AJuPID

Guide of promising practices on legal capacity and access to justice

Reflections for the implementation of the articles 12 and 13 of the UN Convention on the Rights of Persons with Disabilities

This paper includes
summaries in
easy-to-read language

This publication has been produced with the financial support of the Civil Justice Programme of the European Union. The contents of this publication are the sole responsibility of the Project Partners and can in no way be taken to reflect the views of the European Commission.

The AJuPID project Overview

About 4.5 million people with intellectual disabilities live in the European Union (EU). That is about as many people as are living in Ireland. Many disabled people are restricted in their legal capacity; often they have a legal guardian who takes some or all decisions for them. Their access to justice is also limited due to the lack of accessibility or reasonable accommodation.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) confirms the right to full legal capacity and the right to access to justice in Articles 12 and 13. Persons with intellectual disabilities should be able to decide for themselves and access the justice system on an equal basis with others.

The Access to Justice for Persons with Intellectual Disabilities (AJuPID) project aims at informing potential supporters as well as staff in the judiciary about the rights of people with intellectual disabilities and how to support them adequately via training, sensitisation events, a website and this 'Guide of Promising Practices'. These tools are based on a research report comparing the legal systems of five countries – Bulgaria, Finland, Hungary, France and Ireland – in access to justice for persons with disability.

The AJuPID project is co-funded by the Directorate-General for Justice of the European Commission. The project was launched in April 2014 with a duration of two years. It has ten partners from six European countries: Belgium, Bulgaria, Hungary, Ireland, Finland and France.

The Scientific and Ethics Committee

The universities of NUI Galway in Ireland and KU Leuven in Belgium are part of the Scientific and Ethics Committee within the AJuPID project, as they have a renowned expertise in the field of disability rights, and thus led on the research conducted. The Mental Disability Advocacy Centre (MDAC) in Hungary and the European Fundamental Rights Agency are also a part of the Scientific and Ethics Committee, advising the partners on aspects of the UNCRPD in relation to the results and tools of the AJuPID project.

The Service Providing Partners

Five of the partners provide services to people with intellectual disabilities. They are responsible for identifying promising practices of support for disabled people. In addition, they will train supporters of legal capacity and conduct sensitisation events for judges and court staff on the national level. The five partners are:

- Foundation NET, Bulgaria;
- Service Foundation for People with an Intellectual Disability (KVPS), Finland;
- National Federation of Service Providers for Persons with Disabilities (FEGAPEI) France;
- Hand in Hand Foundation (KézenFogva Alapítvány), Hungary;
- National Federation of Voluntary Bodies (NFVB), Ireland.

The European Network

The European Association of Service Providers for Persons with Disabilities (EASPD) is also a partner in the project. EASPD is responsible for gathering information about disability rights on the European Union level and for sharing the results of the project with other organisation in other countries.

Table of contents

Introduction to promising practices

As one of the objectives of the AJuPID project, we aimed at identifying promising practices that would support persons with intellectual disabilities to exercise their legal capacity, to take their own decisions and to access justice; if necessary, with the support of friends, family, professionals and other supporters in their surroundings.

To do this:

- we drew up a questionnaire with criteria which helped us to ask the right questions and to identify promising practices;
- we organised study visits to five countries to learn more about the practices and to see if they would transfer to other national contexts;
- the partners, including the Scientific and Ethics Committee, evaluated each practice;
- we looked at promising practices in place in other countries beyond the European Union.

This effort resulted in this guide of promising practices.

Why "promising" practices?

During the course of the AJuPID project, we realised that there were not only a lot of good intentions around Europe, but also many practices in place that are innovative, yet still on an experimental level. Most of the practices we have chosen have not yet proven to be effective in the long-term, nor have they been mainstreamed at present. Some of the practices could be developed further so as to be in even closer alignment with the prerequisites of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). To reinforce the view that there is still room for development and upscaling, the partners of the AJuPID project decided to call the practices in this guide "promising", rather than "good".

What makes a practice promising?

A promising practice incorporates the philosophy and values shared by the partners of the AJuPID project; these are based on the UNCRPD and our common interest to support people with disabilities in enjoying their legal capacity and gaining access to justice.

The promising practice clearly supports people with intellectual disabilities in taking their own decisions or accessing justice directly, and thus having autonomy and control over their lives. Some practices might not have been designed specifically for persons with intellectual disabilities. However, we consider that they are adaptable and so therefore can be used to assist persons with intellectual disabilities. Some promising practices also support people in gaining more control over their lives, which we reckon constitutes a crucial step towards regaining or securing legal capacity.

All promising practices are based on discovering the will and preferences of a person and supporting their own decision-making, rather than merely acting in their 'best interests'.

AJuPID

Promising practices on legal capacity

> *“**1.** States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*
>
> ***2.** States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*
>
> ***3.** States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*
>
> ***4.** States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.*
>
> ***5.** Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.”*

Article 12, UN Convention on the Rights of Persons with Disabilities

This publication has been produced with the financial support of the Civil Justice Programme of the European Union. The contents of this publication are the sole responsibility of the Project Partners and can in no way be taken to reflect the views of the European Commission.

Network of support –
Empowering People with Intellectual Disabilities

> **Organisation & country:** Regional Society for Support of People with Intellectual Disabilities (RSSPID), Vidin, Bulgaria.
>
> **Date of implementation:** 2013 - 2017.
>
> **Target group:** people with intellectual disabilities, supporters, families, legal guardians, psychiatrists and other experts in the region of Vidin.
>
> **Type of solution:** network of support.

Supported decision-making allows you to take your own decisions
with the help of supporters.
You can decide where to live or how to spend your money.
You can decide with whom you want to have a relationship.
You can decide with whom you want to spend time.
You can decide who you want to be your doctor.
When you find it difficult to make a decision on your own
you can get support from people you choose and trust.
These people are your network of support.

Context and problems targeted

In Bulgaria, as in many other countries, people with intellectual disabilities are still considered 'unable to make decisions' and are thus placed under guardianship. Under the current law and practice, this puts persons with intellectual disabilities at risk of abuse, as the legal guardian may take all the decisions for and on behalf the person concerned, without in any way having to consult them.

In contrast, the 'Empowering People with Intellectual Disabilities' practice aims to replace substitute decision-making and legal guardianship with a type of supported decision-making practice.

Implementing this promising practice

At its broadest, supported decision-making is a natural part of life. Nearly all people faced with a significant decision will seek the support of others.

Supported decision-making is about empowering people with disabilities, recognizing their legal capacity, and supporting them to make decisions about their lives. This allows the person concerned to have control over his or her own life.

The pilot project 'Empowering People with Intellectual Disabilities' aims at demonstrating the practical feasibility of supported decision-making and thereby advocating for a change in legislation concerning the legal capacity of people with intellectual disabilities in accordance with Article 12 of the UNCRPD.

This form of supported decision-making starts with establishing a **network of support** for the person. Sometimes this practice is referred to as a 'Circle of Friends' or a 'Circle of Support'. In order to identify the people who will be included in the network of support, a personal profile is made and the members of the network of support are chosen by the concerned person; a relationship of trust between the person and the members of the network is essential. The network provides the necessary support to the person concerned according to their wishes and choices. The whole process is guided and monitored by a facilitator.

The type of decisions which are covered by the supported decision-making model developed during the project cover the following areas:

- Accommodation (for example the type of accommodation, location, whether to live alone or with others);
- Relationships and lifestyle (includes choosing who to spend time with and doing what activities);
- Choices about work, education and recreation;
- Health issues (consideration of advice from health professionals including making choices about treatment options);
- Financial decisions (how to manage, spend or save money);
- Contracts (providing the necessary support to the person in order for him/her to understand the meaning of a contract).

Specifically excluded from the supported decision-making model developed during the project were decisions about marriage, voting and religion.

Outcomes and results

In the pilot project in the Bulgarian town of Vidin, networks of support have been established for 15 people with intellectual disabilities, with the assistance of a facilitator. Two cases have been successfully taken to court to remove guardianship measures imposed on two persons with disabilities.

As a parent organization with experience in working with people with intellectual disabilities and their families, RSSPID Vidin was able to successfully pilot a supported decision-making practice, which will replace overly restrictive measures under the current guardianship system in Bulgaria.

Expected developments in the future

In the third phase of the programme, the regional branch of the Bulgarian Association for Persons with Intellectual Disabilities (BAPID) in the town of Vidin will establish networks of support for three further people with intellectual disabilities. Professional facilitators will be trained to guide people with disabilities and their families through the process of putting into place the networks of support.

In addition, a training programme in advocacy and self-advocacy will be developed.

A new draft law on legal capacity will be introduced in the near future. This law safeguards the legal capacity of people with intellectual disabilities. It is expected that the proposed new law will allow for networks of support, giving disabled persons the possibility to exercise their rights and to take their own decisions.

Contact details

BAPID
10 Lavele Str. ap.16, 1000 Sofia, Bulgaria
Tel. +359 (0) 2 4174419
E-mail: bapid@bapid.com

Regional Society for Support of People with Intellectual Disabilities (RSSPID)
13 Steffan Karadja Str., 3700 Vidin, Bulgaria
Tel.: +359(0)94644719
E-mail: rdpluz@hotmail.com

Links

Project description:
http://bapid.com/bapid/?page_id=108&lang=en

Self-directed support

Organisation & country: Kehitysvammaisten Palvelusäätiö (KVPS), the Service Foundation for People with an Intellectual Disability, Finland.

Date of implementation: 2010 - 2013.

Target group: persons with disabilities, municipalities responsible for service provision, public servants, supporters, families.

Type of solution: flexible, person-centred support for persons with disabilities.

We call self-directed support SDS for short.
SDS is an option you can choose to organise your social care.
With SDS, you have greater choice about the services you need
to support you in everyday life.
You have control over the funds given to you for your services
by the government.
You can take an active role in organizing your support.

Context and problems targeted

Self-directed support (SDS) is an approach to care, support or independent living that seeks to improve people's choice and control over their support arrangements.

People and their lives, needs and aspirations are different. Service systems tend to narrow the choices for support for persons with disabilities down to traditional, somewhat rigid services which are group-based and may inadvertently congregate people with disabilities together, separate to the broader community (e.g. all the people with intellectual disabilities in one town going to the swimming pool at the same time). Often there are only limited support arrangements to choose from, with not enough really inclusive options. This underlines the point that person-centred planning (PCP, discussed below), as a set of approaches designed to assist people with intellectual disabilities to plan their life and supports, is not enough, if subsequently there are no real choices or the limited options offered are always the same for everyone.

Finland has taken the decision to apply public tendering to all social and health services, including services for persons with disabilities. In the tendering processes service organizers (buyers) are communicating with service providers (sellers) directly with the result that often service users' voices remain unheard.

With the model of SDS, the person with disability is at the centre of planning and organizing services, and support is arranged as flexible as possible around the person, according to his or her real support needs and aspirations.

Implementing this promising practice

The two Finnish NGOs, KVPS and FAIDD, developed a model for SDS that fit in the Finnish legal context as a way of providing disability services. A mutual dialogue with the Ministry of Social Affairs and Health, the Association of Finnish Local and Regional Authorities, the Social Insurance Institution, disabled peoples' organisations, local authorities and service providers was undertaken. Also, an international learning partnership was created, the main partners being 'In Control' and 'The Centre for Welfare Reform' in England.

The principle focus of the pilot project was to increase the number and range of opportunities of self-direction for people with disabilities in the Finnish disability service system.

Models of personal budgeting and person-centred planning were piloted in two geographical areas in collaboration with local authorities. Participants in these pilot projects included people with disabilities, their families, support staff, local authorities and service providers.

The participants were offered training, consultation and peer group activities to support them during the process. The project also produced different materials about SDS and person-centred planning for young people and adults with an intellectual disability.

Process

- **Step 1: Person-centred planning (PCP)**

With PCP, the person's wishes, aspirations and strengths were discussed and described with the person and their closest ones. Self-directed support often focusses on future changes in life and possible support arrangements. Therefore it is vital to discuss also: 'What do I want to keep in my life? What are the things that are working well for me already?'

- **Step 2: Evaluation of support needs**

This was done through self-evaluation or by evaluating the support needs together with the person and the local authorities using the methods and assessment tools that social workers were already using, or the easy-to-read "Näin minä pärjään"–Tool developed during the project. On the basis of the evaluation, a draft of the personal budget was made. If the person, for example, wanted to change their support for housing or what they do in the day, it was vital to know to what kind of services and funding this person is entitled to on the basis of the Finnish disability-related legislation.

- **Step 3: Creation of the personal budget**

A personal budget was derived according to the things the person wanted to change and achieve and their support needs. The things that were already working for the person were left untouched.

- **Step 4: Support plan**

The support plan was made by the person concerned, with the assistance of their entourage and a social worker/case manager. The support plan clarifies, what kind of support arrangements are made, how they are made, and when and how people deal with possible risks. The support plans were then discussed and evaluated by public authorities, responsible for funding.

- **Step 5: Personalizing support**

Often, changes in the support or other arrangements were then put in place. Sometimes this meant hiring a personal assistant or a support worker, changing the place of living from an institution to one's own flat, learning new things or getting a job and getting the right support for it. The personal budget was only used to support activities laid out in PCP.

- **Step 6: Evaluation**

Finally, exchange and evaluation by the person, his or her closest supporters and the public authorities served to make sure that the support is right. This creates a process of positive change and good co-operation between persons with disabilities and local authorities.

Outcomes and results

The results of SDS have been very promising in Finland. Although Finland is still at a phase with no changes in the legal system, the process continues in the pilot areas and new stakeholders are coming on board. Currently, Finnish social care and disability-related legislation is undergoing change and new laws will be based on inclusion, self-determination and equal participation.

There has been clear empowerment of the people with disabilities and their families during the process. Many have moved on in their lives, getting better support or learning new skills. The families have found new strength to enhance their family member's lives.

The cost of the support has remained the same, but clearly with better outcomes. The local authorities have been very satisfied with the evolution of social work and the collaboration of social workers and service users during the process. The importance of hearing the service users' own voices has been realized and local authorities are moving towards real partnership.

The process is appreciated as a very worthwhile experience that moves away from the traditional way of organizing care towards the era of citizenship and self-determination.

Testimonies

Sirpa's Story

Sirpa lived in different group homes for almost 30 years. She suffered because the housing and services were too institutionalised. *"We had schedules for eating and other daily routines. Service was not personalised,"* Sirpa complained. She didn´t want to live in a group home anymore and that is why she was seen as a 'difficult customer'.

Her life changed in 2012 when she moved to her own home: *"It was a huge change. I´ve slept better than ever, because it is so quiet. I can do what I want. It is my home, my rules. I get personal assistants and they do what I ask them to do."*

Sirpa receives services from the South Karelia Social and Health Care District (Eksote). Eksote was one partner in the pilot project for developing self-directed support in Finland. Because of the project, Sirpa finally had the chance to say what kind of services she really wants: *"For the first time in my life I felt that I was listened to. At first I hesitated – can I manage it on my own? But then I thought that it can´t get any worse."*

Sirpa gets personal assistance 4-5 hours per day – as much as she needs: *"My services are even cheaper than before. At the same time the quality of my life has increased significantly."*

Why did it take such a long time? Why did we need a pilot project to make this all happen? *"When I moved away from my childhood home the only possibility was a group home. After that, the system of personal assistance had developed. Because of the self-directed support people are better listened to,"* Sirpa says.

Because of SDS Sirpa is able to direct her own services. She decides on how she wants to live her life and what kind of services she needs.

Pekka's Story

Pekka is a young man who communicates with gestures, signs and vocalizations. He has a diagnosis of severe autism. Sometimes Pekka also writes with some support. Pekka's everyday life can be challenging; he gets frustrated if he does not have enough meaningful activities.

Pekka's mother Kristiina heard that Pekka's hometown Vantaa is about to join the pilot project for self-directed support. She was interested, although she found it difficult to imagine the relevance for Pekka.

Soon after that, Pekka attended project meetings with his mother. During these meetings an individual support plan was made together with Pekka and his supporters. Pekka's views about his own life were clear: *"I´m a man. I want to do men's work. I would like to have a girlfriend."*

Pekka has been working in a local activity centre for years. He was often frustrated, because he did not enjoy craftwork. Pekka's mother was pleasantly surprised, because the project workers and municipality service advisers agreed with Pekka and his plans. *"It was lovely that we were surrounded by people who had the courage to find new ways of doing things and take risks! Happiness and safety are equally important. You cannot achieve anything if you don't have the courage to try,"* says Kristiina.

Self-directed support allowed Pekka to change his workplace. The cost for the municipality remained the same. Pekka now works on a farm with horses and gets flexible support from a local provider. Pekka's supporter says that Pekka's skills, and particularly concentration and self-esteem, have increased significantly. He is calmer and relaxed when being out in nature taking care of horses.

"Pekka has had a huge amount of new experiences. He has learned new skills and he has had an opportunity to do meaningful work. When Pekka is making his own choices he is happier and also healthier. Pekka has had fewer epilepsy seizures and sleeping difficulties lately," mother Kristiina declares.

Kristiina thinks that self-directed support is one way to increase equality, self-determination and inclusion; it enables personalised services. *"Self-directed support is a tool that helps people to make their dreams come true. We all want to live an everyday life that makes us happy!"*

KVPS and FAIDD have been collecting written and video stories about the positive effects of self-directed support. Videos in Finnish: http://verneri.net/yleis/kokemuksia-henkilokohtaisesta-budjetoinnista

Expected developments in the future

So far, Finnish legislation does not include SDS. Together with other stakeholders, KVPS is lobbying to make necessary changes to several laws concerning disability services and social care. These laws include the upcoming disability law and the law on public procurement.

Major strengths of the practice

According to the research, clear strengths of the solution are that SDS is possible even without an adequate legislative framework, if it is made to fit flexibly into the existing service system.

People benefit from individual solutions and support, when they are directing their own support arrangements. There has been a clear empowerment of people with disabilities and their families during the process.

Social workers and case managers have been realizing the importance of hearing and listening to the person's own voice and have moved towards real partnership and personalization. If the support and solutions provided are right, this creates a driver for positive change which leads to more independence and better lives of the persons with disabilities.

People with disabilities need support as well as good quality services and service providers. Therefore SDS creates opportunities for flexible and innovative service provision at local or national level.

Possibilities to further develop the practice in line with the UNCRPD

SDS appears to promote the rights contained in the UNCRPD Articles 9 (Accessibility), 12 (Equal recognition before the law) and 19 (Living independently and being included in the community). SDS is not in contradiction with the Finnish legislation, however it is not officially recognized as a way of organizing social services as of yet.

SDS promotes the self-determination of persons with disability, who can express their wishes and aspirations. With SDS, the person is placed in the driver's seat of their own support.

The EU's Public Procurement Directive recognizes SDS as an example of customer choice, which is not required to be put under public procurement: *"Situations where all operators fulfilling certain conditions are entitled to perform a given task, without any selectivity, such as customer choice and service voucher systems, should not be understood as being procurement but simple authorisation schemes"*[1]. Therefore, the procurement directive is in line with the aim of self-determination in social services across Europe.

Contact details

Aarne Rajalahti, Director of Development Activities,
Kehitysvammaisten Palvelusäätiö (KVPS)
Tel.: +358 (0) 207 713 516
E-mail: aarne.rajalahti@kvps.fi

Links

Näin minä pärjään (Easy-to-read tool for SDS in Finnish):
http://www.kvps.fi/images/tiedostot/Julkaisut-Raportit/Nain-mina-parjaan-2013.pdf

1. Directive 2004/18/EC, Art. 4,
http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32014L0024&from=EN (last viewed 23.06.2015)

Multidisciplinary support for people with social difficulties

Organisation & country: Association pour la Prévention, l'Accueil, le Soutien et l'Orientation (APASO), the Association for prevention, support and orientation, France.

Date of implementation: since 1989.

Target group: persons with social difficulties (with or without intellectual disabilities).

Type of solution: multidisciplinary support as an alternative to legal guardianship.

Sometimes you are facing difficulties with money, friends or family.
A social worker can support you in sorting things out.
The social worker may propose a support contract to you called a MASP.
If you sign this contract, you will receive support to organise your life.
The MASP will be in place for a certain period of time.
During this time, your support person gives you advice and support.
Your support person provides help in financial issues, like going to the bank, but also in personal issues like having relationships.
Your support person will never take decisions for you.
A MASP is a good way to gain autonomy and self-confidence.

Context and problems targeted

In 2007, a new law reformed the guardianship system in France introducing a new measure: the MASP, a personalized social care measure. To a certain extent, the MASP is considered an alternative to legal guardianship. No judge or psychiatrist is involved in the management of a MASP, there is no restriction of legal capacity nor any managing of finances without the consent of the person concerned.

The local authority can either implement the measure themselves (which is mostly the case) or delegate the implementation to a service provider or NGO. In Paris, APASO is one of the two NGOs in charge of the MASP. Since 1989, APASO has been supporting persons with complex difficulties via a multidisciplinary approach.

Implementing this promising practice

The MASP supports people who have trouble in managing their finances or have health problems and receive social benefits. In Paris, the local authorities exceptionally also make this service available to retired people or extremely poor people who do not receive social benefits. 30% of the persons who are using a MASP at APASO are recognized as persons with disabilities by the French administration.

The MASP is initiated by a contract between the local authority and the person concerned. The first contract lasts for a year, but the measure can be extended to up to four years. It is entirely up to the person to decide whether they want an extension.

The person involved also decides for themselves what the objectives of the contract should be: those goals can be financial, health-related, finding employment, etc. A contract is always very personalised, so it may also include very practical points such as learning how to cook or engaging in a sports activity. The contract is of merely symbolic nature, as the person can terminate it at any moment. This occurs very rarely, as the person has chosen to enter the MASP and has the option to leave.

APASO employs various different professionals: social workers, psychologists, lawyers, employment counsellors or activity facilitators. They offer:

- a mix of both individual meetings and group activities (yoga, relaxation therapy, theatre, culture, writing, crafts);
- a mix of both social and legal services, as many of the persons benefitting from a MASP have legal problems, often a hindrance to access to rights.

In Spanish, ‛paso a paso’ means ‛step by step’; this inspired the name APASO. In other words, APASO’s goal is to follow the rhythm of the person concerned.

There are five main areas of support for APASO:

- Budget: to help people regain financial independence;
- Housing: to avoid eviction, to manage a household;
- Health: to assure that the person is taking care of themselves, to see medical professionals when needed;
- Administration: to support the persons in dealing with administrative issues;
- Employment: to support the person in learning French, applying for a job or an internship.

Outcomes and results

At the end of the measure, around 7 out of 10 people preserve their full legal capacity and become independent enough to manage their lives on their own. They are then oriented towards mainstream support services.

3 out of 10 people face problems regaining their autonomy. They may be oriented towards a guardianship measures. Of these three people, two will voluntarily choose the measure, and only one will consider that the measure is imposed against their will.

Testimony

Véronique[2], 55 years-old, is recognized as a person with disability by the local authorities. She signed a contract for a MASP in 2011. Suffering from a mental health problem, she was in the midst of divorce proceedings with her husband, who had beaten her. Unable to pay her expenses (rent,

---

[2] Name has been changed by the editor.

electricity, insurance) on her own following the departure of her husband, Véronique accumulated debts and was very confused about her priorities. A social worker, who was reflecting on requesting a guardianship measure for Véronique, finally decided to direct her towards APASO.

During four years, APASO accompanied Véronique. Initially, she was supported by a MASP-2 (co-management of social benefits), to manage her debts and to allow her to resume payments. After two years, she decided for a MASP-1 (without co-management), as she felt more able and autonomous to manage her own affairs.

Véronique lived in a flat owned by a private landlord. The rent was too high compared to her income. After intensive searching, Véronique was able to move to a transition house. To prepare for her move, she was supported in sorting out her belongings at her home during six afternoons.

Concerning her health, Véronique saw a psychologist at APASO and she was put in contact with an association specializing in the support of abused women. Visits to a general practitioner, a neurologist and a psychiatrist were also arranged.

During her divorce, Véronique was supported by a lawyer of APASO who worked with the attorney, particularly to explain the procedure and issues to her.

Véronique was very committed during the MASP, which was, as a consequence, a real success. She also took part in the socialization workshops of APASO (theatre, writing). At the end of the MASP, she was directed towards a Support Service to Social Life (SAVS).

Major strengths of the practice

This multi-disciplinary approach is a powerful way of supporting people who have complex needs, and are thus susceptible to the imposition of substituted decision-making. The mix of professionals is considered as one of the great advantages of the support via the MASP put in place by a NGO: all aspects can be delegated to the relevant supporter.

Thus, in APASO, one social worker supports a maximum of 25 persons, while normally in France a social worker cares for about 100 people.

A second strength is the fact that the MASP always requires the consent of the person involved. Experience shows that this considerably increases the efficiency of the measure; a relationship of trust gives the people concerned the courage to face their personal issues, because they can be sure to receive support when needed.

Possibilities to further develop the practice in line with the UNCRPD

Although it is important to have universally designed services which provide all people with appropriate support to exercise their legal capacity, there is a potential risk that people with intellectual disabilities will be excluded from benefitting from a MASP under the pretext that this is ‘too complicated’ or that they are ‘not able to give consent’.

In future, the MASP could be made more accessible to persons with intellectual disabilities with the involvement of self-advocates in the multi-disciplinary team or with the assistance of an advisory panel, consisting of self-advocates with intellectual disabilities, who can help ensure that the practice is as inclusive as possible.

Contact details

Emmanuel Feuillard
APASO Paris
88 Bv. Arago, 75014 Paris, France
E-mail: emmanuel.feuillard@apaso.fr

Supported decision-making pilot project

Organisation & country: Értelmi Fogyatékossággal Élők és Segítőik Országos Érdekvédelmi Szövetségének (ÉFOÉSZ), the Hungarian Association for Persons with Intellectual Disabilities with the support of Inclusion International and the Canadian Association for Community Living, Hungary.

Date of implementation: 06/2009 – 06/2010.

Target group: persons with intellectual disabilities, decision-makers, general public.

Type of solution: supported decision-making.

Ten persons with disabilities took part in a pilot project.

Here, we call them participants.

Some participants were under guardianship,
some had their full legal capacity.

The project was called ‘supported decision-making pilot project’.

The project took place in Hungary and lasted for one year.

It showed how supported decision-making can work.

First, every participant defined the goals, he or she wanted to reach.

Some participants wanted to learn how to handle their money better.

Others wanted to learn how to do their shopping themselves.

A supporter helped the participants to achieve their goals.

The supporter also helped participants to find other people close by
who can assist them.

The supporter did not decide for the participants with disabilities.

The supporter provided all the information they needed to make a decision.

The supporter helped the participants in making the final decision.

Context and problems targeted

The project was launched to gain experience in supported decision-making in order to influence guardianship legislation in Hungary. Besides guardianship, no other alternatives were provided for in Hungarian legislation to assist people with intellectual disabilities in managing their affairs and everyday lives. The project aimed to demonstrate that people with intellectual disabilities – irrespective of their guardianship status (partial or full legal capacity) – can manage their everyday lives with support tailored to their needs and without restricting their rights.

Implementing this promising practice

The project was planned to influence the legislation under development at the time, and demonstrate how supported decision-making could work in practice. A so-called 'professional supporter' assisted the participant throughout the whole programme. This supporter was chosen by the project committee, which consisted of special needs teachers and social workers. The project was located in Tapolca, a small town in the Northwest of Hungary, with approximately 20,000 inhabitants. Ten persons with learning and intellectual disabilities from Tapolca and its environs, aged from 18 to 42, participated in the project. Most of the participants lived with their families, except for two persons who live in a group home after having lived in residential institutions for more than five years. The project lasted for a year and every participant defined the goals they wanted to achieve by the end of the programme.

The main task of the project was to define and implement goals chosen by the participants. This process was facilitated by the 'professional supporter' as well as via the creation of support networks around each participant. Relatives, friends, neighbours and others in the closer environment of the participant could become part of the support network.

The implementation of the project was delivered through the following steps:

- **Step 1:** The professional supporter contacted all participants individually. The supporter met and got acquainted to each participant and identified possible other supporters (family members mainly, friends, neighbours etc.) around him/her.

- **Step 2:** Together with the members of the support network, each participant developed an individual plan, in which they identified the goals they wanted to achieve throughout the programme and the possible ways of implementing them.

- **Step 3:** The support network helped the participants to put their plans into action.

- **Step 4:** The professional supporter provided ongoing assistance to the participant with disabilities and to the members of the network.

Outcomes and results

The project made it perfectly clear that the following basic principles have to be taken into account in any policy and law making:

- People with intellectual disabilities should be prepared for supported decision-making, especially those persons who live in institutions. An individual, who has never had the chance to exercise decision-making in practice before, needs to acquire the appropriate skills and experience.
- The support should always be provided individually, taking into account the abilities of the person and their own demand concerning the extent of support provided.
- The collaboration of all the parties, and primarily of parents assisting their child to become as independent as possible, is essential.
- Decisions are often determined by factors that are not apparently logical from the point of view of a third party. The decision can nevertheless serve the individual interests of the person.

- Supported decision-making is closely related to self-advocacy. One of the basic goals of the self-advocacy movement is to encourage the (self-)conscious societal participation of persons with intellectual disabilities. ÉFOÉSZ remarked that participants, who had been engaged in self-advocacy groups before, were more successful throughout the course of the project.
- The role of the professional supporter is crucial in ensuring that persons who do not have relationships of trust with others, such as family members, can also have access to supported decision-making.
- It is essential to recognize the importance of smaller decisions. Everyday decisions, such as how one dresses, are also part of our personality and underline our autonomy.
- If the supporter faces difficulties in helping the person, they may be able to find a solution by collaborating with another professional.

Testimonies

One of the participants wished to be more independent in everyday life, particularly in shopping and handling money. She lives with her partner who helped her a lot in the household chores, but she wanted to be more autonomous. At first, she worked on her basic calculation skills with her supporter. Together they undertook exercises with money, then they started shopping together. She became more and more confident and independent throughout the project, and now undertakes the shopping by herself. During the project, the participant also got married to her partner.

Another participant was very interested in basic woodwork and carpentry. With the help of the supporter, he contacted a local carpentry workshop and the master was pleased to welcome him and teach him some basics about carpentry. The participant went to the carpentry once a week; he learned a lot and was very proud to work with the carpenter. Besides gaining new knowledge and fulfilling his dream, another great benefit was that he also became a part of the local community.

Expected developments in the future

Currently ÉFOÉSZ does not plan to launch other supported decision-making projects. The legislation on guardianship entered into force in 2014. Although it is not fully in line with the UNCRPD and the basic philosophy and principles of supported decision-making, persons with milder intellectual disabilities now do have the possibility of using this method of support.

Major strengths of the practice

Supported decision-making is not just part of a legislation framework, but a general approach towards people with intellectual disabilities, recognising them as autonomous individuals in every aspect of life, including social interaction.

Decision-making in general may not be interpreted as an isolated process. Nobody is truly independent of the influence of others. Our closer social environment (family members, friends, teachers) or other influences (advertisements, social expectations) always have an effect on us.

In almost all cases we make decisions with the assistance of others, simply because of the trusting relationship we have with a certain person or due to the lack of expertise we may have to make a complex decision. In spite of the support provided, a decision always remains independent and fully legitimate.

Many decisions are not based on a logical evaluation of a situation and may ignore the perceived best interest of the person. It is important to underline that persons with intellectual disabilities are able to establish their own choices, as every other citizen, keeping in mind that it is an important legal principle that an unwise decision is still a legal decision.

This described practice demonstrates this.

Possibilities to further develop the practice in line with the UNCRPD

The legislation on supported decision-making entered into force in 2014; it is not fully in line with the UNCRPD as underlined by the CRPD Committee of the United Nations. The Hungarian law on supported decision-making has been criticized for simply re-naming the guardianship role as a 'professional support' role. The same professionals who currently act as guardians can now be appointed as professional supporters but there is no reduction in the caseload of how many people a guardian can support. In addition, there is no real change in the professional's duties – which still seem focused on a 'best interests' approach rather than fully respecting the individual's will and preferences. In this context, it is also a failure to provide legal recognition for the 'natural supports' people with disabilities tend to rely on – including the informal support of friends, family and peers.

In this context, ÉFOÉSZ believes that one of the most important factors in effectively implementing this new paradigm for people with intellectual disabilities is the training of professionals, judges and other persons concerned in order to highlight the importance of change in attitudes. This change could contribute to moving from substitute decision-making to supported decision-making in the vast majority of cases.

Contact details

ÉFOÉSZ
Ms. Reka DANO
E-mail: dano.reka@efoesz.hu
http://www.efoesz.hu/

Supported decision-making trial

Organisation & country: South Australian Office of the Public Advocate (OPA), Australia.

Date of implementation: 2011.

Target group: people vulnerable to placement under guardianship, people with intellectual disabilities, people with cognitive disabilities, the guardianship authority (who were concerned about high rates of guardianship).

Type of solution: facilitating supported decision-making agreements, and supporting the participants with those agreements.

This practice helps people to make their own decisions.

It is designed for people with intellectual disabilities
and people with brain injury.

The person who needs help making decisions chooses a 'supporter'.

The supporter can be a friend, a family member
or someone the person trusts.

The person and the supporter sign a contract
which says the supporter will help.

The supporter cannot make decisions for the person.

The supporter helps the person to understand things,
like what a doctor is saying.

The supporter might tell other people what the person has decided.

The decisions might be about where to live or what medicine to take.

A 'monitor' is there to check that the supporter is helping
and not making decisions for the person.

Context and problems targeted

South Australia had high rates of entry into guardianship, and the OPA (which is the principal statutory body tasked with regulating and appointing guardians) were looking for a project to explore alternatives to substituted decision-making. Drawing on the principles enshrined in the UNCRPD the State of South Australia and the OPA began to explore ways of supporting people to make decisions for themselves, and to avoid entry into guardianship.

The researchers reported early in the pilot that they would approach two pathways to supported decision-making.[3] First, they would test whether it could function 'as an alternative to guardianship (for people who might otherwise be subject to guardianship if they cannot be seen to make decisions for themselves).'[4] Second, they sought to 'test supported decision-making as an early intervention strategy for people not yet under guardianship' which was aimed at preventing 'problems occurring in the future, avoid[ing] the need for guardianship orders and facilitat[ing] age appropriate responses and skills in self-determination.'[5] As well as testing whether supported decision-making provided an effective alternative to substituted decision-making, the researchers sought to identify 'the wider possible benefits of supported decision-making.'

Implementing this promising practice

The project design is quite simple: find people who were at risk of entry into guardianship (the 'early intervention group') and facilitate 'support agreements' with people they trust to help them make decisions over various welfare matters, including decisions about accommodation, health and lifestyle. Financial decisions were not covered. The program is described as a 'process of setting up supported decision-making agreements, and supporting the participants with those agreements.'

The participants were those with intellectual and cognitive disability or brain injury. Facilitators do not provide the support themselves, but help people to identify others who can support the individuals to make decisions, to set up agreements over how they will be supported, and help provide support to both parties in the supported decision-making process. Often the supporters who are chosen by the individual are friends, family or associates. The model works with the 'express will' of the individual, and helps to support people to make and communicate decisions on a whole range of issues in their lives.

The project coordinators enlisted 26 participants. People in serious conflict with their families and with psychosocial disabilities as their primary disability were excluded (for reasons of size and funding). Many of the participants could not read or write, and one woman could not communicate verbally at the outset of the project. Some participants – as often occurs with people with acquired brain injury – had a tendency to make impulsive decisions.

The facilitators would interview a potential participant, and spend time exploring what was important to them, what they wanted to change in their lives, and who they might trust to support them in making decisions. Once a potential supporter was identified, the nature of the project would be explained to them, and both parties would be asked to sign a 'contract' specifying the kind of support. The contract was flexible and tailored to each person and was often very simple in nature. Some contracts were further amended to add in extra criteria that were important to each individual, as they preferred. Specific supporters may have been chosen by the individual for specific decisions – like choosing who supports them for lifestyle decisions, or more significant decisions such as healthcare choices, planning their funeral arrangements or resuming contact with their children.

It is noteworthy that the research comprised an interdisciplinary 'Research Control Group' which included people with lived experience of disability, as well as family supporters. The experience of

---

3. D Chartres and J Brayley 'Office of the Public Advocate South Australia: Submission to the Productivity Commission Inquiry into Disability Care and Support' (Office of the Public Advocate 2010) 12.
4. Ibid.
5. Ibid.

those within the group ranges from law, social work, psychology, medicine, nursing, disability service reform, guardianship, quality improvement to counselling and academic research. This involvement of people with disabilities in the design, monitoring and implementation of the project was an important feature of the project, and in keeping with the directives for participation of people with disabilities under the UNCRPD.

Outcomes and results

The pilot study received a very positive final independent evaluation, and as a detailed model of supported decision making it has attracted international interest. Dianne Chartres and John Brayley, two of the designers and practitioners of the trial, list the general benefits for individuals as relating to 'citizenship; personal empowerment; self-determination; self-esteem; respect for decisions;… confidence in decision making; confidence in rights; development of decision making skills and capacity;… and increase in support networks.'[6] The independent review of the trial provides some empirical evidence to support these claims. The evaluation reported that:

"(T)here were specific benefits to most of the participants. These were seen in their increased confidence in themselves and in their decision making. There was evidence of improvement in decision-making skills. Participants described the growth in their support networks. Many reported that he or she felt more in control of their lives. Participants gave evidence that they had increased their engagement with the community, either through expanding their options or through making decisions that changed their circumstances."

Several people recruited to the project were on 'administration orders,' which is a form of property and affairs guardianship used in South Australia. The independent evaluation found that it enabled some people to successfully apply to come off their administration orders, and hence, fully restore their legal capacity through support.

Expected developments in the future

Since the pilot study, one of the organisers, Cher Nicholson, has continued to develop the model, in particular towards using people from the community to act as supporters. She has been running courses to train others in facilitating supported decision-making and in the near future there will be evaluations of greater numbers, from 26 individuals with support plans in the first instance, to hundreds.

Major strengths of the practice

The project was designed explicitly with Article 12 as its framework, and the trial drew from other parts of the UNCRPD to design the trial (including Article 16 on freedom from exploitation, abuse, and neglect). The trial does not rely on policy and legal change as it is a practice with immediate application whereby participants simply agree on a 'support contract' and begin the support relationship immediately. Yet the results of the trial can also be used to inform the development of policy and law in the future according to the specific needs, barriers or issues that arise as it is applied in practice in the specific place.

---

[6] Ibid 32.

Possibilities to further develop the practice in line with the UNCRPD

The pilot study was specifically developed in the light of the UNCRPD. Where there is room for development is in the broader application of the approach to a greater number of people, though this is starting to occur (see above). A trial in Victoria, Australia, is seeking to apply the approach to individuals who are isolated from family and the community – which may have been the result of institutionalisation. They are seeking to find supporters among citizen volunteers.[7]

Contact details

Office of the Public Advocate (South Australia)
PO Box 213, Prospect, 5082, Australia
Tel.: +61(0)8 8342 8200
E-mail: opa@agd.sa.gov.au

Links

Evaluation of the pilot study:
http://www.opa.sa.gov.au/resources/supported_decision_making

Project Description:
http://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/supported-decision-making/59-supported-decision-making-pilot-project-description/file

---

7. The author of this report is indebted to the following: L Series, 'What If…?' https://thesmallplaces.wordpress.com/2013/05/01/what-if/ (viewed 12 February 2015).

Circles of Support

Organisation & country: Brothers of Charity Services Clare, Ireland.

Date of implementation: 2014.

Beneficiaries targeted: people with disabilities, families and other supporters.

Type of solution: practice, method, technique.

We all need to know other people.

They may be family, friends, neighbours, people we work with or people who help us sort things out in our lives.

People with intellectual disabilities can sometimes find it harder to meet people in their local area.

Often they spend more time with paid staff or their close family, rather than have the chance to make their own friends.

A Circle of Support is a group of people that the person chooses to meet together as friends.

The group help to support the person to make their own decisions about their life.

Sometimes Circles of Support are called 'Circle of Friends'.

Context and problems targeted

People with intellectual disabilities are often socially isolated. Even if they are in receipt of support services, often these services inadvertently isolate people by pushing them into congregated services. This means people with intellectual disabilities often find themselves only having contact with a small number of people – usually paid supporters, fellow service-users, and their close families.

The vast majority of people rely heavily on informal networks to make decisions and to live the type of life that they want. However, for many people with intellectual disabilities these supports are unavailable or damaged by stigma and discrimination. This does not provide strong safeguards for a person's life. Many parents, for example, are concerned about what will happen to their adult son or daughter when they die and often see guardianship and institutional care as the only response.

The isolation experienced by people with disabilities – which is often inadvertently reinforced by services – can be seen as just another form of disability segregation where 'natural supports' are undermined. 'Circles of Support' are aimed at enhancing those natural supports. They seek to intentionally create the informal supports that most citizens take for granted.

Implementing this promising practice

A Circle of Support involves a small number of people coming together regularly to provide support to a person with a disability, who they care about. They might gather once a month, or once every few weeks. It might depend on the nature of the circle, the members or the support needs. Some people use Circles of Support for specific things they wish to achieve (such as finding a place to live or getting a job). Such issue-specific Circles may therefore be time-limited and only last for the duration of the issue. Other Circles go on for much longer and may serve as a source of constant support and counsel for the person over a person's whole life.

Professionals serve as facilitators or can help establish a Circle, though the intensity of their role will vary. Some Circles will require intensive support over a long period, or during periods of crises, while other Circles will function easily from the beginning, though they might seek out periodic support for certain things. It can be useful for a professional assisting with the establishment and facilitation of Circles to be independent of direct service providers.

It is important early on in a Circle of Support that the person – with the support of those closest to them if need be – should establish a vision for his or her life. Once the vision of his or her idea of the 'good life' is clear, it is easier to establish the purpose of the Circle (long term/short term, overarching/specific issue) and to recruit like-minded people who understand the vision and are committed to making it happen.

Some of the key features of Circles of Support include the following:

- Circles are made up of ordinary people and the peers of the person - people from their community and not those of a specific professional class;
- They facilitate ordinary people to play a role in a person's life;
- They invite people in to have a relationship with the person;
- They are made up of people working together towards a common dream or vision;
- They formalise what is typically informal;
- They are personalized based on the individual — no two Circles will be the same;
- They provide a chance to celebrate a person's achievements;
- They provide some relief for families, in terms of safeguarding the life of the person into the future - older parents of people with intellectual disabilities are not forced into thinking that the only safeguards for their sons or daughters are guardianship and institutional care;
- They can provide very practical support, such as identifying people to help with shopping, socialising, and so on.

There is a huge potential for Circles to Support people with decision-making and to follow up on decisions with actions. Ideally, Circles can begin in a person's early life, as needed, but they can also be beneficial for older people.

Outcomes and results

Every Circle is different because of the uniqueness of the dreams and aspirations of the individual at the centre of the Circle, as well as the uniqueness of the contribution of each Circle member. Thus a Circle is well placed to meet the individual needs, wishes and preferences of the person with a disability.

The Circle gives every participant the amount of responsibility they are comfortable with. There is no pressure. Support people in the Circle can be family members, friends, neighbours and other members of the local community as well as support workers and professionals; it is up to the choice of the person with a disability. Because of this large variety of supporters, the responsibility is shared more largely, and often leads to alleviating the large burden on family members.

Expected developments in the future

Circles of Support are very rare in Ireland, and it is envisaged that more and more families and individuals will make use of this practice. At present there are not many people or services in Ireland who are trained to provide this type of assistance to families. It is hoped that this form of support will be especially pertinent once the current reform of the Irish legal capacity and decision-making law is finalised.

Major strengths of the practice

Circles of Support have a number of strengths, including:

- Offering proactive practical support to people with intellectual disabilities to make the decisions that are important to them;
- Circles are informal and can help to counteract the excessive involvement of welfare services and guardians in the lives of people with disabilities;
- It is a practical expression of commitment to the idea that the person with disability is entitled to a good and ordinary life;
- It provides an important avenue for sibling involvement, which can serve as a useful model for age-appropriate support (e.g. by hearing from siblings of the same age it is easier to envisage what is a typical life and to avoid slipping into the mind-set that the person is a child or requires a life defined by ‘special’ services);
- Circles create countervailing forces that temper unequal relationships. This is captured in the saying *Two heads are better than one.* If a parent – or any one person – is the sole supporter of a person there is a tendency to resort to informal substitute decision-making or undue paternalism. People with intellectual disabilities almost always find themselves in unequal relationships. When there is a group committed to a vision of the good life, the power of a single supporter can be more easily challenged;
- The circle helps avoid isolation for both the person and their family. ‘Community care’ is a policy that has often led to people with intellectual disability being known well by no one. Circles facilitate a person being known, validated and supported to live a good life that is ‘profoundly ordinary,’ as with others the same age and in the same place. Families may equally feel isolated by their experience of disability. Circles help share support.

Possibilities to further develop the practice in line with the UNCRPD

There does not appear to be any conflict between Circles of Support and the UNCRPD. Circles of Support are often held as good practice in achieving the support envisaged within the UNCRPD. There may be room to reform laws in such a way that recognize the type of support that occurs in Circles of Support. This might include providing mechanisms to formalize the circle to serve as a ‘micro-board’ to help give expression to a person’s wishes and preferences. However, this is a legal formalization that might be unwelcome as the informal nature of Circles of Support is perhaps its greatest strength.

Contact details

Brothers of Charity Services Clare
Martina Rynne
Tel.: +353(0)65 6849400
E-mail: martinarynne@clare.brothersofcharity.ie

Sensitisation and advocacy campaign for a new law

Organisation & country: a coalition of NGOs, Bulgaria.
Date of implementation: 2013 - 2014.
Target group: lawmakers, civil society and the greater public.
Type of solution: sensitisation, awareness-raising.

People from the government got together with people from civil society.
Civil society are groups of people defending the interests of the citizens.
Together they drafted a new law for people with disabilities.
The new law will replace the old law on guardianship in Bulgaria.
The new law includes supported decision-making.
The new law abolishes all forms of full legal guardianship.
During the campaign for the new law, many events took place:
Films, exhibitions, newspaper articles and programmes on TV and radio
informed the citizens about the new law and the rights of disabled people.

Context and problems targeted

Persons with intellectual disabilities have been ‘invisible’ in the Bulgarian society for many years, as they were hidden away in social care institutions. In addition, the existing guardianship law inhibited people with disabilities from exercising their legal capacity.

A coalition of non-governmental organizations and other advocates familiar with the situation people with intellectual disabilities were facing, have been working for years to change the existing guardianship law. In 2012, the European Court of Human Rights ruled on the case ‘Stanev v Bulgaria’: the Court confirmed that Mr Stanev had been unlawfully detained and subjected to degrading treatment, therefore violating his right to liberty. His legal guardian had admitted Stanev to a remote social care home without his consent for more than a decade. The State of Bulgaria was thus found guilty of the violation of several human rights. Shortly after the ruling, Bulgaria ratified the UNCRPD. The context was therefore suitable for the preparation of change in legislation.

Implementing this promising practice

The Ministry of Justice formed a working group that began to develop new proposals to replace the existing restrictive legislation on guardianship for persons with intellectual disabilities. Experts from civil society organisations, such as Nadya Shabani and Marieta Dimitrova of the Bulgarian Center for Not-For-Profit Law and Aneta Genova of the Mental Disability Advocacy Center (MDAC) contributed significantly to the new bill. By the end of 2013, the Bulgarian Council of Ministers agreed to align Bulgarian legislation to the prerequisites of Article 12 of the UNCRPD, and in 2015, the Ministry of Justice published a draft bill for public consultation.

The new bill will fully replace the existing guardianship law: a system of various measures will be put in place that can respond to the individual needs of each person with an intellectual disability or a mental health problem. These measures include the possibility of making a preliminary declaration in case an individual, under whatever circumstances, loses the capacity to express their will and preferences in the future. Supported decision-making and co-decision-making will be provided for; both measures are based on a relationship of trust between the support person and the individual being supported. There are also measures applicable to urgent crisis situations, to ensure immediate protection of life, health and property of the supported person.

In the meantime, a group of NGOs, including the Bulgarian Association for Persons with Intellectual Disabilities (BAPID) and the Global Initiative on Psychiatry in Sofia, developed and tested support measures. The future principles of the law relating to support measures were applied to a number of cases. The project 'Empower people with intellectual disabilities', led by BAPID, created 53 support networks for independent decision-making by people with intellectual disabilities. During the project action was taken to revoke guardianship measures for four persons with intellectual disabilities. *(See page 6 for details).*

To raise awareness amongst society, the coalition of NGOs conducted various sensitisation events in autumn 2014. Films, exhibitions, interviews, newspaper articles, as well as programmes and discussions on TV and radio informed the public about the provisions in the new law and the legal capacity of people with intellectual disabilities or mental health problems.

Outcomes and results

The public has become more aware of the situation of persons with intellectual disabilities. The new law is based on a paradigm change, as well as an attitudinal change towards people with disabilities; the introduction of the new law has the potential not only to change the legal framework, but to impact on the values shared by the wider Bulgarian society.

The NGOs, which participated in the drafting of the new law and the sensitisation campaign, are now working more closely together to advocate for further change.

Expected developments in the future

The new law is expected to be adopted in 2015 and will fully replace guardianship measures. Supported-decision making has been adopted as a common practice by the organizations involved in the campaign and the pilot. Hopefully, the practice will be shared and adopted further, as required by the new law.

Major strengths of the practice

The approach to drafting a new and innovative legislation by establishing a working group made up of representatives of civil society organizations as well as staff from the Ministry of Justice can be seen as a major strength; this approach led to a draft legislation that is largely in line with the UNCRPD.

The pilot projects on independent and supported decision-making revealed that persons with disabilities, who had formerly been fully dependent on guardians, do have the capacity to find solutions and take decisions for themselves. Giving the power to decide to the individual concerned considerably increased their ability to control their lives and manage their affairs.

Contact details

NET Foundation
19,Rayko Alexiev str., Pazardzhik 4400, Bulgaria
E-mail: foundationnet@mail.bg; mariyana.branzalova@gmail.com

AJuPID

Promising practices on access to justice

> “**1.** *States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*
>
> **2.** *In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.*”

Article 13, UN Convention on the Rights of Persons with Disabilities

This publication has been produced with the financial support of the Civil Justice Programme of the European Union. The contents of this publication are the sole responsibility of the Project Partners and can in no way be taken to reflect the views of the European Commission.

Inclusion Finland KVTL Legal Aid and Legal Expertise

Organisation & country: Kehitysvammaisten Tukiliitto ry (KVTL), Inclusion Finland.

Date of implementation: 1999.

Target group: persons with intellectual disabilities and their families, Ministry of Health and Social Care, Ministry of Justice; officials, the supervisory authority, staff in services.

Type of solution: legal aid, advocacy.

KVTL is an association of people with disabilities.

KVTL supports persons with intellectual disabilities to get justice.

KVTL also supports families of people with intellectual disabilities.

KVTL provides free legal aid for persons with intellectual disabilities and their families.

KVTL also influences laws for disabled people.

KVTL shares information on the real life of disabled people and their families.

Context and problems targeted

In the past years, many changes have been made to the Finnish legislation and services for persons with disabilities due to the ratification process of the UNCRPD; the end of institutional care by 2020 is planned, as well as reforms to municipal services, health and social care.

Persons with intellectual disabilities and their families do not always have access to justice, because:

- they do not have enough power to direct their lives and services;
- they do not have enough information about the UNCRPD;
- they do not have enough information on legislative changes and their impact on their everyday lives;
- they do not always have the means to fight for their rights.

In order to implement the UNCRPD, new legislation and reforms, more information has to be disseminated and people need to be trained on the rights of persons with disabilities.

Implementing this promising practice

KVTL Legal Aid and Legal Expertise improves access to justice for persons with intellectual disabilities on individual, organizational and legislative level via:

1. Influencing legislation
2. Individual counselling and guidance for persons with disabilities
3. Communication and advocacy

Goals:

- Legislation safeguards the rights of persons with intellectual disability and human-rights based services responding to individual needs;
- The service system secures the needed help and support for persons with intellectual disabilities and their families;
- Self-determination of persons with intellectual disabilities is strengthened and persons with intellectual disability get support in decision-making.

Actions:

1. Influencing legislation

KVTL draws attention to the real life experiences and support needs of persons with intellectual disabilities and their families. KVTL Legal Counsels have first-hand knowledge about the real life of persons with intellectual disabilities, but also expertise on:

- how legislation affects the everyday life of persons with intellectual disabilities;
- how the current legislation should evolve;
- how to utilise current legislation to enforce the rights of persons with intellectual disabilities.

KVTL has played a significant expert role in working groups during the drafting of new legislation for persons with disabilities: persons with intellectual disabilities and their family members influence legislation directly, and also have access to background information on new legislation. KVTL makes use of this information also in legal aid and when training persons with intellectual disabilities and staff in services to improve access to rights in everyday life.

2. Individual counselling and guidance

KVTL gives free legal aid to persons with intellectual disabilities and their families. It also provides them with information and tools on their rights; this information is also available to social workers and service providers.

3. Communication and advocacy

KVTL is confronted with everyday life experiences of persons with intellectual disabilities and their families. KVTL uses these experiences to advocate and raise awareness amongst government, municipalities and service providers. KVTL provides information to media on the real life stories and better ways to develop support and services for persons with intellectual disabilities and their families.

Outcomes and results

1. Influencing legislation

KVTL Senior Legal Counsel played a significant role when preparing the new Disability Bill 2015, which follows a person-centred and needs-based approach. The bill leaves room for a strong service user's voice and also includes a section on support and training on communication and decision-making.

2. Individual counselling and guidance

KVTL deals with 1,000 cases a year giving free legal aid; the cases are related to the right to self-determination, the right to be heard, as well as services, and particularly housing and personal assistance.

Legal counsels train persons with intellectual disabilities and their family members, municipalities and staff. In 2014, over 700 participants were trained on the legal background, self-determination, supporting decisions and other legal matters. The trainings increased self-determination and the ability of persons with intellectual disabilities and their family members to receive the support needed. KVTL supports persons with intellectual disabilities and their families with tools and information so they can act on their own behalf and access justice.

3. Communication and advocacy

In 2015, KVTL successfully advocated for a debate on national television concerning the lives of persons with disabilities.

KVTL Senior Legal Counsel is a member of the Legal Counsel Expert Group (led by the National Institute for Health and Welfare THL) that monitors all legal cases related to disability matters. The expert group evaluates and disseminates good practices, which are available at the online service 'Disability Services Manual'. Over 100 cases are already listed; for example, cases on personal assistance and transportation issues are available which persons with intellectual disabilities and their family members can use as precedents to get access to justice.

Testimonies

Getting married

An adult with intellectual disability contacted KVTL Legal Aid. He explained that he would like to get married, but his parents were against it. KVTL advised him that getting married is a personal question that he can decide for himself. The man got married.

Sterilization against a person's will

A healthcare professional contacted KVTL Legal Aid. He stated that a 17-year old girl with a disability had been brought to the doctor for sterilization. When asked for her opinion, the girl voiced that she was against the operation. The healthcare professionals sought confirmation that the person's own opinion should be respected, which KVTL Legal Aid confirmed pointing to the right of self-determination. The operation was not performed.

Personal assistance for persons with intellectual disabilities

In 2009, the legislation concerning personal assistance for persons with disabilities was revised, risking that persons with intellectual disabilities would be deprived of this right. KVTL Legal Counsel intervened: persons with intellectual disabilities have the right to personal assistance and several cases in front of the Supreme Administrative Court have led to an improved application of the law.

Communication and supported decision-making in the new disability bill

KVTL Inclusion Finland Legal Counsel successfully advocated for adding a section on support and training for communication and decision-making to the new Disability Bill 2015.

Expected developments in the future

KVTL is looking into ways of facilitating the articulation of views of persons with intellectual disabilities, and also of persons who need support in communication or have profound disabilities. There is a need to support and strengthen the local advocacy work so that local organisations, persons with disabilities and their families can directly achieve access to justice in their everyday life. To this avail, KVTL is enforcing their support to local actors.

Major strengths of the practice

- A wide network and many contacts with persons with intellectual disabilities and their families, officials as well as other civil society stakeholders, which allow KVTL to act on the individual, organisational and legislative level;
- Expertise is based on experience and direct exchange with the persons concerned;
- A combination of juridical, communication and plain language expertise;
- A solution-oriented approach, including links to other innovative projects.

Possibilities to further develop the practice in line with the UNCRPD

KVTL will intensify its advocacy for supported decision-making in the Guardianship Act and the implementation of the new Self-Determination Bill, which was elaborated as an essential part of the UNCRPD ratification process. In addition, independent living and self-determination (UNCRPD, Art. 19) are high on the advocacy agenda of KVTL.

Contact details

KVTL Inclusion Finland
Sirkka Sivula, Senior Legal Counsel
Pinnikatu 51, 33100 Tampere, Finland
Tel.: +358(0)207 718 311
E-mail: sirkka.sivula@kvtl.fi

Focal points for access to rights in psychiatric hospitals

Organisation & country: Conseil Départemental de l'Accès au Droit (CDAD), the Regional Centre for Access to Rights affiliated to the Ministry of Justice, in collaboration with the Bar of Lille, France.

Date of implementation: since 2011.

Target group: persons with psychosocial disabilities hospitalised without consent.

Type of solution: legal aid and assistance.

Sometimes, you feel extremely upset, confused, angry or sad.
Someone decides that you need to go to a hospital.
You may be sent to a closed hospital that you cannot leave.
To get your rights, you can meet with a lawyer in the hospital.
The lawyer will help you to learn about your rights.
The lawyer will defend you, if you want.
The lawyer does not defend your family's or your guardian's wishes.
The lawyer helps you to defend your wishes and rights.

Context and problems targeted

Access to rights for people who are hospitalised without their consent is very difficult. The person may not be able to seek help and legal aid outside of the hospital because of the nature of their detention and treatment. In this particular case, the French administration realised that access to justice and support to exercise legal capacity should not only be available in court rooms but also in specialised services for people with intellectual or psychosocial disabilities.

This practice initially seeked to support people with psychosocial disabilities. Nevertheless, people with intellectual disabilities – for various reasons, including the widespread prejudice they face – tend to experience mental health issues at a higher rate than the general population. Therefore, this measure, originally designed to assist people with psychosocial disabilities to secure their rights, is also likely to benefit people with intellectual disabilities.

Implementing this promising practice

The Bar of Lille created free legal aid meetings in the hospitals themselves (similar to models in prisons, which are also restricted environments). In France, the Law of the 10th July 1991 created 'access points to rights/legal aid' throughout the country, as a free legal aid scheme. Based on this experience in defending the rights of people hospitalised without consent, in 2011 the Bar of Lille decided to also install some 'access points to rights' for psychiatric patients in psychiatric hospitals. The service is public and financed by the CDAD.

Once a month in each hospital, a lawyer has a three hour permanency: two hours for appointments, one hour where everyone is free to come in. This service is offered for free to the person concerned. If a patient wants to see the lawyer, they do not need to reveal to the hospital why they wish to see a lawyer.

First of all, the meeting consists in giving the patient information about the function of a lawyer and their general rights.

The lawyers are specially trained. In order to defend the rights of people hospitalised without their consent in front of the judge, the lawyer can use a questionnaire to assess whether the client knows and understands their situation. This document is used at the discretion of the lawyer, and will only be handed to an investigator if the lawyer is charged for mismanaging the case.

Outcomes and results

Often, the meeting with the lawyer is the only opportunity for the hospitalised person to express and defend their will and preferences. Indeed, according to the professional code of legal ethics, the lawyer is committed to defending whatever the person wants to achieve, even if the lawyer does not agree. In other words, the lawyer defends the will of the person, rather than their best interest: the lawyer is fully independent and may not communicate with the family.

Practice shows that people making use of this service also find it easier to understand their rights (outside the restricted environment), including some very practical issues such as everyday life questions related to work, housing, or social benefits.

Expected developments in the future

This scheme has been duplicated in other areas in France, although this service is still scarce. Further expansion of this type of service is planned.

Major strengths of this practice

This practice targets people with disabilities who usually experience intersectional discrimination. Moreover, it provides access to justice in closed environments and outside court rooms or services provided by organizations.

As the service is provided by lawyers whose professional code of ethics obliges them to defend the rights of the person in any case, they strictly respect the will and preferences of the person and do not act in his or her best interest. In addition, the lawyer counsels only the person concerned, and not to the family or the guardian.

Finally, this practice is also very effective because all lawyers are especially trained to be part of the service. They receive ten hours of courses on law, psychiatry, support and care, as well as professional ethics.

Possibilities to further develop the practice in line with the UNCRPD

This scheme of local points for access to rights could be extended to all closed psychiatric hospitals, but also to housing services for people with intellectual disabilities. Mental health legislation, which makes involuntary treatment and detention lawful, has been brought into question by the UNCRPD. The UNCRPD indicates that mental health legislation is discriminatory against people with psychosocial disabilities or mental health issues as it applies different standards to healthcare, decision-making and liberty rights compared to other citizens.

Contact details

Hélène GAUTIER-GORRE
Bar of Lille, Palais de Justice, 13 Avenue du Peuple belge, 59034 LILLE Cedex, France
E-mail: acces.droit@avocats-lille.com
www.avocats-lille.com

General information and legal aid

Organisation & country: Autisták Országos Szövetség (AOSZ), the Hungarian National Autism Association, Hungary.

Date of implementation: 2012.

Target group: people living with Autism Spectrum Disorder (ASD), their families and supporters; officials, judges and court staff.

Type of solution: general information, legal aid and practical advice.

AOSZ is the Hungarian Autism Association.

AOSZ gives practical and legal advice to people with autism and their families.

AOSZ informs the general public about challenges people with autism face.

People with autism learn to take their own decisions.

People with autism also learn to communicate better with others and ask for help, if they need it.

Families learn how to better support their family members with autism.

AOSZ also informs judges and others working in courts about how people with autism can take their own decisions and how judges and others working in courts can support them.

Context and problems targeted

Persons with ASD are at high risk of victimization as they may have difficulty in communication, poor social skills and situational awareness, as well as a lack of proper self-reflection. Managing money matters and advocating for their own rights may also be challenging. In addition, it is rare that persons with ASD ask for help and support.

Person-centred support, including supported decision-making, is still very unfamiliar and a new legal institution with no track record, while guardianship is widely known and applied. A change of attitude in the society is an ongoing challenge that is impeded by a lack of information about supported decision-making and other support measures in line with the UNCRPD.

Implementing this promising practice

AOSZ offers a service that is based on absolutely voluntary requisition and aims to provide personalised assistance. AOSZ gives as much assistance as needed, and is required by the clients with ASD. Some of the staff members are parents with children living with ASD, thus they are well aware of the challenges their clients face.

The service is granted in a relaxed and familiar atmosphere. The staff empathetically welcome the client, providing sufficient time for the client to communicate their problem. AOSZ talks to the client individually and/or to parents, family members, supporters or experts who know the client so they can understand all aspects of the problem.

For persons living with ASD:

It is very important to have adequate family support as well as a social network. Thus AOSZ supports the family in taking on responsibility. In addition, AOSZ develops the personal skills, such self-reflection, social skills and communication of people living with ASD, and fosters situational awareness and encourages them to request help, if needed. This is done with the support of various experts and using ASD specific methods.

For supporters and other members of the society:

AOSZ encourages the cooperation and communication of the various experts, such as special needs teachers, doctors, therapists and other supporters as well as the family to give effective assistance and support. Adequate information about supported decision-making is disseminated to the greater public.

AOSZ also raises awareness and trains officials (authorities, courts, etc.) and judges, who may come into contact with persons with disabilities, in order to sensitise them to the barriers people with autism may face, giving them indications on who they may have to inform and who they can to turn to, if assistance is needed.

Testimonies

The case of Rajò

Rajó[8], 58 years old, has never worked and used to live with his father in their apartment.

Rajó had never been under a guardianship measure. Although he could communicate quite well, he was easy to influence and had no sense of the value of money. When Rajó’s father died, he inherited the apartment. Rajó’s life partner tried to support him in every way. However, the partner was not very good at dealing with finances either. Debts for expensive therapies and unnecessary expenditures accrued leading Rajó and his partner to take out loans, which they were unable to repay. The payments for the mortgage on the apartment were also pending, and Rajò was at risk of losing his home.

The psychiatrist suggested that they should contact AOSZ for help. AOSZ negotiated with the bailiff and Rajò sold his property in order to buy a smaller one to repay his debts. AOSZ also assisted him in choosing a new apartment and in calculating his expenditure, as well as his tax liabilities. The organisation also represented Rajò in legal matters.

After the death of his father, Rajò had no family support and no one in his closer entourage that he could trust with financial matters. He needed a financially competent person or advisor to assist him with budgeting and assessing the consequences of various decisions.

Rajò needed to be encouraged to seek help and become aware of his limits. In close cooperation with the therapist, he was able to improve the ability to recognize a given situation. Later, Rajò’s financial problems reoccurred. He therefore decided to apply for a conservatorship.

8. Name changed by the editor.

The case of Solt

Solt[9], 34 years old, lived independently in an apartment. He used alcohol to mitigate the problems arising from autism. Solt was unable to work, but has an aunt whose husband helped him to apply for the respective benefits. Solt's mother was also suspected to be autistic, but has not yet been diagnosed. Other relatives, who could help, were living abroad. Solt had no sense of the value of money and found it difficult to deal with financial issues.

At some point, Solt became acquainted with some people in a pub, who won his trust. They persuaded Solt to buy telephones for them on hire purchase in his own name, but failed to pay the instalments. Solt was then charged and sentenced to 40 days of public work.

Solt reported himself for public work, but he was sent away and instructed to wait until he were summoned. As he received no summoning document, he never participated in any public work. One day, the police checked his identity in the street and arrested him: Solt was sentenced to imprisonment, and his relatives sought help from AOSZ.

In the meantime, Solt was placed under conservatorship, fully limiting his legal capacity. He was imprisoned for a short time and had already started to serve his sentence, so AOSZ could not help at first. Therefore, AOSZ consulted the relatives and also talked to Solt when he was released.

The relatives sought information from the public employer; AOSZ pushed for an inspection of the court documents. It turned out, that the judge had failed to appoint a defender, because Solt did not ask for one. The court did not inform his relatives, either. According to the judge, it was possible to communicate with Solt, and he understood the proceeding, as well as its consequences. At first, a conservatorship was not considered either, as Solt did not explicitly request for one.

It also turned out, that Solt had been informed about his summon to public work via registered mail several times, but did not request for the letters at the post office. The public employer thus returned the documents to the court and refused to employ Solt.

The judge failed to recognize the situation, to take the necessary measures, to seek help and inform those concerned. In addition, the later appointed conservator did not support Solt appropriately.

Outcomes and results

Persons with ASD develop their skills as their self-esteem grows: they exercise their right to make choices and receive support, when needed.

Through the sensitisation of judges and officials working in the justice system, access to justice of disabled persons improves.

Expected developments in the future

The international debate around supported decision-making and the exchange of good practices will contribute to the evolution of support in Hungary. AOSZ envisages to extend its solution to the countryside, and to also target persons severely affected by ASD.

9. Name changed by the editor.

Major strength of the practice

As AOSZ deals with the individual cases via its legal aid service, it has access to information about the dysfunctionalities of the current system in practice. The organization can use this feedback or experience, which feeds into its plan of actions, including advocacy, lobbying and sensitization. This can have a positive impact on the legal and social environment.

Possibilities to further develop practice in line with the UNCRPD

This practice can be used not only to promote the advantages of supported decision-making, but also to map further the difficulties that persons with disabilities encounter concerning the full realisation of their rights, as laid out in the UNCRPD.

Contact details

AOSZ
Dr. Kálozi Mirjam
1053 Budapest, Fejér György utca 10. I./3, Hungary
E-mail: drmirjamkalozi@esoember.hu

---

7. The author of this report is indebted to the following: L Series, 'What If…?' https://thesmallplaces.wordpress.com/2013/05/01/what-if/ (viewed 12 February 2015).

Promoting communication access in the justice system

Organisation & country: ACE Communication, Ireland.

Date of implementation: 2012.

Target group: people with disabilities, families, supporters and people working in the justice system.

Type of solution: training and support to facilitate communication with people with communication disabilities.

Total Communication supports people to communicate with different ways of communication. Total Communication includes speech, learning to listen, sign language, or writing.

In order to support and develop Total Communication, ACE can:

Provide education on total communication, accessible information and communication partnerships.

Provide quality resources to support you to create Accessible Communication Environments.

Make information easy to read – we work with a panel of people with disabilities to produce easy-to-read information.

Support organisations to look at their communication environments and find ways to improve these. This can be done for an individual or for groups of people using a service.

Help services to develop communication action plans and policies.

Support and advise services on consulting with individuals who have high communication support needs. (For example if you are doing a piece of research, developing a service or making a presentation).

Consult with people with disabilities and communication difficulties for services.

Context and problems targeted

Ireland has a major reform of disability services under way with the closure of many institutions and changes to services. The upcoming capacity legislation will place many demands on people with disabilities and supporters to ensure they are promoting communication access and building capacity.

Up to 90% of people with intellectual disabilities may have support needs regarding comprehension, expression, social communication or literacy. These difficulties may be invisible and not always obvious to those in the justice system. Therefore, people with intellectual disabilities and their families do not always have access to justice, because:

- They are often unable to understand the information they are being given or the questions they are asked;
- People in the justice system misinterpret their communication behaviours;
- They may not have support to ensure that they can understand the information they are given and to facilitate the expression of their wishes.

In order to implement the UNCRPD, new legislation and reforms are needed, together with more staff in the justice system and in other public services being trained by people with disabilities to learn about how best to support communication.

Implementing this promising practice

ACE Communication is a company which was set up in 2012 to promote easy-to-read information and total communication (discussed below) in Ireland.

ACE believes that communication access is one of the most important things people need to know about if they are working in the justice system. Without adequate training and knowledge, staff at all levels of the justice system may misinterpret behaviours and communication issues, preventing access to justice. ACE Communication provides training, carries out research, does advocacy work and develops resources and easy-to-read information. ACE does all of its work in partnership with people with disabilities.

ACE promotes 'Total Communication', a practice of incorporating all means of communication, including speech, speechreading, auditory training, sign language, and writing, in a number of ways:

Training

ACE Communication has developed a number of training programmes which are co-delivered with people with disabilities. These are:

- An Introduction to Total Communication;
- Making information easy for everyone to understand;
- Literacy for all;
- Supporting people to make choices;
- Deciding together: consulting with people with complex communication needs.

ACE also delivers training on Lámh which is a sign system designed for people with intellectual disabilities in Ireland.

Resources

ACE Communication has developed two resource CDs to support people with disabilities and staff in services to develop their communication skills and services:

- The *Total Communication CD* includes tools to get people started to create Total Communication environments like calendar templates, visual schedules, getting to know me books, etc.
- The *Making Choices CD* has a range of resources designed to aid people in making decisions about different aspects of their everyday life, such as choosing a career, understanding medication or planning a holiday.

Research

ACE has done research projects consulting with people with disabilities about their views for different organisations in Ireland. This work has supported people with intellectual disabilities to have their voices heard. One example: ACE worked as research consultant for a large Irish project on dental health. This ensured that people with disabilities were included and consulted in the process using Total Communication supports.

Testimonies

"[ACE's] knowledge and skills in the area of Lámh and working with people with intellectual disabilities far outweighed my expectations. Their passion for effective communication was impressive and infectious. From the very start of the course they made me and hopefully others feel at ease and very welcome. I am super excited to go back to work and use my new knowledge. I have seen the person I work with using Lámh with another staff member and have always envied their communication, conversation and connection. I feel now that I can step up and provide the same. I went to the course willing to learn and feel I came back well equipped to communicate with our client much more effectively."

Expected developments in the future

ACE hopes to continue to promote communication access for people with communication difficulties and develop people's skills within services to make this possible. They will do this through their training, resources, presentations at conferences and events and through further developing their resources.

Major strengths of the solution / project

ACE Communication works with trained Speech and Language Therapists that have over 30 years of experience in working with people with disabilities. They work in partnership with people with disabilities to deliver training, to do research and to develop easy-to-read information.

By making sure that interlocutor have the skills to facilitate communication, this supports people with disabilities in accessing the justice system to understand what is happening and to be understood when they are communicating.

Within services, ACE promotes people's right to communicate and this enables people with disabilities to have more choice and control in their everyday lives.

Possibilities to further develop the practice in line with the UNCRPD

The upcoming capacity legislation in Ireland will create enormous demands for all services in ensuring communication access is achieved in order to build people's capacity in different areas. ACE will continue to promote the need for all staff working in public services, particularly the justice system, to develop skills in supporting those who communicate differently.

Contact details

Teresa Gadd / Sarah Cronin
ACE Communication Ireland
Guinness Enterprise Centre, Taylors Lane, Dublin 8, Ireland
Tel.: +353(0)85-1410933
E-mail: acecommunicationireland@gmail.com
www.acecommunicationireland.ie

Supporting a person with disabilities in a court setting

Organisation & country: National Advocacy Service for People with Disabilities (NAS), Ireland.

Date of implementation: March 2011.

Target group: people with disabilities.

Type of solution: independent representative advocacy.

Sometimes people need extra help and support when they have to go to court or are dealing with the law.

They might need someone to help them read a report or they may need help to speak to a lawyer or to a judge.

The National Advocacy Service, NAS for short, provides advocates to people who need them.

NAS support people so that they can be heard in discussions which involve them and understand what is happening in court or other situations involving the law.

Context and problems targeted

Legal professionals and those supporting people with intellectual disabilities and other disabilities, which may impact on decision making, have long reported concerns regarding instruction and participation in the justice system.

Concern has been expressed in recent years by, among others, the Irish Human Rights Commission, about circumstances where, because of reduced capacity, a parent has difficulty in participating in the child care proceedings process, even with the aid of a solicitor representing him or her. Advocacy support may be required to enable a parent to have their views heard and to be involved in the decision-making process accordingly. This need arises because of a person's difficulty in understanding the legal process and/or the reasons for the court proceedings and related difficulties in giving clear instructions to legal representatives. The advocate's role is to support the person to have their voice heard, to raise objections, and to facilitate alternative pathways being discussed and explored.

A court circular following a childcare case involving a parent with an intellectual disability stated that the purpose of appointing a person to assist clients of impaired capacity was to ensure the provision of an effective legal aid service to the person. This is to ensure that the person receiving legal aid has an appreciation of the nature of the proceedings, and of the matters being raised and is in a position to give adequate instructions. 'The person must have some capacity, but the solicitor must be of the opinion that the capacity is so impaired that it is essential that the solicitor have professional assistance to communicate effectively with the client in relation to the subject matter of the proceedings.' (Legal Aid Circular 2/2007).

The Legal Aid Board is required to fund such assistance, but to date there is no formal arrangement in place organising the provision of persons to assist people. Such funding and assistance remains on an ad hoc basis. Not all interactions with justice systems are through the Legal Aid Board funded services, people may also use private law firms or community legal projects.

Some advocacy pilot projects and services from non-governmental organisations had been providing services to those who had or required contact with the justice system and (depending on the exact location in the country) legal professionals, social workers and judges would recommend the appointment of an advocate to support those they felt required assistance.

Implementing this promising practice

The National Advocacy Service for People with Disabilities (NAS) was set up in 2010. It is a countrywide service funded and supported by the Citizens Information Board (CIB). The Comhairle Act 2000 and the Citizens Information Act 2007 give CIB a statutory responsibility in the area of advocacy, particularly for people with disabilities.

NAS provides an independent, confidential and free representative advocacy service that puts the person at the centre and adheres to the highest professional standards. Their vision is to work towards a society that ensures the full participation of persons with disabilities. The NAS identifies the core human rights as being dignity, autonomy, equality and independence; they recognise the capacity of persons with disabilities to make their own decisions equally with others, in accordance with UNCRPD.

Advocates support people:

- to attend court and participate in meetings related to proceedings planned or underway, and to understand reports prepared for court;
- to issue instructions to legal professionals; and
- to understand the representations being made in proceedings and decisions that have to be made.

People with disabilities who require support in decision-making are referred to the NAS. Issues faced by those referred include quality of life, housing, health, access to justice, family and relationship issues. Approximately 15% of casework undertaken by NAS advocates relates to justice issues.

Referrals are made by people with disabilities, family and friends, service providers, statutory agencies and others. Presentations promoting the NAS are made to organisations of and for people with disabilities, professional bodies, health and support agencies and others to promote the service. The work of advocates supporting people in access to justice issues has developed on a 'word of mouth' basis.

Advocates assess referrals according to access and eligibility criteria agreed by the NAS Board and the CIB. Access to justice casework may involve civil or criminal matters and the person seeking advocacy may be directly involved or a witness to the matter. Advocacy services may be requested by judges while proceedings are already under way and are applied for by legal professionals or social workers. There is no guarantee that an advocate from the NAS will be available to support someone in a court matter due to the limited number of advocates available and the waiting lists in operation for the services.

Advocates may assist in applying for legal aid or, if legal aid cannot be applied for, other legal assistance if it is not in place already.

Outcomes and results

Advocates have supported witnesses in cases taken by the State so that they understand the proceedings and can ask questions before and during trials. In child protection cases advocates are mainly acting to ensure that parents with disability have equal access to justice in a situation where the thrust of other statutory support is with the children. This is due to a lack of support services for parents with disabilities.

Advocates have also supported those making applications for safety orders and in family law applications including separation, maintenance and access applications.

Advocates support people to seek legal advice and representation regarding housing issues, insolvency, social welfare law, migration and citizenship matters. Other areas of justice related case work include inheritance and succession, including accessing solicitors to make wills or if people are to receive inheritances or have had difficulty in doing so.

The NAS report on case work to the Citizens Information Board and social policy issues that arise are represented to government in the form of submissions to consolations by various government departments.

Testimonies

Pamela’s case

Pamela is a woman recently diagnosed with an intellectual disability. For a range of reasons the Health Services (HSE) were looking for temporary care orders for her children. Pamela was extremely distressed and confused about what was going on and what role she could play in the court process. Referral to NAS was made by the social worker appointed to work with Pamela’s children.

The advocate met with Pamela to get to know her and worked with her; thereby contacting her solicitor to inform them about NAS and advocacy practice, preparing and supporting Pamela before she attended meetings, during meetings with her solicitor and during court hearings. Pamela finds these meetings very stressful. The advocate also supported Pamela to raise her opinions in relation to reports associated with the court process, to engage as much as possible and to input as effectively as she can.

The advocate also supported her in exploring further her diagnosis of intellectual disability with relevant professionals. The advocate liaised with the landlord on Pamela’s behalf in relation to some outstanding urgent repairs.

So far, Pamela has had a positive and engaging relationship with her solicitor and barrister where she is able to express and input her opinions and perspective; she has also been able to attend the court and discuss the process that is going on around her. Pamela has recently been diagnosed with intellectual disability following exploration of reports carried out by the HSE which she was unaware of - this is still on-going, and Pamela and her advocate are currently looking for a meeting with her psychologist.

John’s case

John was referred to the NAS by his employment support service as it appeared that he was experiencing domestic violence in his family home. It became clear that John was having money taken from his bank account without his consent by a family member.

The advocate supported John to contact the police and report the abuse, and then to make an application to the local district court for a safety order which was granted. John was then supported to identify new accommodation and put a plan in place protecting his finances so that only he could access his bank account.

Expected developments in the future

The Assisted Decision Making Bill 2013 has been under consideration for a while and is currently before Parliament. It is unclear what impact this will have in the appointment of people to support decision-making and in the delivery of advocacy services.

The Citizens Information Act 2007 has not been fully commenced. Discussions continue regarding the establishment of a Personal Advocacy Service and appointment of the Director of Personal Advocacy Service.

Major strengths of the practice

Through the work of the NAS the Irish State accepts responsibility for advocacy, and therefore provides recognition of advocacy supports as a legal right.

Advocates support the exercise of legal capacity and promote personal autonomy.

Possibilities to further develop the practice in line with the UNCRPD

Ireland has yet to ratify the UNCRPD. Comments and observation of access to justice issues are in the remit of the National Human Rights Institutions such as Irish Human Rights and Equality Commission, amongst others.

In developing advocacy responses and the person-centred nature of NAS, consultations will continue to take place with selected other stakeholders including, in particular, the Child and Family Agency, the Legal Aid Board, the courts service and organisations representing people with disabilities through NAS' regional advisory groups.

Contact details

National Advocacy Service for People with Disabilities
National Office, Hainault House, Tallaght, Dublin 24, Ireland
E-mail: info@advocacy.ie

Investigation and Testimony Procedural Act

Organisation & country: Bizchut, Israel.

Date of implementation: 2005.

Target group: people with disabilities, judges, lawyers, health and social care professionals.

Type of solution: legal reform to change evidence and procedures in serious criminal cases involving victims with intellectual and psychosocial disabilities.

In Israel, there is a law called
'Investigation and Testimony Procedural Act'.

This law changes the way that lawyers and judges talk to people
with disabilities in court.

It is used when people with disabilities are victims of serious crimes
like rape or murder.

The law makes it easier for people with disabilities to tell a court
what has happened.

When a crime happens to a person with a disability,
a special investigator is appointed.

The investigator is trained on how to communicate with disabled people.

The investigator makes sure that the police get the right evidence
from the beginning.

When the case goes to court, an expert will help the lawyers and the judge
to ask the right questions to people with disabilities about what happened.

The expert will also help the court to understand the answers given
by people with disabilities.

Context and problems targeted

The Investigation and Testimony Procedural Act 2005 in Israel permits defendants, victims and witnesses with cognitive or mental disabilities to give evidence in a modified court procedure for certain types of serious crimes (e.g. sexual offences, aggravated assault, human trafficking, manslaughter and murder). While concerns about the impact of this reform on the due process rights of non-disabled defendants might be raised, its constitutionality has not yet been challenged before the Israeli Supreme Court. In addition, the fact that the accommodations are available equally to victims and defendants could help to alleviate concerns about fairness or due process in the criminal justice system.

The 2005 Act was lobbied for by civil society on the basis of a pilot project implemented by an NGO called Bizchut, the Israel Human Rights Centre for People with Disabilities, based on this organisation's experience in supporting people with disabilities, generally as victims and witnesses, primarily during criminal prosecutions for sexual and violent crimes.

Implementing this promising practice

The Act applies both to police investigations and to testimony in court. Similar to other innovative practices to make the justice system more accessible to victims, and to children, the Act requires the involvement of 'therapeutic professionals' (e.g. psychologists and social workers) with experience of working with people with intellectual and psycho-social disabilities, who can intervene in the questioning and provision of evidence by people with disabilities, to redirect the questioner, or enable the court to better understand the answers and evidence provided by the person with a disability. It is important to emphasise in this context that these cases are adjudicated only by judges, and that there is no jury.

Neta Ziv was closely involved with the pilot project which led to the introduction of this legislation in Israel through her work with Bizchut – an organisation that promotes the human rights of persons with disabilities in Israel. Ziv describes the new methods of questioning, testimony and cross-examination outlined in the 2005 Act as follows:

Instead of an unmediated and direct impression of a witness by a judge, there is external intervention in this interaction. Testimony by a person with a mental or cognitive disability can be supported, directed, and interpreted by experts from therapeutic disciplines, who are vested with extensive authority. These experts can point to the way a witness should be addressed, what questions she may or may not be asked, how to frame the questions, what her responses mean (or do not mean), what her body language insinuates, etc. In general, these experts provide a type of interpretation to the testimony, by casting it against distinctive behavioural patterns of persons with similar disabilities.

Outcomes and results

Ziv notes: "Reports from Bizchut indicate that since the victim-support project was launched in 2002, and as the Act comes into force, the criminal justice system has started to internalize the need for such accommodations. Police have begun to incorporate changes in the way criminal investigations are conducted and courts are open to new ways to hear testimony. The organization has documented cases in which a police investigation of a woman with severe cognitive disabilities was conducted through pictures and role play; a man testified in court despite his extremely limited verbal capacity; a number of victims with disabilities testified in the absence of the accused, and presently, the court is hearing a case in which the victim — a severely disabled woman — is testifying through the use of pictures and board images."

Expected developments in the future

It would be interesting to see this approach in the future extended to evidence and procedural law in civil cases involving witnesses with cognitive disabilities. It would also be useful to have expert support to work with each individual's witness based on that person's unique communication, rather than relying on generalities about the communication styles of individuals with particular disabilities.

Major strengths of the practice

The major strengths of this practice are its development and piloting by civil society, followed by subsequent implementation through legislative reform. It provides an interesting practice on how access to justice can be effectively achieved for people with intellectual disabilities giving evidence in court.

Possibilities to further develop the practice in line with the UNCRPD

This solution could be brought further in line with the UNCRPD by extending this approach to all civil cases involving witnesses (and plaintiffs or defendants) with cognitive disabilities – and placing more emphasis on the individual's style of communication, from detailed knowledge of the person, and those close to them, about the individual's communication preferences.

Contact details

Prof. Neta Ziv
The Buchmann Faculty of Law
Tel Aviv University, Israel 66978
Tel.:+ 972(0)3 6405237
E-mail: zneta@post.tau.ac.il

Recommendations

Major gaps in providing equal access to justice for people with intellectual disabilities exist. This should not come as a surprise. The United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) has so far provided compliance reviews (or 'Concluding Observations') to over a dozen States Parties to the UNCRPD. The UNCRPD Committee has repeatedly directed governments to review guardianship and to take actions to replace guardianship laws with supported decision-making.[10]

In achieving the transition from substituted to supported decision-making regimes, it is clear that governments are uncertain as to how they can fully realise the 'paradigm shift' of Article 12, including with regard to Article 13 of the UNCRPD. We thus recommend that governments consider implementing ongoing mechanisms to replace the framework of guardianship, mental capacity assessments and 'best interests' decision-making with a supported decision-making regime. This could include:

- undertaking law reform to replace assessments of mental capacity with the provision of supports to exercise legal capacity;
- prioritising the will and preference of the relevant person with intellectual disability rather than a 'best interests' model;
- developing supported decision-making in policy and practice by drawing on the emerging range of promising practices being promoted internationally;
- making clear information and resources available to support people to challenge guardianship orders and arrange alternative supports that do not restrict legal capacity.

---

10. CRPD Committee, 'Concluding Observations', http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5 last accessed 23 June 2014.

We further recommend that governments consider implementing ongoing mechanisms to promote access to justice for people with intellectual disabilities. This could include:

- auditing specific barriers in access to justice, for example, the lack of reasonable accommodations regarding speech and language for people with intellectual disabilities in legal proceedings;
- collecting data on the types of support that people with disabilities are requesting or using in legal proceedings;
- ensuring that legal proceedings – from courtrooms to administrative tribunals and reporting mechanisms – are accessible to people with disabilities in general;
- reforming laws so that denial of reasonable accommodation is deemed by law to be an act of disability-based discrimination.

Finally, it is important to reiterate that even within existing systems of substituted decision-making, some efforts are being made to better respect the will and preferences of adults with intellectual disabilities. In the move away from guardianship systems, we can retain existing forms of support that enhance – rather than undermine – the rights of adults with intellectual disabilities, while rejecting any measures that restrict or deny an individual's legal capacity.

11. Excerpts taken from AJuPID, 2015: „Comparison of legal systems in access to justice for persons with intellectual disabilities in the following countries: Bulgaria, Finland, France, Hungary, Ireland" http://www.ajupid.eu/en/research last accessed 15 June 2016.

Acknowledgements

We would like to thank all the people and organisations in Bulgaria, Finland, France, Hungary and Ireland who welcomed the partners of the AJuPID project, for sharing their practices and giving us the opportunity to learn more about ways to better support legal capacity and to promote access to justice for persons with disabilities.

Abbreviations

AJuPID	Access to Justice for Persons with Intellectual Disabilities
ASD	Autism Spectrum Disorder
CRPD Committee	United Nations Committee on the Rights of Persons with Disabilities
EU	European Union
HSE	Health and Safety Executive
NGO	Non-governmental organisation
PCP	Person-centred planning
SDS	Self-directed support
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

AJuPID

Access to **Ju**stice for **P**ersons with **I**ntellectual **D**isabilities

14 rue de la Tombe-Issoire - 75014 Paris - FRANCE
Tel.: +33 (0) 1 43 12 19 19 - www.ajupid.eu

AJuPID

EASPD
IMPROVING SERVICES
IMPROVING LIVES

FEGAPEI
Les Forces du Handicap

Foundation NET

KézenFogva Alapítvány

KU LEUVEN

mdac
mental disability advocacy centre

NATIONAL FEDERATION OF VOLUNTARY BODIES
Providing Services to People with Intellectual Disability

NUI Galway
CENTRE *for* DISABILITY LAW *&* POLICY

SERVICE FOUNDATION
FOR PEOPLE WITH
AN INTELLECTUAL DISABILITY