland (50%). This is often not a matter of choice but of necessity.

- The numbers of people with learning disabilities will grow substantially and recent figures from the Bamford Review suggest that many young adults leaving special schools may no longer receive services from social services. However, in future years their level of need is likely to increase with a consequent demand for services.
- In the 13 years since Bamford Review (2003) a total of 582 housing placements have been created for ASLD. 47% of these have been in nursing homes, 25% in residential care and only 9% in supported housing.

Finally, whilst it is noted that there will be a welcome consideration to ring fencing provision of accessible homes for disabled people, we would welcome strong and timely action in this regard.

### **Conclusion**

Mencap is committed to achieving change for children and adults with a learning disability in NI and are willing to work with government and other partners to create solutions and achieve the vision outlined in the Programme for Government. Mencap would welcome the opportunity to play a role in the formation of final delivery plans through being positioned as an expert partner throughout the remainder of the consultation process.

To echo the sentiments of other organisations, going forward the process must directly engage with disabled people and specialist organisations to ensure that indicator 42 and measurements are co-designed with people with disabilities. It is our lived and expert experience which will help ensure that the indicator, measure and any subsequent action plans will actually deliver real change for disabled people.

If you have any comments or queries about our submission, please do not hesitate to contact our Director: [Margaret.Kelly@mencap.org.uk](mailto:Margaret.Kelly@mencap.org.uk)

Please see enclosed our examples of sector best practice.

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## Mencap Examples of Sector Best Practice

### 1.0 Early Years and Family Centred Intervention for Children with a Learning Disability

1.1 Whilst the Programme for Government recognises and supports Early Intervention for children it is regrettable that Children with a disability are both hidden in language and within the **Delivery plan of 42 and Outcome 14**.

#### 1.2 The Need

Within Children in NI 's response the current indicator 42 is not always directly applicable to or related to indicator 42 in its current form. Either there should be a separate delivery plan for children with a disability or indicator 42 must integrate the over-arching guiding principles of the United Nations Convention on the Rights of the Child (UNCRC) to be family-centred and responsive to the rights and needs of children and young people with disabilities, be in a non-discriminatory manner (UNCRC article 2). Fundamentally children and young people with disabilities must be given the opportunity to be heard and have their views given due weight and consideration (UNCRC article 12) at all levels in the planning and policy process. This is supported by the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which includes an important and specific focus on children with disabilities. Article 7 provides that in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

#### 1.3 Research Evidence & Sector Best Practice

Research from Pickles<sup>2</sup> (2016) proves that family centred early intervention can have a lasting positive effect both in reducing mental health problems and challenging behaviour.



1.4 Mencap NI has provided an early years integrated wraparound service for children with learning disabilities for 30 years. With a brand new purpose built Children's Centre that provides a hub of services provided by HSCT and experienced nursery staff it plans to develop and expand these services. It's success measures not only the progress of the child's development, but also the family's understanding and access to information and services. We are about to engage in an innovative evidence led family support programme that ensures early family support for children with a learning disability.



<sup>2</sup> Pickles et al (2016) Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. Medical Research Council

## 2.0 Role of Advocates

### 2.1 Indicators: Self Efficacy Indicator 28

#### 2.2 Need

Children and Adults with a Learning Disability can face many challenges throughout their lives in having their voices heard and their needs met. Independent advocacy is central in assisting them to achieve this and in particular in their interaction with statutory services.

2.3 Unfortunately the funding for advocacy services for people with a learning disability has been significantly reduced and it has become more and more difficult to access advocacy services in almost every Trust area. Many HSCTs are choosing to fund advocacy on an as and when basis which makes it almost impossible for independent organisations to provide a quality advocacy service. The Programme for Government must ensure advocacy is appropriately funded if it wants to meet the outcomes for adults and children with a learning disability,

#### 2.4 Mental Capacity Act

Although the sector welcomes the Mental Capacity Act. The experience in England on the introduction of the mental capacity act has been a hugely increased need and demand for advocacy services. It would be essential that PfG takes this into account as the Mental Capacity Act comes into effect.

## 3.0 Mencap Housing

3.1 Mencap are experts in providing adults with a learning disability real choice about where they live and who with. All our housing options are person-centred and tailored to meet an individual's needs and aspirations. Mencap has a vision of ordinary houses in ordinary streets by providing a range of different ways to ensure that flexible, responsive, timely and community based solutions are created for individuals with a learning disability.

3.2 Mencap are currently trialling a number of models in partnership with Golden Lane Housing and will be providing more detailed outcomes in the New Year.

#### TENANT SAID:

"I love living on my own and I am happy in my new flat. I have more independence and I would like to live here for a long time. My goals are to get a placement working with animals and I would like to get a dog."



#### MENCAP SAID:

"We're delighted our tenant has made this move – she felt herself it was time to move into more independent living and we were delighted to help. We've worked with a responsible landlord, who has upgraded their new home in advance of her moving in and this included the installation of a brand new efficient heating system to keep her warm during the winter."

#### GLH SAID:

"We're delighted that the individual has managed to find a very suitable new home and Golden Lane Housing are thrilled we can help make her dream of independent living come true"

#### WHST SAID:

"The Trust is very happy to see this type of development in our area. It is a positive move that people with learning disabilities are now being offered much more flexible options in housing than were previously available."

## 4.0 Lifestyle Support Model

4.1 **Need:** Social isolation is a continuing issue for adults with a learning disability with lack of engaging options for individuals to choose.

**Indicator: 42 & SDS**

### 4.2 Research & Policy Best Practice

Policy directions of Bamford, Transforming Your Care and Self Directed Support.

4.3 Since 2011 Mencap has successfully provided opportunities for adults with a learning disability to engage and participate in their local community by accessing community facilities and services.

4.4 Mencap Currently Provide Solutions to: reducing the number of people seeking places in day care centres, reducing large numbers of people attending day centres from a wide geographical area which make it difficult to maintain friendships at evenings and weekends. Mencap Supports a diverse range of clientele of day centres, aged from 16-87 years, all with different needs.

4.5 **We do this by:** Creating an alternative to the traditional model of day care personalised programmes of activity, exploring individual aspirations and agreeing measurable action plans, activities identified and sourced in the local community', Support provided to access community & public transport.

4.6 Individual's day opportunities are regularly monitored and reviewed and we continue to partner with other relevant organisations in the community to meet individual's needs. This includes Disability awareness training Close working with families/ social workers/ carers

## 5.0 Paid Employment Opportunities

5.1 **Need:** The rate of adults with a learning disability in employment continues to lag significantly behind that of the general population. There are far too many adults with a learning disability who are actively looking for jobs, who cannot access meaningful, long-term paid employment because their learning disability becomes a barrier. Around two thirds of people with a learning disability want to work (Mencap 2008; also NHS surveys 2010) – however only 17% of people with a learning disability are in any form of paid work (Centre for Disability Research 2008), compared with 46% of disabled people as a whole (Office of Disability Issues 2012) and 70% of the general population.

5.2 **Related Indicator 14: Proportion of the workforce in employment...**

### 5.3 Best Practice

5.4 Through programmes such as Workable and ESF Projects, Mencap has a solid reputation in supporting young people and adults with a learning disability to find and keep paid jobs in their local communities.

- 5.5 We achieve this by: improving public perceptions, regarding people with learning disability in the workforce. Mencap provides tailored support in: transitions, identifying vocational aspirations and creating opportunities to develop skills such as: College Support: Vocational Profiling, Job Clubs, Work Placements, Job Matching
- 5.6 Our supported employment team map an individual's journey into suitable & sustainable voluntary work or paid employment and also provide successful employer engagement including delivering Learning Disability Awareness Training to employers across NI
- 5.7 To fully address the rate of adults with a learning disability in employment there is a need for a much more focused transition support service. Mencap has experience of working with young people from 14 years of age to identify and support their transition into employment or training. This early transitions service has proved to be very successful.
- 5.8 However, significantly reduced funding has reduced the availability of this service. This is in-effect an early intervention service and to achieve the outcomes outlined in the Programme for Government it is essential that funding is made available to ensure current young people with a learning disability can and do access employment.



For more details please contact Mencap Director: [Margaret.Kelly@mencap.org.uk](mailto:Margaret.Kelly@mencap.org.uk)

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