



Fact sheet: Independent living for people with intellectual disabilities

1. Can people with intellectual disabilities live independently?

Yes! All disabled people regardless of their impairment have a right to independent living under Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). This article recognises “the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”.

Living independently does not mean doing everything yourself or not having support. Independent living is about having choice and control over your life and having the same range of opportunities as a non-disabled person.

People with intellectual disabilities may need support adjustments and/or more time to access information, ideas and decisions, but with the right support and recognition, those with intellectual disabilities can exercise choice in their lives.

The use of plain language, easy read video and symbols are all examples of adjustments, which have been made to support those with intellectual disabilities to exercise choice.

Even people with complex needs and behaviour that challenges demonstrate preferences, but often non-verbal and non-direct communication is ignored.

General Comment No. 1 on Article 12, about equal recognition before the law, written by the Committee on the Rights of Persons with Disabilities (CRPD Committee), makes it clear that independent living is key for people with disabilities:

“[...] it is imperative that persons with disabilities have opportunities to develop and express their will and preferences, in order to exercise their legal capacity on an equal basis with others. This means that persons with disabilities must have the opportunity to live independently in the community and to make choices and to have control over their everyday lives, on an equal basis with others, as provided for in article 19.”

2. What does independent living look like for people with intellectual disabilities?

What independent living looks like depends on the needs of the individual person. For example, one person may need someone to come in once a week to do budgeting, or access to a support number or warden. Another person might need support workers/personal assistants working with them all the time. Someone else may just need support to access employment or to help them work out how to do something new or different.

There are many different approaches to support independent living for those with intellectual disabilities:

One example is supported housing, where a person chooses where they live and who they live with, but has support from staff to carry out household tasks.

Peer support is a key element of disabled people living independently. Many people with intellectual disabilities choose to access peer support through self-advocacy and people first groups, which are run and controlled by people with intellectual disabilities who then employ non-disabled people to support them.

3. How can you have choice and control if you do not have mental capacity?

Mental capacity refers to decision-making skills, which are different from one person to another. While some people may need support in making certain decisions, this does not mean that their power to make decisions should be taken away. This 'power' to make decisions is referred to as legal capacity. It

includes being able to sign employment contracts, get married, vote, open a bank account, join an organisation or rent an apartment, for example.

People with intellectual disabilities are disproportionately affected by the denial of legal capacity, and are often placed under full or partial guardianship.

Article 12 of the UN CRPD makes it clear that states have a duty to ensure legal capacity of disabled people is recognised, and must abolish substitute decision-making regimes such as guardianship. They must also “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity”.

If a disabled person does not have legal capacity, states must ensure that they have protections in place to ensure that a person’s “rights, will and preferences” are respected. They must restore their legal capacity, so that they are able to choose where and with whom they would like to live, among other.

The UK’s Mental Capacity Act provides a good example of how this can be understood in policy and practice. Under the Mental Capacity Act, a decision about someone’s capacity should be done on a case by case basis. For example, someone may not have the capacity to sign a legally binding contract, but that does not mean they are not able to choose what they eat for dinner.

4. How can people with intellectual disabilities be supported to make their own decisions?

General Comment 1 on Article 12 of the UN CRPD makes it clear that being part of the community and having access to a social network and a support network aids decision making. Living independently and being part of their community helps people with intellectual disabilities be exposed to a wide variety of options.

Decision making is something all people, disabled or not, develop over time. That same principle applies to those with intellectual disabilities. If someone has never been asked what

they want to wear or eat, they are not going to find it easy to decide what they want to do as a job.

Types of decision making processes commonly adopted for people with intellectual disabilities include:

Supported decision making is when the person with an intellectual disability creates/identifies a circle of support (group of people) who they can talk through decisions with, in order to support them to make the decision which is best for them and their circumstances.

Where someone cannot make decisions which are legally recognisable, in many countries an **advocate or guardian** system is in operation. Typically, an advocate will meet the person they are representing, as well as key people in their life, and based on that represent the person without legal capacity in the decision making process. This is also known as **substituted decision making**. States should move away from this system, if they want to comply with Article 12 of the UN CRPD.

Shared decision making generally happens in health settings. It is a process where medical professionals and patients work together to make decisions about treatments and are balancing risks and expected outcomes with persons' preferences.

5. Is Personal Assistance suitable for people with intellectual disabilities?

Many people with intellectual disabilities find personal assistants (PA) extremely useful in living independent lives. There are many things a PA can do which are beneficial to those with intellectual disabilities; for example, offering support to carry out day to day tasks, such as cooking and shopping, providing access to information through reading or translating information into simpler language and helping people navigate new situations or information, such as traveling a new transport route.

Disabled people should always be actively involved in the process of deciding who they want to support them, and this is no different for those with intellectual disabilities.

Managing PAs and paying their salaries can present a challenge for people with intellectual disabilities. However, in many countries in Europe this element of personal assistance can be delegated to an agency, a broker or a co-operative, who will for a small fee do these processes for the PA user.

6. Is independent living safe for those with intellectual disabilities?

Independent living is safe, provided the person has the support they need available to them. Independent living is safer than institutional or segregated care, as people are part of their community and have access to social networks, rather than being isolated.

References and Further Reading

United Nations Convention on the Rights of Persons with Disabilities:

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

General Comment 1 on Article 12: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

General Comment 5 on Article 19:

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en

UK Mental Capacity Act:

<https://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance>

Self-advocacy: <http://self-advocacy.eu/>

Supported decision making: <http://www.right-to-decide.eu>

Person centred approaches to supported decision making
https://www.thinklocalactpersonal.org.uk/assets/Resources/Personalisation/london/Supported_Decision_Making.pdf

Shared decision making: <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>

Peer support: www.peer-support.eu

Making information accessible: www.easy-to-read.eu

European Network on Independent Living and Inclusion Europe,
July 2018