



FACT SHEET: Implementing Article 4(3) of the UN Convention on the Rights of Persons with Disabilities

1. Introduction

Co-production with disabled people in service provision has been proven to increase inclusion and improve the effectiveness and relevance of these services to the lives of those accessing them. As ‘experts by experience,’ disabled people are in the best position to be able to inform and guide Governments and local authorities in order to ensure services are innovative and accessible for all those who require them. Engaging disabled people at this level guards against the potential for decisions being made for us, rather than with us. The European Network on Independent Living (ENIL) seeks to ensure Governments worldwide and at all levels strive to co-produce all relevant services with disabled people in a holistic, rather than tokenistic way. After all, services that do not meet the needs of the very people they have been designed and produced to assist are likely to be costly failures.

Through continued consultancy with user led organisations and further engagement of disabled people within Government decision-making forums, we can improve disabled people’s inclusion within the community and portray disabled people as valued contributors to society. Without this, Governments may find any service or decision made in relation to disability will lack any connection or importance to the lives of the very people it has been designed to enhance.

2. ENIL’s work on promoting Article 4(3) of the UN CRPD

During 2014, ENIL has been implementing a year-long project entitled ‘Proud, Strong and Visible – Promoting Choice, Control and Participation for Disabled People in Europe’ⁱ. Amongst other challenges identified, this project intends to improve good practice in the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) – the right to live independently and to be included in the community - and increase the involvement of disabled people in the co-production of Independent Living services. As one of the key project outcomes, it is hoped



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that Governments will be much better equipped in implementing Article 19, but also, more crucially, that disabled people are provided with the necessary tools in order to fully engage with co-producing effective services and policies.

Furthermore, it is hoped this fact sheet provides some evidence of work directly related to Article 4(3) of the CRPD – which sets out the general obligations - namely that disabled people are involved and consulted in the creating of legislation, policies and decision-making processes affecting them. Within this document, there are several examples provided from which highlight the ways in which Article 4(3) can be realised.

Article 4(3) of the CRPD – General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake: [...]

3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

3. Contents of this fact sheet

This fact sheet provides information on:

- Areas of good practice in relation to engaging and working with disabled people, in line with Article 4(3) of the CRPD;
- ‘Lessons learned’ in respect of examples of poor practice;
- Guidance as to how Governments can improve their approach to co-producing services and policies with disabled people;





This fact sheet will be of relevance to disabled people, their allies, community groups, local and national government officials.

4. Why the need for engagement?

Whilst the disability rights movement has done valuable work, many disabled people in Europe remain socially segregated, pitied and in povertyⁱⁱ. With pressure groups and disabled activists recognising their shared exclusion, a number of organisations have focused on implementing equal participation for all disabled people by considering disability to be the limitation within society. Various organisations led by disabled people have tried to implement the principles of the social model, calling on their government to work with them to implement positive changeⁱⁱⁱ.

Notwithstanding the importance of social model thinking^{iv}, it is worth noting the similarities between the concept of co-production and the phrase 'Nothing About Us Without Us'^v, a slogan borne out of the Disabled People's Movement which refers to the inability to finalise policy without the complete inclusion of those ultimately affected by it. This slogan encapsulates an ethos of empowerment which aims to provide choice and control in order to position disabled people at the centre of their own lives.

Whilst we acknowledge there have been small pockets of positive progress, we also need to be honest and recognise that more has to be done; it has become all too familiar to see 'centralised decision-making' (i.e. target driven processes with minimal involvement of people at community level being involved in shaping design or setting outcomes) and 'negative relationships' (i.e. professionals and people who use services become divided and consider each other to be a barrier to the outcome – 'them and us' culture). Most people who use services want the same opportunities as their peers, but the majority are denied their rights from the first moment. It can be argued that effective engagement can help to address some of the inequalities that exist within policies and services, leading to reducing barriers created by society^{vi}. Nevertheless, there is not a specific methodology to be relied upon as the only process for creating positive change. With reductions in service resources, as well as strained relationships between people in decision-making positions and people who



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use or require services, now is the time to ensure the principles of a co-productive partnership are embedded within a holistic support framework and the lack of empowered participation is addressed.

5. What are the core principles of equal partnership?

ENIL defines **co-production** as inclusive working practices between experts by experience and organisations/professionals. It is about equal partnership and collaboration between parties passionate about improving service provision; every person involved in the process of co-production is valued, respected and listened to, with everyone involved in designing, developing and delivering. Co-production improves services, improves communities and can help make Independent Living a reality for all.

The suggested **core principles of an effective, equal partnership** are based on:

- A shared vision to create a seamless journey for disability rights to become embedded within local and national policy;
- Collective and shared goals that address the challenges outlined;
- Understanding individual/organisational perspective;
- Mutual respect;
- Support and offer to help each other;
- Handling difficulty together;
- Effective communication with honest constructive dialogue;
- Transparency;
- Evidence based decision making;
- Person focused approach to delivering support for disabled people;
- Innovation and learning from national and international best practice.



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A partnership must represent a **broad range of user interests** among people who use or require support now or may do so in the future, and/or are affected by the various government policies or programmes.

The main role of such a partnership will be **to fully implement the voice of disabled people into service and policy design**. In the UK, for example, there was a call for a programme to transform health services to be “the first public service reform programme which is co-produced, co-developed, co-evaluated”^{vii}. In Belgium, Onafhankelijk Leven (OL) has been an active partner in shaping the Personal Assistance scheme for Flanders. As a member of the Advisory Committee organised by the Flemish Agency for People with Disabilities, OL has been able to provide input on Personal Assistance, service provision for disabled people, reimbursement of assistive technology, house and car adaptations and other issues.

The role of a partnership must be the recognition that “real change will only be achieved through the participation of users and carers at every stage”^{viii}. **Co-production goes beyond traditional user involvement activities such as consultation and involving people on recruitment panels, towards more collaborative working between people who design and run services and those who use them.**

6. How can partnerships improve services?

The role of partnerships between governments and disabled people’s organisations could lead to the **following tasks/actions being coordinated**:

- Ensuring disabled people are seen as equal partners in providing and using support, rather than passive, marginalised and isolated individuals.
- Improving and enhancing the experience of using services, promoting dignity and respect in the way people are treated and experience their support.
- Improving access to support by identifying the type of support that would meet the requirements of the individual.



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- Identifying barriers to getting support to promote independence and propose ways to remove the barriers.
- Removing duplication of consultations and limited feedback, as well as increasing efficiency by feeding back on the experiences from other disabled people.
- Identifying where support services are too complicated, restrictive and fragmented and proposing ways to keep things simple.
- Outlining individual, local, regional and national experiences – making links with initiatives in organisations which collect data and evidence of achieving choice and control.
- Sharing the information, actions and outcomes with other networks.
- Helping to agree definitions pertinent to the reasons for establishing a partnership.
- Simplifying the system structures and ensuring language in government policies is accessible to the people it affects.
- Overseeing improvements to services – checking they are making a positive difference to disabled people and not promoting segregation.
- Getting involved in co-productive partnerships and demonstrating the positive effect it will have on services and systems on a local and national level.
- Being a voice for people who are marginalised, oppressed and disempowered.
- Ensuring the experiences and views of disabled people shape the culture within public organisations.
- Supporting training for staff on shaping the culture of the teams and the work of the teams that engage with disabled people.
- Taking on a scrutiny role to measure outcomes of services and policies, which includes auditing and monitoring changes, analysing feedback and giving advice and guidance.



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- Sharing best practice.
- Mapping out services which meet the needs of disabled people and reflect the aspirations and various life-stages of individuals.
- Writing and scrutinising policies, procedures and best practice guidance.

7. Examples of establishing partnerships with groups and/or individuals promoting Independent Living

SCOTLAND - Piloting co-production in the development of local housing strategies

The Scottish Government, in partnership with the Convention of Scottish Local Authorities (COSLA), NHS Health Scotland, Independent Living in Scotland (ILiS) and Disabled People's Organisations identified two local authorities, North Lanarkshire and Argyll and Bute, to take part in a project piloting co-production as a method of working with disabled people to ensure their needs are addressed in their respective local housing strategies (LHS).

A study by Evans, Littlewood, Henderson and Grant (2011) – *Evaluation of Local Housing Strategies Co-Production Pilots with Disabled People* - explored how well the principles of co-production were implemented during the project. They found that the ratio of disabled people to professionals within the pilot groups did not adequately challenge the traditional power imbalance and that role clarification was not always clear. However, they also found that the groups did influence decision-making, particularly through a draft report that reflected the views expressed within the groups, via highlighting issues that were previously unknown and through drawing on the personal experiences of those involved. The researchers recognised that co-production can be costly and that groups need time to begin working together before discussions and conclusions can be made.

Further information:

<http://www.scotland.gov.uk/resource/doc/365083/0124090.pdf>



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ENGLAND - Think Local, Act Personal: National Co-Production Advisory Group

Think Local, Act Personal (TLAP) is a national partnership of more than 50 organisations committed to transforming health and care through personalisation and community-based support. The partnership spans central and local government, the National Health Service, the provider sector, people with care and support needs, carers and family members who are engaged via the National Co-production Advisory Group (NCAG).

NCAG currently comprises of four main areas of membership. This includes a core group of 16-18 members, a further flexible group of 20 people, an unlimited group of members available for email contact, as well as some 'seldom heard' groups. People within the core and flexible group are paid for their work and contributions. NCAG are currently involved in a number of co-production projects with various organisations. Current projects include working with the Skills Academy to support them to develop a tool which will allow people using services to provide feedback on staff, and working with the College of Social Work, providing three representatives to the College's Transitional Professional Assembly and supporting their co-production work. Further work includes supporting the Zero Based Review consultation and supporting the Social Care Institute for Excellence (SCIE) by providing co-production input.

NCAG are also interested in developing co-production products, including supporting the user/carer pages of the Making it Real website, developing support materials for co-production (e.g. "ten top tips for co-production") and sharing 'what works' in co-production through blogs and website.

Further information:

[http://www.thinklocalactpersonal.org.uk/Browse/Co-production/National Co-production Advisory Group/](http://www.thinklocalactpersonal.org.uk/Browse/Co-production/National%20Co-production%20Advisory%20Group/)

UNITED KINGDOM - Equality 2025

Equality 2025 comprised a group of 9 publically elected disabled people, with a Chair, who had the ultimate responsibility to the Minister for



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Disabled People. The remit of Equality 2025 was to provide strategic advice to Ministers and senior officials across Westminster Government that would support the journey towards equality between disabled and non-disabled people in the UK. As with TLAP's NCAG, group members were paid for their work. Equality 2025 was tasked with the following:

- Developing an annual work plan that is agreed by the Minister for Disabled people. This will align to priorities across government.
- Building and maintaining strong links with Ministers and officials to ensure the advice provided meets Government priorities and adds value to the development of policies and services.
- Building and maintaining strong links with key disability organisations, advisory groups, and thought-leaders across the UK to enable members to strengthen their expertise and knowledge base.
- Reporting progress against objectives on a quarterly basis and carrying out robust evaluation of the advice it provides.
- Maintaining a flexible approach which allows it to respond to changing priorities across Government.

The 2010-2015 UK Government made a decision to disband this group in 2012.

Further information:

<https://www.gov.uk/government/publications/triennial-review-of-equality-2025>

SWEDEN – The Stockholm Cooperative on Independent Living: Co-production in shaping Personal Assistance

The Stockholm Cooperative on Independent Living (STIL) is actively represented in various networks and advisory bodies established by the Swedish authorities, where it provides advice on the issue of personal assistance.



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- It is formally recognised as an organisation that must be consulted on new legislation proposals or amendments in the area of personal assistance.
- It is consulted by the largest employment organisation for personal assistance KFO. As an employer of personal assistants, STIL communicates actively with KFO, providing advice and arguments when new guidelines or proposals are presented.
- It is part of the IVO Dialogue Forum. IVO stands for the Swedish Health and Social Care Inspectorate, whom STIL advises from an Independent Living perspective.
- It has an advisory role and is member of the Assistance Forum for the Swedish Social Insurance Agency. This is a formal cooperation, where STIL provides relevant information, ideas and arguments on any proposals for new guidelines or other measures.
- STIL meets regularly with the Swedish Board of Health, the Swedish Work Environment Authority and other government agencies through a formal network of Personal Assistance providers called Assistance Organisers. The network provides relevant information, ideas and arguments on any proposals for new guidelines or other measures.

If your organisation is involved in the co-production of services and/or policies in your local community or at the national level, please let us know. We would like to complete this fact sheet with additional examples of how Independent Living organisations engage with the government at all levels in different countries around Europe. Please write to: jamie.bolling@enil.eu
Thank you.

8. Conclusions and recommendations

During the course of producing this fact sheet, it is clear there is a lack of literature and research in this area. There are a number of organisations



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across Europe who are making strides towards improving the life chances, opportunities and rights of disabled people. In order for change and development to be effective, disabled people must participate at the same level as their non-disabled counterparts. Furthermore, co-production needs to happen at a local, national level and European level. The message is clear: disabled people need to be involved in co-production at all levels, very much within the ethos of 'Nothing About Us, Without Us.'

At a more local level, there are some good examples of inclusive, co-productive practice, particularly in Scotland and Ireland. Of particular interest is the work in Ireland directed at encouraging disabled people to consider working within the Government, thus directly influencing policy and service provision.

Despite this, there was a distinct lack of specific examples of the ways in which Governments co-produced services. The information uncovered certainly discusses a philosophy and ethos in keeping with a co-productive approach. However, there was often little reference to specific examples of the projects and work disabled people are currently co-producing.

There is a clear need for further research and investigation into the area of co-production with disabled people at a Government level. In particular, **the information produced by Governments needs to include specific, measurable examples of how exactly disabled people have been involved in the creation of policy and services.** Without this, there is a possibility the philosophy of co-production claimed by Governments may merely be tokenistic.

8. Further reading

ENIL Fact sheets on Independent Living, Co-production and Personal Assistance: <http://www.enil.eu/policy/faq/>

ENIL Myth Buster on Independent Living: <http://www.enil.eu/news/enil-launch-independent-living-myth-buster/>



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ⁱ European Network on Independent Living (2014) *Proud, Strong and Visible – Promoting Choice, Control and Participation for Disabled People in Europe*, available at: <http://www.enil.eu/news/2014-enil-project-proud-strong-and-visible-promoting-choice-control-and-participation-of-disabled-people-in-europe/>

ⁱⁱ European Network on Independent Living (2014) *Manifesto 2014*, available at: <http://www.enil.eu/wp-content/uploads/2014/03/ENIL-Manifesto.pdf>

ⁱⁱⁱ Ibid

^{iv} The social model of disability argues that someone with an impairment is ‘disabled’ by external societal factors. In other words, we are disabled by the way society is constructed and the disabling barriers we encounter have been imposed upon us by others.

^v Charlton, J.I. (2000) *Nothing About Us Without Us*. San Francisco: University of California Press.

^{vi} Minnaert, L. Diekmann, A. and McCabe, S. (2011) Disability, Representation and Access. In: S. McCabe, L. Minnaert and A. Diekmann. *Social Tourism in Europe*. Bristol: Channel View Publications. pp.145-157.

^{vii} HM Government (2007) *Putting People First*, available at: http://www.cpa.org.uk/cpa/putting_people_first.pdf

^{viii} Ibid



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