Reclaiming our Futures Alliance

An alliance of Disabled People and
their organisations in England

Independent Living for the Future

Our vision for a national independent living support system

Contents

Context

Grassroots campaigning by Deaf and Disabled people since 2010 has been focused heavily on social rights, especially on to the right to independent living and being included in the community as set out in Article 19 of the UN Convention on the Rights of Disabled People (UNCRPD).

Measures imposed through 'austerity' and devastating cuts in social care are having serious adverse impacts that directly affect Disabled people's rights and freedoms in exactly those areas set out in Article 19. Instead of closing Assessment and Treatment Units and moving people with learning difficulties and autism back to their communities, it has become more common for Disabled people to be sent many miles from their homes, families and friends due to a chronic lack of local provision. People with mental health diagnoses may also be sent a long way away for treatment. Local authorities and Clinical Commissioning Groups are introducing maximum expenditure policies which threaten to force Disabled people into residential care against their wishes. The General Comment on Article 19 published by the UN disability committee in 2017 made clear that institutionalisation of Disabled people can also occur in people's own homes, when their basic needs are neglected and they are denied the support they need to leave the house and participate in the community. The rights to independent living and being included in the community set out in Article 19 provide a clear guide to the rights that Disabled people should be able to enjoy and a measurement framework for progression.

Austerity measures are disproportionately affecting Disabled people's right to an adequate standard of living as set out in the UNCRPD. New assessment processes such as the WCA and PIP arbitrarily divide disabled people into the "genuine" and the "undeserving". The huge reduction in financial support available to many disabled people under ESA and PIP reform, combined with delays and failures in the assessment process has resulted in increased poverty and a well-documented deterioration in our wellbeing and quality of life. A number of benefit claimants are being forced to cut down on food and heating, use food banks and borrow money that they are ill-equipped to return, which is traumatising and, in some cases, has resulted in suicide. Current measures seem to have links with a neoliberal approach within which people who are regarded as wealthy, or 'hard working' are perceived as worthy in contrast to people with support needs who are viewed as second class citizens.

There are some acute intersectional issues. Disabled people who have more than one 'protected characteristic' under the Equality Act 2010, who experience

additional inequalities not covered by the Act (related to socio-economic class, or homelessness, for instance), or have dual diagnoses (including substance addictions) are especially disadvantaged in relation to independent living.

There are particular issues for Disabled People who are made subject to the Mental Health Act 1983, with people from BME communities often affected particularly badly, and people deemed to lack capacity under the Mental Capacity Act. Some groups of BME service users are particularly likely to experience the controlling rather than supportive aspects of the psychiatric system. The MH Act authorises detention and compulsory treatment for people diagnosed with a (serious) mental disorder when they/others are thought to need protection. This authorisation removes their right under Article 19 to live in the community, choose their place of residence and exercise choices on an equal level with others. Detention and compulsory treatment, whether exercised through an inpatient setting, or a Community Treatment Order, also run contrary both to Article 12 and to Article 14 of the Convention. Thus, the UNCRPD Committee has recommended an end both to substitute decision-making and to 'compulsory treatment and detention of persons with disabilities on the basis of actual, or perceived impairment'. In both hospital and other settings, the UNCRPD guidance also includes an end to the use of physical and chemical restraint. People who are neurodivergent and people with life limiting chronic illness are also subject to detrimental impacts caused by inappropriate referrals to and interventions used on them within the mental health system.

The language of independent living has been appropriated by Government and public bodies to justify the cuts they are making. Policy documents at national, regional and local government levels repeatedly refer to "helping people to stay independent for as long as possible", often while simultaneously claiming to be in accordance with Article 19 and yet demonstrating a clear failure to comprehend a concept of independent living based on Disabled people's right to exercise choice and control over our everyday lives and to access the same chances in life as non-Disabled people on an equal footing. It is common practice for essential support to be removed from Disabled people through social care assessments under the justification of "helping" them to "improve their independence". Article 19 rights have thus been co-opted and subverted in order to facilitate the retrogression of Disabled people's rights.

There has been recent debate about whether it is useful to still use the language of independent living. We would argue that it is. With certain audiences we are seeking to influence it may be expedient to tailor language in order to be better understood and to convey our messages more effectively, for example referring to cuts to "social care" rather than "independent living support services". Those are

decisions that can be made according to particular circumstances. However, to stop talking about independent living and to shift our focus away from achieving a right to independent living would be a strategic mistake.

Below we set out our demands for a national independent living service capable of upholding and implementing Disabled people's Article 19 rights. It has been shaped and developed through ongoing debate and discussion within the Independent Living Campaign, set up in 2011, in response to the then planned closure of the Independent Living Fund (ILF) and most recently through:

- The independent living workshop at the National Deaf and Disabled People's Summit organised by the TUC Disabled Workers Committee and the Reclaiming Our Futures Alliance in November 2017.
- The 2017 National Independent Living Campaign Conference funded by Disabled People Against Cuts (DPAC) and co-organised with the Reclaiming Our Future Alliance.
- A Reclaiming Our Futures Alliance independent living round table held in May 2018 and follow up email discussions.

Disabled People's Vision of Independent Living Support for the Future

Introduction

The social care and mental health systems are in crisis and as a result Disabled people's rights to an adequate standard of living, to inclusion and equal participation in society are being taken dramatically backwards. Rising levels of charging are increasingly pushing Disabled people out of receiving social care altogether and leading to a growing problem of debt and arrears[1].

The joint report of the Health and Social Care and Housing, Communities and Local Government Committees on the long-term funding of adult social care says:

"The combination of rising demand and costs in the face of reductions in funding has placed the social care system under unsustainable strain. In its present state, the system is not fit to respond to current needs, let alone predicted future needs as a result of demographic trends."

Besides urging that research be undertaken into actual and future levels of need and for corresponding investment, Disabled people have long called for the radical overhaul of both the social care and mental health systems in order to better fit a human rights approach to disability. At present, Disabled people's experiences of independent living and being included in the community differ considerably depending upon impairment, for example people with learning difficulties, people who are neuro-divergent and people with energy-limiting chronic illness

1 An investigation by GMB union has revealed at least 166,000 people are trapped in debt for their social care. http://www.gmb.org.uk/newsroom/social-care-debt

(especially medically contested diagnoses like Myalgic Encephalomyelitis [2]) are less likely to be found to have eligible needs under the social care system while people living with mental distress are largely confined to a separate system without access to the same sorts of support.

Instead, we are arguing for a system underpinned by the social models of disability and distress that can be accessed by all Disabled people regardless of impairment or perceived impairment. Our vision for a national independent living support system would also eliminate the post code lottery that exists within current local authority and CCG administered provision. We believe that all independent living support should be free at the point of need and as the example of free personal care in Scotland has shown this could lead to savings in other areas such as the NHS budget[3]. By building on what was most successful about the Independent Living Fund which had considerably lower overheads than local authority administered support[4], it could also be more cost effective and achieve much better outcomes than the current system.

Terminology

Under the term “Disabled people” we refer to anyone who is disabled by society according to the social model of disability. (See Appendix A).

2 Action for ME (2015) Close to collapse: an interim report on access to social care and advocacy for people with ME/CFS

3 Both the Joint Committee report and the recently published Lord Darzi Review into Health and Social Care recommend the introduction of free personal care.

4 According to the final annual report and accounts of the ILF from end of March 2015, the Fund had a 98% service user satisfaction rate and just 2% of the budget was spent on administration.

Priority Demands

- Set up an independent living taskforce led by Disabled people to develop proposals for a national independent living support service.
- Explore in co-production with Disabled people the strongest legal frameworks for legislating for Article 19 rights, including enshrining the CRPD in domestic legislation and developing an independent living bill of rights.
- Make a case for investment in independent living support, including evidencing social care as a social and economic generator5 and what wider benefits could be saved from savings to NHS budgets.
- Model the amount of funding needed to ensure good quality independent living support meeting need now and in the future to uphold all Disabled people's rights under Article 19.
- Educate the public and promote the benefits of investing in support for Disabled people.

Vision

That the right to independent living as outlined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities becomes reality:

"All Disabled people to have equal rights to live in the community, with choices equal to others, and be fully included and able to participate in the community, through:

- the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, without being obliged to live in a particular living arrangement;
- access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- community services and facilities, for the general population are available on an equal basis to Disabled people and are responsive to their needs."

5 Beresford, P. (2016), All Our Welfare: Towards participatory social policy, Bristol, Policy Press.

Underlying principles

- Social and human rights-based models of disability and distress
- The twelve pillars of independent living (see Appendix B)
- The National Survivor User Network's Manifesto
- Article 19 of the United Nations Convention on the Rights of Persons with Disabilities
- The UNCRPD Committee's General Comment No 5 on Article 19

Core demand

A new universal right to independent living, enshrined in law and delivered through a new national independent living service co-created between government and Disabled people, funded through general taxation, managed by central government, led by Disabled people, and delivered locally in co-production with Disabled people.

Universal right to independent living

The UN CRPD is not enshrined in UK law and recent case law has weakened its application in interpreting domestic legislation; for example, the judgment in Davey vs Oxfordshire states that "great care must be taken in deploying provisions of a convention or treaty which set out broad and basic principles as determinative tools for the interpretation of a concrete measure such as a particular provision of a UK statute. Provisions which are aspirational cannot qualify the clear language of primary legislation."[6]

The inadequacy of the Care Act 2014 to uphold the rights of Disabled people has been proven in practice. Disabled people's concerns that the "well-being duty" implemented through the Care Act would offer insufficient protection against retrogression of our rights were ignored multiple times in the development of the legislation. Our petitioning for a right to independent living as outlined by

6 Davey, R (on the application of) v Oxfordshire County Council & Ors [2017] EWCA Civ 1308 (01 September 2017) Paragraph 62. http://www.bailii.org/ew/cases/EWCA/Civ/2017/1308.html

Article 19 of the UN CRPD to be placed on the statute through the Care Act was dismissed and although the statutory guidance refers to Article 19 (para 1.19), this does not have the legal weight needed to be effective. In addition, it has not been co-ordinated well with provision for mental health service users such as the Care Programme Approach.

We call for new free-standing legislation to implement an independent living bill of rights, drawn up in consultation with organisations of Disabled People and enshrining their recommendations. This legislation would be in accordance with the UNCRPD Committee's General Comment on Article 19, including its call to end detention, substitute decision making and compulsory treatment and to put a focus on intersectional issues too. The legislation would also cover rights to support which enable Disabled people to access the same life chances as non-Disabled people in all areas covered by the twelve pillars of independent living.

Disabled people's rights under the new legislation will need to be communicated in accessible ways, with an appeals process, legal aid, legal status and legal support made available for Disabled people who consider their rights to have been breached.

This legislation should apply to all Disabled people who are resident in the UK, regardless of citizenship or asylum status.

National independent living service

The social care element of Disabled people's right to independent living will be administered through a new national independent living service managed by central government, but delivered locally in co-production with Disabled people. It will be provided on the basis of need, not profit, and will not be means tested. It will be independent of, but sit alongside, the NHS and will be funded from direct taxation.

It will build on and learn from the success of the Independent Living Fund, closed by the coalition government in 2015, and the failures of the local authority care and support system. It will also learn from the experiences of user-led Disabled people's organisations (DPOs), including those run by people experiencing intersectional discrimination and disadvantages, user-led social enterprises and co-ops which have innovated and developed exciting models of self-organised and self-directed care through personal budgets and peer support. It will work with non-Disabled allies who share the critique of the existing system and who work to the social models of disability and distress.

The national independent living service will be responsible for supporting disabled people through the self-assessment/assessment process, reviews and administering payments to individual Disabled people. Individuals will not be obliged to manage their support payments themselves if they choose not to. Alongside establishment of the national independent living service will be investment in local service provision so that within each area Disabled people will be able to choose from a range of peer support options delivered by user-led Disabled people's organisations and co-operatives wherever they live. These services will support them to exercise choice and control over the support they receive and to manage their financial, administrative and employment responsibilities including legal duties as employers. Local Disabled people will be meaningfully involved in investment and commissioning decisions, as well as in researching and monitoring how well provision is meeting need. Disabled people who are involved in these processes will also be demographically representative.

The national independent living service will be located in a cross-government body which can ensure awareness of and take responsibility for implementation plans in all areas covered by the UNCRPD's General Comment on Article 19 and by the twelve pillars of independent living, whether it be in transport, education, employment, housing, or social security. The cross-government body will also be responsible for ensuring that intersectional issues are adequately addressed. Rather than being 'ghettoised' in the DWP as the Office for Disability Issues is at the moment, this will ensure that independent living is mainstreamed in every area of activity as an equalities issue rather than seen primarily as a work and benefits issue.

› Co-created with Disabled people

The national independent living support service will be co-created with Disabled people through an independent living task force led by Disabled people who need/use independent living support.

› Anti-discriminatory

The service will be designed to be anti-discriminatory, challenging current discriminations on the basis of age, ethnicity, sexuality, gender, class, culture, disability and distress. This will include diversity and inclusion at all levels including organisations of Disabled people and structures led by Disabled people involved in delivery of the service.[7]

7 Building on work developed by Shaping Our Lives looking at overcoming barriers to more inclusive user involvement: http://www.invo.org.uk/beyond-the-usual-suspects-towards-inclusive-user-involvement/

› Funded through general taxation

Social care should not be funded through set precepts or levies as evidenced by the difficulties encountered in Australia with their National Disability Insurance Scheme[8]. Funding through general taxation allows greater flexibility to respond to changing levels of need. This could be done, as advocated by a number of recent reports,[9] through "soft" hypothecation, for example a rise in National Insurance that the public understands is in order to adequately fund social care. There is much evidence that the public would be in favour of tax rises in order to fund the NHS and social care, however there is also evidence that the public vote for lower taxes and the creation of a specific levy earmarked for social care has the disadvantage of insufficient flexibility to match demographic changes. Pinpointing tax rises to cover specific areas can also be problematic in that it places the spotlight on particular groups. Funding for social care should as with the NHS be out of general taxation.

› Managed by central government

The national independent living support service will build on lessons learned from the Independent Living Fund in being independent of Local Authorities and CCGs. This will eliminate the current postcode lottery, which has increased since closure of the ILF[10], and enable greater transparency and accountability to Disabled people.

› Led by Disabled people

8 The NDIS was financed by an increase in the Medicare levy in June 2014 from 1.5 per cent to 2.0 per cent of taxable income. This has proved to provide be insufficient funding, and there are now concerns of a lack of public will for an increase.

9 Long-term funding of adult social care - First Joint Report of the Health and Social Care and Housing, Communities and Local Government Committees of Session 2017–19
https://publications.parliament.uk/pa/cm201719/cmselect/cmcomloc/768/76810.htm#_idTextAnchor124
Citizens' Assembly on Social Care: recommendations for funding adult social care
https://publications.parliament.uk/pa/cm201719/cmselect/cmcomloc/citizens-assembly-report.pdf
The Lives we want to Lead: the LGA green paper for adult social care and wellbeing – July 2018
https://futureofadultsocialcare.co.uk/
The Lord Darzi Review of Health and Care Final Report: BETTER HEALTH AND CARE FOR ALL A 10-POINT PLAN FOR THE 2020s, Institute for Public Policy Research; Lord Darzi June 2018
https://www.ippr.org/files/2018-06/better-health-and-care-for-all-june2018.pdf

10 See Inclusion London's report "One Year On: Evaluating the Closure of the Independent Living Fund"
https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/independent-living-social-care-and-health/ilf-one-year-on/

The governance of the national independent living support service will ensure that Disabled people are involved and have a meaningful say at all levels of decision-making with a governing body that is made up of a majority of Disabled people. Structures will limit the involvement of non-user led charities and disability organisations.

› Delivered locally

The new service will be delivered locally through disabled person user-led, public sector, co-operative services replacing the largely private sector provision currently delivering social care and allied services. Alongside the establishment of a national independent living support service, there will be investment in the development of Disabled People's Organisations (DPOs) delivering local services in response to need and ensuring that a range of options are available to support Disabled people to live in the community and exercise choice and control over the support they receive.

DPOs will be resourced to provide support that enables equal participation in society across all areas of Disabled people's lives, including Access to Work[11], housing[12], social security and financial advice and wide-ranging service and resource provision.

However, there must be monitoring mechanisms to ensure that local delivery does not deny the nationally uniform status of the entitlement to support, so that for example disabled people can move to different areas without any loss, or threat of disruption, of funding or support services.

Service provision will include a full range of alternatives to the "white western medical" model approach, psychiatric medication and clinical treatments which are prevalent in mental health services and to the re-defining of service user concepts such as recovery in clinical terms. There will, too, be a wide range of resources which are important to Disabled people who are currently disadvantaged by shortfalls in intersectional provision.

11 So long as Access to Work remains separate – we favour these being rolled into the new independent living service.

12 We also favour Disabled Facilities Grants being eventually rolled into the new independent living service.

Steps to achieving our vision

1. Office for Disability Issues to be placed within the Treasury, Cabinet Office or the Government Equalities Office to give it more reach across different Government departments.
2. Formation of an independent living taskforce with a meaningful influence, led by Disabled people from all demographic backgrounds who need/use independent living support.
3. Funding to make a case for investment in independent living support, including evidencing social care as a social and economic generator and what wider benefits could be saved from savings to NHS budgets.
4. Model the amount of funding needed to ensure good quality independent living support meeting need now and in the future to uphold all Disabled people's rights under Article 19[13].
5. Funding of user-led research into alternative service options and culturally appropriate resources for Disabled people.
6. A communications strategy for raising awareness about what we mean by independent living, Disabled people's human rights and the role of Personal Assistants.
7. Dealing effectively with stigma against Disabled people whether at political, commissioning, or service levels, or within society as a whole.
8. The funding of adequate training for government personnel, commissioners and service providers about the meaning of independent living and its value, led by Disabled people.
9. A strategy for investment in local user-led, public sector and co-operative provision to replace private sector social care agencies/homes.
10. A strategy for closure of institutionalised, segregated settings including long stay hospitals and Assessment and Treatment Units replaced with independent living service in the community.
11. A housing strategy based on universal design, accessibility and lifetime homes principles embedded in and part of the commitment to the building of social/public housing.

13 Both the Joint Committee report on the long-term funding of adult social care and Lord Darzi's review of Health and Social Care recommend a need for data modelling.

12. Fund work to draw up a case for investment in Access to Work, evidencing the level of return on investment to the treasury for every pound spent.
13. Roll Access to Work into the national independent living service.

Legislative and treaty change

- Legislate for a free-standing right to independent living that includes an adequately resourced right to inclusive education.[14]
- Implement the appeals process under the Care Act 2014.
- Bring into force Section 1 of the Equality Act 2010 to introduce a socio-economic duty on public sector bodies and dual discrimination provisions.
- Reverse the changes to legal aid that have restricted eligibility for Disabled people.
- Remove UK reservations and interpretative declaration on Articles 24 of the United Nations Convention on the Rights of Persons with Disabilities[15].
- Amend the Mental Capacity Act 2005 to give full human rights to Disabled people and their families and to ensure that 'best interest' decisions made reflect the will and preferences of Disabled people and introduce an accessible system for people to challenge decisions made about them.
- Bring detention, substitute decision-making and compulsory treatment to an end for all Disabled people.

14 The UN Disability Committee's General Comment No. 5 on the Right to Independent Living and Being Included in the Community made clear that inclusive education is an integral part of Disabled people's rights under Article 19. The UK government continues to have a reservation on Article 24 and maintains its position of offering segregated education as a "choice".

15 Article 24 is the right to inclusive education.

Appendix A

Under the term “Disabled people” we refer to anyone who is disabled by society according to the social model of disability. This includes:

- People physical, mobility or sensory impairments
- People who are Deaf
- People with learning difficulties/disabilities
- People living with mental distress
- People are neuro-divergent
- People living with chronic illness and long-term health conditions.

We recognise that not everyone within these groups identifies as Disabled and respect that not everyone with these experiences considers themselves to have an impairment. There is certainly need for wider discussion and debate on these issues, however for this paper we have taken the position that what unites us all are the disabling barriers and experiences of oppression that we face and we therefore use the term “Disabled people” to refer to all of us.

For more information on the social model of disability and cultural model of Deafness see: https://www.inclusionlondon.org.uk/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/

Appendix B

The 12 Pillars of Independent Living

These are:

- Appropriate and accessible information
- An adequate income
- Appropriate and accessible health and social care provision
- A fully accessible transport system
- Full access to the environment
- Adequate provision of technical aids and equipment
- Availability of accessible and adapted housing
- Adequate provision of personal assistance
- Availability of inclusive education and training
- Equal opportunities for employment
- Availability of independent advocacy and self-advocacy
- Availability of peer counselling

The twelve pillars were developed by Hampshire Coalition of Disabled People building on seven action points, originally devised by the Derbyshire Coalition of Disabled People, which identified the barriers to independent living and how they can be removed:

Information

Disabled people require information on what is available to assist with independent living.

Peer Support

Disabled people need the support of other disabled people to discuss how to make best use of the information obtained and for ongoing support.

Housing

Disabled People need accessible housing. This may be in terms of wheelchair access or in terms of support and advice in relation to having one's own accommodation.

Equipment

Many disabled people need particular types of practical equipment to assist them in living independently.

Personal Assistants

This is the one to one support that some disabled people need to live in their own home and be part of the community.

Transport

This may mean improved public transport in terms of physical access, information about the routes, more assistance for passengers who are unsure about using public transport, and improved routes to take into account the issues for disabled people. It may mean access to personal transport such as the use of cars or support to use other forms of transport.

Access

The most obvious examples concern physical access such as dropped kerbs, level entrances to buildings and provision of accessible public toilets. However, access goes much further than this. There are barriers created by systems, practices and attitudes which prevent disabled people from participating, for example, excluding people with mental health needs from public meetings.

Appendix C

European Network for Independent Living (ENIL) Principles

1. Independent living is a process of consciousness raising, empowerment and emancipation. This process enables all disabled people to achieve equal opportunities, rights and full participation in all aspects of society.

2. Disabled people must be able to control this process individually and collectively. To achieve this goal, we provide peer support and use democratic principles in our work.

3. As equal citizens we must have the same access to the basics of life including: food, clothing, shelter, health care, assistive devices, personal support services, education, employment, information, communication, transportation and access to the physical and cultural environment, the right to sexuality and the right to marry, to have children, and peace.

4. The Independent Living Movement must be a cross disability movement addressing the needs of all disabled persons. In order for this to occur we must rid ourselves of any prejudice we have towards disabled people other than our own and encourage the involvement of disabled women and other under-represented groups. Disabled children should be enabled by their families and society in general to become independent adults.

5. Disabled people must obtain all the requirements for equalisation of opportunities and full participation by defining their own needs, choices and degree of user control.

6. The Independent Living Movement is opposed to the development and maintenance of systems which promote dependency through institutional responses.

7. Disabled people must involve themselves in research and development, planning and decision making at all levels, in matters concerning their lives.

http://enil.eu/

Appendix D

The National Survivor User Network's Manifesto Our Voice Our Vision Our Values

We aim to:

1. Address the injustice and harm that have been caused by cuts to public funding and changes to the benefits system
2. Make the policy of 'getting the right support, at the right time, in the right place, from the right person' a reality
3. Pressure mental health services to make the principle of 'nothing about us without us' a reality at all levels, through meaningful involvement in decisions about our own individual care and genuine co-production to develop services
4. Work together with people from socially deprived and marginalised communities to determine their support and develop alternatives
5. Challenge institutionalised discrimination and put equality back on the agenda for mainstream mental health services
6. Call for a reform of the Mental Health Act 2007 to make it fully compliant with human rights and ensure that people are not harmed or abused
7. Reflect the social model of disability and promote informed choice and alternatives to medication 8. Reclaim, challenge and revive survivor knowledge and research
8. Reclaim, challenge and revive survivor knowledge and research.

To see the full manifesto go to: www.nsun.org.uk/our-manifesto

Appendix E

Inclusion London Briefing on the UNCRPD's General Comment no 5 on Article 19: Living independently and being included in the community

To read the full text of the General Comment go to:
https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx

In August 2017 the UN disability committee published a "general comment" on Article 19. General comments provide an interpretation of the provisions of a treaty. In this case the treaty is the Convention on the Rights of Persons with Disabilities (UNCRPD).

The following points made within the General Comment are useful to note for campaigning within the context of the current situation facing Disabled people in the UK and the right to independent living:

- Investing in independent living is cost effective because it reduces poverty and therefore the dependency of Disabled people. – Para. 5
- There are NO exceptions to whom the right to independent living applies
- Emphasis of the importance of addressing intersectional issues. – Para. 15
- The General Comment criticizes "Inappropriate decentralization, resulting in disparities between local authorities". – Para. 15(k)
- Independent living should not be interpreted solely as "the ability of carrying out daily activities by oneself". – Para. 16(a)
- Article 19 recognises the importance of a "full social life" within the right to independent living including all "spheres of social life" such as cultural, political and leisure activities and "shopping". – Para. 16(b)
- Institutionalisation is not limited to people being kept in long stay institutions but includes where Disabled people are confined in their own homes, isolated and effectively segregated, unable to access the community due to lack of funding in personalised support options. – Para. 16(c)
- The obligatory sharing of personal assistants is mentioned a number of times as contrary to the right to independent living. – Para. 16(c)

- Funding for personal employment must take into account “human rights standards for decent employment”. – Para. 16(d)(i)
- Where a State party introduces measures which regress Article 19 rights in response to economic or financial crisis the State Party is “obliged to demonstrate that such measures are temporary, necessary and non-discriminatory”. – Para. 43
- “State parties must ensure that private institutions are not established in the guise of “community living.”” – Para. 51
- The availability of accessible and affordable housing is crucial for de-institutionalisation. – Para. 53
- It is against Article 19 to exclude Disabled people who require higher levels of support and have more complex needs. – Para. 60
- All personnel working in relevant areas including “civil servants monitoring services” need to be adequately trained on independent living, both training and practice. – Para. 65
- An end must be brought to substitute decision-making and involuntary institutionalization. – Para. 83
- There must be mechanisms to allow Disabled people to appeal against decisions concerning independent living and “substantial” rights to legal aid must be in place. – Para. 82
- Independent living in inherently linked to inclusive education. – Para. 89

Supported by

Alliance for Inclusive Education

Bromley Experts by Experience

Cheshire Centre for Independent Living

Disability Sheffield

Disabled People Against Cuts

Greater Manchester Coalition of Disabled People

Inclusion London

Independent Living Action Group (Bristol Disability Equality Forum)

Mental Health Resistance Network

Merton Centre for independent Living

National Survivor and User Network

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Sisters of Frida