Article 19 – Living independently and being included in the community

Summary

1. The evaluation of Article 19, ‘Living Independently and being included in the Community’ has been extensive. The evaluation of Article 19, will in many instances, assist in the evaluation of other economic, social and cultural rights iterated within the UNCRPD, as the fulfillment of this right greatly assists or facilitates the fulfillment of rights, including civil and political rights. The following provides an overview of the evaluation:

An Independent Living Strategy

i. The absence of a single and holistic independent living strategy in Northern Ireland, an approach that is contrary to those adopted in Great Britain, is a severe and limiting factor for the progressive realisation of Article 19, and the other economic, social and cultural rights of disabled people associated with Article 19.

ii. The Disability Strategy should be used to formulate a sister / or cascading strategy on independent living. An independent living strategy could draw together the existing strategies and commitments identified within the review of health and social care with strategies and programmes on housing, transport and those of other policy areas to provide a truly joined up and integrated approach to the promotion and implementation of independent living in Northern Ireland.

iii. The Northern Ireland Government should provide a clear statement on Independent Living in Northern Ireland. The PSI Report recommended that the Northern Ireland Executive should undertake a review of “Independent Living” and place Independent Living at the centre of its focus on Disability Issues. Considering the clear linkage between the findings and recommendations on ‘Independent Living’, and ‘Choice and Control’ as set out within the PSI Report and Strategic Priority 7 as outlined within the draft Disability Strategy, this evaluation would expect an indication upon the status of the proposed review of independent living.
iv. A free standing legislative right to independent living should be implemented in Northern Ireland.

**Personalisation of Services**


vi. However, prior to the publication of these documents, there was a limited use, or an absence, of the terms ‘personalisation’ or ‘self-directed support’ by the State Party in Northern Ireland. As such, the Northern Ireland Government did not place, and / or was reluctant to place ‘personalisation’ and ‘self-directed support’ at the centre of its legislative, strategic, policy and service delivery. This is despite the terms being used within recommendations concerning ‘Choice and Control’ within the PSI Report (2009) and in the Independent Living Strategy (2008) in Great Britain. This constituted a fundamental failure by the State Party in Northern Ireland to “promote respect for their [disabled peoples] inherent dignity” (Article 1), and a failure to embrace the general principle that “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (Article 3).

vii. The Northern Ireland Government should recognise that the inherent dignity of a person is related to the level of choice and control that that person can exert. It should recognise that the personalisation of services, including self-directed support, should not be confined simply to the provision of health and social care. Rather, it should be extended across all policy areas supporting independent living by disabled people in Northern Ireland.

viii. In exploring the feasibility of introducing provisions equivalent to those within Part 2 of the Welfare Reform Act 2009, an action stemming from the Physical and Sensory Disability Strategy and Action Plan, the Northern Ireland Government should consider recognising that the provisions for financial support under the Part 2 of the Act in Great Britain are considerably wider, for example covering
education, training and employment, than those associated with health and social care and those identified within the Strategy and Action Plan.

ix. The Northern Ireland Government, and / or the public authorities may be subject to challenge in domestic courts, or at the ECtHR, under the Human Rights Act 1998, or ECHR, not only in respect to existing and proposed policies and provisions within health and social care, but within other policy areas supporting independent living by disabled people in Northern Ireland. Particularly, if the personalisation of services and self-directed support are limited to the policy areas identified within the Physical and Sensory Disability Strategy and Action Plan rather than those identified under Part 2 of the Welfare Reform Act 2009.

x. The Northern Ireland Government should monitor and actively promote the innovative practices of Health and Social Care Trusts which employ personalisation and self-directed support effectively to mitigate the impact of spending cuts. The Northern Ireland Government should monitor the extent to which choice and control is being diminished or increased by the roll out of personal / individual budgets, and take action if the goal of increasing choice and control is not being realised.

*Transforming Your Care*

xi. This evaluation welcomes the recognition and use of the term ‘personalisation’ within a Northern Ireland Government strategy. However, the recognition of personalisation has come late to the Northern Ireland Government, and as such, the administration has a lot of catching up to do with the other jurisdictions within the United Kingdom.

xii. This evaluation is heartened that Transforming Your Care recognises that personalisation, independence and control are at the heart of the Review and for those with a physical disability, and that at the core of independence and personalisation is a recovery model of care which assumes that people with a mental health problem can be treated and, with appropriate support, retain full control of their lives.
xiii. This evaluation welcomes the Transforming Your Care proposal for a regional approach to the provision of self-directed support, and individual / personal budgets, including Direct Payments.

xiv. However, this evaluation sees no evidence of a pledge to develop targets for each Transforming Your Care commitment associated with personalisation, self-directed support, or the uptake of Direct Payments. The DHSSPS, in adopting a regional approach, should undertake the development of challenging, but realistic targets, for the uptake of Direct Payments, and Individual / Personal Budgets (when implemented) to assist in the provision of self-direct support for all disabled people.

*Physical and Sensory Disability Strategy and Action Plan*

xv. In respect to the implementation of provisions in Northern Ireland that are equivalent to those within Part 2 of the Welfare Reform Act 2009, this evaluation would argue that there are no significant differences, legislatively or administratively, to warrant a negative outcome to the proposed feasibility study as outlined within the Physical and Sensory Disability Strategy and Action Plan.

xvi. In stating the above, it is recognises that the provision of Direct Payments, a primary means of facilitating the personalisation agenda, is administered through local authorities in Great Britain, whereas in Northern Ireland it is currently done so through local Health and Social Care Trusts. As the Transforming Your Care has committed to a regional approach to the provision of self-directed support and individual / personal budgets, similar arrangements to those associated with Direct Payments could be put in place for personalisation and self-directed support.

xvii. This evaluation would strongly argue, as are the arrangements in Great Britain, that all payments for the provision of self-directed support are administered through local authorities in Northern Ireland. The rationale for this position is based upon the recognition that the provision of financial support under the Part 2 of the Welfare Reform Act 2009 in Great Britain is considerably wider, for example covering education, training and employment, than those
associated with health and social care, and those highlighted within the Physical and Sensory Disability Strategy and Action Plan, and as such, provides better adherence to a 'social model' of disability and compliance with UNCRPD.

xviii. Unfortunately, in Northern Ireland, local authorities are still subject to a local government reform programme which has still to meet fruition. Furthermore, the contiguity of the greater number of local authorities, with the five Health and Social Care Heath Trusts in Northern Ireland could effectively act against a regional approach to personalisation and self-directed support as there would be greater scope for inconsistencies to arise across the administrative regimes of the local authorities. Therefore, this evaluation reluctantly supports the regional implementation of self-directed support, and individual / personal budgets, through the Health and Social Care Trusts, as they may be better placed to administer the payments etc in a consistent manner.

xix. The Physical and Sensory Disability Strategy and Action Plan commits “To enhance access to information, advice and advocacy for patients, clients, families and carers with a view to increasing independence for people with disabilities” delivered through a series of actions, assisted by those to provide a skilled workforce. This evaluation considers that this commitment, if implemented effectively, will meet the recommendation within the PSI Report that, “Relevant Departments should determine and address the skills and development needs required both to support the public and staff in developing approaches toward expanded self-directed support and safeguarding”. This evaluation recommends that there is a clear timescale related to the provision of training. This evaluation recommends that the DHSSPS monitors and evaluates the effectiveness of its training.

xx. This evaluation welcomes the DHSSPS commitment to convene a ‘Disabled Strategy Implementation Group’ to co-ordinate implementation of the Action Plan. This Group will help promote participation in public life, pursuant to the DHSSPS disability duties under the DDA 1996 and in furtherance of Article 29. This evaluation considers the effective implementation, including the active involvement of disabled people and their representative organisations, and
use of the ‘Disabled Strategy Implementation Group’ will assist the State Party in meetings its obligation under Article 4.3. To date, and with many of the Action Plan’s deliverables due in 2012, this evaluation regrettably finds no evidence that this Group has been formed or convened.

xxi. The DHSSPS has made considerable step by recognising the deficiencies within its monitoring and data provision. This evaluation recommends that full and effective monitoring and data promulgation by the DHSSPS is implemented as soon as feasibly possible to further assist it in meeting its obligations under Article 31.

Direct Payments

xxii. Amendments to the appropriate legislative provisions should take place to allow Direct Payments to be made to a carer of someone with mental ill health or others with mental capacity issues.

xxiii. The Independent Living Fund(s) are closed. This evaluation questions whether consideration by the United Kingdom and Northern Ireland Governments has been given to the how the closure of the ILF will affect disabled people moving to Direct Payments and Personal Payments after 2015.

xxiv. The Northern Ireland Government needs to consider whether the current and proposed arrangements, and timelines, for the provision of Direct Payments and the proposed future arrangements in regard to self-directed support and individual / personal payments, will be in place when the Independent Living Fund ceases in 2015. Furthermore, the Northern Ireland Government will need to determine whether the payments under self-directed support will be comparable to those from the Independent Living Fund, for those currently in receipt of the Fund.

Institutional Care

xxv. This evaluation is disappointed to see that again and again the target date for resettlement of patients with learning disabilities has been further delayed. This evaluation recognises that appropriate facilities have to put in place to assist people with learning disabilities move into the community as identified in the Transforming Your Care.
However, this evaluation would argue that the simple recognition by the DHSSPS, in the setting of its first target date for resettlement in 2002, it would have long since initiated activities to assist those with learning disabilities to resettled back into the community. In short, a delay of 13 years for the closure of long stay institutions in Northern Ireland is a clear indication that the Northern Ireland Government is failing to progressively realise the right and obligations contained in Article 19 in this regard.

**Housing, Transport and Legislative Reform**

xxvi. The Equality Commission has been calling for urgent legislative reform of the disability equality legislation in Northern Ireland; particularly in light of developments in Great Britain where the introduction of the Equality Act 2010 has meant that disabled people in Northern Ireland now have less protection against discrimination and harassment than disabled people in Great Britain. This evaluation recommends that reform to disability equality legislation be enacted without delay, in line with the Equality Commission’s recommendations.

xxvii. This evaluation recommends that the recommendations contained with the Equality Commission’s response to the Fourth Action Plan of the ATS are implemented.

**Structural Measures**

**Understanding Article 19**

2. Article 19 has been interpreted as a logical extension of the right to equal recognition before the law in Article 12 of the Convention, in the sense that recognition of legal capacity restores the “power of persons with disabilities to decide about their own lives, while the right to independent living paves the way for persons with disabilities to choose how to live their lives.”

3. Article 19 can be seen as “lex specialis”; a more specific or concrete expression of a general underlying norm when that norm

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is given effect in a particular context. In other words, it gives more specific meaning to the general rights to liberty and security of person (Article 14) and to private (Article 22) and family life (Article 23) in the particular context of disabled people and their living arrangements. Therefore, the elimination of living arrangements that segregate and isolate people with disabilities (e.g. institutionalisation), unless that choice is made by the disabled person, should be fulfilled.

4. In respect to the Article 19’s linkage to Article 12, 14, 22 and 23, this evaluation considers Articles 5, 8 and 14 of the European Convention on Human Rights (ECHR) and how these rights are given effect in domestic legislation through Human Rights Act 1998 (HRA 1998). In respect to the reporting these rights please refer to the relevant sections on the related articles.

5. Under Article 19 States Parties are required to ensure that people with disabilities are able to live in the community with accommodation options equal to others, and that these options support the inclusion and participation of people with disabilities in the life of the community. Article 19 requires that States ensure that disabled people have the opportunity to choose with whom they live on an equal basis with others.

6. In order to realise these freedoms, States Parties are obliged to ensure that disabled people have access to a range of support services that they may require in order to live freely in the community, and to avoid isolation and segregation from the community. The UNCRPD also requires that steps are taken to ensure that mainstream community services and facilities must be available to disabled people on an equal basis with others and responsive to their needs.

7. Under Article 19, the right to live independently and be included in the community is a mixture of civil and political, economic, social and cultural rights. The JCHR clearly outlines the legal obligations placed upon the State Party under Article 19:

- Article 19(a) concerns self-determination, a recognisable civil and political right. However, its realisation is strongly

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dependent upon the availability of options, as envisaged by Article 19(b).

- Article 19(b) confers economic, social and cultural rights, and upon access to mainstream community services and facilities as envisaged by Article 19(c).
- Ensuring equal access to and responsiveness of community services and facilities in turn depends upon measures to combat disability discrimination, including reasonable adjustments in the context of goods, facilities and services (also see Article 5).

8. Different types of rights impose different legal obligations. Therefore, compliance with the obligations imposed by Article 19 requires the State Party to take a variety of different actions and measures. Again, the JCHR⁴ provides us with direction:

- Article 19 (a) implies rights to self-determination in relation to matters affecting where and with whom a disabled person lives and the means by which disabled people are involved in decisions affecting them. This suggests a need for legal and/or administrative mechanisms which protect and promote choice and control regarding where and with whom disabled people live.
- Article 19 (b) appears to recognise social and economic rights of disabled people and as such obliges a contracting State to “take measures to the maximum of its available resources with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law”⁵.
- Article 19 (c) is more in the nature of a civil and political right to non-discrimination in relation to accessing goods and services, including the duty to make reasonable accommodations, legislative measures for which are required with immediate effect, but which in practice (such as in relation to making premises accessible) may take time to be realised in practice.

9. Finally, the JCHR remind us that:

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⁵ Article 4(2) of UNCRPD
“The precise nature of these legal obligations must always be borne in mind when considering the extent to which the UK has implemented the right to independent living and when making recommendations about the sorts of action which the State should be taking in order to fulfil its treaty obligations in that respect.”

Process Measures

**Defining Independent Living**

10. In 2002, the Disability Rights Commission (DRC) originally proposed a definition, of which the Government has adopted, of independent living:

   “All disabled people having the same choice, control and freedom as any other citizen—at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations”.

11. This evaluation recognises the work the Joint Committee on Human Rights (JCHR) has undertaken in regard to independent living in both its inquiry and reports on:

   - ‘A Life Like Any Other? Human Rights of Adults with Learning Disabilities’;
   - ‘Implementation of the Right of Disabled People to Independent Living’.

12. In recognising the work of the JCHR, it worth quoting the following:

   “Independent living is as relevant to people living in residential care as it is to someone living in their own home, and as relevant

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to people with significant cognitive impairments as to a university graduate.\textsuperscript{10}

13. In ‘A Life Like Any Other? Human Rights of Adults with Learning Disabilities’, the JCHR supported the independent living as a basis for Government policy, explaining that, as concept, it was important that independent living did not mean leaving people without support:

“When we refer to independent living, we refer to the Disability Rights Commission interpretation, which promotes choice and autonomy for people with disabilities in their daily lives. This may mean different things for different people. It should not be confused with situations where people with learning disabilities have been moved to supported living in the community without adequate support. One of the first things that we learned in this inquiry was that a ‘one size fits all approach’ was not appropriate.

We consider that the principles of independent living and promoting the participation of disabled people in community life are core themes of the UN Disability Rights Convention. It has a clear basis in other human rights standards and principles, such as freedom, equality and autonomy.”\textsuperscript{11}

14. In the ‘Implementation of the Right of Disabled People to Independent Living’, the JCHR states that:

“Independent living, in short, is freedom for disabled people. Individual freedom has long been cherished by our common law tradition. The Disabilities Convention simply recognises that for some people positive steps have to be taken in order to secure that freedom.”\textsuperscript{12}

15. To understand how the right to independent living has been fulfilled in Northern Ireland, this evaluation benchmarks Northern


Ireland legislation, policies and programmes against those established within the rest of the United Kingdom.

**Great Britain**

16. The United Kingdom’s Initial State Party Report\(^{13}\) states that:

“The UK’s approach to independent living goes well beyond the right as described in Article 19 and encompasses increasing choice and control, removing barriers and inclusion in the community. This approach underpins the rights set out in many of the other articles of the Convention. It lies behind a number of policies that are in place or are being developed.”\(^{14}\)

17. The Initial State Party Report outlines three broad areas associated with independent living:

- ‘Choice and Control’;
- ‘Removing Barriers’; and
- ‘Inclusion in our Communities’.

18. In regard to ‘Choice and Control’, the United Kingdom Government reports that in England the ‘Independent Living Strategy’\(^{15}\) sets out actions to improve the choice and control disabled people have over the services they need to live their daily lives as part of the community, through the provision of ‘Personal Budgets’, where individuals control the money appointed to them by their local authority. Currently, there are seven pilot schemes which give the ‘Right to Control’ which provide a legal entitlement for disabled people to choose how they use the money available to them from six separate funding streams covering housing, employment and personal care. Similar pilot schemes give disabled people more choice and control over the funding spent on their health care\(^{16}\).

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19. The Second Annual Report of Independent Living Scrutiny Group\(^{17}\) highlighted three key areas that impacted on disabled people over the year 2010-11, both positively and negatively. In short, the Scrutiny Group found that:

- The use of Direct Payments and Personal Budgets has really made a difference and has provided greater choice and control for disabled people. It is therefore important the drive to personalisation must continue.
- The impacts of the funding cuts and benefit reforms are causing real concern for Disabled people. The concern centred on fears about the impact of spending cuts, reform of the welfare benefits system and changes to social care.
- Communication is essential. The more disabled people know about the help that is available and how to access it, the more it will help them to have choice and control. There is a need for much more and much better (more accessible) communication about what currently exists to help disabled people and what is planned for the future.

20. In respect to the ‘Right to Control’ pilot schemes, the Scrutiny Group wondered “whether there is enough equality monitoring on how personal budgets are being used (including in new ways) to improve outcomes and if personalised support is equally available to all groups.”\(^{18}\)

21. In respect to ‘Removing Barriers’\(^{19}\), the United Kingdom Government is taking forward policies such as:

- Work Programme (see section on Article 27 regarding employment schemes in Northern Ireland); and
- Education Green Paper ‘Support and aspiration: A new approach to special educational needs and disability’ (see section on Article 24 regarding special educational needs and disability in Northern Ireland);


• Welfare Reform Bill (including Universal Credit) (see section on Article 28 regarding the provision of social protection).

22. The United Kingdom Government also reports that it supports disabled people to live in their own homes, through the provision of several funding programmes, such as the ‘Supporting People’ programme. Such programmes work with individuals to help them gain the skills to live more independently. Furthermore, the ‘Disabled Facilities Grant’ is a mandatory grant that helps to fund provision of adaptations that enable disabled people to live as comfortably and independently as possible.

23. The United Kingdom’s Initial State Party Report also reports that “home ownership and assured tenancies have to be matched and co-ordinate with a package of care specifically designed to support the individual in the home of their choice.” The Scrutiny Group observed that “a number of concerns people have for example that all too often the only accessible housing that is available is in deprived high-crime areas. People also expressed concerns about such things as poor street lighting and transport links and the lack of visibility of the Police.”

24. The United Kingdom’s Initial State Party Report also states that disabled people may choose to live in residential homes. The report also states that care homes are registered with the Care Quality Commission under the Care Standards Act 2000.

25. In respect to the ‘Inclusion in our Communities’, the Initial State Party Report refers to the Localism Bill, primarily for England, which will introduce a range of measures to devolve more powers back to individuals, communities and councils. The report states

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20 Department for Communities and Local Government Website on Housing for older and disadvantaged people: [http://www.communities.gov.uk/housing/housingolderpeople/](http://www.communities.gov.uk/housing/housingolderpeople/)

21 Department for Communities and Local Government Website on Housing for older and disadvantaged people: [http://www.communities.gov.uk/housing/housingolderpeople/](http://www.communities.gov.uk/housing/housingolderpeople/)


that disabled people need more support to fully participate in local decision making (see section on Article 29 regarding public participation in Northern Ireland). The United Kingdom’s Initial State Party Report further states that overarching legislation like the Public Sector Equality Duty encourages public authorities to create policies and services that reflect the advice of disabled people (see section on Article 4 regarding the participation of disabled people in decision making processes in Northern Ireland).

**Northern Ireland Executives Contribution to The United Kingdom’s Initial State Party Report**

26. In respect to Northern Ireland, the United Kingdom’s Initial State Party Report states:

“In Northern Ireland the Supporting People programme provides a range of services, including advice and guidance, to enable disabled people and others with support needs to live as independently as possible. It helps to deliver the Northern Ireland Supporting People Strategies 2005/10 and 2010/15, the PSI Homelessness Strategy and the Bamford Review of Mental Health and Learning Disability and Ageing in an Inclusive Society. The new Physical and Sensory Disability Strategy 2011/15, developed in accordance with the Convention, builds on this work with the intention of creating a society in which disabled people are encouraged and enabled to overcome barriers in their lives.”

27. And

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26 Please note the footnotes associated with the United Kingdom’s Initial State Party Report and the Northern Ireland Executive’s contribution to the Initial Report were inserted for this evaluation.


28 Please note, that the Northern Ireland Housing Executive website states “In January 2012, Department for Social Development asked that finalisation of the new strategy be postponed pending the outcome of the review of the Supporting People Commissioning Body” [http://www.nihe.gov.uk/supporting_people_strategy](http://www.nihe.gov.uk/supporting_people_strategy)


31 ‘Bamford Review of Mental Health and Learning Disability.’ (Northern Ireland) [http://www.dhsspsni.gov.uk/index/bamford/published-reports.htm](http://www.dhsspsni.gov.uk/index/bamford/published-reports.htm)

“In Northern Ireland a Strategic Action Plan (2009 / 11)\textsuperscript{33} was published in 2009 and a Regional Autistic Spectrum Disorder (ASD) Network Group\textsuperscript{34} was established. Through this Group, for the first time, individuals, parents, and carers have an unprecedented say in designing and planning services. The Network Group significantly improved waiting times and developed a Care Pathway for Children and Young People\textsuperscript{35} to bring consistency to autism assessment across the region. It has also begun to develop a diagnostic ASD service for adults.”

28. In addition to the information reported within the United Kingdom’s Initial State Party Report, the Northern Ireland contribution\textsuperscript{36} also states:

“The Executive has set a target that no-one will remain unnecessarily in hospital by 2013. A Regional Resettlement Team established to ensure the resettlement of those patients in long stay hospitals who have been deemed medically fit for resettlement. Patients and their representative groups and relevant voluntary organisations have membership of the Resettlement Team and significant opportunity to have their voice heard.

The Bamford Review of Mental Health and Learning Disability\textsuperscript{37} advocates that people with a mental illness should be treated in the community unless there are sound clinical reasons for not doing so. The Review also recommended that they should also have access to education, training, employment, housing and leisure activities enjoyed by the wider community. The aim is to ensure that people with a mental illness reach their full potential,


\textsuperscript{34}ASD Network http://www.hscboard.hscni.net/asdnetwork/index.html


\textsuperscript{36}‘United Nations Convention on Rights of Persons with Disabilities: (UNCRPD) - Northern Ireland Executive’s Contribution to the UK Government Report to the UN Committee’ (OFMDFM)(2011) http://www.ofmdfmni.gov.uk/executives_contribution_to_the_uk_government_report_to_the_united_nations_committee_-_amended.pdf

live as normal a life as possible and participate in the life of their communities.”

Report of the Promoting Social Inclusion Working Group on Disability

29. In 2003 the Office of the First Minister and deputy First Minister, established the ‘Promoting Social Inclusion Working Group on Disability’. This Group was given the task of identifying the main barriers to participation experienced by people with disabilities and to make recommendations on how these could be removed. In 2009, the ‘Report of the Promoting Social Inclusion Working Group on Disability’\(^\text{38}\) was published. The foreword states that:

“The Group’s conclusions and recommendations represent a culmination of a significant amount of work involving a major survey of people with an activity limiting disability [The Northern Ireland Survey of Activity Limitation and Disability]\(^\text{39}\), consultation with people with disabilities as well as the expert advice within the Group itself. The recommendations are also firmly anchored around the principles of the United Nations Convention on the Rights of Persons with Disabilities, which aim to promote dignity, independence and access.”\(^\text{40}\)

30. In 2011, the Independent Mechanism for Northern Ireland (IMNI) provided evidence to the Joint Committee on Human Rights (JCHR) inquiry into the ‘Implementation of the Right of Disabled People to Independent Living’. In it written evidence, it stated that:

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“...we are concerned that the PSI Report took five years to complete and although published in December 2009 it is still awaiting a formal response from Northern Ireland Executive.”

31. Although this evaluation notes that no formal response has been forthcoming from the Northern Ireland Executive, the Northern Ireland Executive is consulting on a draft Disability Strategy (see later) which is based upon some of the recommendations contained within the PRI Report.

32. In making recommendations contained within a section on ‘Choice and Control’, the PSI Report recognised that:

   “Although the recommendations proposed within this section of the report focus largely on direct payments and the concept of more individual control over social care packages, all five Subgroups identified choice and control as crucial underpinning themes to the report”

33. The PSI Report supports the statement by:

   “Choice and control are not only based on the ability of and opportunity for disabled people to control financial packages. These concepts run much deeper and call for a change in attitudes and approach – a change that recognises the rights of disabled people and supports them to empower themselves as individuals.”

34. The PSI Report provides five (5) recommendations, supported by evidence and evaluation, in regard to ‘Choice and control’. They are as follows:

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The Department of Health, Social Services and Public Safety should set more challenging targets for uptake of Direct Payments across all eligible groups;

The relevant Departments should consider options for widening the scope of Direct Payments within and beyond health and social care;

In addressing barriers to the uptake of Direct Payments, the Department of Health, Social Services and Public Safety should ensure that individuals have access to effective advocacy and good risk assessment and risk management processes;

The Department of Health, Social Services and Public Safety should ensure that the drive toward self-directed care is supported by proportionate safeguarding arrangements, having particular regard to the needs of younger people; and

Relevant Departments should determine and address the skills and development needs required both to support the public and staff in developing approaches toward expanded self-directed support and safeguarding.

35. In respect to its section on 'Independent Living' the PSI Report state:

"The concept of independent living is an important one for disabled people at all stages of their lives. The freedom and opportunity to make choices represents a doorway to real inclusion into society and recognition that disabled people can make important decisions about their own lives."\(^{45}\)

36. Importantly, the PSI Report states that:

"In further developing and promoting independent living, Departments here should mirror the work that has already been undertaken by the Office for Disability Issues\(^ {46}\) and work to develop a programme of awareness-raising in order to create support for an independent living approach across all sectors. It is vital that the ethos of independent living does not stop at the

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\(^{46}\) [Office for Disability Issues](http://odi.dwp.gov.uk/)
37. The PSI Report makes the following recommendations in respect to ‘Independent Living’:

- The Northern Ireland Executive should undertake a review of “Independent Living” and place Independent Living at the centre of its focus on Disability Issues. The review should identify practical and innovative ways to enable disabled people to live their lives the way they want to; and
- Government Departments should support activities that enable disabled people to live independently. Government must recognise the right to Independent Living by supporting or introducing legislation on this issue.

38. In respect of ‘Housing’, the PSI report makes the following recommendations:

- Increase funds for housing, floating support and Direct Payments and invest in supporting disabled people to access the housing and personal support they require to live independently;
- The Northern Ireland Housing Executive should develop and maintain a register of homes where disability adaptations have been undertaken as part of its role in undertaking adaptations to public sector dwellings and in the administration of Disabled Facilities Grant for private sector properties; and
- Disabled people should be provided with choice as to where they live and with whom. To do so, they need information on the options, comprehensive social care support from one

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50 Northern Ireland Housing Executive [http://www.nihe.gov.uk/index.htm](http://www.nihe.gov.uk/index.htm)

51 Disabled Facilities Grant [http://www.nihe.gov.uk/disabled_facilities_grant](http://www.nihe.gov.uk/disabled_facilities_grant)
single point of contact and appropriate housing, to enable them to live independent, autonomous lives in the community in a home of their own choice. This will require close working relationships between health and social care providers and housing agencies.

39. In respect of 'Transport', the PSI report makes the following recommendations\(^\text{52}\):

- Transport providers should be proactive in identifying and utilising new developments in technology to make transport more accessible for people with disabilities, for example through audio aids and electronic transmission of timetabling information;
- DRD [Department for Regional Development]\(^\text{53}\) should continue to consult both formally and informally on the Accessible Transport Strategy\(^\text{54}\), including the Action Plans\(^\text{55}\);
- In fulfilling its statutory ‘disability duty’ it is recommended that DRD, in conjunction with Translink\(^\text{56}\) (and other transport operators) continue to exploit technology where barriers persist and to reflect such positive action in Disability Action Plans;
- Policymakers and transport providers should mainstream disability considerations from an early stage in policy development and service provision to address the barriers that prevent people with disabilities from making successful journeys from the point of departure to destination;
- The Department for Regional Development should conduct a targeted publicity campaign to ensure that disabled people have access to and knowledge of the Concessionary fares scheme; and
- An inter-agency approach should be taken to ensure that disability considerations are factored into decisions regarding the planning, design and location of static street furniture.


\(^{53}\)Department for Regional Development [http://www.drdni.gov.uk/](http://www.drdni.gov.uk/)


\(^{56}\)Translink [http://www.translink.co.uk/](http://www.translink.co.uk/)
40. In respect of ‘Lifelong Learning, Sports, Arts and Cultural Activities’ and Attitudes\(^57\), the PSI report makes the following recommendations:

- A mapping exercise of support service provision, which enables people with disabilities to participate in lifelong learning, arts, sports and cultural activities, should be carried out and a centralised register or database of accredited / qualified operators (support workers e.g. trained note takers etc) should be set up and administered in response to this;
- Consideration should be given to re-establishing funds designated for enhanced disability access, based on the successful Accessibility Fund previously administered by Adapt NI\(^58\);
- Notions of lifelong learning should be extended beyond classroom based or qualification-orientated opportunities to recognise that supported employment experiences and involvement in Arts and Sports can be forms of lifelong learning; and
- People with disabilities should be supported to pursue volunteering opportunities through the provision of financial assistance with equipment, travel and communication.

**Draft Disability Strategy**

41. In March 2012, the Northern Ireland Executive published a draft Disability Strategy entitled, ‘A strategy to improve the lives of disabled people- 2012-2015’\(^59\). This three-year strategy sets out a series of priorities for improving the socio-economic position of disabled people in Northern Ireland.

42. The draft Disability Strategy has been shaped by the recommendations of the ‘Report of the Promoting Social Inclusion Working Group on Disability’ which Office of the First Minister and Deputy First Minister (OFMDFM) state is the most significant piece

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\(^58\) Adapt NI [http://www.adaptni.org/](http://www.adaptni.org/)

of work so far undertaken by the government in Northern Ireland in respect of disability. The executive summary states that:

“The recommendations in the PSI Report on Disability outline the actions required to address the identified inequalities experienced by people with disabilities and to tackle the barriers that disabled people continue to face in our society. The recommendations in that report have provided the rationale for many of the strategic priorities in this document.”

43. This evaluation will examine the recommendations made within the PSI Report against the commitments made within the draft Disability Strategy.

44. Strategic Priority 7 ‘Independent Living / Choice and Control’ states that it will:

“Increase the level of choice, control and freedom that people with disabilities have in their daily lives.”

45. In support of Strategic Priority 7, the draft Disability Strategy states:

“Many of the recommendations in the PSI Report relate directly to the concept of Independent Living which supports the social model of disability and advocates greater choice and control for disabled people. It recognises that in order for people with disabilities to live independent lives practical support, systems and resources are required.

Different policy areas have been identified that relate to many of the areas associated with independent living in the PSI Disability Report.

The Supporting People Programme currently funds a range of housing support services in over 900 schemes, providing support to approximately 15,000 service users at any one time. Services can range from provision of wardens in sheltered

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housing schemes, to housing related advice services, to capacity and confidence building on housing matters, thus enabling vulnerable people to secure or maintain a tenancy or remain in their own home. However, the Supporting People Programme is not an independent living programme. Independent living is about the ability to make choices about a wide range of issues such as housing, care, social activities and transport. Currently there is no widespread Independent Living Programme here encompassing all of these areas. We aim to get Executive departments to work together more effectively so we can develop more independent living programmes for people with disabilities.”

A Review of Independent Living and an Independent Living Strategy for Northern Ireland

46. The PSI Report recommended that the Northern Ireland Executive should undertake a review of “Independent Living” and place Independent Living at the centre of its focus on Disability Issues.

47. In 2011, the Independent Mechanism for Northern Ireland (IMNI) provided both written and oral evidence at hearing for the Joint Committee on Human Rights (JCHR) inquiry into the ‘Implementation of the Right of Disabled People to Independent Living. The Third-third Report of Session 2010-12 reports the evidence submitted by IMNI in regard to a review of independent living in Northern Ireland:

“Northern Ireland does not appear to have made progress on developing a strategy of its own. The independent mechanisms for Northern Ireland (Equality Commission for Northern Ireland and Northern Ireland Human Rights Commission) told us that the Promoting Social Inclusion Disability Working Group (PSI Working Group) reported to the NI Executive in December 2009 recommending that the NI Executive undertake a review of independent living and place it at the centre of its focus on disability issues. The NI Executive has not responded to this.”

48. In commenting on these reports, the JCHR states:

“We note with disappointment the lack so far of an equivalent strategy in Northern Ireland. It is regrettable that the Northern Ireland Executive has not yet responded to the proposals of the PSI Working Group made in 2009.” 64

49. In response to the JCHR comments the UK Governments response was simply:

“The Government notes the Committee’s points, which are for the devolved administrations in Northern Ireland, Scotland and Wales to consider.” 65

50. Understanding that there should be a clear linkage between the findings and recommendations on ‘Independent Living’, and ‘Choice and Control’ as set out within the PSI Report and Strategic Priority 7 as outlined within the draft Disability Strategy, this evaluation would expect an indication upon the status of the proposed review of independent living. Unfortunately, the Equality Commission in its response to the draft Disability Strategy had to state that:

“The Commission welcomes the inclusion of this Strategic Priority but is concerned that the current wording appears to stop short of proposing an inter-departmental strategy on independent living.” 66

51. The Commission continues by recommending:

“…that Government Departments work together to undertake a joined up and strategic approach to ensure effective delivery of independent living programmes.” 67

52. The PSI Report also recommended that Government Departments should support activities that enable disabled people to live

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independently and that it must recognise the right to Independent Living by supporting or introducing legislation on this issue.

53. In its response to the draft Disability Strategy, the Equality Commission raised the issue of a free standing legislative right to independent living, as iterated by the JCHR:

“Despite the UK having ratified the UNCRPD, independent living does not currently exist as a freestanding, justiciable right in UK law. This Report argues that the existing matrix of human rights, equality and community care law, while instrumental in the protection and promotion of the right to independent living, is not sufficient. The right to independent living should be added as an outcome in any forthcoming Bill on adult social care in England.

We also recommend that all interested parties, governmental and non-governmental, immediately start work on assessing the need for and feasibility of free-standing legislation to give more concrete effect in UK law to the right to independent living. The Government should publish their assessment of the need for and desirability of such legislation in the light of the forthcoming first report of the UN Committee on Disabilities.”

54. The JCHR recommended that the right to independent living should be added as an outcome in any Bill on adult social care in England. This evaluation would recommend the same consideration is given in Northern Ireland.

55. This evaluation recognises that ‘Independent Living’ constitutes the formulation and coordination of legislation, policies and programmes to enable disabled people to independently across a range of policy areas, such as housing, transport, and including those relating to ‘Choice and Control’.

56. In respect to fulfilling the right and obligations set down within Article 19, it can be argued that Northern Ireland, like that for the entire United Kingdom (and as iterated in the United Kingdom’s Initial State Party Report), has implemented independent living which goes well beyond the right as described in Article 19.

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57. However, this evaluation considers the absence of a single and holistic independent living strategy in Northern Ireland, an approach that is contrary to those adopted in Great Britain, as a severe and limiting factor for the progressive realisation of the economic, social and cultural rights of disabled people associated with Article 19.

58. This evaluation recommends that the Disability Strategy is used to formulate a sister strategy on independent living. An independent living strategy could draw together the existing strategies and commitments within the review of health and social care with strategies and programmes on housing, transport and other policy areas to provide a truly joined up and integrated approach to the promotion and implementation of independent living in Northern Ireland.

59. An independent living strategy should fully embrace the personalisation of services, currently being realised in health and social care, through self-directed support, and the effective and extensive promotion and uptake of Direct Payments, through their extension to other policy areas associated with independent living to facilitate increased choice and control for all aspects of disabled people’s lives in Northern Ireland.

60. An effective and coordinated independent living strategy, developed in adherence to Article 4.2, would not only assist the Northern Ireland Government in meeting its obligations to progressively realise the economic, social and cultural rights associated with independent living (under Article 19 and, for example, Articles 20, 25, 27, and 28) but it would further assist it in complying with the general principle under Article 3 of “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”.

61. In coming to this conclusion, this evaluation recognises the range of legislative and policy provisions currently in place, and being put in place, to promote and progressively realise the right to independent living, within health and social care, housing and transport. However, in the absence of an effective and integrated independent living strategy for Northern Ireland, and in respect to the commitment with the Disability Strategy to: "We aim to get Executive departments to work together more effectively so we

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69 See Article 4.2, UNCRPD.
can develop more independent living programmes for people with disabilities” ⁷⁰, this evaluation seeks to determine how the existing and currently planned changes to health and social care and housing provide for the progressive realisation of the right to independent living and being included in the community.

**Independent Living Fund**

62. The Independent Living Fund (ILF) was set up to enable disabled people to live independent lives in their community rather than in residential care. The ILF was established as a charitable trust.

63. Payments from the ILF can be used to pay a care agency or employ someone to provide personal and/or domestic care. In most cases, recipients must:

- get social services support worth at least £340 a week or £17,680 a year - this can include direct payments or services like going to a day centre
- get or be entitled to the highest rate care component of Disability Living Allowance
- have less than £23,250 in savings or capital - including any money of a partner of the recipient ⁷¹.

64. The amount a recipient obtains is based on the cost of the care needed, worked out on an hourly or weekly basis. The maximum amount the ILF awards a recipient will depend on when they applied to the fund. Recipients’ savings, income and certain other benefits and expenses also affect how much they receive. However, as ILF payments are used to pay for care, they are not counted as income, and do not affect the benefits of the recipient.

65. In 1992, the ILF was closed to new users and a new fund was created in 1993 to receive new applicants. In Great Britain, the National Health Service and Community Care Act 1990 imposed new responsibilities on local government. The new fund required applications to be made by local authorities, and required a

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⁷¹ NI Direct - The Independent Living Fund - an introduction
minimum local authority contribution of £200 per week to each user’s care package, the approximate cost of a place in residential care. In 1996, the Community Care Act 1996 made Direct Payments to service users by local authorities possible (see later). Access to Direct Payments was extended to a range of groups of services users over the following years, and legislation in 2001 created a legal duty on local authorities to offer a Direct Payment to anyone eligible for community care services.

66. In light of policy developments across the social care landscape, DWP commissioned an independent strategic review of the ILF in 200772. On 12th July 2012, the Department for Work and Pensions (DWP) commenced public consultation on the ‘Future of the Independent Living Fund’73. Within the document it states:

“The review noted that the ILF had played a significant role in the history of independent living and that its achievements over the previous 18 years had been important. But it concluded that, in the long run it would be highly anomalous to continue to administer a large amount of social care funding through a cash limited, discretionary fund administered by a board of trustees under a different set of rules and remits from the mainstream care and support system.”

67. The ILF was finally closed to new users in 2010.

68. The public consultation on the ‘Future of the Independent Living Fund’ seeks the views on the Government’s proposal as to how the 19,373 existing users of the ILF should have their care and support needs met from 2015, stating that:

“While the Government is fully committed to funding users’ care package up to 2015, we do not believe that the continued operation of the ILF as a legacy fund would be sustainable or justifiable.”

69. This evaluation questions whether consideration by the United Kingdom and Northern Ireland Governments has been given to the

how the closure of the ILF will affect disabled people moving to Direct Payments and Personal Payments after 2015. The current provision of Direct Payments in Northern Ireland will be considered below along with the proposed changes to health and social care which involve the promotion and use of Direct Payments. This evaluation initial asks if the current arrangements in the provision of Direct Payments and the proposed future arrangements will fully meet the needs of those currently in receipt of the ILF.

**Personalisation and Self-Directed Support**

71. In Great Britain, another means of supporting independent living is through the personalisation of services or ‘self-directed support’.

72. The rationale behind self-directed support is to give people real choice and control over the support they receive, as opposed to other people deciding for them. People can choose to be involved in the planning and organising their own support, or they can choose others to do it for them.

73. A central part of the personalisation agenda to give service users choice and control over their care and support are ‘Direct Payments’ and ‘Personal Budgets’.

74. Direct payments are cash payments given to service users in lieu of community care services they have been assessed as needing, and are intended to give users greater choice in their care. The payment must be sufficient to enable the service user to purchase services to meet their eligible needs, and must be spent on services that meet eligible needs.

75. Direct Payments confer responsibilities on recipients to decide how their eligible needs are met, either by employing people, often known as personal assistants, or by commissioning services for themselves. Service users can get support in fulfilling these responsibilities from direct payment support services commissioned by local authorities, often from user-led organisations. Like community care services, Direct Payments are means-tested so their value is dependent on a person's income and assets as well as their eligible needs.

76. Direct payments are available across the UK and to all client groups, including carers, disabled children and people who lack mental capacity. However, they cannot be used to purchase residential care or services provided directly by local authorities.
77. Personal Budgets are an allocation of funding given to users after an assessment which should be sufficient to meet their assessed needs. Users can either take their Personal Budget as a Direct Payment, or – while still choosing how their care needs are met and by whom – leave local authorities with the responsibility to commission the services. They can also take up a combination of the two.

78. One version of a local authority managed Personal Budget is an Individual Service Fund (ISF), under which the budget is held by a care provider but the service user can choose how some or all of it is spent. ISFs have been used to apply Personal Budgets to residential care.

79. As a result, Personal Budgets provide a potentially good option for people who do not want to take on the responsibilities of Direct Payments. Since 2008, Personal Budgets have been rolled out in England. Known as Individual Budgets\textsuperscript{74} in Scotland, they will be rolled out under its self-directed support strategy, which is being turned into legislation.

80. In 2012, the Equality Commission published ‘Disability programmes and policies: How does Northern Ireland measure up?’\textsuperscript{75}, this research concluded that:

> “This system (Self Directed Support) would appear to be in greater compliance with the UNCRPD than the system of direct payments as it increases the choice and control for the individual. The payments can be used to pay for anything, including a football season ticket provided that it meets the agreed aims drawn up at the start of the process.”\textsuperscript{76}

81. There is no national strategy in Northern Ireland for the implementation of self-directed support.


82. In examining the literature associated health and social care, including that on Direct Payments, in Northern Ireland, this evaluation concludes that there was a limited use, or an absence, of the terms ‘personalisation’ or ‘self-directed support’ prior to the publication of the consultation documents on the draft ‘Physical and Sensory Disability Strategy’\(^{77}\) by the Department of Health, Social Services and Public Health in 2010. On initial observation, this evaluation would argue that Northern Ireland Government did not place, and / or was reluctant to place personalisation and self-directed support at the centre of its legislative, strategic, policy and service delivery. This is despite the terms being used within the recommendations concerning ‘Choice and Control’ within the PSI Report (2009) and in the Independent Living Strategy (2008) in Great Britain.

83. However, this evaluation is pleased to report a project being undertaken in the Southern Health and Social Care Trust, in conjunction with ‘In Control’\(^{78}\) (see later). However, as this is a small scale project, it is likely to have limited impact, in extent, not only in the geography covered by that Trust, but across Northern Ireland. The project has be used to inform the recommendations and actions relating to a review of health and social care in Northern Ireland and the new Physical and Sensory Disability Strategy (please refer to the following section on “Review, Strategy and Action Plans for Health and Social Care”).

84. This evaluation recommends that the Northern Ireland Government should recognise that the inherent dignity of a person is related to the level of choice and control that that person can exert. Furthermore, the Northern Ireland Government should recognise that the personalisation of services, including self-directed support, should not be confined simply to the provision of health and social care, rather it should be extended across the all policy areas relating to the lives of disabled people in Northern Ireland.


\(^{78}\) In Control Website: [http://www.in-control.org.uk/](http://www.in-control.org.uk/)
85. This evaluation seeks to highlight the important messages provided in 'Personalisation and Human Rights: A Discussion Paper'\(^{79}\). In the discussion paper, the researchers examine the introduction of much greater “personalisation” within the health and social care services in Scotland, through the widespread implementation of the national strategy of self-directed support\(^{80}\). The discussion paper argues that:

“a current Scottish manifestation of “personalisation” – the national Self-Directed Support Strategy together with the associated legislation process – creates a solid platform to build on and should be implemented locally in such a way that the human rights principles lie at its core are clearly evident in the lives of individual men and women.”\(^{81}\)

86. Significantly, the discussion paper, makes the following observation:

“There is significant scope for the Convention [European Convention on Human Rights or ECHR] rights in the Human Rights Act [1998] to be better understood and applied more consistently to advance the personalisation agenda. As the European Court of Human Rights [ECtHR] has repeatedly stated “the very essence of the Convention [ECHR] is respect for human dignity and human freedom”\(^{82}\) and rights such as Article 8 [within the ECHR] extend to “aspects of an individual’s physical and social identity including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world”\(^{83}\)

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and


and


\(^{82}\) Pretty v UK (application no. 2346/02) Grand Chamber judgement of 29 April 2002, para 65


http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-60596

\(^{83}\) Evans v UK (application no. 6339/05) Grand Chamber judgement of 10 April 2007 at para 57

http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-80046; citing Pretty v UK (application
as well as “to conduct one’s life in a manner of one’s choosing.”

A personalised approach, centred on participation of the individual is necessary for the full realisation of these rights.

87. In 2010, as part of the Independent Mechanism for Northern Ireland, the Northern Ireland Human Rights Commission contracted a legal opinion regarding ‘Compliance of the Domestic Law of Northern Ireland with the UN Convention on the Rights of Persons with Disabilities: A Gap Analysis’. The legal opinion states that:

“Articles 19 and 20 UNCRPD provide plenty of scope for persons with disabilities who have been disappointed in public authority provision in relation to their social care arrangements to attack those failings.”

88. The author of the legal opinion further states that judicial review may limited success as the courts may be sympathetic to the current availability of resources, by stating:

“The provision of community social care arrangements will inevitably focus on the question of resourcing, and I would be careful to add that while Articles 19 and 20 UNCRPD could be used to strengthen a challenge in relation to the failure or refusal of an authority to provide a particular service or meet an identifiable need, I suspect that the Courts will be mindful of the budgetary constraints to which public authorities are subject. Indeed, there have already been examples of a tendency to overly sympathise with public authorities in their reliance on these sorts of argument in this regard in Great Britain.”

84 Pretty v UK (application no. 2346/02) Grand Chamber judgements of 29 April 2002, para 62.
86 For an example of judicial mindfulness of budgetary constraints vis-à-vis the provision of services to persons with disabilities see R (Domb) v Hammersmith and Fulham BC [2008] EWHC 3277 Admin per Harrison J and, affirming that judgement, the decision of the Court of Appeal [2009] EWCA 941. It is however worth noting the judgement of Sedley LJ, who in refusing the appeal, observed that “I do so with very considerable misgivings because the appeal itself has had to be conducted on a highly debatable premise—that the prior decision of the local authority that council tax was to be cut by 3%
approach of courts in Northern Ireland to the same issue is an area worth supervising closely.”

89. In respect to UNCRPD, this evaluation would argue that the mindset within the Northern Ireland Government prior to 2010 constituted a fundamental failure within its institutions in respect to the “promote[ion of] respect for their [disabled peoples] inherent dignity” (Article 1), and a failure to embrace the general principle that “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons” (Article 3).

90. Furthermore, in light of the comments of the ECtHR, the Northern Ireland Government may wish to consider its existing policies and provisions, and its current and planned policies and provisions, regarding its recognition of personalisation and self-directed support within this jurisdiction. The Northern Ireland Government, and/or the public authorities that constitute the State Party in Northern Ireland, may be subject to challenge in domestic courts, or at the ECtHR, under the Human Rights Act 1998, or ECHR, not only in respect to existing and proposed policies and provisions within health and social care, but within other policy areas targeted at supporting disabled people in Northern Ireland.

91. Before moving on to specific review, legislation, strategies, policies and programmes that may promote the progressive realisation of the right to independent living, it is worth considering evidence gathered by the JCHR in its report on ‘Implementation of the Right of Disabled People to Independent Living’ in regard to the personalisation of adult social care.

92. The JCHR states that:

“While personalisation has the potential to increase choice and control, and may lead to innovative methods of delivering services more efficiently, there is the potential that it might be
seen a means to delivering services more cheaply, but not necessarily as effectively as before.”

93. With the recommendation that:

“National and local government should monitor and actively promote the innovative practices of local authorities which employ personalisation effectively to mitigate the impact of spending cuts. The Government should monitor the extent to which choice and control is being diminished or increased by the roll out of personal budgets, and take action if the goal of increasing choice and control is not being realised.”

94. Therefore, this evaluation recommends that the Northern Ireland Government adopt the recommendations of the JCHR in respect to the personalisation of adult services in Northern Ireland.

_Reviews, Strategies, Action Plans and Projects that may Contribute to the Progressive Realisation of the Right to Independent Living_

95. This section examines current activity in Northern Ireland that may contribute to the progressive realisation of the right to independent living. These actions are highlighted by the following:

- Transforming Your Care: A Review of Health and Social Care in Northern Ireland;
- Transforming Your Care: Draft Strategic Implementation Plan;
- Physical and Sensory Disability Strategy and Action Plan (2012-2015); and
- Southern Health and Social Care Trust project on Self-Directed Support.

96. It is important for the reader to recognise that in the evaluation of the reviews, legislation, strategies, policies and programmes that

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89 ‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland.’ (December 2011) Department of Health, Social Services and Public Safety 
90 ‘Transforming Your Care: Draft Strategic Implementation Plan’ (June 2012)
http://www.dhsspsni.gov.uk/disability_strategy_draft_version_1_december_2010-3.pdf
may progressively realise the right to independent living in Northern Ireland, dialogue will take place throughout on the personalisation of services, self-direct support and Direct Payments, as many to the inter-related initiatives facilitate or propose their delivery.

**Transforming Your Care: A Review of Health and Social Care in Northern Ireland and the Draft Strategic Implementation Plan**

97. In December 2011, the HSC Board published the review of health and social care in Northern Ireland, ‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland’ (TYC). This was followed in June 2012 by the ‘Transforming Your Care: Draft Strategic Implementation Plan’ (SIP). The TYC and SIP outline how health and social care services, including those for disabled people, will be reformed in Northern Ireland.

98. The Department of Health, Social Services and Public Health (DHSSPS) has established a Whole System Planning approach to the planning and reform of health and social care. This encompasses the following:

- The new Public Health Strategy;\(^92\);
- The Quality 2020 Implementation Plan;\(^93\);
- The TYC Transformation Programme;\(^94\);
- Commissioning Plan(s) (including LCG Plans);\(^95\);
- Quality Improvements and Cost Reduction Plans;
- Trust Delivery Plans; and
- Infrastructure Development (Capital) Plans.

99. DHSSPS has devolved responsibility for many of the TYC outcomes to the HSC Board who will take the lead, working alongside the 5 local commissioning areas in delivery.

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\(^{95}\) See ‘Transforming Your Care: Draft Strategic Implementation Plan’ (June 2012) [http://www.dhsspsni.gov.uk/tyc-strategic-implementation-plan.pdf](http://www.dhsspsni.gov.uk/tyc-strategic-implementation-plan.pdf)
100. In total, the TYC made 99 recommendations. The SIP and the accompanying Populations Plans do not cover all aspects of the TYC proposals. The SIP also includes a number of existing strategies, including the implementation of the:

- DHSSPS ‘Physical and Sensory Disability Strategy and Action Plan (2012-2015)’; the

101. A specific regional work stream that will be a key vehicle for the delivery of the transformations set out in the Population Plans will be Integrated Care Partnerships (ICPs). These will evolve from the 17 Primary Care Partnerships and will be clinically led with GP carrying out a critical leadership role. The aim of the ICPs will be to ensure that services areas close to patients’ / users’ homes as possible, are personalised and seamless; empowering patients and promoting health and prevention of illness where possible.

102. In respect to this evaluation, the key TYC recommendations being acted upon within the SIP, and through ICPs are:

- Care to be provided as close to home as practical.
- Personalisation of care and more direct control, including financial control, over care for patients and carers.

103. This evaluation is heartened that the TYC states “Personalisation, independence and control are at the heart of the Review and for those with a physical disability.”

104. In regards to services for those with physical and sensory disabilities, the TYC highlights that the DHSSPS Physical and Sensory Disability Strategy for Northern Ireland is in the final

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stages of development and that it will formalise in policy terms the changes to the model of support for disabled people\textsuperscript{100}.

105. In respect to service for those using mental health services, the TYC states that, “At the core of independence and personalisation is a recovery model of care which assumes that people with a mental health problem can be treated and, with appropriate support, retain full control of their lives.” The TYC strongly endorses this approach\textsuperscript{101}.

106. The TYC key proposals in this area are:

- More control for service users over budgets, with continued promotion of Direct Payment, and a common approach to personalised budget with advocacy and brokerages support where required (for people with physical and sensory disabilities)\textsuperscript{102};
- Promote personalised care promoting the uptake of Direct Payments among mental health service users with involvement of current recipients to share their experiences, and advocacy and support where needed (for people with mental ill health)\textsuperscript{103}; and,
- Greater financial control in the organisation of services for individuals and carers, including promoting uptake of Direct Payments with involvements of current recipients to share their experiences, and advocacy and support were needed\textsuperscript{104}.

107. As can be seen above, for those using mental health, physically disability and learning disability service, within TYC, there is a strong emphasis on the inclusion of current recipients to share

their experiences, and the provision of advocacy and support were needed.  

108. In regard to Direct Payments which can be used to support personalisation and self-directed support for disabled people, this evaluation will discuss this issue separately under the ‘Direct Payments’ section.  

109. The SIP states for physical disability and mental ill health services respectively:

“In line with the personalised care agenda, the proportion of people with self directed and individual budgets will increase.”  

110. And

“In continuing to focus on personalised care of service users, increasing the uptake of self directed and individual budgets can be achieved with the involvement and support of carers.”

111. Within the SIP, a key regional programme emanating from TYC is the:

‘Implementation of a regional approach to the provision of self-directed support and individual budgets’

112. It states that,  

“The programme scope should include provision of self-directed support and individual budgets (if desired) to older people who need support and individuals with physical disabilities, learning disabilities or mental health issues. As a minimum, clear information on the financial package available should be given to those using the service.”

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106. ‘Transforming Your Care: Draft Strategic Implementation Plan.’ (June 2012). Page 34.  


108. ‘Transforming Your Care: Draft Strategic Implementation Plan.’ (June 2012). Page 42.  

113. After three years, the SIP commits to

“Increase uptake among older people, those with LTCs [Long Term Conditions] physical and learning disabilities of self-directed support and individual budgets.”

114. A commentary on the three year commitment within the SIP notes the omission to increase the uptake in those with mental health issues of self directed support and personalised budgets. It should also be noted that within the entire SIP, or the associated Population Plans, there are not set targets for the increase of self-directed support and individual / personal budgets. Without set targets it will hard to evaluate the impact of the SIP, Population Plan, and / or the Physical and Sensory Strategy, in respect to the uptake of self-directed support and Direct Payments.

115. In regards to monitoring, the SIP states that a successful collaborative approach to integrated monitoring of delivery will depend on small team with clear responsibilities for managing and monitoring delivery across local areas, regional workstreams and the TYC programme management office. The team will be a mechanism for information sharing, transparent monitoring and reporting of delivery performance to plan, and applying and refining the best common standards and approaches to programme delivery.

116. In respect to the assessment of impact, this will be done through the identification and monitoring of transformation programme benefits (quality and productivity) during 2012. Furthermore, the SIP makes a commitment to integrated transparent monitoring arrangements. It states that these will be established using existing mechanisms wherever possible, either regionally or locally, and co-ordinated in a regular systematic way across the programme management community. For each benefit, a means of measurement (indicator) will need to be confirmed together with a baseline measure and its means of application.

117. Importantly, this evaluation sees no evidence of a pledge to develop targets for each TYC commitment associated with

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personalisation, self-directed support, or the uptake of Direct Payments. Developing challenging but realistic targets, based upon known baseline data, for example in respect to the uptake of a particular service, is a crucial means, if not the only robust means, of measuring success. This is disappointing as the TYC provides data on the uptake of Direct Payments, for example, for those with physical disabilities. The commitments to implement

- the DHSSPS ‘Physical and Sensory Disability Strategy and Action Plan (2012-2015)\(^{113}\) and,
- a regional approach to the provision of self-directed support and individual budgets\(^{114}\)

should be providing targets based upon using this data.


118. In February 2012, the Department of Health, Social Services and Public Health published ‘Physical and Sensory Disability Strategy and Action Plan (2012-2015)\(^{115}\), whereby it states that:

> “It has been developed in accordance with the articles stated in the United Nations Convention on the Rights of Persons with Disabilities and therefore supports the values of dignity, respect, independence, choice, equality and anti-discrimination for disabled people.”\(^{116}\)

119. In ‘Providing Better Services to Support Independent Lives’ the Strategy describes how the Health and Social Care (HSC) can contribute to the provision of better services and support to help disabled people live independent lives. Importantly, the Strategy states that:

> “This strategy promotes the view that all services should be delivered within a “personalised” framework, and that therefore


there is a need to vigorously promote this approach in an attempt to reshape and modernise services.”

120. Furthermore, in regard to self-directed support, the Strategy states:

“This strategy supports the aim of providing support packages which are based around the person’s individual circumstances and which are chosen and controlled by them. It also acknowledges that there are lessons to be learned from the implementation of self directed support and individualised / personalised budgets in other parts of the UK and from pilot projects in NI.”

121. In ‘Section 3 – Providing Better Services to Support of the Independent Lives’ of the Action Plan outlines a series of recommendations along with actions, outcomes, responsibilities and timescales in respect to:

- Personalisation;
- Information, Advice and Advocacy;
- Provision of a Skilled Workforce;
- Equipment – Procurement and Standardisation;
- Rehabilitation;
- Respite / Short Break Care;
- Service Redesign;
- Transition Support and Planning;
- Day Opportunities;
- Housing; and
- Transport.

122. Here, this evaluation will limit its comments to personalisation, information, advice and advocacy and the provision of a skilled workforce.

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123. This evaluation welcomes the recognition and use of the term ‘personalisation’ within a Northern Ireland Government strategy. However, the recognition of personalisation has come late to the Northern Ireland government, and as such, the administration has a lot of catching up to do with the other jurisdictions within the United Kingdom.

124. The actions to implement the recommendation under the ‘Personalisation’ heading “To promote independent living options that afford people with disabilities the maximum possible choice and control over the services they receive” clearly demonstrate the Northern Ireland is running behind the rest of the United Kingdom in respect to the implementation of effective independent living for disabled people. This conclusion is evident as the DHSSPS will:

“Explore the feasibility of introducing in NI provisions equivalent to Part Two of the GB Welfare Reform Act 2009, “Disabled people: right to control provision of services” either through administrative means or by means of legislation.” by September 2012.”

125. In 2005, in Great Britain, the Prime Minister’s Strategy Unit published the report ‘Improving the Life Chances of Disabled People’. This report set out a cross-government strategy to improve disabled people’s opportunities and quality of life, with the commitment of achieving full equality for disabled people by 2025. The report recognised that disabled people are often expected to fit into an inflexible framework of service provision, rather than services being personalised to respond to individual need. Subsequent publications including the concordat ‘Putting People First’ (2007) and the ‘Independent Living Strategy’ (2008) have outlined commitments to creating a system that allows

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http://www.dhsspsni.gov.uk/disability_strategy__draft_version_1___december_2010-3.pdf


disabled people to have maximum choice and control over the support services they receive.

126. In Great Britain, the Welfare Reform Act 2009\textsuperscript{124} reformed the welfare and benefits systems to improve support and incentives for people to move from benefits into work and to provide greater choice and control for people with a disability. The Department for Social Development (DSD) introduced the Welfare Reform Act (Northern Ireland) 2010\textsuperscript{125}. Unfortunately, although it covered the majority of the provisions set out within the Welfare Reform Act 2009 it did not take forward the provisions within Part 2 of the Welfare Reform Act 2009\textsuperscript{126}.

127. Briefly, Part 2 of the Welfare Reform Act 2009 conferred regulation-making powers that can be used to give adult disabled people greater choice and control over the way in which relevant services, such as:

- the provision of further education
- facilitating the undertaking of further education or higher education;
- the provision of training
- securing employment
- facilitating continued employment;
- enabling disabled people to live independently or more independently in their homes;
- the provision of residential accommodation for disabled people;
- enabling disabled people to overcome barriers to participation in society.

are provided by relevant authorities, such as local authorities.

128. The DHSSPS recognises that “These are the provisions which would potentially have the biggest impact for this strategy and the Department will need to consider whether and how these provisions would be taken forward in NI. If introduced these

\textsuperscript{124} Welfare Reform Act 2009
\textsuperscript{125} Welfare Reform Act (Northern Ireland) 2010
http://www.dhsspsni.gov.uk/disability_strategy__draft_version_1__-december_2010-3.pdf
provisions could enable disabled people in NI to have more control over the way a range of services are provided to them."\textsuperscript{127}

129. This evaluation would argue that there are no significant differences in respect to both the legislative or administrative measures required to implement equivalent provisions, to those contained within Part 2 of the Welfare Reform Act 2009, between the jurisdictions in Great Britain and that of Northern Ireland to warrant a negative outcome to the proposed feasibility study.

130. This evaluation recognises that the provision of Direct Payments, a primary means of facilitating the personalisation agenda, is administered through local authorities in Great Britain, whereas in Northern Ireland it is currently done so through the local Health and Social Care Trusts. As the TYC has committed to a regional approach to the provision of self-directed support and individual budgets\textsuperscript{128}, similar arrangements to those associated with Direct Payment could be put in place for personalisation and self-directed support.

131. However, considering that UNCRPD is based upon a ‘social model’ of disability rather than a ‘medical model’ of disability, this evaluation would strongly argue that, as are the arrangements in Great Britain, all payments for the provision of self-directed support are administered through local authorities in Northern Ireland. The rationale for this position is based upon the recognition that the provision of financial support under the Part 2 of the Welfare Reform Act 2009 in Great Britain is considerably wider, for example covering education, training and employment, than those associated with health and social care, and those associated with ‘Improving Services and Support’ within the Strategy and Action Plan.

132. Unfortunately in Northern Ireland, local authorities are still subject to a local government reform programme which has still to meet fruition. Furthermore, the contiguity of the greater number of local authorities, with the five Health and Social Care Heath Trusts in Northern Ireland could effectively act against a regional approach to personalisation and self-directed support as there would be

http://www.dhsspsni.gov.uk/disability_strategy__draft_version_1__-december_2010-3.pdf

\textsuperscript{128} ‘Transforming Your Care: Draft Strategic Implementation Plan.’ (June 2012). Page 42.  
greater scope for inconsistencies to arise across the administrative regimes of the local authorities.

133. This evaluation would expect a positive outcome from the feasibility study to ensure that the following measure as outlined within the Strategy and Action Plan is implemented on time:

“Determine the feasibility of introducing self directed support / personalised / individualised budgets in NI which take account of the need for specialist support and lessons learned through their implementation in other parts of the UK.” by March 2013.129

134. Furthermore, the action associated with the recommendation “To commission more personalised services appropriate to the needs of individuals” states that “Person-centred planning will be adopted as mainstream practice & evidenced in person centred plans” will be implemented by April 2013.130 This evaluation would stress the importance of promptly progress of this action.

135. In regard to the recommendation to “To enhance access to information, advice and advocacy for patients, clients, families and carers with a view to increasing independence for people with disabilities.” again, the Action Plan provides a series of actions, assisted by those to provide a skilled workforce for completion by April 2013.131

136. In April 2011, The Equality Commission in response132 to the Strategy and Action Plan stated recommended that the DHSSPS should consider, in promotional campaigns, what actions are required to target the particular needs of disabled people with multiple identities through the provision of accessible information and advice, and consider targeting the particular needs of disabled women.

http://www.dhsspsni.gov.uk/disability_strategy_draft_version_1_-_december_2010-3.pdf
http://www.dhsspsni.gov.uk/disability_strategy_draft_version_1_-_december_2010-3.pdf
http://www.dhsspsni.gov.uk/disability_strategy_draft_version_1_-_december_2010-3.pdf
137. This evaluation notes that the actions related to the provision of training are without specified completion dates. This evaluation supports the Equality Commission recommendation that there is a clear timescale related to the provision of training. Furthermore, this evaluation supports the Equality Commission recommendation that the DHSSPS monitors and evaluates the effectiveness of its training. The Equality Commission states that the proposed actions are in line with Article 25. This evaluation agrees with this finding.

138. The Equality Commission also welcomes the DHSSPS commitment to convene a ‘Disabled Strategy Implementation Group’ to co-ordinated implementation of the action plan, as it will help promote participation in public life, pursuant to the DHSSPS disability duties under the DDA 1996 and in furtherance of Article 29. Furthermore, this evaluation considers the effective implementation and use of the Group assists the State Party in meetings its obligation under Article 4.3.

139. The DHSSPS states that:

“...particular difficulties with data within health and social care in terms of quantifying the overall response to need because of the variability in definition and comprehensiveness of information’ and that there is ‘very little official disability-specific data available to health and social care planners’. In addition, we note that the Department has indicated that there is an ‘absence of a comprehensive set of data in respect of children and young people with disabilities.’”\(^{133}\)

140. And that there is an

“...absence of a comprehensive set of data in respect of children and young people with disabilities.”\(^{134}\)

141. The Equality Commission recommended that the DHSSPS undertakes a comprehensive review of data collection in relation to disabled people with physical and sensory disabilities, including


\(^{134}\)
those with multiple identities, with a specified timescales to fill gaps where data is not available\textsuperscript{135}.

142. This evaluation would consider that the DHSSPS has made considerable step in recognising the deficiencies within it monitoring and data provision. Therefore, this evaluation recommends that full and effective monitoring and data promulgation by the DHSSPS is implemented as soon as feasibly possible to further assist it in meeting its obligations under Article 31.

\textit{Southern Health and Social Care Trust project on Self-Directed Support}

143. In its ‘Annual Progress Report on Section 75 of the NI Act 1998 and Section 49A of the Disability Discrimination Order (DDO) 2006’\textsuperscript{136} to the Equality Commission, the Southern Health and Social Care Trust reports that:

“A project has been developed to roll out Self Directed Supported to provide people with disabilities or care needs increase choice and control over their care arrangements regardless of their Section 75 grouping. Development of a resource allocation system provides an equitable way of allocating resources across programmes of care.”

144. This is a small scale project, piloted with 30 people\textsuperscript{137}, being started independently, conjunction with In Control, by the Southern Health and Social Care Trust. The project is entirely within the control of the Trust, and if successful will be promoted to the other Trusts\textsuperscript{138}. The research undertaken on behalf of the Equality Commission reports that:

“Within this system it is expected that choice will be maintained even in reduced resourcing. The scheme will however be subject to the legislative problems above if the person with the disability is unable to consent or the necessary legal structures are not put in place.”

145. In June 2012, The Southern Health and Social Care Trust produced a working draft, ‘Southern Health Economy-Population Plan ‘Changing for a Better Future’. This is a population plan to support the implementation of the review of health and social care in Northern Ireland, ‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland’.

146. In respect to a delivering service outcomes for older people (not disabled people), the Trust has a prioritised initiative to:

“Promote and enhance the use of Personalised Budgets, DS and Direct Payments for people to organise packages of care to help them to remain independent and provide choice control over their care (Will be subject to a resolution of issues raised by Judicial Review with respect to those with LD [Learning Disabilities])”

147. From this initiative the Trust will:

- Implement the recommendations of the evaluation and outcome of the local Self Directed Support;
- Increase in the number of people in receipt of a Direct Payment; and
- Increase in the range of options for care through partnership working with community / voluntary sector to provide viable alternatives to traditional mainstream services.

Direct Payments


up?" research it contracted out to Disability Action. In respect to Direct Payments, the research report outlines the legislative framework which facilitates independent living as principally:

- Carers and Direct Payments Act (Northern Ireland) 2002 (CDPA).
- Personal Social Services and Children’s Services (Direct Payments) Regulations (Northern Ireland) 2004;
- Chronically Sick and Disabled Persons Northern Ireland Act 1978; and

Direct Payments allow claimants to make more of the decisions that affect their lives and may help them to live more independently. Someone in receipt of Direct Payments can decide how their needs will be met, by whom and at what time. This effectively provides a level of choice and control to the individual. Direct Payments are provided by local Health and Social Care Trusts, unlike in Great Britain where they are provided by the local authority.

Direct Payments are available to:

- Disabled people over 16;
- Older people who receive services from the Trust;

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142 Disability Action – Home Page http://www.disabilityaction.org/
• Disabled parents;
• Parents of disabled children;
• Carers over 16 for services to meet their own needs;
• People affected by mental illness\textsuperscript{148}.

151. Trusts can only offer Direct Payments to claimants if they are satisfied that they are able and willing to manage Direct Payments, or with help if needed\textsuperscript{149}.

152. Direct Payments are not available for:

- health services, for example, community nursing, speech and language therapy, or chiropody; or
- services provided by other organisations such as the Northern Ireland Housing Executive\textsuperscript{150}.

153. A person in receipt of Direct Payments can still get payments from the Independent Living Funds. Furthermore, Direct Payments are ignored when working out entitlements to any income related social security benefits, such as Income Support, Job Seekers Allowance (income related), Tax Credits, Disability Working Allowance or Housing Benefit. Similarly, Direct Payments are ignored in child support maintenance calculations and are not considered as part of the recipients’ taxable income\textsuperscript{151}.

154. In providing a response to the draft Disability Strategy, the Equality Commission observed that:

“The Commission notes the observation of the Bamford Monitoring Group that whilst targets in relation to Direct Payments have been achieved these were set against a very low baseline. The Group also highlights the considerable variation in availability of Direct Payments across Trusts.”


areas and the need for more progress towards self-directed support and personal budgets.”

155. As discussed in “Personalisation and Self-Directed Support” within this evaluation, the Equality Commission has observed that further progress is needed to be made in respect to self-directed support and personal budgets. The TYC has identified that encouraging the uptake of Direct Payment has been a target for several years and mechanisms have been put in place to promote uptake and support people within managing their own budgets to purchase services or employ support directly.

156. The variation in availability of Direct Payments across Trust areas was indirectly picked up by the TYC, as it states:

“The Review was told that perceived bureaucracy and inconsistent promotion of Direct Payments have been constraining factors.”

157. The TYC advocates a regional approach to tackle the inconsistent promotion and bureaucracy affecting the uptake of Direct Payments. In regard to those with physical and sensory disabilities, the TYC states that:

“While the uptake of Direct Payments is growing, in particular among people with a physical disability, there is potential to grow this and other self-directed support approaches considerably within this group. Feedback from some indicates that bureaucracy is a barrier to uptake of Direct Payments and a regional approach is needed to tackle this issue and encourage greater uptake.”

158. Furthermore, for those with mental ill health, the TYC also proposes the regional approach to promote the uptake of Direct Payment should include the:

“…involvement of current recipients to share their experiences, and the provision of advocacy and support where needed should

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be considered. As a minimum, clear information on the financial package available should be given to those using the service.\textsuperscript{155}

159. This evaluation considers that this commitment, if implemented effectively, will meet the recommendation within the PSI Report that, “Relevant Departments should determine and address the skills and development needs required both to support the public and staff in developing approaches toward expanded self-directed support and safeguarding.”\textsuperscript{156}

160. Interestingly, the TYC provides no commentary regarding a regional approach for the promotion and uptake of those with learning disabilities. However, those with learning disabilities are included within the SIP regional programme to implement a regional approach to self-direct support and individual budgets.

161. An Equality Commission investigation has also identified that people with learning disabilities face serious challenges such as poor communication from healthcare staff, a lack of understanding of their health needs, and a lack of user friendly written information in accessible formats\textsuperscript{157}. Overcoming serious barriers such as these will be key to the effective uptake of self-directed support and Direct Payments by those with learning disabilities.

162. In 2010, as part of the Independent Mechanism for Northern Ireland, the Northern Ireland Human Rights Commission contracted a legal opinion regarding ‘Compliance of the Domestic Law of Northern Ireland with the UN Convention on the Rights of Persons with Disabilities: A Gap Analysis’\textsuperscript{158}. The legal opinion states that:

“Advocacy through the strategic use of Judicial Review proceedings by Law Centre (NI) to ensure that Health and Social Care Trusts meet their obligations toward persons with disabilities has been the most important weapon in the battle to ensure that needs in social care provision are effectively met.”\textsuperscript{159}

\begin{flushleft}
\textsuperscript{155} Transforming Your Care: A Review of Health and Social Care in Northern Ireland.’ (December 2011) Department of Health, Social Services and Public Safety. Page 91. \\
\url{http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf}
\textsuperscript{156} Section 75 Formal Investigation into the Accessibility of Health Information for People with a Learning Disability 2006-2008.’ Equality Commission for Northern Ireland, Belfast. \\
\url{www.equalityni.org/archive/tempdocs/LiteratureRev(f)I.doc}
\end{flushleft}
163. The legal opinion states that senior Health and Social Care Trust officials will often agree to put packages in place without the need for going to court, but not before proceedings are threatened and / or lodged. At the time of writing the legal opinion stated that a number of judicial review applications yet to be determined by the High Court in Northern Ireland will examine the extent to which the Trusts set up under the Health and Social Care (Reform) Act (Northern Ireland) 2009 adhere to their duties under the Carers and Direct Payments Act (Northern Ireland) 2002. The author notes that a particular focus of criticism in these proceedings will be the extent to which current departmental guidance (in force since March 2004) is compatible with the HRA 1998 and EHCR.

164. The research undertaken on behalf of the Equality Commission reports that the judgment in the judicial review regarding PF and JF v the Southern Eastern Health and Social Care Trust (2011) highlighted a legislative gap in Northern Ireland in respect to the consent requirement in Section 8 of the Carers and Direct Payments Act (Northern Ireland) 2002 which is required to lay a proper legal basis for a Direct Payments scheme entered into directly with a carer in the case of a person under mental disability.

165. The research highlights that in England, Section 146 of the Health and Social Care Act 2008 and the Community Care, Services for Carers and Children's Services (Direct Payments)(England) Regulations 2009 effectively avoided the problem to be found in

160 Practice Note: Judicial Review (revised 30 September 2008) and the annexed Pre-Action Protocol require parties to exchange correspondence prior to the commencement of proceedings in an effort to encourage the possibility of resolution at an early stage to avoid accrual of costs.
Section 8 of the Carers and Direct Payments Act (Northern Ireland) 2002 by amending Section 57 of the Health and Social Care Act 2001\textsuperscript{168} (the equivalent provision of Section 8). This amendment allowed for payments to a suitable representative of a patient with a disability which has deprived the disabled person with the power to consent. The judgement for the judicial review commented that it was:

“somewhat surprising that the Department in this jurisdiction was apparently unaware of the English amendment or the need to amend Section 8 to lay a proper legal basis for a direct payments scheme entered into directly with a carer in the case of a person with a mental disability”\textsuperscript{169}.

166. The research highlights that this judgement will affect a number of people currently on Direct Payments. It recommends that action should be taken by the authorities in Northern Ireland to apply for a controller to be appointed on their [a claimant / recipient of Direct Payments] behalf under Article 101(1) of the Mental Health (Northern Ireland) Order 1986\textsuperscript{170} where applicable or pass the necessary legislative amendment.

167. This evaluation also recommends that amendment to the appropriate legislative provisions takes place to allow Direct Payments to be made to a carer of someone with mental ill health or others with mental capacity issues.

\textit{Institutional Care}

168. At the time of drafting, the ‘Disability programmes and policies: How does Northern Ireland measure up?’, stated that:

“Northern Ireland lags behind the rest of the UK in the speed of change from institutional care to independent living.”\textsuperscript{171}

169. In March 2009, the Northern Ireland Audit Office reported that 256 patients remained in long-stay hospitals in Northern Ireland despite the DHSSPS setting a target in 1997 that all patients in long-stay learning disability hospitals would be resettled by 2002\textsuperscript{172}. This research undertaken on behalf of the Equality Commission further stated that the target has been revised repeatedly and is now set for 2013.

170. Indeed, as reported above, the additional information provided by the Northern Ireland contribution\textsuperscript{173} to, but not used by, the United Kingdom’s Initial State Party Report states:

“The Executive has set a target that no-one will remain unnecessarily in hospital by 2013.

171. In recognition that there are around 200 long-stay inpatients in learning disability hospitals, the TYC states:

“A critical element in changing the model of care and support for people with a learning disability is to end long-term residency in hospitals.”\textsuperscript{174}

172. The TYC recognises that those inpatients should be resettled into the community. It proposes to closing long stay institutions and to completing the resettlement process by 2015.

173. The TYC states that new community facilities are being developed for the assessment and treatment for people with learning disabilities which will support the resettlement programme. Here, the TYC outlined the Northern Ireland Housing Executive’s ‘Supporting People’ programme (see below).

174. This evaluation is disappointed to see that again and again the target date for resettlement of patients with learning disabilities has been further delayed. This evaluation recognises that appropriate

\textsuperscript{172} ‘Resettlement of long-stay patients from learning disability hospitals’. (March 2009) Northern Ireland Audit Office. 

\textsuperscript{173} ‘United Nations Convention on Rights of Persons with Disabilities: (UNCRPD) - Northern Ireland Executive’s Contribution to the UK Government Report to the UN Committee’ (OFMDFM)(2011)
http://www.ofmmdfmi.gov.uk/executives_contribution_to_the_uk_government_report_to_the_united_nations_commission_-_amended.pdf

facilities have to put in place to assist people with learning
disabilities move into the community as identified in the TYC.
However, this evaluation would argue that the simple recognition
by the DHSSPS, in the setting of its first target date for
resettlement in 2002, it would have long since initiated activities to
assist those with learning disabilities to resettled back into the
community. In short, a delay of 13 years for the closure of long
stay institutions in Northern Ireland is a clear indication that the
Northern Ireland Government is failing to progressively realise the
right and obligations contained in Article 19 in this regard.

**Housing**

175. The Housing Executive and the Health and Social Care Trusts
have specific responsibilities for the provision of housing
adaptations. Therefore, it is essential that there are strong
interagency working arrangements in order to develop
independent living options for disabled people.

176. At the time of publication, the DHSSPS ‘Physical and Sensory
Disability Strategy’\(^{175}\) recognised that the DHSSPS and the
Department for Social Development were engaged in an
Interdepartmental Review of Housing Adaptations Services which
was to continue until early 2012. A Joint Housing Adaptations
Steering Group (JHASG), established after the last DHSSPS /
Housing Executive Joint Fundamental Review of Housing
Adaptations Services in 2002, provides cross sector support for a
core group managing the current review.

177. The Strategy reports that the central focus of the group will be on
processes that directly affect the lives of disabled people such as
current and potential future demand for the housing adaptations
service, interdepartmental resources and co-ordination issues.

178. The Strategy further states that it is anticipated that the core group
will provide a report with recommendations for submission to the
Ministers for Health, Social Services and Public Safety and Social
Development in early 2012.

179. The Supporting People programme helps deliver the Northern
Ireland Housing Executive’s (Housing Executive) Supporting

\(^{175}\) ‘Physical and Sensory Disability Strategy A Consultation Document 2011 – 2015.’ Department of
http://www.dhsspsni.gov.uk/disability_strategy__draft_version_1__-december_2010-3.pdf
People Strategies and the PSI Homelessness Strategy 2010-15. This was communicated in the United Kingdom’s Initial State Party Report states.

180. The Supporting People programme is managed by the Housing Executive in partnership with the:

- Health and Social Care Board;
- Health and Social Care Trusts; and
- Probation Board for Northern Ireland.

181. The Supporting People programme provides a range of services, including advice and guidance to enable disabled people and others, with support needs to live as independently as possible.

182. Research undertaken on behalf of the Equality Commission reported from a review of supporting people programmes across the United Kingdom:

“a lack of robust, peer-reviewed research evidence which explores the impact in terms of outcomes for service users as well as the effectiveness of different types of programme administration/funding in terms of the ability of service providers to meet the housing-related needs of vulnerable adults. The evidence available predominantly highlights the positive impacts of SP for service users in terms of outcomes such as independent living and quality of life. However, such outcomes have not been measured using robust research methods and there is a lack of evidence from service users themselves. None of the literature reports any adverse outcomes for service users although the review does reveal some concerns that the

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177 Please note, that the Northern Ireland housing Executive website states “In January 2012, Department for Social Development asked that finalisation of the new strategy be postponed pending the outcome of the review of the Supporting People Commissioning Body” [http://www.nihe.gov.uk/supporting_people_strategy](http://www.nihe.gov.uk/supporting_people_strategy)

178 *A Strategy to Promote the Social Inclusion of Homeless People, and those at Risk of Becoming Homeless, in Northern Ireland.* Department for social Development (July 2007) [http://www.dsdni.gov.uk/cv-homeless.pdf](http://www.dsdni.gov.uk/cv-homeless.pdf)


180 Please note the footnotes associated with the United Kingdom’s Initial State Party Report and the Northern Ireland Executive’s contribution to the Initial Report were inserted for this evaluation.

181 Housing Executive Supporting People website: [http://www.nihe.gov.uk/index/advice/supporting_people.htm](http://www.nihe.gov.uk/index/advice/supporting_people.htm)
services do not adequately address the needs of different groups (e.g. ethnic minority groups).”

183. The research on behalf of the Equality Commission concluded that in view of the evidence on access to information and the potentially lower uptake of services for certain types of disability contained within Article 9 [of the same report], that further research is recommended on the impact of the Supporting People programmes for disabled people.

184. The Equality Commission has been calling for urgent legislative reform of the disability equality legislation in Northern Ireland; particularly in light of developments in Great Britain where the introduction of the Equality Act 2010 has meant that disabled people in Northern Ireland now have less protection against discrimination and harassment than disabled people in Great Britain.

185. In 2011, the Independent Mechanism for Northern Ireland (IMNI) provided written evidence to the Joint Committee on Human Rights (JCHR) inquiry into the ‘Implementation of the Right of Disabled People to Independent Living’. The IMNI reported that one recommendation the Equality Commission has made for legislative reform of the Disability Discrimination Act 1995, which was addressed in the Equality Act 2010, and is specifically relevant to the progressive realisation of rights within Article 19. This is that landlords and managers are required to make disability-related adjustments to the physical features of the common parts of let residential premises, where it is reasonable to do so and when requested by a disabled tenant or occupier. Such additional


184 The introduction of such a duty would require landlords to make alterations to the physical features of common parts, such as installing a stair lift, handrail, or ramp. The duty to make the alteration to the common parts will only apply where the disabled person is placed at a substantial disadvantage compared to non-disabled persons. In addition, landlords will only be required to make adjustments, where it is ‘reasonable’ for them to do so. Importantly, the costs and any reasonable maintenance costs of the alterations will be borne by the disabled tenant. The Equality Commission’s detailed recommendations for legislative reform of the DDA 1995 and other equality legislation is available at: http://www.equalityni.org/archive/pdf/Priorities_for_legislative_reform0602091.pdf
protection for disabled people in Northern Ireland will reduce the risk of disabled people being isolated in their own homes, when a simple alteration, such as a handrail or ramp, would enable the disabled person to access the common parts of their home.\textsuperscript{185}

\textbf{Transport}

186. Access to affordable and inclusive transport facilitates disabled people’s access to health, educational and employment opportunities and contributes to their independence and quality of life, including their involvement in the community and in general day to day social activities\textsuperscript{186}. The provision of affordable and inclusive transport not only progressively realises the rights within Article 19 but other article with UNCRPD.

187. In 2011, the Independent Mechanism for Northern Ireland (IMNI) provided written evidence to the Joint Committee on Human Rights (JCHR) inquiry into the ‘Implementation of the Right of Disabled People to Independent Living’. It stated that:

\begin{quote}
"Over the last five years there has been considerable progress in respect to the provision of accessible and inclusive transport in Northern Ireland. For example, the removal of the transport exemption from the protections of DDA legislation and investment in accessible public transport and infrastructure."
\end{quote}

188. The Equality Commission recommended that the measures are assessed to enhance the independence of disabled people, for example:

http://www.equalityni.org/archive/word/IMNI_Joint_Response_JCHR270411.doc

\textsuperscript{186} The PSI Working Group Report on Disability highlighted for example that employment rates for disabled people are very low. In 2009, the employment rate for people with a disability of working age was 31%, less than half that for people without a disability (75%). This low level of employment has persisted over time. The report also acknowledged those other important relationships to affordable inclusive transport - access to services, opportunities and correlation to level social and economic activity etc. The Department of Regional Development acknowledges that access to transport is of particular importance in rural areas where the 2008 Living Cost and Food Survey found that rural families spend 15% of household expenditure on transport.

http://www.equalityni.org/archive/word/IMNI_Joint_Response_JCHR270411.doc
• The provision of affordable accessible transport, with the equalisation of the concessionary fares scheme to apply to all disabled people regardless of how they acquired their disability.
• The benefits of the concessionary fare scheme to apply to all bus routes, participation in the scheme should not be restricted by geography.
• Better provision of written accessible information.188

189. In 2005, the Department for Regional Development published the Accessible Transport Strategy (ATS) 2005-2015. This Strategy seeks to address the range of barriers that impede use of the transport system by older people and people with disabilities; barriers which prevent them from carrying out everyday functions or leave them excluded from activities that others are able to enjoy.

190. In April 2012, the Equality Commission responded189 to the Department for Regional Development’s Fourth Accessible Transport Strategy Draft Action Plan (ATS) 2012-2015190. The Equality Commission noted and welcomed the range of achievement in delivering accessible transport by the Department for Regional Development. However, the Equality Commission recommended the following:

• The need for legislative reform of the Disability Discrimination Act (DDA) to provide appropriate protection for disabled people using transport and other services.
• The need for ongoing engagement with disabled and older people.
• The need for review and amendment of the concessionary fares policy.
• The need for review of the availability of seating for disabled and older passengers and the associated improvements to allocations and signage on various modes of transport, in

particular, buses to ensure older and disabled people have access to appropriate seating.

- The need to take into account the impact of Government’s proposals for Welfare Reform on access to transport.
- The need for regular disability equality and general equality awareness training for transport providers, including extension of this provision to taxi operators.
- The need for clear impact measures to ensure the effective delivery of the strategy.
- The need for a clear commitment to delivering accessible transport provision beyond the life time of the current action plan.

**Context & Outcomes**

*Contact with Health and Social Care Trusts*

191. The ‘Adult Community Statistics for Northern Ireland 2010-11’ provides information on a range of community activities gathered from the Health and Social Care Trusts (HSC Trusts). The tables within the report find that in 2011:

- 15,683 persons were designated as mentally ill;
- 9,173 persons with learning disabilities were in contact with the HSC Trusts;
- 6,381 persons with physical disabilities, whose primary disability is neither visual or auditory and under 65, were in contact with the HSC Trusts;

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192. Designated Mentally Ill - refers to persons who in the professional opinion of a doctor - GP or Psychiatrist - are suffering from a mental or psychiatric illness. Mental illness means a state of mind which affects a person’s thinking, perceiving, emotion or judgement to the extent that he/she requires care or medical treatment in his/her own interests or in the interests of other people.

193. Learning Disabled - refers to persons who have a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning. To be included in this group a person must be on the Trust’s register of learning disabled people.

194. Face-to-Face Contact - A contact which is made by one or more health professionals with a patient or client. The contact occurs when the patient/client attends a clinic or a domiciliary visit is made to see the patient/client. The data in the tables refer to the number of people who had at least one face to face contact during the year and not the actual number of contacts made.

195. Physically Disabled / Sensory Impaired - refers to persons who are substantially and permanently disabled by illness, or otherwise, including the chronically sick. This group will include the following groups: blind, partially sighted, deaf with speech, deaf without speech, hard of hearing and general classes (i.e. those whose primary disablement is neither visual nor auditory).
• 638 blind\textsuperscript{196} persons, under 65, were in contact with HSC Trusts;
• 761 partially sighted persons\textsuperscript{197}, under 65, were in contact with HSC Trusts;
• 155 hearing impaired persons (Deaf with speech) under 65 were in contact with HSC Trusts;
• 255 hearing impaired persons (Deaf without speech), under 65, were in contact with HSC Trusts; and
• 1,061 hearing impaired persons (Hard of Hearing), under 65, were in contact with HSC Trusts.

**Provision of Care Packages**

192. In June 2011, the number of care packages\textsuperscript{198} in effect for all Programmes of Care\textsuperscript{199} was 12,356. Of these, 8,149 were nursing home care\textsuperscript{200} and 4,207 were in residential care\textsuperscript{201}. Twenty per cent (20\%) of all care packages were for those with disabilities, with:

• Twelve per cent (1,536) within the Learning Disability Programmes of Care\textsuperscript{202};

\textsuperscript{196} Blind and Partially Sighted - refers to persons who are either registered or registerable as blind or partially sighted.

\textsuperscript{197} Blind and Partially Sighted - refers to persons who are either registered or registerable as blind or partially sighted.

\textsuperscript{198} Care Packages - These are the main forms of care recommended through care management, which include the functions of assessing need, care planning, co-ordinating and reviewing services.

\textsuperscript{199} Programmes of Care are divisions of health care, into which activity and finance data are assigned, so as to provide a common management framework. They are used to plan and monitor the health service, by allowing performance to be measured, targets set and services managed on a comparative basis. In total, there are nine Programmes of Care. This definition is restricted to cover just community activity.

\textsuperscript{200} Nursing Home - A nursing home is a facility staffed by nurses 24 hours per day, which provides services for clients/patients requiring residential nursing care. Medical care continues to be the responsibility of the client/patient’s GP. The premises must be owned, managed or leased by the HPSS or a health care contract must exist between the HPSS and the owners of the premises for the provision of care.

\textsuperscript{201} Residential Care Home - This is residential accommodation, staffed 24 hours a day, providing board and general care to residents. Such premises are provided for vulnerable persons (e.g. children, the elderly, the physically disabled and those mentally ill or with a learning disability) who require care and supervision in the circumstances where nursing care would normally be inappropriate. The premises must be owned, managed or leased by the HPSS or a health care contract must exist between the HPSS and the owners of the premises for the provision of care.

\textsuperscript{202} Learning Disability POC - This programme covers all activity, and resources used, by any health professional, including all community contacts where the primary reason for the contact was learning disability, regardless of age. All community contacts with Down’s Syndrome patients who develop dementia, for any dementia related care or treatment should be included. All contacts in learning disability homes and units should also be included.
Five per cent (625) within the Mental Health Programme of Care\textsuperscript{203}, and
Three per cent (403) within the Physical and Sensory Disability Programme of Care\textsuperscript{204}.

193. The number of care packages within the Learning Disability Programme of Care increased by four per cent (4\%) for 1484 in 2007 to 1539 in 2011. The proportion of residential care packages has change only slightly, down from fifty six per cent (56\%) in 2007 to fifty three per cent (53\%) in 2001\textsuperscript{205}.

194. The number care packages within the Mental Health Programme of Care decreased by 21 per cent from 796 at March 2007 to 625 at June 2011. In March 2007, residential care packages represented fifty eight per cent (58\%) of all care packages within the Mental Health Programme of Care. Whereas in June 2011, forty eight per cent (48\%) were residential care packages\textsuperscript{206}.

195. The number of care packages within the Physical and Sensory Disability Programme of Care remained constant at approximately 400. In March 2007, residential care packages represented twenty one per cent (21\%) of all care packages within the Physical and Sensory Disability Programme of Care. Whereas in June 2011, seventeen per cent (17\%) were residential care packages\textsuperscript{207}.

Residential Homes

196. In 2011, there were 25 residential homes (356 places) solely for the use of persons with mental ill health, 43 residential homes (539 places) solely for the use of persons with physical and/or sensory disability.

\textsuperscript{203} Mental Health POC - This programme covers all activity, and resources used, by any health professional, including all community contacts where the primary reason for the contact was due to mental health. If the reason for contact is that the patient has dementia, the activity should be allocated to the Elderly Care Programme of Care. However, Down’s Syndrome patients who develop dementia should remain in the Learning Disability Programme of Care. All work and resources relating to residential accommodation for the Elderly Mentally Infirm should be excluded. This is included in the Elderly Care programme.

\textsuperscript{204} Physical and Sensory Disability POC - This programme includes all community contacts by any health professional where the primary reason for the contact is physical and/or sensory disability. All patients and clients aged 65 and over are excluded. These contacts should be allocated to the Elderly Care programme.


places) for persons with learning disabilities, and 2 residential homes (16 places) for those with physical and sensory disabilities in Northern Ireland\(^{208}\).

**Direct Payments**

197. In 2010, for all programmes of care, 1773 people received Direct Payments. The number of Direct Payments to those with physical and sensory disabilities has risen slowly from 372 in 2008 to 587 in 2010\(^{209}\). Amongst people with mental health issues, the uptake of Direct Payments has been lower than among other groups. At May 2011, a total of 81 people with mental ill health were in receipt of Direct Payments\(^{210}\). The number of people with learning disabilities taking up Direct Payments has increased from 218 in June 2008 to 561 in May 2011.

198. If we place the receipt of Direct Payment in context with the number of people in Northern Ireland in receipt of Disability Living Allowance\(^{211}\) (183,000) and Carers’ Allowance\(^{212}\) (53,000), we can see that Direct Payments currently represent a very small element of community social care in Northern Ireland.

**The Need to Improve Health and Social Care**

199. As part of its engagement plan, the TYC undertook an online survey\(^{213}\). It was completed by 673 individuals, of which 91 per cent worked for an organisation providing health and social care and 95 per cent provided responses on their own behalf. Respondent were asked to how they would rate a series of aspects of Health and Social Care in Northern Ireland in terms of whether they require improvement or not. The following is a brief outline of the findings:

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\(^{213}\)
• 71 per cent of stated that a fair, or a lot of, improvements was needed in respect to the availability of mental health services (n = 292);
• 64 per cent of stated that a fair, or a lot of, improvements was needed in respect to the quality of mental health services (n = 262);
• 71 per cent of stated that a fair, or a lot of, improvements was needed in respect to the range of day provision for people with a disability (n = 262);
• 65 per cent of stated that a fair, or a lot of, improvements was needed in respect to Health and Social Care services for people with a learning disability (n = 208);
• 74 per cent of stated that a fair, or a lot of, improvements was needed in respect to Health and Social Care services for people with mental health problems (n = 208);
• 62 per cent of stated that a fair, or a lot of, improvements was needed in respect to Health and Social Care services for people with physical and sensory disabilities (n = 206).

200. The findings from the TYC online survey provide clear evidence that respondents who worked for organisations providing health and social care saw a need for improvements to Health and Social Care services for disabled people.