



## ENABLE Scotland

### The Same As You? 2000-2012: Consultation Report

September 2012

#### Introduction

ENABLE Scotland is the largest voluntary organisation in Scotland of and for children and adults who have learning disabilities and their families. We have a strong voluntary network with around 4,000 members in 51 local branches as well as 500 national members throughout Scotland. Around a third of our members have a learning disability. ENABLE Scotland campaigns to improve the lives of people who have learning disabilities and their families and carers. ENABLE Scotland also provides social care services to more than 2,000 people across Scotland who have learning disabilities or mental health problems in 29 local authority areas.

ENABLE Scotland held a consultation event, funded by the Scottish Government, at our Committee Weekend on 25 August 2012. The event was attended by 96 people, including people who have learning disabilities, parents, carers and professionals. We also held four consultation events across Scotland with our local ACE groups (groups made up of people who have learning disabilities) in Elgin/Inverness, Annan, Paisley and Edinburgh. These events were also funded by the Scottish Government.

This response is based on views gathered in all of these meetings as well as opinions received from other members of ENABLE Scotland, people who have learning disabilities, parents, carers and members of staff. ENABLE Scotland is happy to work closely with the Scottish Government to tackle any issues which have been highlighted in our response.

#### Responses to Consultation Questions

##### Progress and Challenges

##### **Question 1 – Do the findings of the evaluation broadly reflect your views about services for people with learning disabilities/carers?**

ENABLE Scotland has a breadth of views about services for people who have learning disabilities and their parents and carers, some of which are reflected in the document and some of which are not.

We welcome the Scottish Government's investment in evaluating "The Same As You?" at such a critical point. People who have learning disabilities are among the most disadvantaged and vulnerable in our society and public services are of particular importance to supporting and protecting many people who have learning disabilities and their families across Scotland. As

noted by the Commission on the Future of Public Services<sup>1</sup>, however, “our public services are now facing their most serious challenges since the inception of the welfare state”.

Some of our members raised concern that the findings of the evaluation rely on a very small sample of people who have learning disabilities and their families. The evaluation process formally consulted with just fifty adults who have learning disabilities and fifty family carers. Everyone formally consulted was over the age of 18. According to the latest official statistics there are 26,036 adults who have learning disabilities across Scotland<sup>2</sup>, there are many more children and thousands of family carers. We are concerned that the findings of the evaluation may not be representative of the wider population of people who have learning disabilities.

Other members expressed particular concern that the evaluation interviewed a higher proportion of people who are in paid work than is representative of the general population of people who have learning disabilities. 22% of people who have learning disabilities interviewed were in paid employment, however, the official statistics on learning disability<sup>3</sup> suggest that the employment rate is much lower at 15.5%.

We are concerned that such discrepancies will mean that this evaluation is not as reflective of the larger population as it could be. We are also concerned that use of the 22% figure gives an unrepresentative view of the numbers of people who have learning disabilities who are in employment, when the gap between this and employment for the general population is wider.

Additionally, ENABLE Scotland would like to ask the Scottish Government how they intend to find out more about the experiences of children and young people who have learning disabilities across Scotland. We are concerned that a full representation of views from children and young people will not have been established if children and young people’s views have not been taken into account.

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<sup>1</sup> <http://www.scotland.gov.uk/Resource/Doc/352649/0118638.pdf>

<sup>2</sup> [http://www.scd.org.uk/sites/default/files/final\\_2011\\_essay\\_statistics\\_release\\_-\\_learning\\_disability\\_statistics.pdf](http://www.scd.org.uk/sites/default/files/final_2011_essay_statistics_release_-_learning_disability_statistics.pdf)

<sup>3</sup> *ibid.*

## **Question 2 – Can you give examples, either locally or nationally, of what you think has worked well over the last 10 years of The Same As You?**

The closure of long stay hospitals has resulted in an increased awareness of people who have learning disabilities in their local communities. This has been a key success of “The Same As You?”, as acknowledged within the command paper.

Other examples of policies that have worked well over the last decade include:

### Healthcare

ENABLE Scotland feels that, broadly, healthcare is an area where some improvements have been made in recent years.

Service models which have been introduced to provide additional support for people who have learning disabilities using healthcare services have had a largely positive impact. “Tackling Indifference”, NHS Scotland’s national overview of healthcare services for people who have learning disabilities, recommended that “there is a named specialist practitioner known to each primary care team for children and adults.”<sup>4</sup>

In some NHS health boards this has taken the role of a Learning Disability Liaison Nurse. Their role includes, amongst other things, providing assistance with the co-ordination of care at attendance, admission and discharge, provision of accessible information about treatment and support of relatives who have a learning disability if they are affected by a patient’s illness or hospital stay<sup>5</sup>.

Initial research into the role of Learning Disability Liaison Nurses in South East Scotland found that this position had played an important role in raising the profile and status of people who have learning disabilities in hospitals, developing effective systems and processes and improving the patient experience.<sup>6</sup>

Our members generally agreed, expressing the view that Learning Disability Liaison Nurses, have been a good development. They were able to highlight a number of examples of good practice by Learning Disability Liaison Nurses:

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<sup>4</sup> <http://www.lothianstrokemcn.scot.nhs.uk/publications/documents/QIS-TacklingIndifference-Dec2009.pdf>

<sup>5</sup> <http://www.nhslothian.scot.nhs.uk/Services/A-Z/LearningDisabilities/Documents/LearningDisabilityToolKit.pdf>

<sup>6</sup> <http://www.era.lib.ed.ac.uk/bitstream/1842/3641/1/LDdocument.pdf>

“The nurse is not always on duty but they try to have her on if there is an admission of someone with a learning disability. That has made a huge difference.”

“(Liaison Nurses) try and ease the admission for the person and make sure they are available to communicate with the person who has a learning disability or their carer. However, in the ward, if the person does not have support staff there all day every day then they don’t get any support.”

“The nurse was able to sort out some inflexibility experienced on respiratory wards.”

We would add, however, that some of our members felt that GPs were often “less interested” in people who have a learning disability than they were with other patients. Often this was because they did not feel that their health concerns were taken seriously because they had a learning disability.

### Education

We note the greater numbers of people who have learning disabilities attending mainstream schools, as referred to on page 16 of the command paper. People who have learning disabilities and their families welcome the greater number of people going into mainstream education.

However, disabled pupils in Scotland are almost twice as likely to be excluded as their non-disabled peers and pupils with additional support needs are 5 times more likely to be excluded<sup>7</sup>. ENABLE Scotland is concerned that a basic lack of understanding by some classroom teachers and support staff is acting as a major barrier to inclusion and may also contribute to high rates of exclusions among pupils who have additional support needs.

We believe that mandatory training must be introduced for teachers and learning support assistants, in initial teacher education courses (ITE) *and* continuing professional development (CPD) to decrease the use of exclusions, increase confidence and improve relationships between schools and parents.

### Personalisation

Many of our members highlighted personalisation as an example of an improvement in their lives. 1,249 people who have learning disabilities used direct payments in 2011, and whilst progress has been slow since direct payments were introduced in 1997, many people expressed their view that it had allowed them greater levels of choice and control over the support they received.

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<sup>7</sup> Scottish Government (2010). Summary Statistics for Schools in Scotland 2010.

Choice and control over services was a key theme of what people wanted to see in their lives. Some of our members said that, where it was available, self-directed support had enabled them to change the way they received social care services for the better.

“My life has changed. With an individual budget I now have choices I did not have before.”

“I should decide when meetings about me happen and who should go to these meetings.”

“My son is now starting to live.”

ENABLE Scotland is pleased that the Scottish Government has prepared a National Strategy for Self-directed Support and the Social Care (Self-Directed Support) (Scotland) Bill in recent years. We strongly support moves towards giving people more access to tools that can give them more choice and control over their lives.

However, some of our members felt that the level of choice and control made available to them might be under threat as a result of decreases in local authority budgets across Scotland.

#### Local Area Co-ordination

“The Same As You?” recommended that “Health boards and local authorities should agree to appoint Local Area Coordinators (LACs) for learning disabilities from current resources used for managing care and co-ordinating services.”

Our members noted that the introduction of Local Area Co-ordinators across Scotland has been a positive step, however they had some concerns that the financial difficulties faced by local authorities may put these roles under threat.

The Evaluation of the Implementation of Local Area Co-ordination in Scotland<sup>8</sup> found that interventions may have saved local authorities money in the longer term by preventing individuals and their families experiencing crises.

ENABLE Scotland believes it is vital for long-term sustainability that the emphasis is not solely placed on care in a crisis. Preventative services can provide a more cost-effective approach as well as a better response for the individuals, families and groups involved. LACs are an example of how this can work in practice.

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<sup>8</sup> <http://www.scotland.gov.uk/Resource/Doc/173461/0048415.pdf>

### **Question 3 – Can you give examples of issues in current work and/or policies that still need to be addressed?**

#### Lifelong Carers

Recommendation 26 of “The Same As You?” said that “Life plans for people who have learning disabilities who live with their parents should include plans for a time when parents may no longer be able to provide care.” Most carers, however, still do not have a written plan for what will happen in the future and such plans are rare.

Caring Together, the Scottish Government’s Carers Strategy, also recognised that “much more needs to be done to achieve practical support on a consistent and uniform basis”. We believe that this is particularly applicable to older family carers of people who have learning disabilities.

For the first time there is a generation of people who have learning disabilities who are outliving their parents. As such, there are more lifelong carers of people who have learning disabilities whose caring responsibility will not cease until their death. More should be done to support lifelong carers before they reach old age – either to help them continue caring or to stop their day-to-day caring role.

Emergency planning has been shown to be a valuable practical example of support to older family carers – but little information and advice is available to assist in this process. ENABLE Scotland’s Lifelong Carers Project was launched with the support of Big Lottery funding in 2009 and has succeeded in supporting many families throughout Dumfries and Galloway and Ayrshire to plan for emergencies

It is essential that local authorities and other agencies are encouraged to be part of the emergency planning process. If they are to achieve their aims, emergency plans can not exist in isolation. Each emergency plan should be linked to the appropriate statutory agency.

#### The roles of national and local Government in the lives of people who have learning disabilities

There is some general concern amongst our members about the level of local government compliance with policies from the Scottish Government. We are concerned that, at present, Single Outcome Agreements are not always sufficiently clear and measurable, and not enough independent scrutiny is brought to bear in assessing progress towards them.

Members of our National ACE group (Advisory Committee of ENABLE Scotland), a self-advocacy group made up solely of people who have learning disabilities, felt that unless Scottish Government policy could be made mandatory then progress in many areas would be limited and subject to local interpretation. The Single Outcome Agreement was noted as a partnership agreement between local and national government but this was felt to be an

insufficient process in terms of policy implementation. ENABLE Scotland believes that this must be addressed.

### Public Attitudes and Awareness

As per page 51 of the command paper, we agree that there have been some improvements in terms of attitudes towards people who have learning disabilities since “The Same As You?” was written. However, adults who have learning disabilities remain amongst the most marginalised people in our society. Nine out of ten experience bullying and abusive behaviour within their communities<sup>9</sup> and in 2007, ENABLE Scotland’s Speak Up research<sup>10</sup> found that:

- 93% of children who have learning disabilities have been bullied
- 46% of children who have learning disabilities have been physically assaulted
- Half have been bullied persistently for more than two years
- Bullying is not just a school issue
- 40% are too scared to go to places where they have been bullied

ENABLE Scotland is disappointed that, “there has never been funding for a national public education programme comparable to that of ‘See Me’ around mental health issues and ‘One Scotland, Many Cultures’ around race, religion, faith and belief.”

ENABLE Scotland calls on the Scottish Government to launch a major public awareness campaign with the aim of improving public attitudes towards people who have learning disabilities. We would particularly urge the promotion of a major campaign about the effects of bullying on the lives of people who have learning disabilities.

### Education staff training

We note the greater numbers of people who have learning disabilities attending mainstream schools, as referred to on page 16 of the command paper. However, disabled pupils in Scotland are almost twice as likely to be excluded as their non-disabled peers and pupils with additional support needs are five times more likely to be excluded<sup>11</sup>.

ENABLE Scotland is concerned that a basic lack of understanding by some classroom teachers and support staff is acting as a major barrier to inclusion and may also contribute to high rates of exclusions among pupils who have additional support needs. Teachers themselves have identified Additional Support Needs as one of the top three areas in which they need more training

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<sup>9</sup> Mencap, Living In Fear, 2000

<sup>10</sup> [http://www.enable.org.uk/enabledirect/publications/documents/speak\\_up- bullying\\_report.doc](http://www.enable.org.uk/enabledirect/publications/documents/speak_up- bullying_report.doc)

<sup>11</sup> Scottish Government (2010). Summary Statistics for Schools in Scotland 2010.

so that they can feel confident when supporting learners who need some extra support<sup>12</sup>.

ENABLE Scotland calls on the Scottish Government to do all within its power to introduce mandatory training for teachers and learning support assistants, in initial teacher education courses (ITE) *and* continuing professional development (CPD) to be introduced in the following areas:

- general topics of additional support needs, inclusion and equalities (this would include a knowledge of relevant legislation).
- specific topics of behaviour management strategies, communication strategies and learning disability/autistic spectrum disorder awareness.

ENABLE Scotland believes that mandatory training on additional support needs will lead to improved educational achievement, a decrease in the use of exclusions as a means of managing behaviour, increased confidence and self esteem for the learner and improved relationships between schools and parents.

#### Prevention and anticipatory care

ENABLE Scotland believes it is vital for long-term sustainability that the emphasis is not solely placed on care in a crisis. Preventative services can provide a more cost-effective approach as well as a better response for the individuals, families and groups involved.

For some people who have learning disabilities, eligibility criteria may assess them as being at a low risk. However, in the medium to long-term, without access to preventative services or modest support they may reach a critical risk and require more resource-intensive services.

We believe that further investment is required in preventative and anticipatory services such as short breaks and respite and Local Area Co-ordination to help prevent more resource-intensive spending in the long term.

#### Short breaks and respite care

For many families, short breaks and respite services are a necessary and valuable part of their lives. Short breaks can help families to carry on caring as well as offering enjoyable opportunities to the child or adult being cared for.

However, at present there are simply too few respite and short breaks services in Scotland and there is no statutory right to respite care. In advance of an application to the Short Breaks Fund, ENABLE Scotland sent out a questionnaire to parents of children who have learning disabilities aged 0-17. Out of 129 responses, 59 families (45.7%) said they have never had a short break of 2 days or more and only 32 (24.8%) had received a short break or respite in the previous twelve months.

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<sup>12</sup> Donaldson, G (2010). Teaching Scotland's Future: Report of a review of teacher education in Scotland.



We believe the Scottish Government should be acting to ensure that short breaks and respite are more freely available to families across Scotland.

### Co-production

The Partners in Policymaking courses were a well valued tool for self-advocates, parents and carers. The courses ran out of funding a number of years ago in Scotland, though they continue in England and Ireland. Our members have suggested that a leadership programme of this kind should be re-introduced in order to encourage genuine co-production across Scotland.

### Transition

Experiencing change can be a stressful time in anyone's life – whether the change is moving school, house, job or any other form of transition – this can cause upheaval and anxiety. For people who have learning disabilities this can be an even more difficult journey. Often their lives are disrupted and disjointed by services which don't work well together or which don't effectively communicate or inform those involved.

ENABLE Scotland believes that responsibility for transition should be placed with adult social services rather than falling between education or children's services. Local authorities must also be further encouraged by the Scottish Government to carry out their statutory duty under the Educational (Additional Support for Learning) Act 2004 to put a transition plan in place rather than parents having to request one.

## **Good practice – Organisations**

### **Question 4 – Can you provide examples of what you have done over the last 10 years, within your organisation, to improve services and access to services within your local area?**

As a membership organisation of individuals who have learning disabilities and their families, ENABLE Scotland fully embraced the principles embedded in “The Same As You?” of putting people and families at the heart of decision-making and support. We can only give a small snapshot of some of the ways that we have improved services and access to services since “The Same As you?” was published.

As a support organisation, ENABLE Scotland has worked with individuals, families, local authorities and other funding agencies to transform its services over the last 10 years and to deliver the information and support that people want. Examples include:

- Making the move to work – Developing a broader range of employment support so that young people and adults who have learning disabilities can make the transition into work. In 2009 we embarked on an ambitious 8-year programme in schools, Stepping Up, funded by Inspiring Scotland, to give young people aged between 14 and 18 the skills, experience and confidence to develop post-school career plans and to move on to vocational courses or into jobs. We have a similar Big Lottery-funded project, Transitions to Employment, to help young people and adults in college increase their chances to move on to work. This work has been enhanced by the development of an online hub, Make the Move<sup>13</sup>, to provide young people with information and encouragement.
- Transforming day services – ENABLE Scotland ran Carisbrooke, a well-regarded Day Centre in Airdrie for adults with complex needs. Now Carisbrooke has closed and we provide an alternative flexible day service for those adults. Each individual has a tailored plan that makes use of local facilities and means the person has a presence in their local community like anyone else. Staff have also worked with local facilities and businesses to increase their accessibility to the people whom they support eg. adapting changing facilities, or providing liquidised food for people with specific dietary needs.
- Increasing choice and control and independent living – when people first moved out of long-stay hospitals, many went to live in small group homes with three or four other people. In recent years, ENABLE Scotland has worked with the individuals, and their families where appropriate, to transfer people into individual supported living tenancies where they could have more privacy, independence, and choice over their living arrangements.

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<sup>13</sup> <http://www.makethemove.org.uk/>

- Personalisation – More recently, we have taken a lead in self-directed support and personalisation to give individuals more choice and control over their lives and more say in the kind of support arrangements they need and want. We are currently working with the Scottish Consortium for Learning Disability, the Institute for Research and Innovation in Social Services (IRISS), In Control and the Health and Social Care Alliance Scotland (formerly Long-Term Conditions Alliance Scotland) to deliver Changing Support Changing Lives<sup>14</sup>. This is a programme of conferences, workshops, master classes and consultancy to increase the capacity of individuals, families, care providers and commissioners to make the transformation to self-directed support.
- Planning for the future – many families seek information and advice about the best way to plan for the future once parents are gone and ways to safeguard the finances of their sons and daughters who may be unable to manage money or vulnerable to exploitation. ENABLE Scotland provides information and guidance on wills, trusts and guardianship through its enquiry line ENABLE Direct 0300 0200 101 and through talks and stalls at events. The ENABLE Trustee Service provides a service for families who set up discretionary trusts and who need administrative and legal support to manage the trust.

As a campaigning organisation, we have lobbied at a local and national level for continuous improvement in the opportunities open to children and adults who have learning disabilities and in the support structure for them and their families. Examples include:

- Accessible information – running the Keep it Clear campaign so people could alert any business or provider when they sent out information that someone could not understand. We also established an Accessible Information Unit to provide practical training to groups, and have delivered this to a number of local authority, voluntary sector and health sector staff, as well as undertaking commissioned work on behalf of public sector agencies to enable them to meet their equality duties and reach the broadest possible audience. We strongly believe that making information accessible to people who have learning disabilities is fundamental to ensuring that they have equal rights and are not excluded. Information that is clear and accessible to people who have learning disabilities is also accessible to others who may have literacy issues and makes a more inclusive community for all of us.
- Anti-bullying work – ENABLE Scotland has run several campaigns focused on anti-bullying work and has recently launched a new project, “Open your mind not your mouth”, to raise awareness amongst young people, to foster a better understanding of the impact of bullying behaviour, and to help develop a culture where diversity is celebrated.

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<sup>14</sup> <http://www.changingsupport.org.uk/>

- Listening to children and young people – too often the voices of children and young people who have learning disabilities are left out when decisions are made about them and their future. ENABLE Scotland has developed a network of local children’s advocacy groups – Speak4Yourself – to give young people the skills and confidence to represent their views within their local communities and to the Scottish Government.
- Lifelong Carers – For a number of years ENABLE Scotland has raised the profile of lifelong carers – family members, mostly parents, who have spent a lifetime caring for their disabled sons, daughters and other relatives. Some family carers have been providing day-to-day support at home for over 50 years. These family carers need practical help to keep caring for as long as they are able. They and their relatives also need sensitive support to plan for the inevitable time when the family carer can no longer provide a home or practical care due to changing circumstances or death. ENABLE Scotland has run two Lottery-funded projects in rural areas for Lifelong Carers which established the importance of emergency planning for carers in this situation. We have worked with other agencies and the Scottish Government to undertake some research into emergency planning provision across Scotland (‘Picking up the Pieces’ report to be published shortly).

## **Good practice – Individuals**

### **Question 5 – What have you done, as an individual, to make positive changes in your local area?**

ENABLE Scotland's membership branches across Scotland provide a crucial lifeline to people who have learning disabilities. Our branches offer various activities across Scotland, engaging people who have learning disabilities and their parents and carers in their local communities and encouraging greater levels of social inclusion. Our branches offer many thousands of families across Scotland an informal family network to tap into for support. The work of our branches is largely built on the individual efforts of members of ENABLE Scotland and other people who have learning disabilities and parents and carers.

Individual members of ENABLE Scotland have asked us to highlight the following activities they have been involved which have made a positive impact on the lives of people who have learning disabilities in their local area:

- Strategic involvement in friendship networks such as Dates 'n' Mates and "FUN" in Perth
- Attending the Scottish Parliament's Cross Party Group on Learning Disability and giving views
- Local hustings ahead of the recent Scottish Parliament elections to ensure that people who have learning disabilities were able to give their views
- Carers networks – such as North Lanarkshire Carers Together - and involvement with local carers centres across Scotland
- Involvement in Partnership In Practice meetings with local authorities and health boards to ensure better services for people who have learning disabilities in the local area
- Learning disability awareness training in out-of-school clubs
- Representation on health groups and community planning partnerships
- Running session on healthcare and producing health information leaflets for people who have learning disabilities
- Consultation responses to various councils on local issues related to learning disability and also on things that affect the lives of people who have learning disabilities, such as employment and public transport
- Carrying out police training on learning disability issues

## **Future Priorities – Healthcare**

### **Question 6 – What still needs to be done to ensure that people with learning disabilities have access to better and more appropriate healthcare?**

#### Health Inequalities

We are concerned to note that the evaluation has highlighted a greater prevalence of conditions such as respiratory disease, dementia, epilepsy, difficulties with hearing and vision and mental health issues. This is despite the implementation of the Scottish Government's Equally Well<sup>15</sup> framework, which emphasised the importance of tackling the underlying causes of health inequalities.

ENABLE Scotland believes that further research into the causes of these differences is required and firm action must be taken to tackle the health inequalities suffered by people who have learning disabilities across Scotland.

This includes:

- Increasing the level of screening pertinent to Learning Disability mortality rates in order to detect health issues at as early and preventable a stage as possible.
- This should coincide with the production of accessible information and free guides for carers on how to discuss health matters. The introduction of such a resource on bowel screening for people who have learning disabilities and carers in Renfrewshire is a good example<sup>16</sup>.
- Improving communication between healthcare staff and people who have learning disabilities. During the consultation process some of our members described language used by health care staff as “confusing” and “jargon”. Some people felt that GPs were “less interested” in people who have learning disabilities. Disability awareness courses, not just for GPs and Doctors but across the healthcare sector, should be improved to ensure people who have learning disabilities receive adequate support throughout the healthcare system.
- Extending healthy lifestyle initiatives, such as Healthier Scotland, to ensure that people who have learning disabilities are better aware of what is available. Managing a healthy diet and exercising regularly can be a challenge for many people who have learning disabilities. Initiatives including free training on healthy eating and how to cook have been successful across Scotland through networks such as ENABLE Scotland's branches.

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<sup>15</sup> <http://www.scotland.gov.uk/Resource/Doc/229649/0062206.pdf>

<sup>16</sup> <http://www.paisleydailyexpress.co.uk/renfrewshire-news/local-news-in-renfrewshire/paisley-news/2012/09/15/new-bowel-screening-resource-aimed-at-buddies-with-learning-difficulties-87085-31833647/>

## Nursing role

“Promoting Health, Supporting Inclusion”<sup>17</sup> and the 2012 report “Strengthening the Commitment”<sup>18</sup> both recognise the important role nurses play in the lives of people who have learning disabilities. ENABLE Scotland believes that the Scottish Government must ensure that people who have learning disabilities have access to expert learning disability nurses. We call on the Scottish Government to make it a requirement for all Health Boards to employ experienced nurses who have a learning disability qualification and work exclusively to support people with a learning disability and their families through hospital admission and attendance. Further work should also be done to ensure that better disability awareness training is available to all healthcare staff.

## Greater integration of health and social care services

Our members also expressed frustration at the effect of a lack of joined-up work between health and social care staff. Some people who have learning disabilities said that a lack of joined-up working had caused them to have to stay in hospital for longer whilst arrangements were made for on-going care after they were discharged. In other cases, some people told us that they had been moved into inappropriate short-term settings, including nursing homes, for short periods of time.

ENABLE Scotland is, in principle, in favour of greater integration of health and social care and the principles behind these proposals. We agree that doing nothing is not an option given the financial pressures of providing health and social care services. We are particularly concerned, however, that within the Government’s initial consultation paper on these proposals<sup>19</sup> there is no mention of how or when the proposals will affect learning disability services. The Government must clarify how these proposals will affect social care groups beyond older people in the future and produce a clear timescale for change.

## Health and Safety

A number of our members raised a concern about health and safety barriers in hospital and “red tape” stopping people from receiving the correct level of support in hospital. One member raised the issue of two people being required to turn someone whilst they were in bed. Health and safety is an important concern, but its practical implementation by healthcare staff must enable the provision of better healthcare rather than prevent it.

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<sup>17</sup> <http://www.scotland.gov.uk/Publications/2002/07/15072/8572>

<sup>18</sup> <http://www.scotland.gov.uk/Resource/0039/00391946.pdf>

<sup>19</sup> <http://www.scotland.gov.uk/Resource/0039/00392579.pdf>

## **Future Priorities – Education**

### **Question 7 – What still needs to be done to ensure that people with learning disabilities have access to better educational opportunities?**

ENABLE Scotland's view is that children, young people and adults who have learning disabilities have the same rights to an education that will help them to reach their full potential. Education should be meaningful and purposeful, building not just knowledge but also self-esteem and skills for life, enabling all young people to become "successful learners, confident individuals, responsible citizens and effective contributors". This is the key aim of the Scottish Government's Getting It Right for Every Child (GIRFEC)<sup>20</sup> programme, and this approach is embedded into Curriculum for Excellence<sup>21</sup>.

#### **Appropriate training for teachers**

We note the greater numbers of people who have learning disabilities attending mainstream schools, as referred to on page 16 of the command paper. However, disabled pupils in Scotland are almost twice as likely to be excluded as their non-disabled peers and pupils with additional support needs are five times more likely to be excluded<sup>22</sup>.

ENABLE Scotland is concerned that a basic lack of understanding by some classroom teachers and support staff is acting as a major barrier to inclusion and may also contribute to high rates of exclusions among pupils who have additional support needs. Teachers themselves have identified Additional Support Needs as one of the top three areas in which they need more training so that they can feel confident when supporting learners who need some extra support<sup>23</sup>.

"I was a Learning Support Assistant and I had no clue how to manage in a classroom with learning difficulties. We were expected to just get on with it the best we could."

ENABLE Scotland calls on the Scottish Government to do all within its power to introduce mandatory training for teachers and learning support assistants, in initial teacher education courses (ITE) *and* continuing professional development (CPD) to be introduced in the following areas:

- general topics of additional support needs, inclusion and equalities (this would include a knowledge of relevant legislation).
- specific topics of behaviour management strategies, communication strategies and learning disability/autistic spectrum disorder awareness.

<sup>20</sup> <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

<sup>21</sup> <http://www.educationscotland.gov.uk/thecurriculum/whatiscurriculumforexcellence/>

<sup>22</sup> Scottish Government (2010). Summary Statistics for Schools in Scotland 2010.

<sup>23</sup> Donaldson, G (2010). Teaching Scotland's Future: Report of a review of teacher education in Scotland.



ENABLE Scotland believes that mandatory training on additional support needs will lead to improved educational achievement, a decrease in the use of exclusions as a means of managing behaviour, increased confidence and self esteem for the learner and improved relationships between schools and parents.

### **Speech and language therapy**

Many people who have learning disabilities find it difficult to communicate verbally. If support is not in place to help them do this then they can find it difficult to progress through the education system.

Our members are concerned that many people have to wait a long time for an assessment and much longer for therapy. According to a 2009 report by the Royal College of Speech and Language Therapists<sup>24</sup>, over half of children and young people referred to speech and language therapy wait longer than nine weeks for assessment. Children and young people then wait on average between two and six and a half months for therapy with some having to wait for ten months. This is causing many people to give up waiting.

ENABLE Scotland feels that this gap must be addressed to improve access and the academic achievements of people who have learning disabilities within mainstream education.

### **Work Preparation**

ENABLE Scotland believes that historically there has been a lack of preparation for future employment for people who have learning disabilities in schools. We believe that 'enterprise' ideas should be introduced from an early age to develop a greater focus on vocational skills and greater aspirational development.

Additionally, we believe schools should have staff committed to ensuring vocational outcomes from school rather than simply directing people to college courses. One example is ENABLE Scotland's Stepping Up project which started in 2009. Stepping Up is aimed at young people aged 14 to 19 and aims to support them from school into a first job. As part of this approach, Transition Co-ordinators directly support the young people to help them find out about the world of work, visit workplaces, travel independently, start work and make sure young people are better off by working.

### **Further Education**

"The Same As You?" valued the role of further education colleges in enabling people who have learning disabilities to achieve their full potential. ENABLE Scotland is concerned that recent developments affecting colleges, including reductions in college funding have and will continue to affect people who have a learning disability in a disproportionate manner.

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<sup>24</sup> [http://www.rcslt.org/news/docs/Managers\\_Survey\\_A4\\_Scotland\\_proof](http://www.rcslt.org/news/docs/Managers_Survey_A4_Scotland_proof)

Last year, the Scottish Consortium for Learning Disability published “If I don’t get a place next year, I don’t know what I’ll do”<sup>25</sup>, a briefing paper on the result of changes in college provision and their impact for people who have learning disabilities. The report found that part-time courses for people who have learning disabilities had been cut by more than a third and most students had received very little notice that their college place was being cut.

ENABLE Scotland is concerned that, given the significance of changes to college course funding, we are likely to continue to see many people lose their college places, often something that has become an important part of their social life and community engagement.

In consultation with our members on the role of colleges, a number of parents and carers agreed with the command paper that “some college courses are not offering people who have learning disabilities the range or level of opportunities which they are looking for”. Whilst colleges can fulfil an important role in the lives of people who have learning disabilities, some people saw colleges as simply being a replacement for day centres.

One of our members said that they were concerned that the college course their son attended was not personalised to his specific requirements:

“Lecturers can vary in their approach to people who have learning disabilities – some are good and some aren’t. Even if they ask what you want in college, there are no guarantees that you will get it. Often, this lack of understanding of individual circumstances can often result in poor outcomes.”

“He enjoys the culture of being at the college, rather than the curriculum. His needs don’t change. It takes time (to personalise support at school and college) but that time is well spent.”

Given the increased focus upon employability outcomes at colleges as a result of Putting Learners at the Centre<sup>26</sup>, we are concerned that people who have learning disabilities will miss out on crucial employment opportunities. We would expect colleges to include people who have learning disabilities in their plans and amend both outcomes and curriculums to reflect this.

ENABLE Scotland is currently in the process of compiling responses to Freedom of Information requests to each college on the changes in provision for students who have additional support needs over the last five years and will publish the findings in late-2012.

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<sup>25</sup> [http://www.sclld.org.uk/sites/default/files/sclld\\_joint\\_briefing\\_report\\_for\\_web\\_0.pdf](http://www.sclld.org.uk/sites/default/files/sclld_joint_briefing_report_for_web_0.pdf)

<sup>26</sup> <http://www.scotland.gov.uk/Resource/Doc/357943/0120971.pdf>

We call on the Scottish Government to:

- Ensure regional outcome agreements recognise the role college plays in the lives of people who have learning disabilities
- Provide support for projects like Stepping Up and Transitions to Employment which encourage greater employment aspirations amongst people who have learning disabilities in education.

## Future Priorities – Independent Living

### **Question 8 – What still needs to be done to ensure that people with learning disabilities are able to live independently?**

The definition of independent living as developed by the Independent Living in Scotland movement means that all disabled people have the same **freedom, choice, dignity** and **control** as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.

#### Support

ENABLE Scotland believes that self-directed support can help people who have learning disabilities to achieve independent living as well as better outcomes and a better chance of getting the support that is right for them and their family.

Many people express an interest in using personalised budgets or self-directed support to take greater control over their lives. Beyond direct payments, which have been available to disabled people across Scotland since 1997, personalisation is slowly developing with local authorities taking vastly different approaches with different timescales. Our members said that there was still a general lack of awareness around personalisation.

ENABLE Scotland welcomes the Social Care (Self-Directed Support) (Scotland) Bill<sup>27</sup>. However, we believe that the Bill should explicitly state that self-directed support should become the default option offered. Unless there is a commitment to wholesale transformation we are concerned that people will be denied the opportunity this Bill intends to provide. We remain concerned that if self-directed support is not the default position, it will only happen for the few.

Our members said that, whilst support services have given a greater consideration to being “more person-centred” over the last decade, often this could be “tokenistic”. Some support providers were not always successful. For example, some people have had good experiences of being involved in interviews for staff members – but this had been limited. ENABLE Scotland believes that this should be a requirement of all support services for people who have learning disabilities.

“Some organisations say that they include people but they are not always very good at it. They do it to look good but they are not really doing it if the person doesn’t feel included.”

<sup>27</sup>[http://www.scottish.parliament.uk/S4\\_Bills/Social%20Care%20%28Self%20directed%20Support%29%20%28Scotland%29%20Bill/Bill\\_as\\_introduced.pdf](http://www.scottish.parliament.uk/S4_Bills/Social%20Care%20%28Self%20directed%20Support%29%20%28Scotland%29%20Bill/Bill_as_introduced.pdf)

## Co-production

The Partners in Policymaking courses were a well valued tool for self-advocates, parents and carers. The courses ran out of funding a number of years ago in Scotland, though they continue in England and Ireland. Our members have suggested that a leadership programme of this kind should be re-introduced in order to encourage genuine co-production across Scotland.

## Housing

ENABLE Scotland is pleased that since “The Same As You?”, there have been significant numbers of people moving into their own homes. However, far too many people who have a learning disability are living in residential and nursing homes because of cost pressures. Our members told us that, in one local authority, people who have lived in their own home for many years are moving or being moved into residential care.

“Their needs have not changed, but the level of support that the Social Work department are prepared to provide has changed.”

Our members commented that more support should be available for people through the transition from their family home to their own tenancy. Transition is often a difficult experience for people who have learning disabilities and their families.

Our members also express some concern about UK Government proposals that will see cuts in the amount of housing benefit that people can get if they are deemed to have a spare bedroom in their council or housing association home. If the bedroom tax goes ahead, our members are concerned that it will hit people who have learning disabilities living in supported accommodation particularly hard.

## Transport

Many of our members expressed their concern for the future of the concessionary travel scheme, particularly in the light of the UK Government’s Welfare Reform Act. A number of the benefits replaced within the terms of the Welfare Reform Act are known as ‘passport benefits’. This is because they enable people to qualify for other entitlements. For instance, receipt of the higher rate of the mobility component of Disability Living Allowance enables people to qualify for concessionary travel and blue badge schemes.

“If I get mine (Disability Living Allowance) cut – it will mean I lose my bus pass. I rely on mine to get out and about and make new friends. It means I will be financially worse off. If I’m not out and about using my bus pass I’m stuck at home using my electricity. The bill increases.”

ENABLE Scotland is pleased that the Scottish Government has prepared the Welfare Reform (Further Provision) (Scotland) Bill to mitigate some of the impacts of welfare reform. We believe that people receiving Disability Living Allowance at present should continue to receive access to passported benefits after the introduction of the UK Government’s new Personal Independence Payment. We would like to see eligibility for these benefits move to the enhanced or standard rate mobility component or enhanced or standard rate care component of the new Personal Independence Payment.

## **Future Priorities – Employment**

### **Question 9 – What still needs to be done to ensure that people with learning disabilities have access to better employment opportunities?**

#### **Employment Opportunities**

ENABLE Scotland remains disappointed that still only a small minority of people who have learning disabilities are in paid employment. “The Same As You?” said that “local authorities need to give a much greater priority to developing a range of employment opportunities for people with learning disabilities”. However, the most recent eSAY statistics<sup>28</sup> suggest as few as 4,046 people (15.5%) of all adults who have a learning disability were in employment or training for employment in 2011. At the same time, the figures show that as few as 3.9% of people who have learning disabilities are known to be in “open employment”, i.e. in a workplace that is not specifically set up for people who have learning disabilities. This does not compare favourably with the current Scottish employment rate of 70.7%<sup>29</sup>.

We recognise that there remain multiple barriers stopping people who have learning disabilities entering the labour market. These barriers include a shortage of places within Supported Employment services, a lack of knowledge about what help is available to help people into work and whilst they are in work (including benefits such as Access to Work) and some attitudinal problems with parents, carers and employers.

Many of our members also remain concerned about a perceived “benefits trap”. They believe that the disregard amount, under which you can earn a certain level of income before it affects your benefits, was too low. Some of our members told us that this had “prevented their progression into full-time employment”.

#### **Supported employment**

Supported employment can be a successful route into work for people who have learning disabilities. We agree with comments in the command paper that supported employment increases people’s chances of successful employment – as well as being cost effective. There are, however, too few opportunities for people who have learning disabilities to access supported employment schemes across Scotland. We would like to see further commitments to extending these opportunities across Scotland in any future strategy.

#### **Increase aspirations**

ENABLE Scotland believes developing young people’s aspirations from an early age is vital. All schools should have staff committed to ensuring

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<sup>28</sup> [http://www.sclde.org.uk/sites/default/files/final\\_2011\\_esay\\_statistics\\_release\\_-\\_learning\\_disability\\_statistics.pdf](http://www.sclde.org.uk/sites/default/files/final_2011_esay_statistics_release_-_learning_disability_statistics.pdf)

<sup>29</sup> <http://www.scotland.gov.uk/Resource/0039/00396572.pdf>

vocational outcomes from school, rather than simply being a route towards further education. Additionally, we believe that 'enterprise' ideas should be used successfully in primary schools to develop social skills developed with a greater focus on vocational skills.

An increasing number of people we support have been nominated for the Work Programme - despite having significant barriers that might make them better suited to other services. Parts of this programme have a mandatory element that a person may not understand or be able to participate in, which may have a significant ramification upon the person's entitlements. We would like to see a better assessment and referral process by Jobcentre Plus.

Colleges are changing their focus to employability outcomes - this should also include people with disabilities, and we would expect both outcomes and curriculums to reflect this.

For many people who have learning disabilities, finding a job is the first challenge, but maintaining that job can be a further challenge in the long term. On-going in-work support is very important to sustaining employment. Many people require a link person to help them to resolve problems, beyond just the first few months. However, there is a lack of funding for such support – we believe that this should be extended.

#### Other comments

Our members have made a number of other suggestions that we would like the Scottish Government to consider:

- The public sector should “lead by example” by employing a specified quota of people who have learning disabilities. “The Same As You?” recommended this approach for health boards, but we believe that all public bodies should be required to do the same.
- The provision of subsidies for those employers who take on staff who have learning disabilities. This should coincide with a concerted effort for greater engagement and education for employers about the important role that can be played in the workplace by people who have learning disabilities
- Launch an awareness raising campaign concerning benefits like Access to Work which can help people into employment



## **Future Priorities**

### **Question 10 – What other future priorities do we need to focus on? (Please list these in order of most importance first)**

Whilst the four areas covered in the previous four questions are important, there are many other aspects of the lives of people who have learning disabilities which should not be forgotten.

Our members highlighted a number of areas which require greater future priority. ENABLE Scotland is happy to work closely with the Scottish Government to tackle any of the issues which are highlighted below. We would like to stress that all of these priorities are important. These include:

#### Welfare Reform

- Proposals in the UK Government's Welfare Reform Act are likely to result in around £2bn being removed from the Scottish economy<sup>30</sup>. Under the current proposals disabled people will be disproportionately hit by these changes. Many disabled people and their families already live in poverty, and many disabled people need to spend more than non-disabled people to achieve the same standard of living<sup>31</sup>. Despite the UK Government's stated commitment to supporting disabled people to lead independent and active lives we believe that the proposed changes to the benefits system will have the opposite effect.

We welcome the Scottish Government's attempts to mitigate some of the effects of the Welfare Reform Act for disabled people in Scotland and the introduction of the Welfare Reform (Further Provision) Bill. ENABLE Scotland believes that access to welfare rights advice and money management will be a crucial resource for people who require expert guidance after losing their benefits. Many people will also require expert support in preparation for an appeal to cuts in the levels of their benefits.

#### Public Attitudes

- ENABLE Scotland would like to see the launch of a major public awareness campaign with the aim of improving public attitudes towards people who have learning disabilities. ENABLE Scotland is particularly keen to see the promotion of a major campaign about the effects of bullying behaviour on the lives of people who have learning disabilities.

#### Carers

- Improving support for lifelong carers. Including greater consideration of the transition to (and from) the caring role. This could include distinct

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<sup>30</sup>[http://www.strath.ac.uk/media/departments/economics/fairse/backissues/Fraser\\_of\\_Allander\\_Economic\\_Commentary\\_Vol\\_34\\_No\\_2.pdf](http://www.strath.ac.uk/media/departments/economics/fairse/backissues/Fraser_of_Allander_Economic_Commentary_Vol_34_No_2.pdf)

<sup>31</sup>[http://www.demos.co.uk/files/Counting\\_the\\_Cost\\_-\\_web.pdf?1292598960](http://www.demos.co.uk/files/Counting_the_Cost_-_web.pdf?1292598960)

“How to let go” and “Planning for the future” courses, as well as training on emergency planning. We believe that the impact of caring for a son or daughter who have learning disabilities for the rest of your life is still under appreciated and needs more attention by local and central government.

#### Learning to manage money

- Better support required to enable people who have learning disabilities to manage their own finances. As the move towards self-directed support and personalisation continues, this should open up more opportunities for adults who have learning disabilities to know about and manage their own finances. However, few adults who have learning disabilities have had the opportunity to develop their financial literacy skills. This should include the ability to open your own bank account, budgeting, dealing with (and avoiding) debt. The provision of accessible information and training in this area would be welcome.

#### Mental Health

- Greater support on mental health issues – particularly for children and young people.

#### Justice

- It is estimated that as many as 500 prisoners (and a further 1,500 who require some additional support) in Scotland’s prisons have a learning disability<sup>32</sup> that “interferes with their ability to cope within the criminal justices system”<sup>33</sup>. We are concerned that there are very few trained learning disability nurses working in Scotland’s prisons and little planning is in place for people who have learning disabilities on leaving prison and reintegrating back into the community. We believe that rolling out a simple assessment could assist prison officers to identify people who have learning disabilities in prison and better outcomes for people who are leaving prison.

#### Better joined-up consultation

- Improved and joint consultation processes between national and local Government. Some of our members were concerned that “local consultation processes are being carried out for the same purpose as national consultation”.

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<sup>32</sup> <http://www.prisonreformtrust.org.uk/Portals/0/Documents/No%20One%20Knows%20-%20the%20views%20of%20prison%20staff%20in%20Scotland.pdf>

<sup>33</sup> Learning Disability Practice (2010) The Challenges of running a learning disability service in a Scottish prison; Vol.13 (2) pp. 22-26