Background

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 5000 members in 44 local branches and via individual membership. Around a third of our members have a learning disability.

ENABLE Scotland campaigns to improve the lives of people who have learning disabilities, their families and carers. ENABLE Scotland provides social care services to more than 2,000 people across Scotland who have learning disabilities or mental health problems.

Social security entitlements are vital source of support for our members and we are pleased that the Welfare Reform Committee is giving organisations and individuals the opportunity to express their opinions on the ways in which any new devolved powers can be used to improve the support available.

People with a learning disability in Scotland are more likely than average to be reliant on social security benefits due to a combination of high rates of unemployment, part time working and low pay. Many carers of a person with a learning disability are also reliant on benefits whilst others are unable to access benefits which recognise their caring role.

ENABLE Scotland would emphasise that the devolution of parts of the welfare system provides an excellent opportunity to reframe the narrative around the welfare system. It has to be clear that the welfare system is about empowering citizens, facilitating participation and recognising everyone’s contribution and value to society. Further, it provides an opportunity to examine and influence the culture and ethos embedded in the benefits delivery system.

ENABLE Scotland asks that, in keeping with recommendations of the Christie Commission, the Committee considers how to effectively engage people who are part of the social security system in shaping future delivery.

ENABLE Scotland would emphasise that there is a need to look at welfare within the whole spectrum of essential public services such as health, education, children’s services, but in particular social care. Many recipients of social care are asked to make a contribution to the cost of their care based on the amount they receive in benefits. It would be ineffective to increase these only for them then absorbed by increasing care charges.

Furthermore, many of our members also access passported benefits via their social security entitlements. These include; the concessionary bus travel and blue badge schemes, the Scottish Welfare Fund and free dental treatment. Any changes made to devolved benefits could widen or limit access to these. ENABLE Scotland urge that these
entitlements provide vital sources of support for disabled people; and should not be lost as an unintended consequence of changes to devolved benefits.

These are just some examples of the potential unintended consequences that can arise by considering welfare powers in isolation. We urge the Committee to ensure that any changes in welfare benefit policy do not negatively impact on other areas but rather act as springboards for improvements in other policy areas.

Finally, throughout this evidence ENABLE Scotland refer to issues we have identified with the Scotland Bill in its current form, we would also urge the Committee to question key UK Government officials and Ministers about the potential impact of the recent Emergency Budget announcements and the Welfare Reform and Work Bill on further devolution. e.g. further reduction in benefit cap to £20,000, given it includes benefits to be devolved, such as Carers Allowance.

a) Personal Independence Payments, Disability Living Allowance Attendance Allowance and Carer's Allowance

At present the above benefits are demand led with no overall cap on the amount that can be spent.

In contrast, ENABLE Scotland understand that the Scottish Government is likely to have a limited devolved budget and under which to operate them. Whilst Scotland may have the option to top up or widen the access to these benefits, it is unclear how this will be funded or what the implications will be on reserved benefits.

We would urge the Welfare Reform Committee to seek clarity on how the devolved and reserved elements of the welfare system would work together to produce the best outcomes for disabled people and carers in Scotland.

**Personal Independence Payment, Disability Living Allowance & Attendance Allowance**

Disability benefits are crucial to disabled people across Scotland; facilitating disabled people’s participation in society and enabling them to take up opportunities that would otherwise be inaccessible. These benefits are not only a cash transfer to cover the additional costs that arise by virtue of having a disability but can also mean an increase in their other benefits due to additional disability elements, access to additional benefits for family members such as Carers Allowance and access to passported benefits such as a blue badge or bus pass.

Despite the transition from Disability Living Allowance to Personal Independence Payment being underpinned by a worrying UK Government policy intention to cut the expenditure on this benefit by 20%, ENABLE Scotland has demonstrable positive results for people who have learning disabilities on this benefit.

ENABLE Scotland have so far assisted with 51 claims to the Personal Independence Payment. Of those approximately 75% have been successful, 50% of refusals have been overturned at mandatory reconsideration and 50% have been overturned on appeal.
Whilst we are pleased with the vast majority of cases that we have assisted with we are aware that our clients are receiving an intensive level of support from both ENABLE and often other organisations to help ensure these claims are as strong as possible. We remain concerned about the potential results for people with a learning disability who do not have such support.

It is also worth noting that we have also seen cases where it is likely that the person refused the Personal Independence Payment would have been likely to have been awarded the lower rate of the care component of Disability Living Allowance due to being unable to cook a main meal due to their disability.

Under the Personal Independence Payment there is no equivalent of low rate care and being unable to cook a main meal in itself does not bring enough points to qualify for the benefit.

ENABLE Scotland are open to further discussion around continuing with the Personal Independence Payment or maintaining Disability Living Allowance but we feel that the decision making and evidence gathering processes are more important for both benefits than the criteria its self.

Consequential Impacts

ENABLE Scotland would urge the Committee to seek clarity as to how the devolved and reserved elements of welfare would work together to ensure the best outcomes for disabled people.

Part of this will be for the Committee to consider the consequential impact of making changes to devolved benefits on other reserved benefit entitlements, as the current benefit system is intertwined with many benefits having implications on entitlement to others.

For example, should the Scottish Government decide to increase the rate at which Carers Allowance is paid this could simply mean that a claimant who also receives Income Support would lose this benefit on a pound for pound basis; meaning no actual net gain for the claimant. Conversely, entitlement to disability and carers’ benefits often result in increases to other means tested benefits that will remain reserved.

It is vitally important that we have clarity on these issues as soon as possible.

Administration

On the introduction of the Personal Independence Payment there were significant delays in making decisions on claims. This meant that the claimant did not receive the money they were entitled to for a prolonged period but also that they were unable to receive related disability elements in other benefits or that their carer was unable to access Carers Allowance.

These issues have improved significantly in recent months and we call on the Committee to ensure that timescales remain the same or better on devolution of these benefits.
We would also like to take the opportunity to raise an issue that we have experienced in the Personal Independence Payment claim process when supporting claimants, in the hope that this could be remedied when these benefits are devolved.

In order to start a claim for the Personal Independence Payment claimants must make a lengthy telephone call and then fill in a lengthy claim form in addition to this.

Whilst this telephone call may not present difficulties for some claimants, it is our experience that people who have learning disabilities often need support to make this call. This can mean delays in claims until the person can be supported to make the initial call. It also means a repeat appointment a short time later to assist with the completion of the claim form once received. This places significant pressure on specialist welfare advice services with limited resources. This could be resolved by allowing welfare advisers to make the additional call remotely in the way this was be done for Disability Living Allowance.

ENABLE Scotland urges that the devolution of these benefits provides a timely opportunity to look at and resolve the administrative issues that place barriers to people accessing their entitlements. Accessibility must be a central consideration when thinking about how devolved benefits will be administered in future.

**Assessments**

The Personal Independence Payment is focused on specific medical assessments being carried out, where as Disability Living Allowance and Attendance Allowance have tended to rely on requesting written medical evidence from sources (such as the claimant’s GP) with the possibility of a specific medical assessment if it is required.

ENABLE Scotland suggest that devolution of these benefits provides an opportunity to redesign the evidence gathering process to ensure that evidence is gathered in the best and most cost effective way. ENABLE Scotland feel that a specific medical assessment is rarely the best way to assess any claimant’s disability and that it is in fact particularly unsuited to assessing those with a learning disability who can be particularly vulnerable to negative decisions in any process which involves communicating their difficulties. Benefit specific medical assessments tend to produce snap shots of a claimant’s life rather than a long term picture and people with a learning disability may underplay their difficulties or not understand the questions asked.

It is our opinion that the best evidence will usually come from the people who know the claimant best such as GP’s, consultants, support workers or family members and that these are often the sources of evidence where opinions should be sought.

We would also recommend that the evidence gathering process be amended in order to produce information which makes it easier for decision makers to make accurate decisions. The current medical evidence templates sent to medical professionals are inadequate and often do not prompt those completing them to ask themselves the right questions about their patients or the people they support when completing them.

We strongly recommend that these templates be redesigned and that consideration be given to other methods of evidence gathering such as phone calls that would allow those supplying evidence to respond in a more open way with a dialogue between them and
decision makers rather than being restricted to yes no answers or limited capacity to respond.

ENABLE Scotland would be happy to be fully involved in this process. Should this model or a similar model remain when these benefits are devolved, ENABLE Scotland would emphasise that assessors should be equipped with the communications skills and competencies to be able to support the person to give an accurate representation of themselves and their life.

**Carers Allowance**

Within the context of a changing demographic it is clear that, many more of us will take on a caring role. The welfare system needs to be responsive to this in recognition of the contribution made by unpaid carers in preventing more costly health and social care interventions. Many carers are currently unable to access benefits which recognise their caring role.

This is something ENABLE Scotland would like to see remedied when this benefit is devolved to the discretion of the Scottish Parliament.

ENABLE Scotland are supportive of opening up discussions on the possibility of extending Carers Allowance access, increasing the current earnings limit and increasing the rate of payment. However, we would highlight to the Committee that our analysis of the Scotland Bill, in its current form, would not facilitate that flexibility.

At Clause 19(4) defines ‘carers benefit’ as a ‘benefit which is normally payable in respect of the regular and substantial provision of care by a relevant carer to a disabled person with a “disabled person” defined as “a person to whom a disability benefit is normally payable” and ‘relevant carer’ defined ‘as person who— (i) is 16 or over, (ii) is not in full-time education, and (iii) is not gainfully employed’.

Our analysis of this section suggests that the Scottish Parliament would be restricted in their creation of a new carers benefit. This section, in its current form, prescribes to whom carers benefits would be payable, stipulating that the recipient would be over 16, not in full time education and not gainfully employed; and requiring that the cared-for person is in receipt of disability benefit. ENABLE Scotland would suggest that this drafting will impact on the discretion of the Scottish Parliament thereafter to create carers benefits that are fit for purpose and meet the needs of all carers in Scotland, and not just those who fit this narrow definition.

These drafting concerns were identified by ENABLE Scotland in the Draft Legislative Clauses and raised with the then Secretary of State for Scotland, Alastair Carmichael MP, on 12th February 2015. It is unfortunate that the opportunity to amend the draft clauses before they formed part of the Bill was not taken however we continue to work with MPs and will work with Peers in the hope that this can be rectified as the bill progresses. We have also written to the Secretary of State for Scotland, David Mundell MP, asking that he make this change when the Scotland Bill returns at Report Stage. We have also shared these concerns with the Scottish Parliament’s Devolution (Further Powers) Committee.
ENABLE Scotland would also highlight to the Committee that Carers Allowance is a benefit which can in certain situations reduce the income of the disabled person. Many disabled people receive an additional element in their means tested benefits that recognises that they do not have anyone in receipt of Carers Allowance for them (the severe disability premium) and any changes which open up access to Carers Allowance may have significant implications for this group of claimant. It will be crucially important that all of the implications of any changes made to this benefit are considered.

b) Universal Credit (housing element and administrative arrangements arrangements) and Discretionary Housing Payments

ENABLE Scotland strongly believe that the Universal Credit system is fundamentally flawed and will mean devastating cuts in entitlement for many people with a learning disability. We are pleased that the Scottish Government is likely to get some powers over its administration and feel that these could be used to lessen some of our current concerns.

The Scottish Government has announced\(^1\) that they intend to use these powers to give claimants the option of more regular payments and the ability to have the housing costs element paid directly to their landlord and we are supportive of this announcement. We feel that these changes will help people with a learning disability to budget and lessen the likelihood of rent arrears.

With the devolution of the housing element of Universal Credit, ENABLE Scotland would suggest that consideration is given to the rates of non-dependent deductions to ensure these are proportionate of non dependents income. The current flat rate of non dependent deduction is disproportionately impacting on families who have non dependents with relatively low incomes; for example families who have adult children with learning disabilities on low/benefit income living at home who would currently have the same flat rate of deduction applied as families who have a non dependent resident on a relatively high income who can contribute to housing costs.

Further, while the devolution of housing element of Universal Credit will hopefully provide the opportunity to remove the ‘bedroom tax’ as applied to those on Universal Credit. This will not be the case for housing benefit recipients not in receipt of Universal Credit.

ENABLE Scotland is pleased the Scottish Government has provided additional funding for these claimant by working with the UK Government to remove the previous cap limiting their ability to top the Discretionary Housing Payment fund. We hope to see this funding commitment maintained.

We however highlight that this does not remedy the impact of the ‘bedroom tax’ for everyone. Those affected by it who lose a proportion of their Housing Benefit can apply for a Discretionary Housing Payment whereas those who lose all of their Housing Benefit entitlement as a consequence of the ‘bedroom tax’ cannot as you must have some entitlement to Housing Benefit to be able to apply for a discretionary housing payment.

\(^1\) [http://news.scotland.gov.uk/News/New-benefits-powers-for-Scotland-1bef.aspx](http://news.scotland.gov.uk/News/New-benefits-powers-for-Scotland-1bef.aspx)
The Scotland Bill in its current format will not tackle this as these powers are set to remain reserved whilst the housing element of Universal Credit will be devolved.

c) the Work Programme and Work Choice

ENABLE Scotland strongly believe that people with a learning disability should have the opportunity to work where it is possible for them to do so.

ENABLE Scotland recognise that many people who have a learning disability who are able to work require support to find and maintain employment. ENABLE Scotland currently deliver the work choice programme as well as other employment schemes.

We also recognise the benefits of work for people with learning disabilities, their carers and families, employers, the economy and society in general. Unfortunately, people with a learning disability are currently far more likely than average to be unemployed, work part time and/or be in low paid work.

Our experience in providing supported employment services means that we are well placed to recognise the barriers into employment for people with learning disabilities and to make suggestions to overcome these.

It will be necessary to consider a variety of models to deliver devolved employment support models.

ENABLE Scotland would highlight that evidence shows, that mandatory employment schemes such as the work programme (success rate of less than a quarter) have very limited success in comparison to those that are optional such as work choice (success rate of around two thirds).

One model that may be explored would be for those seeking support to find employment are allocated a budget and that they are then free to spend this budget with their preferred support provider. This would bring funding for supported employment into line with the move towards self directed support for those in receipt of social care services and would attract the same benefits that such a system brings such as tailored rather than standardised services and the ability to make service users active participants in the process rather than passive recipients.

ENABLE Scotland is currently contributing to Fairer Scotland discussion on the future of Employment Support in Scotland. We would suggest Committee evidence is considered together with response received to this consultation.

ENABLE Scotland would like to highlight to the Committee that the ‘Access to Work’ scheme is one of the most important elements of the employment support system for disabled people. It provides critical support to meet the practical support needs of disabled people in the workplace, for example, a British Sign Language interpreter for a Deaf employee during meetings, or a job coach for an adult with learning disabilities.

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It is disappointing, therefore, that the Scotland Bill, in its current form, does not legislate to devolve responsibility of Access to Work in Scotland to the Scottish Parliament.

ENABLE Scotland believes that the devolution of Access to Work is necessary to deliver integrated and accessible Employment Support in Scotland. Failure to devolve Access to Work in parallel with the ‘Work Programme’ and ‘Work Choice’ will limit access for disabled jobseekers in Scotland and increase bureaucracy for specialist support organisations and employers.

‘Access to Work’ does not currently integrate well with employability programmes that are not delivered by the DWP. For example, if you are a person on Work Choice you can use Access to Work to get pre-employment support in interviews or agree support whilst transitioning into work. Persons supported by the Employability Fund, (Scottish Government’s largest training programme), do not have access to that support and face increased negotiation and bureaucracy to get the support.

Given that post-devolution the employability programmes will not be delivered by the DWP, failure to devolve Access to Work in parallel will limit access for Scottish jobseekers and increase bureaucracy for specialist support organisations and employers.

Furthermore, Access to Work is currently delivered via call-centres with the intention to move to more online processes. Access can be very difficult for people who have learning disabilities in Scotland who need to phone up and answer questions on cost and support. Most often this is done with a support worker/family member, but this needs to be arranged in advance and be difficult to negotiate.

If Access to Work in Scotland is coordinated by the same body delivering the programme, the support is likely to be more accessible.

ENABLE Scotland is seeking to influence this as the Scotland Bill progresses. However, as the intention at this stage is not to devolve this part of employment support we would urge the Committee to seek clarity as to how the devolved and reserved elements of employment support would work together to ensure the best employment outcomes for disabled people.

Furthermore we would suggest the Committee examine how devolved employment support programmes will intersect with reserved employment support matters, for example, conditionality of Job Seekers Allowance (JSA) and Employment Support Allowance (ESA) which will continue to be assessed and implemented by the Department for Work and Pensions (DWP).

d) the Regulated Social Fund, new benefits, top-ups and delivery of benefits overall.

The Committee may wish to look at various models for the delivery of devolved benefits in Scotland. ENABLE Scotland would point to the Scottish Independent Living Fund as a model put in place to manage a newly devolved benefit. ENABLE Scotland supported the creation of a new Scottish body to deliver the Independent Living Fund as we recognised the positive aspects that this would bring to the lives of our members. We also welcomed the approach taken to the creation of this body, involving disabled people, in keeping with
the recommendations of the Christie Commission, that public services are designed with and for people who actually use the services and are not imposed upon them in a ‘top down’ approach.

Irrespective of the chosen delivery structure ENABLE Scotland would emphasise that devolution of these benefits creates a strong opportunity to create a cultural shift in the delivery of benefits. It is necessary that this culture moves from one of mistrust where claims must be scrutinised to prevent misuse of public funds to one that recognises the fact that the vast majority of claimants are making genuine claims for benefits that they are entitled to.

ENABLE Scotland would put that the risk of denying or delaying genuine claims is more significant than the risk that a small number of claimants may receive a small amount of (recoverable) payments that they may not be entitled to.

We would also highlight that the welfare system is an extremely complex system. Devolution of some benefits but not all, has the potential to increase this complexity, and therefore people need to be properly supported to ensure they are not disadvantaged. ENABLE Scotland wish to see those delivering benefits properly trained and supported to ensure high accuracy of decision making and customer service. All staff including decision making staff should be equipped with the skills to recognise where someone needs extra support negotiating the welfare system; and make appropriate referrals to advocacy or welfare advice services rather than issuing a negative decision at first instance.

Alongside this, ENABLE Scotland would urge that a properly funded advice sector, including specialist provision, is fundamental to deliver impartial advice and support to claimants as required.

We would like to take this opportunity to share findings of new research by ENABLE Scotland with the Committee. Our research evidences the difficult journey parents of children who have learning disabilities go through, not only navigating the complexities of the welfare system, but also being confronted by upsetting deficit-focused forms and processes.

Claiming DLA is difficult - the forms are horrendous and it is so upsetting having to justify every bit of support your child needs and having to write in minute detail all the things your child can’t do. Then feeling you are viewed as a waster for claiming financial support for your child. (Parent of child with genetic condition and associated learning disability)

Someone from the local authority came to fill out the DLA claim form - she was very insensitive and handed me a leaflet on my child's condition and asked me to “tick” what's wrong with her from the list. (Parent of child with learning disabilities and genetic disorder)

ENABLE Scotland would like to see the welfare system reframed to look more positively at disability in terms of, ‘what the person can do with support’ and how benefits payments

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ENABLE Scotland, Exploring Concerns around a Child’s Diagnosis of a Learning Disability (including ASD): Experiences of Parents, Young People and Professionals in Scotland, 2015 (to be published)
could support participation and remove barriers. Notwithstanding, we recognise that it is difficult to design a disability claim process that is not deficit focused. We are however clear in our opinion that these parents experiences could have been greatly improved with proper support through the claim process to help them understand why they were being asked these questions. Parents and individuals should feel reassured that this is money that they are entitled to and that can be used to improve their or their child’s life.