

Consultation on Carers Legislation



RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately

1. Name/Organisation

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3. Permissions - I am responding as...

Individual / Group/Organisation

Please tick as appropriate

(a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate

Yes No

(b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick ONE of the following boxes

(c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

Are you content for your **response** to be made available?

Please tick as appropriate

Yes No

Yes, make my response, name and address all available

or

Yes, make my response available, but not my name and address

or

Yes, make my response and name available, but not my address

(d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

Yes

ENABLE Scotland response to the proposals on Carers Legislation

ENABLE Scotland welcomes the proposals to improve the lives of family carers and is pleased to have the opportunity to submit views. We have discussed the proposals with our Parents and Carers Committee (a central representative part of our membership), sent a summary of the proposals to our local membership groups, held a small consultation event, and encouraged people to submit views to us via an online survey which was vigorously promoted through our social media channels. Our response is based on a collation of the views of our members and those who responded to our survey. This response has also been endorsed by Down's Syndrome Scotland.

About ENABLE Scotland: ENABLE Scotland is Scotland's largest charity of and for children, young people and adults with learning disabilities, and their family carers.

We provide innovative community-based services that help people with learning disabilities live, work and enjoy meaningful participation in their local community, and have a Scotland-wide network of local membership branches, a membership base of over 4,000 individuals, and a presence in 30 of Scotland's 32 local authorities. We employ almost 2,000 charity and social care staff.

ENABLE Scotland was founded in 1954 by a small group of families anxious to improve services, support and opportunities for children with learning disabilities and their families. At that time, children with significant disabilities were excluded from school and their parents were left to fend for themselves. The few support services available tended to isolate children and adults with disabilities in specialist facilities or institutional care. Our founder members set out to highlight the support needed by families and to prove that all children and adults with learning disabilities could learn and develop, and should be entitled to the same choices and life chances as anyone else. Today all children go to school, no matter their disability, and most adults with learning disabilities live in their local communities. However, the greatest level of support still comes from their families, parents or siblings, who can spend a lifetime caring.

Learning disability is a lifelong condition and there is also a high prevalence of attached physical and sensory impairments. In the 1950s, when ENABLE Scotland was founded, most parents of children with learning disabilities were led to expect that their children would die young and pre-decease them. Although people with learning disabilities are still likely to die 20 years before their peers in the general population, improvements in medical treatment over the second half of the 20th century mean we now have the first generation of people with learning disabilities who are outliving their parents. As such, there is a growing cohort of lifelong carers of people with learning disabilities whose caring responsibilities will not cease until their own death.

The Carer's Strategy and the Care21 research report, *The future of unpaid care in Scotland*¹, recognised the impact on carer health of sustained caring over time. The research report highlighted that carers of people with learning disabilities or carers of people with mental health problems were most likely to have been caring for over 20 years (over 4000 carers took part in the research) and were most likely to be offering the most intense care - over 50 hours per week. The length of time caring and the intensity of care had significant impact on carer health and wellbeing. For this reason, ENABLE Scotland believes that the length of time that a carer has spent (or is likely to spend) caring for a relative needs to be given greater weighting in any decisions around assessment and support for carers.

CONSULTATION QUESTIONS

The Carer's Assessment: Carer's Support Plan

Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?

✓ Yes

No

Our members are very much in favour of changing the name. A significant proportion of the carers that we consulted had never had a carer's assessment and those that had an assessment found the process stressful. However, changing the name is not enough and there needs to be a proactive programme of reaching out to carers. Many family carers of children, young people and adults with learning disabilities are sometimes reluctant to ask for or acknowledge the need for support - especially when they are older. Caring for a child or adult with a learning disability is a lifetime commitment that generally lasts until the carer dies (unlike many other caring situations where the cared-for person's health declines and the caring comes to an end). Given the impact of caring over time and the worries of older carers about inevitable unexpected emergencies and the future care of their relative, these are often the carers most in need.

There would also need to be a corresponding commitment and change in legislation to ensure implementation of the agreed support.

Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?

✓ Yes

No

If all family carers can be eligible for support, this may help to remove some of the stigma of asking for or accepting support. There is also often little recognition of the other daily demands that carers face. For example, many family carers work or

¹ The Future of Unpaid Care in Scotland: Headline Report and Recommendations.
<http://www.scotland.gov.uk/Publications/2006/02/28094157/0> Appendix 3.

care for other family members too (other children, parents). People have different capacities, abilities and circumstances and it is not helpful to have crude assessment tools or criteria that may fail to take account of these.

The level of care needed is only one part of the story for carers of children and adults with learning disabilities. Caring for someone with a learning disability is a lifelong commitment from that person's birth onwards and there needs to be greater recognition of the cumulative impact of this on their family carers – whatever level of informal or statutory support the person may need. For example, parents and carers who are either looking for a diagnosis for their child or have been given a diagnosis of developmental delay need both emotional and practical support. The lack of appropriate support and information can have a negative and long-term impact not just on the parents but also family relationships and most importantly on the development of the child with a learning disability. There are many parents and family carers who would find it difficult to ask for help and support.

Of the 26,117 adults with learning disabilities known to local authorities, 8,489 adults live with family carers (and the living arrangements of a further 5,689 adults are unknown). Of these 8,489 adults, there are 3,165 adults aged over 35 living with family carers. Just under two-thirds of the 3,165 aged over 35 live with a parent carer (as opposed to a sibling, niece etc).²

Of those adults with learning disabilities still living at home with a parent carer, this includes 1001 adults aged over 45, 273 aged over 55, and 41 adults with learning disabilities aged over 65.³

As individuals get older and parent carers get frailer or die, other family members often pick up the caring responsibilities and there are another 159 adults with learning disabilities aged over 65 being cared for by other family carers.⁴

It is wonderful that people with learning disabilities are living longer and leading more fulfilling lives but we must also recognise in tandem that there are many more parents who have been caring for their sons and daughters for over 30, 40, 50 years. They need increasing support as they themselves age, including assistance with emergency planning and future planning, whatever the level of their relative's needs.

The Scottish Government expects that some carers will require only 'light touch' provision. There are some concerns by carers that removing the substantial and regular care test will lead to 'light touch' assessment which may fail to take account of all of the circumstances surrounding the person and their carer. There needs to be a robust assessment process and checks in place to avoid this.

² 2012 Statistics Release: Adults with learning disabilities known to Scottish local authorities (eSAY). Annex A: National Level eSAY Statistics. Table A8. <http://www.sclld.org.uk/sclld-projects/esay/publications-and-resources/statistics-releases>

³ Ibid.

⁴ Ibid.

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services?

✓ Yes

No

A change in this direction signals a move towards desirable strategies of early intervention and prevention. The offer of support to a family who is caring for a relative demonstrates that the family's unpaid input is valued and may prevent the need for more intensive support services at a later stage.

There are estimated to be 120,000 people with learning disabilities in Scotland but only 26,117 adults are known to social services. Many children and adults have health needs that impact on their carers but may not receive or be eligible for social care support. People who need care can also sometimes refuse care support and this may leave their family carer more isolated.

Health inequalities in the early years can have a significant bearing on the health of their families and the resources available to their parents or carers and wider community. *Growing up in Scotland* (GUS, 2013⁵) provides an insight into the interplay of disability on the health and lives of those caring for them.

A MORI Poll (2010)⁶ for Parenting across Scotland suggested that parents of a child with a disability were more likely to use informal childcare (75% compared to 61%). Grandparents, in particular, were heavily relied on for childcare with 58% of parents surveyed using them for childcare at some point in a year, and 32% of parents using them as their main source of childcare. Support that looks at the family as a unit will help to address health inequalities appearing during the early years, support parental health and wellbeing and the development of a child, and overall wellbeing in society.

As previously mentioned in Q2, the level of care needed is only one part of the story for carers of children and adults with learning disabilities. Caring for someone with a learning disability is a lifelong commitment and there needs to be greater recognition of the cumulative impact of this – whatever level of informal or statutory support the person may need. Of the 26,117 adults with learning disabilities known to local authorities, 8,489 adults live with family carers (and the living arrangements of a further 5,689 adults are unknown). Of these 8,489 adults, there are 3,165 adults aged over 35 living with family carers. Just under two-thirds of the 3,165 aged over 35 live with a parent carer (as opposed to a sibling, niece etc).⁷

⁵ <http://growingupinScotland.org.uk/>

⁶ Parenting across Scotland (PAS) (2010) What Scottish parents tell us: Summary of IPSOS MORI Poll undertaken for PAS 2010. <http://www.parentingacrossScotland.org/media/134337/final%20report2.pdf>

⁷ 2012 Statistics Release: Adults with learning disabilities known to Scottish local authorities (eSAY). Annex A: National Level eSAY Statistics. Table A8. <http://www.sclld.org.uk/sclld-projects/esay/publications-and-resources/statistics-releases>

It is wonderful that people with learning disabilities are living longer and leading more fulfilling lives but we must also recognise in tandem that there are many more parents who have been caring for their sons and daughters for over 30, 40, 50 years. They need increasing support as they themselves age, including assistance with emergency planning and future planning, whatever the level of their relative's needs.

Sometimes a family crisis means the cared-for person moves to live with a different family carer. This can disrupt existing care arrangements and leave both the cared-for person and their carer unsupported and fighting to have their needs recognised. This is particularly the case if the "new" carer lives in a different local authority area and the family has to start the assessment process afresh. It is important that a family carer can access support even where their relative is not in receipt of or eligible for social care support.

Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?

Yes

No

Anything which ensures more support can be targeted at family carers is good. Caring for someone with a learning disability is a lifelong commitment and there needs to be greater recognition of the cumulative impact of this.

Self-assessment and self-referral are mechanisms that value the carer's perspective and are in line with self-directed support mechanisms and, as such, contribute to overall coherent social care systems. Carers that identify their own support needs and request help need to be fully supported.

The proposed legislation should also take note of the fact that some young people are caring for their siblings, not their parents. In our experience, siblings often take on at least some of the caring role for their learning disabled brother(s) or sister(s). Tensions can be created when the non-disabled child receives much less attention from their parent(s), impacting on family dynamics. Young carers sometimes worry about having to take on the full responsibility of caring for their disabled sibling when their parents can no longer cope or when they die. Caring can be an extremely positive experience but may also have detrimental effects on a young person's health and wellbeing e.g. lack of sleep, negative impact on educational achievement, anxiety, stress and less opportunities to play and just be a child. There are very few services available that provide support to siblings and this is something that should be addressed in the proposed legislation.

Question 5: Should we remove from statute the wording about the carer's ability to provide care?

Yes

No

Our members felt quite strongly that it must be easier for carers to get a Carer's Support Plan – so anything that removes any barriers for carers is helpful. They also highlighted that the caring role is not static but changes over time because of the changing needs or circumstances of either the cared-for person or the carer. Carers want better recognition of their needs and more consistency in care across local authority areas.

The Scottish Government expects that some carers will require only 'light touch' provision. There are some concerns by carers that removing the tests about 'substantial and regular care' and about 'ability to care' will lead to light touch assessment which may fail to take account of all of the circumstances surrounding the person and their carer and people who need support will be left unsupported. This cuts across all age groups but there is particular anxiety that many elderly people are being left to care regardless of their physical capacity to do so. Family carers do not always recognise their own care needs and may need sensitive support to do so.

As learning disability is a lifelong condition, there are an increasing number of older parent carers who need help to plan for inevitable emergencies and for the future when they can no longer care. A stage may also be reached where the family carer and cared-for person achieve co-dependency and provide mutual support for each other. In this case, it needs to be recognised that the adult with a learning disability is also a carer. Rather than look at 'ability to care' it might be helpful if the assessment process can include something related to 'the circumstances of the carer that will facilitate care giving'.

We propose that the Carers Support Plan should include a duty to incorporate anticipatory care planning.

Some carers do feel that an assessment of 'ability to care' carries connotations of a personal test that they may pass or fail. A more positive approach is needed that considers the assets of the carer and support required for them to continue in this role.

Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?

Yes

No

Our members felt very strongly that the legislation needs to specify a timescale. They thought that 12 weeks was reasonable. The key issue is that carers must be given feedback, not left in limbo after requesting or receiving an assessment.

It also needs regular review – at a minimum an annual review. Timescales and arrangements for review should be discussed with the carer at the time of the original assessment. ENABLE Scotland would like to see local authorities having a

duty to offer carers a review once a year. It is also important that carers can trigger a review at any time if their circumstances change.

Question 7: How significant an issue is portability of assessment for service users and carers?

ENABLE Scotland has membership groups across Scotland and this is a significant issue for our members. Our members want consistency of services and support during a move from one local authority to another. The consultation paper recognises that families are more dispersed than previously. Family members who live in different local authorities may share caring responsibilities and support needs to move seamlessly from one area to another and for there to be robust and co-operative communication between local authorities when someone moves. The Carer's Support Plan should be a living document and there should be a process path for transferring it between local authorities. This would also apply to children and young people through various stages of transition.

The following example from one of our local membership groups indicates some of the issues for families (names have been changed):

Louise lived with her mother in a small town in a rural local authority. She received 12 hours support per week via her local social work department as well as attending the activities of the local ENABLE Scotland branch where she had a network of friends. A few years ago Louise's mother had a heart attack. This led to Louise moving permanently to stay with her sister Fiona in a nearby city in a different local authority. Fiona is a single person who works full-time in order to maintain her home. Fiona sought assistance and advice from both Louise's previous local authority and from her own local authority. She expected that there would be day services and support in the city similar to those Louise had received in her home town which would give Louise meaningful activities and help her develop a new network of friends - as well as enabling Fiona to continue to work. However, the previous local authority said Louise was no longer their responsibility and her new local authority said Louise was not at risk and was therefore not a priority for support. Their only advice was to signpost the family to the local regeneration agency for employment options but Louise did not fit their criteria. Fiona was left to research options for Louise herself. She managed to get Louise a college place for a year and then linked into voluntary groups. Through links with the local ENABLE Scotland branch in the city, Louise now has a work-related placement and is finally recognised as a 'person in need of services' by her new local authority. The family feel that they had to 'start again' when Louise moved. It would have made a huge difference if there had been some co-operation between her old and new local authorities, and a recognition by both authorities that this was a transition crisis point for Louise, her mother and sister.

Question 8: Should the Scottish Government and COSLA with relevant interests work together to take forward improvements to the portability of assessment?

✓ Yes

No

It would be helpful if the relevant interests included representation from carers and third sector carer organisations.

Information and Advice

Question 9: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?

✓ Yes

No

As the consultation paper points out, access to timely and relevant information is the "golden key" for carers. However, information alone is not enough.

The carers that we consulted stressed that any information provided has to be short, sharp and accessible as carers are hard-pressed and have many demands on their time and energy. Our members pointed out that being handed a leaflet or signposted to a website is not enough. Many carers feel overwhelmed and will not follow this up. They need actively linked to sources of support, for example by a link worker. There needs to be a multi-agency approach to information but a single point of contact is also very important.

There was some discussion of which agency should provide this service – the local authority or a commissioned information provider. The provider is less important than the quality and standard of service, and consistency of provision. Ideally, local authorities should be aware of and signpost carers to relevant sources of support services and to key link workers who can assist the carer through the maze of information.

There also needs to be a broader and more strategic approach to information provision. For example, many children experience long delays and multiple referrals before a diagnosis is made. Evidence suggests that the information provided by different professionals in the early stages of diagnosis needs to be co-ordinated through a single point of contact and the professionalism in providing this information was seen as vitally important.

Question 10: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?

Yes

✓ No

Both local authorities and Health Boards have duties to support carers. Given the significant impact that caring can have on the health of carers, and the key role of GPs in identifying carers and signposting them to resources, ENABLE Scotland feels that Health Boards should retain responsibility for preparing Carer Information Strategies, with funding attached.

The integration of health and social care is also an opportunity to take a more strategic approach and ensure good quality information and advice is available. The key issue is ensuring that there are sufficient resources to deliver good quality information and advice to families and a co-ordinated strategic approach across local areas.

Support to Carers (other than information and advice)

Question 11: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?

✓ Yes

No

Our members want local authorities to have a duty to support family carers even though it will come with an eligibility framework. Many family carers of children and adults with learning disabilities only ask for support if they have a crisis – so a duty on local authorities to consider and offer support to all carers might mean that a crisis point is avoided and the health and wellbeing of the carer (and the person they care for) can be maintained for longer.

There is some concern that the existing eligibility framework (originally developed for older people) will be used or adapted for carers. ENABLE Scotland would like to see a new eligibility framework developed – that takes account of all carer groups. A key issue for members of ENABLE Scotland is lifelong caring. Learning disability is a lifelong condition and there are at least 2000 adults with learning disabilities aged over 35 living with a parent carer in Scotland and another 1000 aged over 35 living with another family member. Eligibility criteria must take account of lifelong caring and include the length of time that family carers have cared or are likely to have caring responsibilities.

Preventative care is crucial. Any eligibility criteria should include consideration of the risks, and the impact on outcomes, of failing to provide anticipatory care. We propose that the Carers Support Plan should include a duty to incorporate anticipatory care planning.

As mentioned above, the proposed legislation should also take note of the fact that some young people are caring for their siblings, not their parents. In our experience, siblings often take on at least some of the caring role for their learning disabled brother(s) or sister(s). Tensions can be created when the non-disabled child receives much less attention from their parent(s), impacting on family dynamics. Young carers sometimes worry about having to take on the full

responsibility of caring for their disabled sibling when their parents can no longer cope or when they die. Caring can be an extremely positive experience but may also have detrimental effects on a young person's health and wellbeing e.g. lack of sleep, negative impact on educational achievement, anxiety, stress and less opportunities to play and just be a child. There are very few services available that provide support to siblings and this is something that should be addressed in the proposed legislation.

The duty to support carers and young carers must also have resources attached to it for it to be successfully implemented.

Question 12: Alternatively, should we retain the existing discretionary power to support carers and young carers?

Yes

No

While we welcome the introduction of the discretionary power in April 2014, ENABLE Scotland members would prefer to see this replaced by a duty on local authorities and health boards to support carers.

Question 13: Should we introduce a duty to provide short breaks?

Yes

No

ENABLE Scotland is very pleased to see that this is under consideration as short breaks can be vital for both the family carer and their relative. Our members have long been calling for families to have stronger rights to a break and for wider and more regular availability of such support. Although we welcome the idea of a Short Breaks Statement, there is some concern that it may lead to a revived focus on services or residential respite care. It is very important that "short breaks" is defined creatively in order to open up opportunities for both the carer and cared-for person to enhance their wellbeing and resilience. It can also be more cost-effective to send someone on a holiday than use a local short breaks service.

ENABLE Scotland's experience in talking to carers is that there is often confusion amongst carers about what constitutes a 'short break'. They often need reassurance and guidance in planning one, in being creative about a short break, and how to define an outcome.

Some carers will not take up an offer of a short break due to concern about the suitability or the standard of the temporary care. It does not assist the carer's wellbeing if they spend the short break worrying about their loved one. It would help if family carers had more choice and control over the short break and self-directed support could assist in this respect. Thanks to Scottish Government funding (via Shared Care Scotland and through the Keys to Life, Time for You

fund), ENABLE Scotland, in association with Down Syndrome Scotland and PAMIS, has been able to offer small grants of up to £500 to family carers so they can organise a break that suits them and their loved one. This is very much appreciated by the families and is something that could be rolled out further. We have been inundated with applications which demonstrates the need for short breaks for families

A partnership approach by agencies in North Lanarkshire highlights what can be done to identify needs and priorities. North Lanarkshire Carers Strategy Implementation Group, supported by NHS Lanarkshire Carer Information Strategy Group obtained funding for a 9-month appointment of a Short Breaks Development Worker within North Lanarkshire. The post-holder was hosted by North Lanarkshire Carers Together and began work in January 2013 to map local services, identify good practice nationally, and consult carers about issues and needs. Part of the mapping work indicated that short breaks was a major issue particularly for older carers and that this will only increase as the balance of care shifts. Amongst reasons for carers **not** accessing short breaks were; lack of information, eligibility criteria, apparent lack of choices, and relationship conflicts if the person they cared for did not want to accept alternative support. The final report and recommendations can be obtained from North Lanarkshire Carers Together.

Stages and Transitions

Question 14: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on managing stages of caring? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).

✓ Yes

No

Our members and the carers we consulted are concerned to ensure that the responsibilities of local authorities and health boards and the 'rights' of carers are robust and transparent. It is crucial that all carers but particularly older carers (whose own health may not be robust) are assisted to plan for inevitable emergencies. We are disappointed that the only mention of emergency planning in the consultation document (page 11) suggests that it will be an issue covered in guidance. We understand the difference between legislation and guidance and that there can be limitations to including issues in the legislation, but we would strongly urge the Scottish Government to include a duty on local authorities to consider emergency planning as part of the Carer's Support Plan assessment and planning process.

With that caveat, we offer the following comments on the Guidance and what it might include.

The carers whom ENABLE Scotland consulted on this question struggled with the different definitions of 'stages' and 'transition', including the definition of transition mainly relating to the move from children's to adult services. Learning disability is a lifelong condition and there are other transition points in the lives of adults with learning disabilities including a move from school or college into work (which may need a degree of intensive support for a while), or changes in residential arrangements.

There are also significant stages for children and adults with learning disabilities and their families which need to be included in any statutory guidance. This includes (but is not limited to):

- Diagnosis - parents and carers who are either looking for a diagnosis for their child or have been diagnosed with global developmental delay need both emotional and practical support. The lack of appropriate support and information can have a negative and long term impact not just on the parents but also family relationships and most importantly on the development of the child with a learning disability if appropriate early intervention is missed.
- Emergency planning – as carers of people with learning disabilities get older there is a particular need to think about and plan for inevitable emergencies. These emergencies might be unexpected and sudden such as the carer becoming ill suddenly or planned such as anticipated hospital admissions. Planning for emergencies can also help carers and other family members think about more longer-term planning for the future. ENABLE Scotland has published a research report, *Picking up the Pieces*⁸, which gives recommendations and examples of good practice from local authorities.
- Future planning – as mentioned above, we now have the first generation of people with learning disabilities who are outliving their parents. Parent carers, who have cared for and advocated on behalf of their sons and daughters all their lives, have enormous anxieties about the future for their loved ones once they are no longer here to look out for them. These carers – and their loved ones - need sensitive support to plan for a time when the carer may decline and die – even where the care arrangements have already changed. This planning will include practical issues like wills, trusts and financial planning as well as dealing with the emotional impact.
- Bereavement planning – Most people with learning disabilities will experience the loss of their parents, who are often still their primary carer. The emotional upset can be compounded if their care or living arrangements also need to change at the same time. Other family members and support staff may need access to resources or appropriate training to support someone with a learning disability through bereavement. If the cared-for person dies this can be a very difficult transition for the family carer and they should be able to access appropriate support including from

⁸ Picking up the Pieces: Supporting Carers with Emergency Planning.
[http://www.enable.org.uk/enabledirect/publications/Documents/Picking%20Up%20The%20Pieces%20\(web%20version\).pdf](http://www.enable.org.uk/enabledirect/publications/Documents/Picking%20Up%20The%20Pieces%20(web%20version).pdf)

carer groups.

It is also very important that the Guidance and the assessment and planning process recognise that people's care needs can change frequently. This is particularly the case where someone has profound and complex disabilities, often involving multiple conditions, and where their health needs can fluctuate greatly. Family carers need to be able to access varying levels of support, dependent on the particular circumstances at the time. However, their experience at the moment is that support is very static.

ENABLE Scotland would also like to see robust monitoring of timescales, processes and outcomes – ie are local authorities following the legislation and guidance and what is the impact.

Question 15: Should new carers' legislation provide for young carers to have a Carer's Support Plan if they seem likely to become an adult carer? Any agreed support recorded in the Carer's Support Plan would be put in place after the young carer becomes a (young) adult carer.

Yes

No

There should also be arrangements in place to ensure that the young carer is provided with appropriate support **before** they become an adult carer. This support might come under the provisions of different legislation e.g. Additional Support for Learning Act and should be recorded in the Child's Plan (GIRFEC) as set out in the Children and Young People Act. Clear links to complementary pieces of legislation should be included in Guidance.

Transitional arrangements (from young carer to adult carer) should be clearly specified in secondary legislation so that the young person providing care experiences a smooth continuity of support.

As mentioned above, the proposed legislation should also take note of the fact that some young people are caring for their siblings, not their parents. In our experience, siblings often take on at least some of the caring role for their learning disabled brother(s) or sister(s). Young carers sometimes worry about having to take on the full responsibility of caring for their disabled sibling when their parents can no longer cope or when they die. Caring can be an extremely positive experience but may also have detrimental effects on a young person's health and wellbeing e.g. lack of sleep, negative impact on educational achievement, anxiety, stress and less opportunities to play and just be a child. There are very few services available that provide support to siblings and this is something that should be addressed in the proposed legislation.

Under the Additional Support for Learning Act a CSP is a Coordinated Support Plan but under the proposed Carers' legislation, a CSP is a Carers Support Plan. The similarities in terminology and acronyms have the potential to create confusion.

Carer Involvement

Question 16: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

✓ Yes

No

Carers are supposed to be 'equal partners in care' and it is vital that their voices are heard and they are able to contribute their ideas and knowledge to the structures put in place to support them in their caring role and to achieve positive outcomes for their loved ones.

Individuals and carers using self-directed support to achieve personalised care and outcomes can have the opportunity for carers to be involved in the planning, shaping and delivery of services for the people they care for. However, it is important that all carers, not just those who use self-directed support, get this opportunity and that it applies to support structures beyond integrated health and social care.

Individuals may have different aspirations and ideas from their family carer and may need independent support or advocacy to articulate these.

Question 17: Should we make provision for the involvement of carers' organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?

✓ Yes

No

If carer organisations are to be involved in the planning, shaping and delivery of services and support to carers then they need to be appropriately and adequately resourced to do so.

Question 18: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?

✓ Yes

No

Comments: --

Question 19: What are your views on making provision for young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers?

Article 12 of the United Nations Convention on the Rights of the Child states that young people have a right to express their opinion and be taken seriously. It is crucial that young people are involved in the planning, shaping and delivery of services for themselves and the person they care for. It should not be assumed that service providers know what young carers want and need – the young people who will be affected by the planned services should be consulted and listened to at every stage, so that their needs are met appropriately. Consultation must not be perfunctory or tokenistic and any communication with young people should be ‘child-friendly’ and suitable to their level of understanding.

As mentioned above, the proposed legislation should also take note of the fact that some young people are caring for their siblings, not their parents. Siblings often take on at least some of the caring role for their learning disabled brother(s) or sister(s). There are very few services available that provide support to siblings and this is something that should be addressed in the proposed legislation.

Planning and Delivery

Question 20: Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers strategies which must be kept under review and updated every three years?

✓ Yes

No

Comments:

Question 21: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

✓ Yes

No

ENABLE Scotland welcomes this commitment and agrees that more and better carer support services are needed. However, there are concerns about the definition of ‘sufficient’, and the inclusion of the phrase ‘as far as is practicable’. Hard-pressed family carers worry about the availability of enough resources in the current economic landscape. This is an area where consultation and co-production with carers and carer organisations is vital. Carers must be involved in helping to decide and shape any carer support services in their area. It is also vital that all relevant agencies across all sectors – statutory, private and voluntary – co-operate

and work together to offer relevant options, solutions and support and that a creative approach is taken. Keeping carers involved and informed is essential.

Another key issue is the need for better 'mapping' of existing facilities and better signposting to all the available local resources.

A major concern for carers is the varying levels of support and services on offer in different parts of Scotland and the 'postcode lottery'. Our members would like to see more consistency in the types and availability of support across the country.

As mentioned above, there are very few services available that provide support to siblings, including young sibling carers, and this is something that should be addressed in the proposed legislation.

Identification

Question 22: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

Yes

No

We believe that there should be consideration of placing a duty on Health Boards to identify carers and that this should be done through the Carers Register at GP surgeries.

We agree that duplication and multiple registers should be avoided – however it is hoped that the forthcoming integration of health and social care services might lead to better information-sharing and signposting to appropriate sources of support (subject to appropriate confidentiality and data protection protocols).

Identification of carers remains a challenge. There are many reasons why carers may remain 'hidden'. There are an estimated 120,000 people with learning disabilities in Scotland but fewer than 27,000 are known to local authorities. There are 16,000 children and young people with additional support needs due to learning disabilities whose families may also need a degree of health and social care support. However, diagnosis can be a challenge for many families. There are many individuals whose learning disability is not picked up or acknowledged. As a result their carers may not get the support they need.

Learning disability is not an illness and many people with learning disabilities may seldom visit their GP. However, the latest learning disability strategy for Scotland, The Keys to Life⁹, has highlighted the significant health inequalities faced by people with learning disabilities who, on average, are likely to die 20 years before their peers in the general population.

A randomised controlled trial of health checks for adults with learning disabilities

⁹ The keys to life. 2013. <http://www.scotland.gov.uk/Publications/2013/06/1123>

has been completed in Scotland. This initiative has provided evidence to support the inclusion of health checks for adults with learning disabilities in the GP contract. Recommendations 22 and 23 of the Keys to Life state:

“That by the end of 2015 all NHS Boards across Scotland should ensure there is a dedicated primary care liaison resource to support General practice and primary care teams to ensure their services are equitable and, where required, targeted for people with learning disabilities.”

“That the Learning Disability Strategy Implementation Group will work with the Primary Care Division of the Scottish Government to explore how the GP contract in Scotland can best meet the needs of people with learning disabilities, including the possibility of the reintroduction of an enhanced service for people with learning disabilities and including additional learning disability indicators in the Scottish Quality Outcomes Framework by June 2014.”

These recommendations also offer opportunities to identify family carers and to link them into sources of information, advice and support. Embedding this within the GP contract would improve the identification of carers.

Work should be done to ensure that there is greater awareness among education staff, health professionals and social workers of the needs of young carers and the potential impact of caring, on their health and wellbeing. The latest Additional Support for Learning Implementation Report to Parliament¹⁰ (published April 2014) only reports 842 young carers across the whole of Scotland’s schools. This may illustrate a lack of awareness on the part of education staff, plus possibly a reluctance by young people to self-identify as a carer or to ask for help. Whatever the reasons behind the low figures, it is clear that more needs to be done to support young people who find themselves in a caring role.

Question 23: Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?

Yes

No

Comments:

Question 24: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

Yes

No

Comments:

¹⁰ Implementation of The Education (Additional Support for Learning) (Scotland) Act 2004 (as amended): Report to Parliament 2013 <http://www.scotland.gov.uk/Publications/2014/04/3050> (page 24)

Carer and Cared-for Person(s) in Different Local Authority Areas

Question 25: What are the views of respondents on the lead local authority for undertaking the Carer's Support Plan and agreeing support to the carer where the carer lives in a different local authority area to the cared-for person(s)?

A majority of the people we consulted think that the lead local authority for undertaking the Carer's Support Plan and agreeing support to the carer should be the local authority of the cared-for person.

The local authority of the cared-for person has the responsibility to ensure a joined-up support plan that includes unpaid care and family support when appropriate. The local authority therefore should have both a good practice motive, as well as an economic motive, to ensure that unpaid carers are supported to be included in the lives of their relatives to the extent they wish and are able to contribute.

If local authorities can agree (via COSLA) that the Carer's Support Plan should be the responsibility of the local authority where the cared-for person resides, this may aid the collection of data about the support required by carers, the numbers of carers in Scotland, and evaluation of the effectiveness of the support provided.

There should also be co-operative communication between the relevant local authorities as necessary. The Carer's Support Plan should be a living document and there should be a process path to enable it to be transferred between local authorities if either the cared-for person or the carer moves.

Question 26: What are the views of respondents on which local authority should cover the costs of support to the carer in these circumstances?

A majority of the people we consulted think that local authority of the cared-for person should cover the costs of support to the carer.

If local authorities can agree (via COSLA) that the Carer's Support Plan should be the responsibility of the local authority where the cared-for person resides, this may aid the collection of data about the support required by carers, the cost of this support, and evaluation of the effectiveness of the support provided.

There should also be co-operative communication between the relevant local authorities as necessary. The Carer's Support Plan should be a living document and there should be a process path to enable it to be transferred between local authorities if either the cared-for person or the carer moves.

Question 27: Should the Scottish Government with COSLA produce guidance for local authorities?

✓ Yes

No

Other relevant parties should also be involved in the development of this Guidance.

Consideration should also be given to involving local authorities who are not members of COSLA in the development of and adherence to the Guidance.