

FINANCE COMMITTEE

DRAFT BUDGET 2014-15

JOINT RESPONSE FROM THE INDEPENDENT LIVING IN SCOTLAND PROJECT AND INCLUSION SCOTLAND

Summary of our response

1. Context

- One in five adults in Scotland are disabled. They are experiencing increasing significant disadvantage. This cuts across a number of the national outcomes and indicators within the National Performance Framework.
- The NPF as it stands, is not a suitable means of capturing performance or influencing change in relation to disabled people put simply, relating 'real life' to the strategic indicators and outcomes as set out in it is difficult.
- The principles and practices of independent living as defined by disabled people themselves and set out in 'Our Shared Vision for Independent Living in Scotland' support delivery of the Scottish Government's overarching purpose. They do this by promoting an understanding of disability equality that ensures policy and practice protects the human rights of disabled people that will in turn ensure their equal contribution to a flourishing Scotland. Disabled people cannot "flourish" in Scotland, and the Government cannot meet its targets, without an understanding of this; of the need for practical assistance and support to live an ordinary life and to enjoy their human rights as others do.

2. Recommendations

- All spending decisions and thus the Government's economic policy, should be directly aligned to the social policy of Government to ensure the Government can meet its targets and, the policies of and obligations to the equality, human rights and independent living of disabled people, become a reality. A human rights based approach to decision making can support this. We recommend that all future Government spending decisions, including mainstream policies not specifically relating to disabled people, are taken with this at their heart.
- Independent living and how it relates to human rights and the participation of disabled people in society is not readily understood. We recommend that decision makers use the ILiS guide to coproduction, to work with disabled people locally and nationally. This will help them to understand how their indicators and outcomes – and thus policies and practices towards them – relate to disabled people.
- We recommend that DPOs are supported and funded to work in collaboration with policy and decision makers locally and nationally – including to speak out when things go wrong and that this support is sustained.
- We recommend that efforts and resources are directed to those services run by and for disabled people.

- We recommend that a separate, unique forum, run by and for disabled people – with a similar role to the Third Sector Interface – be developed and supported in each LA in Scotland to feed into the Community Planning structures.
- We recommend that – in coproduction with this network of DPO's – a set of sub-indicators specifically highlighting what would need to happen to make 'x' indicator work for disabled people be developed in coproduction with disabled people; e.g. 'reduce the proportion of individuals living in poverty' underpinned by a statement around what contributes to the poverty of disabled people specifically.
- We do not believe you can achieve equality by seeking to support one disempowered group, at the expense of disempowering another.
- Social care is in crisis in Scotland; the elastic in the money for it has snapped, disabled people's needs are unmet and they, along with social work staff, are struggling to manage the daily stresses that this causes. Given its fundamental role in promoting, protecting and supporting the human rights of disabled people; we believe it is fundamentally unfair that users of community care should be asked to pay towards it. We recommend that the Scottish Government work with LAs to make social care free at the point of delivery.
- We recommend that LA's be required to gather data to fill gaps in their knowledge around the 'real costs of social care', and that to do this, they must record unmet need on the basis of a broad, human rights based approach to social care
- We recommend that the Scottish Government, COSLA and others – in coproduction with disabled people – consider and publically set out, quickly, what they plan to do to address the crisis in funding for social care in Scotland.

Introduction

3. The Independent Living in Scotland (ILiS www.ilis.co.uk) project aims to support disabled people in Scotland to have their voices heard and to build the disabled people's Independent Living Movement (ILM). It is funded by the Scottish Government Equality Unit to make the strategic interventions that will help to make independent living the reality for disabled people in Scotland and hosted by Inclusion Scotland.

4. Inclusion Scotland is a network of disabled peoples' organisations and individual disabled people. Inclusion Scotland's main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people's everyday lives and to encourage a wider understanding of those issues throughout Scotland. It is a consortium of Disabled People's Organisations and is steered by Disabled People's Organisations (DPO's). DPO's are organisations led by and for disabled people. You can find out more about them in the ILiS publication "It's Our World Too", available at www.ilis.co.uk.

5. Both ILiS and Inclusion Scotland are part of a wider Independent Living Programme in Scotland. This programme seeks to make independent living a reality for disabled people in Scotland. The Scottish Government, CoSLA, NHS Scotland and the Independent Living Movement have shared aspirations for independent living. These are set out in the "Our Shared Vision for Independent Living in Scotland"¹.

¹ <http://www.scotland.gov.uk/Publications/2013/04/8699>

6. **Independent Living means:** “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not 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**” (definition developed by disabled people, adopted by the partners in the Independent Living Programme – the NHS, The Scottish Government and COSLA, and set out the vision for independent living).

7. For many disabled people, this practical assistance and support (such as access to the environment, advocacy, personal assistance, income, and equal opportunities for employment), underpinned by the principles of independent living, **freedom, choice, dignity and control**, is essential for them to “flourish”; to exercise their rights and duties of citizenship, via their full and equal participation in the civic and economic life of Scotland.

8. The role independent living plays in protecting the human rights of disabled people in this way, is recognised and underpinned by international human rights and equalities obligations to which the UK and Scotland are party to; including the recognition that all of the rights outlined in the European Convention on Human Rights (ECHR) and Human Rights legislation belong to disabled people, and that these are further strengthened and contextualised by the rights set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

9. How we spend our money in Scotland is key to making obligations, policies and aspirations such as these become the reality. We therefore welcome the opportunity to comment as part of the committee’s scrutiny of the draft budget.

Independent living and the National Performance Framework

10. The Scottish Government’s purpose; “to focus Government and public services on creating a more successful country, with opportunities for all of Scotland to flourish”² is welcome. So too is the outcome that in Scotland, we will have “tackled all significant inequalities in Scottish society”. **Independent living as defined by disabled people and set out in the Vision for Independent Living, supports this purpose and the outcomes that underpin it.**

11. The UNCRPD recognises that when human rights are enjoyed equally by disabled people, then they can play their part in contributing to society in ways that will result in “significant advances in the human, social and economic development of society [including] the eradication of poverty”³. All these things align with the intentions of the NPF.

12. The UNCRPD recognises further – in Article 19 – independent living and the essential role of “practical assistance and support” in ensuring disabled people can “participate in society and lead an ordinary life”.

² www.scotlandperforms.com

³ United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); ratified in the UK in 2009

13. Thus **the principles and practises of independent living promote an understanding of disability equality that ensures policy and practise protects the human rights of disabled people that will in turn ensure their equal contribution to a flourishing Scotland.**

14. Without such practical assistance and support, many disabled people cannot; enjoy the human rights they are entitled to⁴ on an equal basis to others, live free from discrimination and harassment as the Equality Act 2010 promotes, nor contribute to a wealthier and fairer, healthier, safer and stronger, smarter and greener Scotland⁵.

15. **Put simply, disabled people cannot “flourish” in Scotland, without the practical assistance and support to do so.** That is why the Government’s commitments and obligations to disabled people’s equality and human rights, and to independent living, are so important.

16. Our response is predicated on this; on the definition and understanding of independent living and on how it relates to the equality and human rights of disabled people, as set out above.

17. **We believe that all spending decisions and thus the Government’s economic policy should be directly aligned to the Government’s own social policy and that a human rights based approach supports this. Only then can the policies of and obligations to the equality, human rights and independent living of disabled people become a reality.**

18. We refer the Government to the Human Rights based approach of the PANEL principles⁶. The principles and practices of independent living fit within this framework and we recommend it as a tool to help ensure spending decisions and economic policy are aligned to social policy and human rights.

19. **We recommend that all future Government spending decisions are taken with this at their heart.**

20. The remainder of this response highlights some of the specific challenges to this so far, and details how the economic policy of Government could better support the outcomes of independent living and human rights for disabled people.

21. **The reality**

a) **Comment on general progress being made in relation to any specific indicator or target in the NPF**

One in five adults in Scotland are disabled. They are experiencing increasing significant disadvantage⁷. This cuts across a number of the national outcomes and indicators within the National Performance Framework.

⁴ ILiS; “ILiS Response to the JCHR Inquiry into the Implementation of Article 19 of the UNCRPD”, 2011

⁵ ILiS; “Response to the SDS Strategy in Scotland”, 2010

⁶ SHRC; “Why Scotland needs a National Action Plan for Human Rights”, 2012

⁷ EHRC & the Office for Public Management; “Significant inequalities in Scotland:

22. Fairer and greener: participation, solidarity and poverty

- when the extra costs of being disabled are taken into account, 47.5% of families with disabled people in the household, live in poverty⁸
- disabled people are more likely to live in fuel poverty (33% compared to 23% of non-disabled people)⁹
- people who have experienced homelessness are more likely to be disabled¹⁰
- disabled people constitute only 6% of formal volunteers and around 4.3% of public appointments (compared to 20% of the population at large)¹¹
- 74% of disabled adults experienced restrictions in using transport compared with 58% of non-disabled adults¹²
- Only 42% of disabled people claim to have equal access to justice and 44% report barriers in accessing justice¹³

23. Healthier

- disabled people experience significant health inequalities in Scotland:
 - only 39% of disabled people, compared to 92% of non-disabled people, say they are in good health
 - disabled people have poorer mental health than non-disabled people
 - disabled people have poorer dental health than non-disabled people
 - people with learning disabilities live 20 years less on average than the general population¹⁴
- there are significant levels of unmet needs within the Social Care system¹⁵:
 - Some LA's cannot afford to provide overnight support, instead they may offer a 'visit' or incontinence pads. This limits what disabled people can do between 8pm and 8am, is undignified and unsuitable¹⁶
 - "I was told that, even although I need help to pull my pants down and to get on the toilet during the day, I couldn't get help to do this at night because that would mean I was getting the same amount of support as someone 'much more disabled' than me"
 - "My care was cut. I cant go out and see family and friends any more. All I have time to do is get up, eat and go to bed"
 - "in my LA area they only allow 2 baths a week"¹⁷
 - 87% of councils in England and Wales have set eligibility at a higher level for 2013/4¹⁸ (n.b. via the SDS strategy, CoSLA and others are planning a questionnaire to gather specific data in Scotland – but, given similarities in

Identifying significant inequalities and priorities for action", 2010

⁸ "Destination Unknown"; Demos report, 2010

⁹ Scottish Government; "Disability Evidence Review", 2013

¹⁰ Macpherson, S. and Bond, S.(2009) *Equality issues in Scotland: a review of research, 2000-08*. EHRC.

¹¹ DRC (2006) Disability Agenda "Increasing Participation & Active Citizenship"

¹² The Life Opportunities Survey"; Office of National Statistics, 2010

¹³ "1 in 4 Poll"; Capability Scotland 2009

¹⁴ Scottish Government; "the Keys to Life: learning disability strategy"; 2013

¹⁵ <http://www.ageuk.org.uk/professional-resources-home/public-affairs/reportage/past-issues-of-reportage/reportage-february-2012/viewpoint-is-there-a-gap-in-social-care-funding/>

¹⁶ ILiS engagement with Lothian Centre for Inclusive Living

¹⁷ ILiS, various engagement with disabled people, 2012/13

¹⁸ <http://www.scope.org.uk/news/massive-economic-benefits-providing-social-care-disabled-people>

policies, demand and supply figures, and data; it is fair to assume similar figures will emerge from Scotland)

24. **Wealthier and smarter: productivity and employability**

- 46.9% of disabled people are in work, compared to 71% non-disabled adults¹⁹
- by the age of 26, young disabled people are more than three times as likely as other young people to agree with the statement “whatever I do has no real effect on what happens to me”²⁰
- disabled people are less likely to have a degree and more likely to have no qualifications than non-disabled people²¹ (23% of disabled people have no qualifications compared to 9% of non-disabled people²²)
- disabled people take up less than 0.5% of all apprenticeship places²³
- people with Additional Support Needs (ASN) of any description, are almost twice as likely to be NEET than those without ASN²⁴

N.b. It should be noted that for many specific groups, e.g. people with learning disabilities and mental ill health, the stats can be much more extreme.

25. The circumstances outlined above represent significant challenges for Scotland. Undoubtedly there are pockets of progress, but for disabled people, there is a chasm between their experience and the aspirations set out in the NPF. Unless they are addressed, disabled people cannot enjoy – nor contribute to – a wealthier and fairer, smarter, healthier, safer and stronger and greened Scotland. Furthermore, **the Government will not hit its targets if it does not take action to address this. It is neither just nor economic sense to continue in this way; to pay high costs to keep disabled people dependent rather than enabling them to participate in and contribute to society.**

26. **Changing the reality – delivering on the purpose of Government**

a) Are the national indicators and purpose targets an effective means of measuring the performance of government?

27. Whilst there is much rhetoric addressing the realisation of the national outcomes for disabled people in Scotland; including policies such as Keys to Life, the National SDS Strategy, the shared Vision for Independent Living; the reality is clearly different from the aspiration. For this reason **we believe that the NPF as it is just now, has shown itself unable to bridge the gap between rhetoric and aspiration, for disabled people in Scotland.**

28. The relationship between independent living, equality and human rights and the participation in and contribution to society, of disabled people, is not always

¹⁹ Annual Population Survey, 2010

²⁰ Burchardt (2005) ‘The education and employment of disabled young people: frustrated ambition’

²¹ Scottish Government; “Disability Evidence Review”, 2013

²² Office for National Statistics (2009) “Labour Force Survey, Jan - March 2009”

²³ EHRC; “Modern Apprenticeships. Equality and the Economy: spreading the benefits”, 2013

²⁴ Scottish Government; “Summary statistics for attainment, leaver destinations and healthy living, No. 3: 2013 Edition - Attainment and Leaver Destinations”; 2013

understood. Furthermore, independent living means different things to different people, at different times and in different arenas. This makes it difficult to identify indicators of and measures for progress in this arena.

29. We note that the indicators used to measure progress²⁵ are relevant for all people including disabled people. However, the harsh realities noted above mean that policy and decision makers do not readily understand how these relate to disabled people in their day to day lives.

30. Without this understanding, and not knowing what success should look like makes it difficult for policy and decision makers to ensure that their progress towards the national outcomes and indicators take account of and progresses the rights of disabled people.

Coproduction

31. Yet despite this, the voice of disabled people continues to be under-represented in public policy and decision making²⁶:

“We have stopped hearing from disabled people...[we are having] abstract theoretical discussions and not [talking about] how we make sure that a grown man who is not incontinent isn’t given pads because we can’t afford to get somebody into his home to enable him to use the toilet...We are missing those issues if we talk at this level...We assume that we have the laws, therefore it’s fine”²⁷

32. This is particularly disappointing because hearing and understanding real life stories and examples directly from disabled people can help policy and decision makers understand the reality and what needs to change, in an efficient and compelling way.

33. However, **relating ‘real life’ to the strategic indicators and outcomes as set out in the NPF, is difficult – disabled people do not necessarily live their lives – nor conceptualise them – in such apportioned ways.**

34. Disabled People’s Organisations (DPO’s) and coproduction can help with this. DPO’s support disabled people to have their voices heard and to influence local and national decision making:

“Glasgow Disability Alliance (GDA www.glasgowdisabilityalliance.org) understands that by nurturing people to share their experiences networks widen, understanding of rights increases and individual abilities develop. People are revitalised through this informal mentoring system.”²⁸

35. Through their work, DPO’s support the capacity of disabled people to engage collectively with decision makers to make change happen. Recent examples include; round table advisory sessions between DPO’s and the Health and Sport Committee on the SDS Bill; direct work with the Adult Support Team in the Scottish Government

²⁵ <http://www.improvementservice.org.uk/local-outcome-indicators/>

²⁶ ILiS; “Ready for Action”, 2009

²⁷ ILiS; “Report of the Solutions Series: implementation of Article 19 of the UNCRPD in Scotland”, 2013

²⁸ External Evaluation of Glasgow disability Alliance

on the future of the ILF; work with COSLA on welfare reform; evidence in Geneva on the implementation of the UNCRPD in Scotland and so on. Further, a recent report by the House of Commons Public Accounts Committee found that, within the first 14 months of the Workfare operation, of the 104,000 people taken off incapacity benefit, the programme only placed 3.7% in a job lasting more than three months. Contrast these figures with those provided by the user-led (DPO) Glasgow Centre for Inclusive Living. At the termination of its ESF funded “Professional Careers Service”; of those assisted to find traineeships within local social housing associations; 82.4% gained full-time employment; 94.1% gained an academic qualification; and 11.7% went into further education²⁹.

36. ILiS has published a guide to coproduction to help with this; “All Together Now”, available on www.ilis.co.uk. **We recommend that decision makers use this tool kit to work with disabled people. This will help them to understand how their indicators and outcomes – and thus policies and practices towards them – relate to disabled people. It will also enable disabled people, as coproduction partners, to grow their understanding of how policies and practises evolve.**

37. However, we note that despite their essential contribution to policy making, and in particular in ensuring that policy and practise progresses Scotland’s aspiration to tackle significant inequality – many Disabled People’s Organisations, e.g. advocacy organisations are losing their funding³⁰. This is primarily due to a tendency by decision makers to fund front line or life and limb provision, at the expense of empowering disabled people to contribute to a flourishing and inclusive Scotland

Localism

38. The difficulties disabled people face in influencing and monitoring the national outcomes, are compounded with a focus on localism.

39. We acknowledge that ‘legitimate’ localism creates opportunities for local communities to decide on solutions best suited to them however, there is little effort made to ensure disabled people can engage meaningfully in local decision making. In an environment of under-resourced community engagement with disabled people and their organisations, and where the strongest pockets of capacity are national; ensuring disabled people in all localities across Scotland are included, resourced and supported to engage meaningfully is a significant challenge which needs to be addressed.

40. We note that Third Sector Interfaces (TSI) are set up to support local people, through local organisations, to input to local decision making. However, they are representative of the whole of the third sector locally. This means that those with seldom heard voices – such as disabled people and their community based organisations – rarely get a seat at the TSI table, or their voices are overshadowed. The result is that they cannot bring their specific issues to these key decision making forums.

²⁹ House of Commons Committee of Pubic Accounts “DWP: work programme outcomes.” Thirty-third Report of Session 2012-13” <http://www.publications.parliament.uk/pa/cm201213/cmselect/cmpubacc/936/936.pdf>

³⁰ “Thriving or Surviving”; Disability Lib, 2008

41. A focus on local decision making has resulted in clear variances in how the rights of disabled people are enjoyed, alongside the progression towards national outcomes across Scotland. In this sense, localism has come head to head with the human rights of disabled people. This is particularly so, when decisions and actions are not ‘co-produced’ with disabled people.

42. One such example includes the experiences of disabled people who use social care services. Decisions on this e.g. eligibility, charging, provision and so on, are made locally. The result is inconsistency in provision, a post-code lottery and severe impediments to moving from one Local Authority area to another (e.g. to take up employment). Details of this are widely reported, including in ILiS’s response to the Joint Committee on Human Rights available on <http://www.ilis.co.uk/independent-living-policy/consultation-responses>.

43. In addition to the inconsistencies and difficulties in exerting influence locally, disabled people tell us that they do not know where to turn when things go wrong or when they want to influence things, and it is not clear who is accountable for what (please see the ILiS response to the Scottish Government’s strategy for Self Directed Support for an example of this)³¹. This lack of clear accountability means disabled people are denied remedy and access to justice in relation to their rights. This is further compounded by the limited access to the justice system itself, as outlined above.

44. **We recommend that DPO’s are supported and funded to work in collaboration with policy and decision makers locally and nationally – including to speak out when things go wrong.** This would mean they can support disabled people to contribute to policy and practise in Scotland. This will help decision and policy makers in setting and monitoring outcomes (including those as part of the NPF and in the Single Outcome Agreements).

45. **We suggest that a separate, unique forum, run by and for disabled people – with a similar role to the Third Sector Interface – be developed and supported in each LA in Scotland.** We believe that such a forum would enable and empower some disabled people to develop skills and confidence to go on to participate in other Third Sector forums as well other policy and service development arenas where their voice and influence is sadly lacking.

46. **We further recommend that – in coproduction with this network of DPO’s – a set of sub-indicators specifically highlighting what would need to happen to make ‘x’ indicator work for disabled people be developed in coproduction with disabled people; e.g. ‘reduce the proportion of individuals living in poverty’ underpinned by a statement around what contributes to the poverty of disabled people specifically.**

b) Links between performance information and the Scottish Government’s spending priorities

³¹ <http://www.ilis.co.uk/get-active/independent-living-policy/ilis-consultation-responses/>

47. In addition to our recommendations above on the need to align public spending with social policy objectives and obligations (2.7) – and our recommendations on how to help make this happen through the NPF/SOAs (4a – 4.1 – 4.19) – we offer comment on one overarching theme in the Government’s economic policy – that of equity – and on one specific area of public spending – social care.

Equity

48. Our drive for is for an equal society; where all of Scotland’s people can enjoy equally the human rights they have and participate, on an equal basis, in our society. As we set out above, for this to be the case for disabled people, they may need practical assistance and support.

49. However, we do not believe that the concept of ‘equitable distribution of resources’ achieves this.

50. For some disabled people, this means losing some or all of the support they have, so that another disabled person can get the some of the support that they need. When money needs to be found to meet new demands or unmet needs, it is often taken from within the same budget – or a budget with a similar purpose. In other words, budget decisions are based on the maxim: ‘rob Peter to pay Paul’. We recognise that to an extent, much of public spending could arguably be accused of the same. However, in the case of disabled people (a protected group in Equality Legislation) it is unfair to support disabled people by reducing support to another disabled person, rather than from the whole of society’s resources.

51. This is seen most clearly in social care – which is provided on the basis of National Eligibility Criteria and not universally available as the NHS is. Many cash strapped LAs are seeking to ‘top slice’ those people who have some social care (it is worth noting that, as a result of the operation of ‘high level eligibility criteria’³², this care is rarely enough to meet their rights to participation e.g. to meet friends, to take part in voluntary activity and so on) in order to release some funds to meet the needs of those who have none, or very little i.e. below even that required to meet the sort of life and limb criteria operating.

52. We also draw the Committee’s attention to the provision of cycle lanes – but note that similar arguments could be made around other areas of public spending. We support the purpose and understand the value and benefits of these. However, they are funded from resources from the whole of the local community. Social care also benefits all of Scotland’s people by ensuring all its citizens can contribute equally – when appropriate support to do so is in place – is funded only from a discrete, finite resource and where this resource gets stretched, disabled people pick up the short fall. They pick this up either in their pockets – by paying higher charges for it – or in their wellbeing and human rights – by doing without.

53. We note that the Government has duties to promote the equality of disabled people, set out in the Equality Act 2010. In addition it is widely understood that, for

³²<http://www.scotland.gov.uk/Topics/Health/Support-Social-Care/Support/Older-People/Free-Personal-Nursing-Care/Guidance>

disabled people to have equal opportunity, they should not always be treated the same, sometimes they need to be treated differently – e.g. some disabled people need extra money to live, just so that they have an income somewhere close to that of their non-disabled peers (as recognised in the benefits system e.g. enhanced payments for disabled people, on top of Universal Credit). This situation is explained by the Nobel Prize winner in economics, Professor Amartya Sen. He highlights that disabled people have two major economic ‘handicaps’. The first is ‘income handicap’ which results in the majority of disabled people having less money than their non-disabled counterparts. The second is ‘conversion handicap’. Here disabled people often need to spend more – or to have more spent on them – to achieve the same ‘goods’ or outcomes as their non-disabled peers. Equitable resource allocation among disabled people misses this nuance³³.

54. We do not think you can achieve equality by seeking to support one disempowered group, at the expense of disempowering another.

Social care

55. We have already outlined the importance of personal assistance and support for disabled people, above. However, as we have alluded at above, **social care is in crisis in Scotland^{34 35}; the elastic in money for social care has snapped, disabled people’s needs are unmet³⁶ and they, along with social work staff, are struggling to manage the daily stresses that this causes³⁷.**

56. Demand, and therefore the funding required for, residential and home care for adults is set to increase at around three times the rate anticipated for NHS services³⁸, and with the Independent Living Fund (ILF) closed, this money is no longer available to ‘top up’ LA provision.

57. To date there have been two responses to the gap between supply and demand of community care – one has been to raise thresholds for accessing services i.e. to provide care and support for only those with critical support needs; and the other has been to charge the people who are receiving the services, to pay more for them. Neither of these approaches recognises the value of social care for human rights – nor the poverty experienced by users of it.

58. Whilst every £1 spent on preventative and community services generates benefits to people, carers, local and central Government worth an average of at least £1.30³⁹, LA’s are focussing on life and limb/crisis intervention – they are not providing the preventative, low level support disabled people need. This not only represents an inefficient use of public resource that will lead to an increase in

³³ Wiebke Kuklys; "Amartya Sen's Capability Approach: Theoretical Insights and Empirical Applications," Springer, Berlin 2005

³⁴ <http://www.unison-scotland.org.uk/stuc2009/7.html>

³⁵ <http://www.communitycare.co.uk/articles/28/01/2011/116193/cuts-are-ravaging-personalisation-say-social-workers.htm>

³⁶ <http://www.ageuk.org.uk/professional-resources-home/public-affairs/reportage/past-issues-of-reportage/reportage-february-2012/viewpoint-is-there-a-gap-in-social-care-funding/>

³⁷ <http://www.unison-scotland.org.uk/stuc2009/7.html>

³⁸ Prof David Bell (2012:19), *Fiscal Sustainability: Issues for the Finance Committee Work Programme 2012*

³⁹ <http://www.scope.org.uk/news/massive-economic-benefits-providing-social-care-disabled-people>

demand over time, but leaves unacceptable levels of gaps in provision of social care⁴⁰ and ultimately, in Scotland's collective progression on the NPF.

59. Further, charges for community care only contribute 2.2% (approx. £50m) of the cost of social care⁴¹, they cost individual disabled people up to 100% of their income⁴². Only 38% of the revenue collected from charging goes back into paying for social care services⁴³.

60. Given the above points, it is fundamentally unfair that users of community care should be asked to pay towards it.

61. This crisis is compounded by the fact that we do not readily and effectively record 'unmet need' in Scotland – and what understanding we do have, is based largely on need that falls outwith the operation of high level eligibility and not 'needs' or rights to support to participate in society and lead an ordinary life. This means that LA's are operating on an incomplete picture and cannot therefore fully understand the true scale of the issue in their area. In turn this means they cannot set a budget for social care appropriately, nor highlight to the Scottish Government why they may need more money to meet demand in this respect.

62. Lastly, the integration of health and social care, whilst welcome in terms of the seamless provision it could result in, generates a timely conversation around the future of funding social care. Integrated budgets will bring together 2 systems of entitlements – one free at the point of delivery and universally available, and the other chargeable at present and provided on the basis of eligibility criteria. Whilst in practise the budget will be integrated, in reality, arbitrary lines on support for the wellbeing of our nation will still be drawn in order to consider who should access what and whether it is free at the point of delivery or not.

63. Given the complexities and challenges outlined, we **recommend that LA's be required to gather data to fill gaps in their knowledge around the 'real costs of social care', and that to do this, they must record unmet need on the basis of a broad, human rights based approach to social care** (especially important just now, given that LA's and health boards will shortly be determining their respective contributions to the integrated budgets as part of health and social care integration, we suggest that this is a priority).

64. We recommend that the Scottish Government work with LA's to make social care free at the point of delivery.

65. We further **recommend that the Scottish Government, COSLA and others – in coproduction with disabled people – consider and publically set out, quickly, what they plan to do to address the crisis in funding for social care in Scotland.**

⁴⁰ <http://www.scope.org.uk/news/massive-economic-benefits-providing-social-care-disabled-people>

⁴¹ LFR3 analysis, ADSW, 2010

⁴² Care charging league, Learning Disability Alliance, 2013

⁴³ In control, 2012