

Children and Young People Strategy 2017

Mencap Consultation Response April 2017

1.0 About Mencap

Mencap is a charity organisation with over 60 years' experience of working alongside and representing the interests of children, young people and adults with a learning disability and their families. We provide information, services and support to people with a learning disability and their families at key times of their life.

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”.¹

Too many of our children and young 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 Children and Young People Strategy must ensure that the lived experience of children and young is actively improves over the 10year strategy and that this can be clearly evidenced and measured.

2.0 Key acknowledgements and recommendations

Having participated in each of the initial stages of the ‘Children and Young People Strategy’ 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.

¹ Equal Lives Bamford Review of Mental Health and Learning Disability, DHSSPS 2005

Mencap would like to acknowledge and thank the Children and Young People Strategy team for several inclusions within the consultation document, notably;

- CYPs Team's complete dedication to co-production and co-design and their absolute commitment to hearing all children and young people's voices. We would recommend the engagement process, commitment and approach undertaken within this strategy is implemented across all governmental departments as best practice.
- Acknowledgement of UNCRC with a focus on rights based person-centred approach.
- Recognition of early intervention and prevention with a special note for marginalised and vulnerable groups.
- Acknowledgement of the significant barriers to children and young people with a learning disability when accessing leisure and play activities.

Whilst Mencap appreciates 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 some elements of the strategy can be strengthened to ensure improvements in the quality of life for people with disabilities are realised;

- Although we understand CYPs have started to look at tackling this issue, the lack of disaggregated data for children and young people with a learning disability and level of unmet need in children services needs to be identified and addressed.
- Throughout the documents there is very specific references to the issues children with a (learning) disability face. However, there is a lack of specific focus on indicators in terms of achieving outcomes for children and young people with a (learning) disability, that looks at measurable evidenced based outcomes. For our society to really turn the curve on issues that affect children and young people with a learning disability it must be written within the indicators and outcomes, otherwise it risks becoming invisible.
- Inclusion of UNCRPD Rights with particular (but not exclusive) focus on Article 7 Children with Disabilities, Article 8 and 49 Accessibility and accessible format and Article 24 Education

3.0 Consultation response

Every week, 2 children are born very week in Northern Ireland with a learning disability, for whom, early intervention is widely recognised to boost their early development and reduce the inequalities they face.

Mencap welcomes the 8 key interdependent areas of focus found within the delivery plan for improving the quality of life for people living with a disability and how they are aligned with the Children Services Co-operation Act (2016).

3.1.1 Children & Young People Are Physically & Mentally Healthy

Mencap commends the recognition of problems with demand to access to mental health services outweighing service provision and would like to add that individuals with a

learning disability, have increasing barriers that professionals only see their disability, limiting access to mainstream services.

Mencap agrees that service provision needs to be more flexible based on an individual needs and need for transitional planning is key in ensuring a child or young person with a learn

3.1.2 Evidence Base:

Mencap agrees with strategy highlighting early prevention and importance of supporting and empowering parents. The reference to Programme for Governments commitment on Early Intervention is important, however, as Mencap Stated in our PfG consultation Response, the commitment to ensuring Children with a (learning disability) needs to be stated more clearly in the headline indicators, to ensure they do not become invisible.

Furthermore, recognition of Children and young people with a disability of complex health needs including life limiting conditions require support, but concern that their immediate disability becomes a barrier to access support.

Noting extra effort is required from services is required to ensure children and young people are given the opportunity to achieve in education have time and space to play; are listened to; and have their rights respected through a person centred approach. Furthermore, the acknowledgement of the importance of transition

3.1.3 Suggestion on indicators

However, the recognition of additional support this doesn't seem to be reflected in the indicators, Mencap would recommend the following within the indicators:

- Include the strengthening of multi departmental approach to key transitions for children and young people.
- GHQ is not the only way we target mental health amongst children is this is not accessible to children and young people with a learning disability.
- Measurement and monitoring of demand and provision of children services, documenting unmet need.
- Understanding and inclusion of children who have a learning disability within mainstream health and social care services.

Best Practice

3.1.4 Mencap Family Support Plan

Too often you hear parents talking about 'standing at a cliff edge' in reference to transitioning from children to adult services. But what if we could turn the curve to ensure future success. Ensuring early intervention for families with young children with a learning disability is vitally important.

While there has been a general recognition and acceptance of the importance of early intervention for children in general and disadvantaged families in particular this has not been the case for families with children with a learning disability.

Mencap is committed to ensuring young children with a learning disability get the best start in life as the most effective way of changing outcomes for them as adults.

However, that means using an evidence based approach and ensuring families with a child who has developmental delay or a learning disability are part of the early intervention framework and approach.

We are currently developing a menu of early intervention approaches and working to ensure we measure their impact and effectiveness. In conjunction with the Tizard Centre and Kent University we are taking forward an evidence informed early family support programme called Early Positive Approaches to Support (EPAtS). EPAtS is about building family resilience as early as possible, to prevent challenging behaviours before they become habitual. It is focused on building family capacity and providing a toolkit of evidence based approaches and activities to support the whole family. It aims to increase resilience within families and allow families to recognise when problematic behaviours are starting to develop so that they can support their child effectively and quickly. As the child grows into adulthood behaviours are less likely to become a barrier to life opportunities.

3.1.5 Research

Further longitude research showing the importance of Parent-mediated social communication therapy proves that strengthening and empowering the family support with a child, can reduce behavioural and other barriers later within a child's life. ²

3.2.0 Children & young people enjoy play & leisure

3.2.1 Highlights

Mencap fully agrees with the identification of providing all children, including those with a disability and those living in marginalised, vulnerable or disadvantaged situations, with safe, accessible, inclusive spaces for play and socialisation has many benefits in terms of physical and mental health, education, skills development and the increasing of social confidence as well as contributing to wider community cohesion.

3.2.2 Evidence base:

Mencap agrees the evidence reviews focused on the extent of children and young people with a (learning) disability participate in leisure activities and as children get older access decreases and that their needs have to be taken into account when monitoring service provision.

However, Mencap would like to explore this even further by looking at children with a learning disability accessing mainstream community and leisure services.

This would not only promote diversity, inclusion and understanding amongst children, it would increase an individual's mental health and wellbeing, confidence and reduce social isolation and stigma of learning disability.

Resource and support must be given to community, leisure and youth groups and sporting groups on how to become more accessible and inclusive.

² **Pact et al (2016)** Parent-mediated social communication for young children with autism (PACT): long-term follow up of a randomised controlled trial; Open Access; Kings College London

3.2.3 Suggestion on indicators:

Mencap would recommend a slight rewording of this indicator to emphasise the importance of accessibility to play:

“Enjoyment experienced by children & young people as they enjoy fully accessible play in their homes, their communities, their schools & their local play facilities.”

3.2.4 Best Practice

Changing Places Campaign is UK wide Mencap Campaign on accessible toilets. Without a fully accessible toilet, no play, sport or leisure facility is fully accessible and for individuals can be one of the main barriers in accessing activities. We recommend that Changing places become standard with every new accessible leisure space³

Mencap continue to invite policy decision makers to our new Mencap Centre as demonstration of best practice in a fully accessible centre and play park. Mid- Ulster Council have commissioned a report from Outdoor Recreation NI on best models of inclusive and accessible outdoor space. Mencap would suggest the recommendations in report should be embedded as best practice ⁴

3.3.0 Children & Young People Learn & Achieve

3.31 Highlights And Evidence Base

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.’

3.32 Indicators

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. Therefore, the indicators must include a statement of where GCSE is not attainable a mechanism is in place to measure progress.

3.31 Best Practice

Relationship and Sexual Education is extremely important for young people with a learning disability, but currently not compulsory in SEN schools.

The Family Planning Association’s ‘ Just Ask’ is an innovative project, currently running in Northern Ireland, which aims to improve the sexual health of people with learning disabilities by enabling them to: Develop their sexuality and sexual identity,

³ http://www.changing-places.org/the_campaign/why_are_changing_places_toilets_important.aspx

⁴ <http://www.outdoorrecreationni.com/projects/mid-ulster-district-council-parks-play-strategic-plan/>

Achieve sexual health as opposed to sexual ill-health, Exercise their right to establish adult friendships and relationships.

The project enables people with learning disabilities to participate more fully in society. This improves their quality of life and challenges the social exclusion they often experience. Mencap recommends that similar projects are carried out across NI.

3.5.0 Children & young people live in safety & stability

3.5.1 Highlights:

Mencap agrees that all children regardless of background or SEN/ disability should receive the knowledge and skills that will support into adult. Furthermore, focus on collaboration from all children's authorities to collaborate effectively to support children through transitions with greatest focus on vulnerable, marginalised and disadvantaged groups with a focus on provision for 8-12 year olds.

3.5.2 Evidence Base

Mencap agrees that internet safety is vitally important for children and young people, as they are at greater risk of cyber bullying and grooming. Suggestion that evidence base takes into consideration accessible support in content and training for children and young people with a learning disability.

It is widely accepted that children and young people are much more likely to be a victim of bullying (both face to face and cyber), which may then escalate to a disability hate crime. Research shows that 1/3 children and young people admit to have being bullied, feeling lonely and afraid. However, too many do not feel safe enough or comfortable to report it to the appropriate authorities.

3.6.0 Children & young people experience economic & environmental well-being

3.6.1 Highlights and Evidence Base

Mencap acknowledges the concern of NEET population being the highest in the UK. However, there is no mention on the importance of transition, especially for young adults with a learning disability from full time education to either Further Education, Training or Employment.

3.6.2 Evidence Base

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. Once again, the inclusion of early intervention should be bolstered with evidence based measures designed to engender progress and transparency.

Furthermore, access to accessible childcare is extremely important, however, for most children with a learning disability it is extremely difficult to find accessible and affordable childcare. The reality is that families more often than not are financially better off if one

parent leaves employment to become a carer, regardless if they want to stay in employment.

3.6.3 Best Practice

Transition from School & Employment & Personal Development

There are many transitions in the life of a person with a learning disability, arguably one of the most important is at 19, from Children Services to Adult Services as it sets a trajectory for what follows in adulthood. Experience shows that a unified approach from both statutory and third sector providing person centred joint up working, creates a clear pathway that has best outcomes for the individual and their family.

An NI example of this practice is a number of Health and Social Care Trusts established a specific Transition Service. After a process of review, the SHSCT commissioned a Team to focus solely on transition for young adults aged 18-21 years. This provided young people with a Key Worker to ensure a more coordinated and focused service that provided young people with a greater degree of choice and options. In the WHSCT a similar service was established and the key worker service was delivered by statutory services but also voluntary partners. Mencap delivered the key worker service in the WHSCT. The research evidence from QUB, “Don’t Box Me in”, Dr Bernie Kelly 2013, indicates the effectiveness of this approach and recommends that young people should have a clearly identified keyworker during transition from Children’s to adult services.

Alongside this the Southern Regional College established a Stakeholder Forum in which a range of supporting organisations attended to discuss, support needs/levels through college, through-put, eligibility criteria and program/service availability. The main purpose of the forum is to provide up to date information and to fill any gaps so that the young people (family/Carers) get options/choice and most importantly a continuation of services, advice and support which is not always the cause. The need for co-ordination and planning across a number of both statutory services and voluntary partners is critical to good transition outcomes.

3.6 Children and young people make a positive contribution to society

3.6.1 Highlights

Mencap agrees with CYPs highlighting the need to actively encourage and support children to contribute to society and to form part of the decision making process. Furthermore, the highlighted importance of including a wide variety of methods and structures provided to ensure all children and young people’s views are heard, valued and taken into account.

Unfortunately, children and young people with a learning disability views are often unheard, dismissed and dramatically undervalued. Many children and young people are talked down to and are constantly patronised and condescended because people only see their disability. Their rights are not respected and sometimes blatantly ignored.

3.6.2 Evidence Base

Mencap agrees with the strategy that participation should be for all and that specific,

inclusive and targeted mechanisms are put into place to ensure hearing from all voices including those children with a disability. Furthermore, that using Youth Services is a great way to identify and engage with those seldom heard voices.

3.7.0 Children & young people live in a society which respects their rights

3.7.1 Highlights

Mencap's vision is a world where children, young people and adults with a learning disability are valued equally, listened to and included. This reality is only achievable if an individual with a learning disability rights are respected and everything we do in Mencap is ensuring a person's rights are understood, valued and the individual and family members are empowered to challenge barriers using a rights based approach.

3.7.2 Evidence Base and Indicators

Although it is important that children and young people within Section 75, there no acknowledgement of children with a (learning) disability in focus of ensuring rights. Mencap would strongly recommend that both in Evidence Base and Indicator that children and young people with a learning disability rights are understood, monitored and that there is clear demonstration of education to the understanding of these rights to others.

3.7.3 Best Practice

Tor Bank SEN School has been awarded as Rights Respecting schools which aims to build the capacity of children as rights-holders to claim their rights, and the capacity of adults as duty-bearers to fulfil their obligations.⁵

3.8.0 Children & young people live in a society in which equality of opportunity & good relations are promoted

3.8.1 Highlights

Mencap agrees that all children should be supported to develop positive attitudes by challenging discrimination and promoting equality for all and that this must be facilitated through legislation, practice, awareness and understanding and acknowledgement of difference and tolerance of others.

3.8.2. Evidence Base

Mencap agrees that all Section 75 groups are treated equally and perceptions of young people need to be tackled. Furthermore, Shared Education needs to go further than its legal definition to include learning together. For many children with a learning disability, they attend Pre-School in SEN settings, who move into a SEN School until they leave at 19. By this age it is argued they have been removed from mainstream setting and miss opportunities to integrate with other peers. This creates invisibility of their issues and inclusion which continues into adulthood.

⁵ <http://www.torbankschool.org.uk/our-school/rights-respecting-school>

3.8.3 Indicators

Whilst promotion of good relations within a religious context is significant in Northern Ireland, the indicator should not solely focus on religion and ethnicity, that all Section 75 groups are considered within good relations as they are evidenced to be most at risk/ It is important to note the recording, monitoring and reporting of incidents of bullying) and (Disability) Hate Crimes.

3.8.4 Best Practice

Raising awareness of diversity and difference is a key component to ensure societies attitudes are changed. Mencap NI Youth forum, saw this problem and created an awarded winning film that tackles understanding of what it is like to have a disability.

The film “MY NOT SO ORDINARY LIFE” tells the story of a teenage girl who finds that all sorts of everyday experiences lead her into dramatic situations. A concert becomes an ear-splitting horror film, household lights become sci-fi robot lasers and people talking to her can become a melodrama in this multi-genre short film raising awareness about autism and learning disability.⁶

Dream Scheme NI is a charity that works with vulnerable adults at risk, many young people they work with a labelled and stigmatized by their peers and local community. Mencap NI Youth Forum partnered with Dream Scheme and theMAC and created a project around empowerment that included community work, skills building and all participants received a qualification at the end. This project was co-led by the young people and not only broke down barriers between the two groups who may have had preconceived ideas, they raised awareness in their local communities also.

4.0 Conclusion

Mencap thanks the Children and Young People Strategy team the opportunity to respond to this consultation and are committed to achieving change for children and young people with a learning disability in NI and would be willing to work with government and other partners to create solutions and achieve the vision outlined in the Children and Young People Strategy.

Mencap would welcome the opportunity to play a supporting role in the formation of final delivery plans through being positioned as an expert partner throughout the remainder of the consultation process. If you have any questions or queries, please do not hesitate to contact Fiona.Cole@mencap.org.uk.

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⁶ <https://www.youtube.com/watch?v=LcILU8ftD-g>

Children and Young People Strategy Focus Group

Friday 24th March

The Youth Forum and Inclusion Hub discussed the following issues: (13 young people 18+)

- Play and Leisure
- Health
- Safety
- Equality/ Rights
- Education and Learning
- Inclusion
- Independence

Feedback from the Activity Ideal Northern Ireland:

- More Gender Equality
- More Clubs, discos and bars for young people with a learning disability
- More safety for young people with a learning disability
- Young people to have more opportunities to share their opinions and freedom of speech
- More job opportunities and training for young people with a learning disability
- Race Equality to be discussed more as I have been bullied from where I come from
- No bullying
- Everyone's opinions to be respected
- More safety in public transport
- Safer community
- Better services
- Better environment for young people with a learning disability
- Gay marriage to be legalised
- Better arrests on bad people and rapists
- More inclusive leisure facilities (for example: cinema, theatre and sports clubs)
- Better services
- Give young people more opportunities to help with cyber bullying
- More play activities. I feel there is limit access to play activities for my younger siblings
- "I would not go out unless Mencap are organising an event."
- Loyal transport
- Better pregnancy prevention services and give us more talks about contraception
- More sure start activities
- Help with medication
- "I want to be able to go to tech and do the same as other young people as I only have pathways to do in tech but I would love to do my GCSE's."
- Help at the Doctors
- Independence-Get help with getting a house and live in privacy
- Health and Social Care- Special allowances for waiting to see doctors for anyone with a learning disability
- Transport- Buses need to be more often and take their time with young people with a learning disability. Be more patience.

- More support groups for people with a learning disability
- Support us to become more independent
- Support for housing
- Support for parents with a disability
- Safety and Inclusion is a big deal for me
- Disability awareness training for people in all areas including health services, restaurants and public transport
- Renewable infrastructure being built in this country
- Political correctness not intimidating out freedom of speech
- Paramilitaries to disappear from our streets
- Providing internet safety information for all ages
- A government that is committed to organising a budget and solving the issues raised by the public.
- The great thing is working at Orchardville and Mencap
- I got bullied by my teacher so I think needs to be better teachers and give them more training

Feedback from Moving Debate Activity:

Inclusion:

Barriers:

- Judgement
- Accessibility
- Education and awareness of learning disabilities
- Generation..... seen as older folks
no opportunities

Positives:

- More integration and needs to be more positive in areas of learning
- Mencap services
- Dignity and respect
- Awareness training

Independence:

Barriers:

- Transport
- Parents!
- Teachers
- Education providers
- Learning- essential skills/ where?
How? And what?

Positives:

- CHOICE
- Can do things by myself
- Decisions

Equality/ Rights:

Barriers:

- Rights are not taught in school
- Shoving opinions down public's throat
- Knowledge on rights of young people

- Need support to use our voice

Positives:

- It is great to have my own opinion
- Right to vote

Feeling Safe:

Barriers:

- More support for bullied victims
- More Mental Health Support
- Schools need to deliver online safety training as a compulsory subject
- Police can intimidate us

Positives:

- Cyber bullying tolerated less which is good
- Can feel safe around Police especially because of the Northern Ireland politics of certain groups

Education/ Learning:

Barriers:

- Teachers do not have enough awareness and training about disabilities or know how to support you.
- Difficulty to access education in tech
- More relationship and sex education- should be made compulsory in schools

- Public stereotypes are a barrier and can't learn

Positives:

- More support is given but still has a long way to go
- Getting to know more about courses
- Need more time for this but getting there

Play and Leisure:

Barriers:

- Learning how to go to leisure appointments
- Cinema/ spa- need support with these services I feel like I am missing out
- Limited buses

- Availability of activities differs across Northern Ireland
- Need more integrated services

Positives

- Free transport in rural areas for PWLD
- Gateway club

Health:

Barriers:

- Need extra time for all appointments
- Need for more easy read materials in hospital
- Health visitor/ Everywhere
- Easy words not used in Health settings

- Talk to me NOT MY FAMILY OR CARER
- Lack of available appointments unless you ring early

Positives:

- Dentist have OK waiting times
- Explaining things is very important to the person

To close the session the young people shared the following feedback:

- Courses open to all- Even with a disability
- Less cuts of funding for leisure activities for disabled people
- Full time job opportunities
- More support groups over certain ages and a mixture of disabilities involved
- More self-sustaining ways of working (e.g) Projects