Uloba
Independent
Living

# My life, my choice!

## Empowerment through Supported Decision-Making

# Easy read versjon

The report is long and contains a lot of text. This easy read part tells you the most important things from the report

## Support to make decisions about your own life in Norway

Everyone has the right to make decisions about their own life, but sometimes we need help and support to make decisions. What clothes should I wear? Where do I want to live? Where do I want to work? How can I get Apple TV? What does this letter mean? When we get help to understand or make up our mind, we receive what is called decision support. Making decisions with such support is called supported decision-making.

Disabled people who want organised support to make decisions about their life should have this choice. But Norway has no system for such support today. Instead, many people have guardians. The guardians are supposed to talk to the people they are guardians for about what they want, but not all guardians do that, and it is the guardian who has the power to make decisions. That is not how it should be. It is a violation of the human rights of disabled people.

Norway has signed the UN Convention on the Rights of Persons with Disabilities. The convention is an agreement between countries about the human rights of disabled people. The agreement says that everyone who needs it should be offered support to make their own decisions. The agreement also says that you cannot deny people the right to make their own decisions just because they are disabled. The Norwegian Government and the Norwegian parliament, the Storting, have decided that the agreement should apply in Norway. The work to make this happen is still under way.

Norway needs a law to guarantee that people who want support to make decisions about their own life can get it – a law on supported decision-making.

## Supported decision-making boards – support to make decisions about your own life

Uloba has run a project to try to find out how we can make a good support system for helping people to make their own decisions. We have looked at a Canadian model to try to find out what we should take from it and what we should perhaps do differently. As part of the project, ten disabled project participants tested what it is like to have their own board. Children and adults from all over Norway, some with and some without guardians, have taken part in the project.

We have decided to call our system the 'supported decision-making board', but often we simply call it 'the board'. Each project participant has been the 'board owner' of their board. That means that they have been the boss of the board. They have chosen people they know well and trust to be on the board with them. Some of the board owners had help choosing their board. The people who have been part of the board together with the board owners we call 'board members', or just 'members' for short. The members' job has been to help the board owners with anything they need to be able to make decisions about their own life. Some boards met often and others less often. Uloba thinks that it is important for board owners to be at the board meetings if they want to and are able to. Most of the board owners have taken part in the meetings, but not all.

The members were not paid to be on the board. They had a duty of confidentiality. That means that they are not allowed to talk to other people about the things they talk about in the board, unless the board owner wants or needs the members to tell other people what the board has talked about.

A board should have more than two members. Many boards had five members. You do not need many friends or a large family to have a board. Some people have asked their assistants or other people they spend a lot of time with. The most important thing is that the board owner and board members know each other well and trust each other. That is the best way of making sure that the board owner gets good support.

Some board owners in the project speak or use sign language, while others use what we call augmentative and alternative communication (AAC), which means sounds or body language. It is important that the board members know the board owner well enough to understand what he or she is saying, no matter how the board owner says it.

## What has Uloba learnt from testing the supported decision-making board system?

We have learnt a lot about important things to think about when helping someone to set up a supported decision-making board. We have also learnt a lot about what we need to teach the board members to make sure that they do a good job.

A lot of things make it difficult for disabled people in Norway to make decisions about their own life. The reason for this is that disabled people are discriminated against. A board cannot solve every problem, but we have seen that board owners get more control over their life when they have a board. They are also able to do more of the things they want and need when they have a board.

We have seen that it can be a good idea to set up a board while the board owner is still a child. That way, people get to know each other well and the board owner gets to practise making decisions. The board’s meetings provide good practice in making your own decisions. If you are not used to making decisions for yourself, it can be difficult to start when you turn 18.

We have also seen that board owners and members spend more time together and get to know each other better when they are in a board.

Some boards have found that others show more respect for the board owner's wishes when they tell them about the board. Other boards have found that other people do not take the board seriously because there is no law yet that says that people have to listen to the board.

All the boards that took part in the Uloba project have said that they would like to continue the board after the project is over.

## Can you have a supported decision-making board today?

Uloba would like more people to have the opportunity to have a board, but Norway does not have the law we need to make this possible. That is why we have worked, and will continue to work, to get Norway to make such a law. What Norway needs is a law on supported decision-making.

Many people in Norway who know a lot about human rights agree with Uloba that all disabled people must have the right to choose supported decision-making instead of a guardian if that is what they want.

We hope that the project and what we share can help us to put in place the law Norway needs to allow more people to make decisions about their own life. We hope that other support systems will be developed. That way, everyone who needs support to make decisions can choose the system that suits them best.

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# Introduction

We all make big and small decisions in our lives on a daily basis. What clothes should I wear? What should I make for dinner? Where do I want to work? What will it take to get a job there? Where do I want to live? We receive decision support when we ask people we trust what they think we should choose, or when we ask someone to explain something to us.

Being in control of your own life is a human right. The UN Convention on the Rights of Persons with Disabilities (CRPD) acknowledges that some of us may need a formalised form of decision support in order to achieve self-determination. In Norway, however, we have no legislation, system or models for supported decision-making. The UN, Equality and Anti-Discrimination Ombud (LDO) and human rights organisations such as Uloba are calling for Norway to introduce legislation and a system for supported decision-making, but so far, disabled people have had to do without.

Norway continues to force disabled people into arrangements under the Guardianship Act where the right to make decisions about their life is given to someone else. The Norwegian authorities are working to change the Guardianship Act and have developed a conversation technique for guardians to use when providing decision support. The technique is called Seeing the Other, and voluntary training is offered to guardians. Such techniques exclude everyone who has no explicit form of communication, such as spoken or sign language. Criticism has also been levelled at such techniques following their use by the child welfare service.

> Contrary to their intentions of promoting empowerment and motivation, the effect of the techniques is often demotivating, alienating and objectifying. When children and young people realise that they are made the object of a method based on specific interview techniques, they report that this establishes a distrust in the support system as a whole as well as the person charged with helping them. (Joranger, 2022, Summary)

So how can good decision support be provided? That is the question that we have tried to answer through our project Empowerment through Supported Decision-Making, which has produced the supported decision-making board model. We believe that the road to good decision support begins with understanding what self-determination is and what it is based on. It is about having the opportunity to make decisions based on your own will and wishes. It is about having the opportunity to understand and be understood, even if that requires someone acting as an interpreter for you.

In such case, it is important that this is done by someone who knows you and your story and knows how you express your values and wishes. It is also about having the opportunity to learn the form or forms of communication you need. That you have been given access to necessary aids. That someone still understands your form of communication and allows you to continue to develop it after you finish school and move into a home of your own. That you have been able to experience and learn that you can make decisions for yourself.

What is the current situation of disabled people in this respect? We live in a society where disabled people encounter discrimination and obstacles at every turn because Norway has yet to undergo the paradigm shift in terms of thinking and policy that is required in order to implement the CRPD. Naturally, this affects the ten project participants' possibility for real self-determination, as described in this report.

The project has produced a first version of the supported decision-making board model. We have faith in this model because we see that it allows the project participants a higher degree of self-determination. We believe that what is needed to further strengthen the right of self-determination is for decision support to be enshrined in law.

We would like to extend our heartfelt thanks to all the project participants and their selected board members who have contributed their time and openly shared their experience in this vital project. We would also like to thank all the reference group members for fruitful conversations, and the DNB Savings Bank Foundation for its considerable support.

We hope that the experience outlined in this report can be of use in the further development of legislation and different decision support models. It is important that our model does not become the only supported decision-making model available. Nor must a supported decision-making board be forced on people, as guardianship is today. It is about having freedom of choice, including being free to choose what form of formalised decision support you want – if you want it at all.

Vibeke Marøy Melstrøm, Secretary General
Elin Rise, project manager

Uloba – Independent Living Norge SA

# Definitions

### Supported decision-making board/board

The name of the model developed by Uloba for disabled people who want a formalised form of decision support to help them to take control of their life. When we refer to a supported decision-making board/board, we mean all the board members and the board owner.

### Board owner

The person who wants decision support and is supported by a supported decision-making board.

### Board member

Person who the board owner has chosen to be part of the board supporting him/her.

### Board meeting

A meeting of the supported decision-making board.

### Explicit form of communication

An expression of will made orally, in writing, through any direct means, manually, mechanically, digitally, electronically, using sign language or alternative means of communication, including the use of reasonable adaptation or such support measures as the person in question requires.

### Implicit form of communication

An expression of will based on a best interpretation of the person's body language, expression or repeated behaviour in the person's life story.

### Close persons

Persons who are important to the board owner, know the board owner and whom the board owner trusts. They do not have to be members of the board owner's family.

# Uloba's involvement

Uloba SA is part of the Independent Living movement, which is a global liberation movement of and for disabled people. Uloba's vision is a world in which disabled people have the freedom to lead full lives and participate in all areas of society.

More than 30 years ago, Uloba took inspiration from the American Independent Living movement and developed the equality tool citizen-controlled personal assistance (BPA) in Norway. The BPA scheme gives disabled people in need of assistance the opportunity to take responsibility for and control of their own life.

In 2016, Uloba started a pilot project inspired by the microboard model developed by the organisation Vela Canada in British Columbia. Microboards give disabled people the opportunity to take more control of their life by receiving individually adapted support from a microboard of close persons. There are now more than 1,100 microboards in British Columbia.

What originally triggered Uloba's interest was the question of whether a microboard could ensure co-leadership of BPA arrangements for disabled persons who need support in the work leader role. The BPA scheme entails a potential source of vulnerability for this group. It is often the parents who take on the role of co-leader. Some people have no close persons who can take on the role when their parents grow old and die, and they may lose the opportunity to use the BPA scheme for this reason.

Toril Heglum (1970–2019) was an important advocate for the Independent Living ideology and the human rights of disabled people in Norway. It was due to her that the transition from pilot project to a full-scale project took an important turn from focusing on self-determination in a BPA perspective to self-determination in a human rights perspective. She became seriously ill in spring 2019, but wanted to contribute to the last. Only weeks before her death, she shared her greatest wish for the project, and this has been an important guiding principle in our work.

**Toril Heglum, 2019:**
'Make no compromises when it comes to "leave no one behind". Do not fail in solidarity where others fail and discriminate based on (assumed) cognitive or psychosocial etc. functional impairment.'

**'Make no compromises when it comes to leave no one behind.'**

Toril Heglum, former project manager 2019

# Project implementation

From Vela Canada's Principles and Functions for Microboard Members:

'All people are assumed to have the capacity for self-determination. This capacity will be acknowledged, respected, and demonstrated in all of the dealings of the Microboard.'

## Method

During the project period, Uloba has tested the Canadian microboard model. We have worked to adapt the model to Norwegian conditions and ensure that it safeguards supported decision-making in a human rights perspective and our own Independent Living ideology. Uloba staff have followed up the boards. We have seen what worked and what didn't work and provided guidance through one-to-one conversations with board owners and board members as well as in meetings with whole boards and bigger gatherings to which all the supported decision-making boards were invited. Exchange of experience and concrete examples have been important to form a shared understanding of how to provide good decision support.

The coronavirus pandemic brought a number of challenges. One of the project participants never got a board up and running. The situation also severely limited physical contact, but Uloba staff have met eight of the nine board owners in person at least once during the project period. The board owner who we have not met in person is a young child. This was initially due to the pandemic, and later to the parents not being available when we have tried to arrange a meeting. In the cases where communication allows, the Uloba staff's primary contact was with the board owner. We have also attempted different approaches, including conversation supported by drawing and sign-supported speech. Our impression is that the board owners found the experience positive, but that good communication will require us to acquire better communication skills and/or have a long-standing relationship, so in some cases, our primary point of contact has been a board member.

Towards the end of the project period, we interviewed each of the boards using an interview guide, but we let the conversation flow naturally, so not all the boards were asked all the questions. The interviewees had the opportunity to submit supplementary information after the interview.

Implementation of the supported decision-making board model will require the introduction of a law and a system for supported decision-making, with different decision support models to choose from. Norway ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2013, but the Convention has yet to be incorporated into Norwegian law. The project has therefore also campaigned the Ministry of Justice and Public Security and politicians to achieve this.

## The work towards a law and a system for supported decision-making

Norway ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2013, but the Convention has yet to be incorporated into Norwegian law. Furthermore, Norway made an interpretative declaration concerning Article 12 of the Convention stating Norway's understanding of how Article 12 is to be followed up. The article in question prohibits declaring people incompetent on grounds of functional impairment and entitles those who need it to decision support. Norway, however, considers that the Convention allows people to be deprived of legal capacity on grounds of functional ability. In other words, Norway has not made a reservation concerning the Convention's content, but established its own interpretation – which is in conflict with the rest of the content of the article and how it is understood by the UN committee that monitors the Convention's implementation.

When the pilot project started in 2016, it seemed unlikely that Norway would live up to the promises it made to disabled people when it ratified the CRPD. None of the major parties in the Norwegian parliament, the Storting, wanted to incorporate the Convention into Norwegian law. The situation has changed, however. On 5 October 2022, the Government stated that CRPD shall have the force of Norwegian law. An expert committee has been appointed to consider how the Convention is to be incorporated into Norwegian law.

The Guardianship Act will have to be amended for Norway to fulfil its obligations under the CRPD. The reason for this is that the CRPD does not allow people to be deprived of their legal capacity and put under guardianship on grounds of functional impairment as set out in the Guardianship Act Section 20, Section 22 and Section 33 second paragraph.

Section 33 second paragraph is the provision most commonly used in relation to people with intellectual disabilities, and we can refer to this as ‘deprivation of legal capacity by stealth’. Under this provision, no legal decision is required to deprive a person of legal capacity, but the right to self-determination can nevertheless be lost simply by a doctor writing a simple certificate declaring that the person does not have the capacity to give consent. This is where Norwegian law is in conflict with Article 12 of the Convention referred to above.

Future legislation must be based on Article 12 of the Convention, which states that persons with disabilities ‘enjoy legal capacity on an equal basis with others in all aspects of life’. It also states that persons with disability shall have access to the support ‘they may require in exercising their legal capacity’.

In connection with the project, we had a legal opinion prepared by Professor Kjetil M. Larsen of the University of Oslo. See the link to the legal opinion under Bibliography. The conclusion was that the Convention does not permit deprivation of legal capacity on grounds of functional impairment. Through the project, we have communicated this to the Storting, the Government and the Ministry of Justice and Public Security, which is working on amendments to the Guardianship Act. This work has included meetings and presentations by Professor Larsen. We and the Equality and Anti-Discrimination Ombud both expect the ongoing work of the Government and Storting to produce a supported decision-making act in which our model will be one of several alternatives intended to ensure that everyone will be able to access decision support and control their own life.

Following dialogue with the Ministry of Justice, we have submitted a proposal to establish supported decision-making as a trial scheme under the Guardianship Act. This would entail a legal provision permitting the Ministry to allow trials, provided that they are governed by separate regulations. These regulations would then allow supported decision-making without the a guardian being appointed.

## The supported decision-making board model

The supported decision-making board model is inspired by the microboard model developed by the organisation Vela Canada. This is how the organisation describes its model:

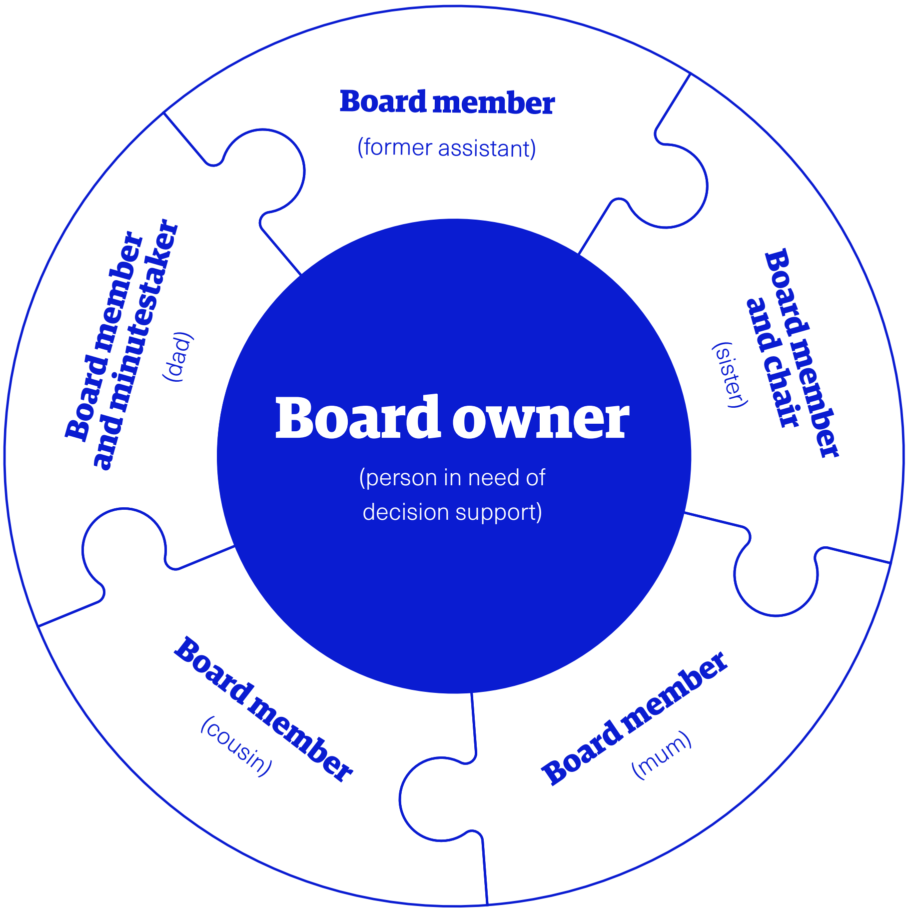
A Microboard is a small group of committed family and friends (a minimum of 5 people) who join together with a person with a disability to create a non-profit society (board). Together, they help the person:

- plan their life
- brainstorm ideas
- advocate for what they need
- monitor services and ensure they are safe
- connect to their wider community
- do fun things together

A microboard can also access and manage individual funding for services that the person needs.

The supported decision-making board model is based on the guide and principles from the microboard model, including the voluntary, unpaid board organisation with several board members whose relationship with the board owner constitute their qualification. The supported decision-making board model also has clear roots in the Independent Living ideology, is designed in a human rights perspective, and attempts have been made to adapt it to Norwegian conditions. The difference between the microboard model and the supported decision-making board model that most clearly reflects this, will be the training provided for supported decision-making boards.

### Supported decision-making board example



### Roles in a supported decision-making board

- The board owner is the person in need of decision support, and he or she owns the board.
- The board members are the board owner's close persons. Their function is to provide decision support.
- It is the board chair’s responsibility to convene and chair the board meetings.
- The minutes-taker takes minutes from the meetings.

### Example from the guide for supported decision-making boards

- To be a member of my supported decision-making board, you must be a person who I know well and trust. You also have to know me well and wish to maintain our relationship.
- As a member of my board, you will have a valuable responsibility to listen to, understand and respect my wishes and needs.
- It is also important to me that you treat the other board members in an open and respectful manner, and that you ask if there is anything you don't understand.
- If it is not possible for me to understand or make up my mind about the decisions we are discussing, you must always base your thinking on what you know that I like and need to have a good life.
- Sometimes, the supported decision-making board must undergo training provided by Uloba. I need you to participate in this training, share your thoughts and experience, and ask if you have any questions.
- As a board member, you will be subject to a duty of confidentiality about the matters discussed. You are of course allowed to help me to express my wishes in relation to others when I need help.

## Uloba's facilitator role

### Training

It has been important for Uloba to ensure that the model does not develop into a new guardianship regime for disabled people whereby a group of people make decisions about the board owner.

To prevent this from happening, Uloba has assisted in the establishment of boards on a trial basis, provided training and facilitated reflection on topics such as self-determination, different forms of communication, human rights (CRPD) and the Independent Living ideology. The importance of the board members' role in safeguarding the board owner's self-determination is a key consideration.

### Duty of confidentiality

Uloba has drawn up declarations of confidentiality for board members and provided training about what information is sensitive, what can be stored and where.

### Technical and administrative support

During the pandemic, the need arose for secure digital communication platforms where the boards could hold their meetings and store relevant documents. Uloba acquired, paid for and provided training in how to use such a platform.

It was an important premise for Uloba when choosing the technical solution that Uloba should not have access to the boards' private channels and areas. The boards themselves are responsible for their channel and for what is stored there, but Uloba provides training.

### Evaluation

The support the board owner receives should be evaluated annually. Based on the experience gained during the project, we have therefore developed a guide for such evaluations and how they should be followed up with a view to improving the board's work. This guide has not been trialled during the project period.

### Legal support from NFU

Legal support has been required on several occasions. During the project period, Uloba has offered to pay for membership of the Norwegian Association for Persons with Developmental Disabilities (NFU) for those who want it, so that they can access legal support from the NFU support system on a par with other NFU members.

## Project participants and resources

### Board owners (project participants)

The project has had ten participants in need of decision support. Two of the project participants are siblings. Most of the participants were recruited from among Uloba's members, except for two who were recruited via a reference group member. Half of the participants have an explicit form of communication, while the other half have an implicit form of communication. Some use a combination of communication forms. The ages given below are their age at the time of the project start-up in 2019.

### Age

- Under 10 years: 1
- 10–17 years: 2
- 18–30 years: 3
- 30–45 years: 4

### Birth sex

- Girl/woman: 5
- Boy/man: 5

### County

- Vestfold og Telemark: 2
- Troms og Finnmark: 1
- Vestland: 1
- Trøndelag: 1
- Agder: 1
- Viken: 3
- Rogaland: 1

### Guardianship status

- A family member is the participant's guardian and a board member: 5
- Adult not under guardianship: 2
- Under 18 years: 3
- Deprived of legal capacity: 0

## Board members

Nine out of the ten project participants have established and trialled a supported decision-making board. One of the ten participants did not get board meetings off the ground due to the pandemic. The project participant's parents had their hands full safeguarding life and health. The parents are nevertheless presented here, as they have participated in joint meetings under the auspices of Uloba and contributed valuable reflections throughout the project period. A total of 47 board members have been involved in the projects, with each supported decision-making board being made up of between two and seven members.

### The board members' relationship with the board owner are distributed as shown below:

- Parent: 15
- Sibling: 11
- Aunt/uncle: 6
- Former or current citizen-controlled personal assistant (BPA): 5
- Other close relationship: 4
- Brother/sister-in-law: 2
- Cousin: 2
- Grandparent: 2

## Reference group

The project's reference group is comprised of relevant professionals and other members with valuable expertise and experience. There have been seven reference group meetings, but selected group members have also participated in other meetings and conversations when Uloba has needed their specialist knowledge. At its meetings, the reference group has discussed the project's progress and important issues related to the project, including communication with board owners and the legal framework conditions for supported decision-making. The job titles and employment relationships listed below were correct at the start of the project. Some of the people involved have changed positions and employers during the project period, but they all chose to continue their involvement with the project.

- Cato Brunvand Ellingsen, National Institute on Intellectual Disability and Community (NAKU)
- Jan Tøssebro, professor, Norwegian University of Science and Technology (NTNU)

- Benedikte-Marie Lio, central board member, Youth Mental Health Norway
- Helga Brun, parent and psychologist
- Elfinn Færevåg, parent
- Jens Petter Gitlesen, president, Norwegian Association for Persons with Developmental Disabilities (NFU)
- Hedvig Ekberg, secretary general, Norwegian Association for Persons with Developmental Disabilities (NFU)
- Helge Hjort, lawyer, law firm Advokatfirmaet Sulland
- Katrine Hellum-Lilleengen, lawyer, member of the Norwegian Bar Association (MNA), Norwegian Confederation of Trade Unions (LO)
- Martin Kolberg, member of parliament, Labour Party
- Berit Vegheim, general manager, civil rights foundation Stopp Diskrimineringen
- Alette Reinholdt, BPA manager, JAG Assistanse
- Torill Vebenstad, senior adviser, department of health and social affairs, Office of the County Governor of Hordaland
- Lars Fredrik Eriksen, specialist adviser, Signo school and resource centre
- Vibeke Marøy Melstrøm, entrepreneur and Secretary General, Uloba – Independent Living Norge SA
- Ann Kristin Krokan, political special adviser, Uloba – Independent Living Norge

## Steering committee

The steering committee consists of Uloba's senior management and has had regular meetings focusing on the project's progress and content in particular.

- Ann Kristin Krokan, political special adviser, Uloba – Independent Living Norge
- Jan Kåre Stura, chair of the board, Uloba – Independent Living Norge
- Knut Flaaum, special adviser and entrepreneur, Uloba – Independent Living Norge
- Ståle Bratlie, vice secretary general, Uloba – Independent Living Norge

**Project owner:**

- Vibeke Marøy Melstrøm, Secretary General and entrepreneur, Uloba – Independent Living Norge SA

## Working group

**Project staff:**

- Kristin Torske, political adviser, Uloba – Independent Living Norge
- May Nina Hansen Auby, political adviser, Uloba – Independent Living Norge

**Hired project staff:**

- Erik Strøm, adviser and partner in Boldt

**Project manager:**

- Elin Rise, project manager innovation, Uloba – Independent Living Norge

# Framework conditions

## Pandemic

Text from one of the parents of a board owner who uses an implicit form of communication:

‘The bag with the swimsuit and shampoo is still hanging on its hook, but the usual trips to the swimming pool won't happen. Playgrounds and exercise, play centres, school days and trips to the shops, all the normal everyday activities, are suddenly gone. You're thinking. I can tell by the frown on your forehead. You're smiling, but you pinch us and pull our hair hard. This isn't right.’

The pandemic brought huge challenges related to in-person meetings, progress and carrying out plans, but also experience of how supported decision-making can be organised, facilitated and operated in an extreme situation.

Several project participants and Uloba staff members belong to high-risk groups for serious COVID-19 illness. In solidarity with the high-risk groups, Uloba had strict infection prevention measures in force much longer than society at large. One of the ten project participants never got the board meetings off the ground, as the participant’s parents, who were also the first two board members, had their hands full safeguarding life and health.

## Barriers to self-determination created by society

In order to achieve equality for disabled people, it must first be acknowledged that it is not the individuals who need to change, but the barriers that society creates for them. Uloba has long-standing experience of identifying and demolishing the barriers in society that prevent disabled people from living equal lives. According to the UN, Norway has a long way to go to achieve the paradigm shift in terms of thinking and policy that is required in order to implement the CRPD. This impacts on and presents obstacles to self-determination in a number of areas. The areas that stand out based on experience from this project are:

- Discriminatory legislation
- Discriminatory attitudes and prejudice
- Inadequate access to communication training and/or maintenance

This is described in more detail in the chapter 'Discrimination in society still hinders self-determination'.

## Funding

The pilot project was funded by Uloba with support from the Norwegian Directorate for Children, Youth and Family Affairs (Bufdir). The main project that this report describes was funded by Uloba with support from Bente Skansgård's Independent Living Fund and considerable support from DNB Savings Bank Foundation.

> **'...Being able to be the main character in your own life is important for achieving selfdetermination. To be taken into account. To be taken seriously and listened to.'**

Lars Fredrik Eriksen, reference group member and specialist adviser, Signo school and resource centre

# Experience and results

Karl Elling Ellingsen, professor (NTNU/NAKU, 2019, 0:10):
'The ability to decide for yourself doesn't just happen by itself, and it's not handed to us neatly wrapped with a bow on top when we turn 18. It's something we have to practise and learn.'

We have been in continuous dialogue with board owners and board members throughout the project period and collected experience from joint gatherings, participating in board meetings, group and one-on-one conversations, and a concluding interview based on an interview guide. In this chapter, we present the experience gained.

## Increased self-determination

It is difficult to measure the exact level of self-determination achieved. In this chapter, we describe why we believe that supported decision-making boards increase the self-determination of board owners in the project.

### Board meetings provide practice in making decisions for oneself and being the focus of attention

Board meetings provide practice in making decisions for oneself. This is not necessarily something that disabled people living in Norway have had much practice of in life.

Board owner:
'All my life, I've found it difficult to take part in a conversation. I've used my (family member) as an interpreter. What the conversation is about. I still don't know if I will be able to start a conversation. I sometimes want my turn to speak. You don't always get your turn to speak. But I have to work on this myself too. Now I'm talking. Now you need to listen.'

The supported decision-making board has kept the principle from the Canadian system it was modelled on that the board owner should always be present at board meetings, unless the owner's age, wishes or situation suggests otherwise. As with all the principles, the boards have been allowed to test alternatives to find out what works for them, as it has been important for Uloba not to insist on rigid principles, but to be open to considering different experiences during the project period. The board owner has been present at the meetings of seven of the nine supported decision-making boards. In one of the two cases where the board owner was not present, the board owner was a young child whom the parents did not deem it expedient to involve at this stage. In the other case, the supported decision-making board members have not considered it useful for the board owner to attend the formal meetings because the owner uses an implicit form of communication. Other boards whose board owner uses an implicit form of communication have reached a different conclusion.

In one case, where the board owner uses a combination of explicit and implicit communication, the board places great importance on the board owner being present. The board owner prepares for the meeting by making coffee and welcoming everyone. They also try to adapt meetings to allow the board to consider a more formal agenda, but also enable them to engage with the board owner on the board owner's own terms.

Excerpt from Uloba's interview with the supported decision-making board:

Board member: And everything is based on what (the board owner) wants, we support her wishes.

Board owner: Now we'll sing. Lille Pusekatt.
(The board members all sing Lille Kattepus.)

Board owner: Sing it again.

(They all sing the song again. This time, the board owner joins in.)

Uloba has observed that the board owner has requested the same song in previous board meetings, and that the board has taken the time to sing it. Sometimes, they have also started the meeting with a song.

Lars Fredrik Eriksen, reference group member and specialist adviser, Signo school and resource centre

'Some might say that such participation is only of quasi-significance to self-determination, but it is really important. It's about showing the board owner that we are here with you now. I believe that feeling, sensing or understanding that you are the focus of an event or conversation, as is the case at such a meeting, is empowering in itself. Being able to be the main character in your own life is important for achieving self-determination. To be taken into account. To be taken seriously and listened to.'

Another board member, who is also a parent, describes how the board owner has quite strong opinions when the two are alone, but finds it difficult to express these opinions to others.

Parent and board member:
'When we talk about things like that, just the two of us, you have quite strong opinions. They fade when we talk here because you're so preoccupied with being nice. You're so very nice, because you don't want to hurt us by saying anything negative. I would really like you to be able to show the part of yourself that says: Hold on, this isn't what I want!'

Jan Tøssebro, reference group member and professor, NTNU:
'We can hope that, with time, the person will become more experienced, but we also have to allow for the fact that boards must differ based on what situations the board owners can manage to express themselves in. There is a definite risk of the board owner becoming small in a big board. Be open about challenges and risks.'

Uloba believes that the supported decision-making board model with several board members will not necessarily be right for everyone. We are different, after all. The board of the board owner in question has stated that the board owner has expressed opinions and wishes more clearly in relation to family members and assistants in other situations since the board work began. The board owner also wants the board to continue. It is important to Uloba to be aware that although a supported decision-making board can provide many people with necessary training in expressing their wishes in a group setting, others may never feel comfortable doing so. Possible solutions could be for one board member or a small number of members to speak to the board owner between meetings, or for the board owner to find another supported decision-making model.

Parent and board member:
'The board meetings have always focused on him taking ownership of the board. This takes time, and we're not there yet. But he's getting

better at it. Maintaining an awareness that he should own the board is important, and that he should be involved in what we're talking about – that we're not talking over his head.'

Uloba has chosen to keep the principle that the board owner should be present at board meetings, unless the owner's age, wishes or situation suggests otherwise. We believe that the training provided will raise board members' awareness about not excluding the board owners from their own boards, if that can be useful to them.

### Support from people who know you and your form of communication

Berit Vegheim, reference group member and general manager of the civil rights foundation Stopp Diskrimineringen:
'It's not about people lacking the mental capacity for communication, but about the people around them lacking the mental capacity to understand.'

One of the fundamental conditions of this model is the acknowledgment that all people have opinions about how they want to live their lives, but they have different ways of expressing their opinions.

Text from a parent of a board owner who uses an implicit form of communication:
'We all carry a life story. The story of who we are and what matters to us. Our needs, thoughts and wishes. We carry experiences that have shaped us, that form a framework of memories. Great moments when time stood still. Happiness, togetherness, but also insecurity, fear and sadness. What do I feel good at? Confident about? What makes me insecure, what challenges me, and when do I need help? We all carry a life story. I'm carrying two. My own story is a light burden, even if it contains a lot of lived life. But I also carry your story, (board owner). That is a huge responsibility, a heavy burden, unwieldy. You don't ask me to carry it. You don't ask a lot.

You say: **'Listen to my thoughts, face me, see me, take me seriously.'**
You say it without words.
You say: **'Sing in my ear'** when you turn my face and place my mouth against your ear.
You say: **'I'm insecure'** when you go silent and turn away.
You say: **'I want to play with you'** when you nudge me with your legs.

You say: **‘I’m thirsty’** when you go over to the sink.
You say: **‘I want to take a break’** when you stop and lean against me on our walks.

You tell me all this without words. Because I know you. Because you teach us your language, because we are making a language together. I carry your story, but also your language. I must pass it on to the people who spend time with you. All the people you have to let into your life because you need their help. Some will listen. Some add to your story. New experiences will be added, new knowledge will be generated. But the story is still rooted here, with me.’

The most important principle from the Canadian model is that the board members are people with whom the board owner has a relationship of trust. The board members should know and spend time with the board owner – not just in connection with board meetings. In order to be able to provide good decision support, whether by adapting questions or interpreting answers, it is important to know the board owner and how he or she communicates.

Board member:

‘But it is perhaps most natural for (board owner) that it's us sitting here, also because we’re closest to him when it comes to communication. You can't just include anyone, even if they have a close relationship. It's about being able to read him. (...) It's a prerequisite that we’re able to communicate with the person concerned.’

Knowing each other well is particularly important in cases where the board owner uses an implicit form of communication, in order to interpret the board owner’s preferences and wishes in relation to different matters as well as possible. And let there be no doubt: everyone has preferences and wishes.

Mother and board member:

‘After all, (board owner) feels joy the same way as I feel joy.’

The board must aim to provide more of what brings the board owner joy, but they must also be aware that lives are not static, but dynamic. They must facilitate opportunities to discover new things in life that may also bring joy.

### More people help – more gets done

Life is full of big and small choices to be discovered, sought out and managed. Feedback from the supported decision-making boards shows that when more people are involved and willing to spend time helping, the board owners are able to do more of what they want and need.

Board owner:

‘I have a board that helps me to sort out things. I have my own flat, so there's a lot to organise in connection with that. (...) We discuss who can help me with my computer or mobile phone. Where I want to go on holiday. When I need to buy a new washing machine or fridge, when stuff breaks. Someone to help me to paint the walls of my flat. Someone to help me to talk to the board of the housing cooperative. Someone to help me with other things that I cannot do for myself. I have some mates who I'm with in my free time. Then I don't need as much help from my board.’

Some parents describe that they have their hands full following up existing services and/or the board owner’s health situation. One father told us that fairly soon after the board was established, the board owner finally got help installing AppleTV. This may seem a small thing, but it was something the board owner really wanted, which the parents had been aware of for a while. However, they had not had the time or energy to prioritise it, as there were so many other things going on in the board owner’s life that had to take priority. To the board member who did it, it was a piece of cake.

A mother who was a member of a different board realised early on that this model, with several involved members, could have this effect of enabling the board owner to have more needs covered.

Mother and board member:

'If parents have to deal with it all alone, we have to deal with the medical side first.'

She used Maslow's hierarchy of needs to illustrate this. The five levels in the hierarchy of needs are, listed from top to bottom:

- Growth and self-actualisation
- Self-esteem needs
- Social needs
- Safety needs
- Physiological needs

(Mørch, 2021)

She explained that, as a parent, she was constantly working to ensure that the board owner's needs at the lower levels of the pyramid were met, and that a supported decision-making board would give the board owner the opportunity to have needs met at more of the levels. Uloba has seen that this is precisely what happens.

## More perspectives from people who know you

In cases where the board owner uses an implicit form of communication, it appears to be an immense source of strength that more people who know the board owner well cooperate on interpreting the board owner's wishes and preferences. This is especially true as the parents have often been the only ones providing assistance when choices were to be made. They describe it as both challenging and liberating that more people who know the board owner consider the various issues facing the board owner.

Parent and board member:

'You have to deal with the uncomfortable things. You must put up with being corrected. I must put up with being corrected by my own kids. In some areas, I am extreme in their eyes. (...) No matter how close the relationship between (board owner) and me has been through the years, (board owner) isn't me. That is really important.'

Parent and board member:

'This is a journey. Not just for you, but for me, too. From having to ask others to spend their time on us to finding approaches to determine what my child wishes and wants.'

Eight of the nine boards include members who are about the same age as the board owner, usually siblings. Vela Canada reports how important it is to include people of the same age. They can say more about, and perhaps more easily understand, what's important to people their age compared to the older parent generation. In one board meeting, recruitment of new assistants was discussed. The board owner is female and uses an implicit form of communication. It proved difficult to recruit female assistants, and the question was whether or not the board owner was open to hiring male assistants. Below, the board reflects on how they dealt with the issue.

Board member older than the board owner:

'In principle, I think that gender discrimination is wrong. But I know that the assistance situation is a lot more vulnerable. It was still difficult to provide input, because it conflicted with my own opinions.'

(Other board members agreed.)

Board member of the same age as the board owner:

'In these matters, it's also not easy to get an answer to what you (board member) want. Then I think it's good that we all bring our different perspectives, because together we should be able to arrive at something about right. And being (board owner)'s age and trying to imagine how I would have felt about it, I feel that the answer is no.'

Of course, other children cannot be board members when the board owner is a child, but Uloba proposes to use the same solution as in Canada, where board members are encouraged to ask children of the same age what they think about different things – for example which birthday party themes are popular these days.

## Early establishment builds a committed support network

Parent of a board owner who is a young child:

'It's different with children. It's not so much about helping them to make choices. Us parents do that. It's more about getting to know him and how he communicates. Spending time together. Building a stronger support network around him.'

Experience from Vela Canada shows that starting up microboards can be a door opener for contact and friendships between family members, friends of the family and the board owner. We recognise this in our project.

One of the parents of a young child in the project described how the board owner's first year was dominated by health issues and hospital visits. The usual family gatherings didn't happen, and distance grew. There was no 'natural space' for the rest of the family to get to know the board owner, but when they invited the family to take part in the board, contact increased.

Parent and board member:

'This model is incredibly important for children. The supported decision-making board has opened up an opportunity for more family members to get to know (board owner), and not least her form of communication, better. We have a book about "deaf culture" that is being passed around between board members, and an aunt has started taking sign language lessons.'

Another parent of a child who is a board owner made the following reflections on the importance of establishing a board at an early age.

Parent and board member:

'Your self-image is formed during childhood. If a person has been oppressed, it's not easy to stand up and say that your voice matters at the age of 18.'

The reflections of an adult board owner confirms this view.

Board owner:

'My problem is that, since childhood, I haven't always been open. I haven't. Have always had others speaking on my behalf. Always. I think that has perhaps left a bit of a mark on my life. That I've always had someone there to help me and speak on my behalf. When I really should have been using my own voice. (...) I haven't started doing so since I grew up. (...) I think it's about time I tried to speak up for myself. Instead of being the person who others speak on behalf of. I feel that someone has made the choices for me. That I perhaps didn't like.'

In conversation with reference group member Professor Jan Tøssebro about establishing boards for young adults, he says that establishing boards early in life could have a positive effect on self-determination as well as recruitment of board members.

Jan Tøssebro, professor, NTNU:

‘We see quite clearly that family members in particular are more involved when you are 22 than when you are 52. (...) For example when it comes to housing arrangements and things like that. It's easier to get things moving early on. Several factors support setting up boards at an early age, or at least during adolescence or early adulthood.’

## The board owner and board members spend more time together

Several board members have stated that having undertaken the role of board member has been a door opener for more contact with the board owner. The parents describe more contact and activities being initiated between board members and the board owner, including outside board meetings. That board members maintain or step up contact with the board owner, to be the best possible source of support, is also part of the model's objective.

Board member:

‘I've got to know (board owner) in a completely different way since the board was established. That is linked to us being together with her more often. But it has also inspired me to contact (board owner) more often myself.’

Board member:

‘When I was asked, I thought that it might be a good way of becoming a bit more involved as a family member, because at first it could be a bit difficult with (board owner)’s needs, getting the hang of that. But, like, with the commitment that the board involves and all that, I also want to be involved, and had to become more involved. I do want to play my part, and to a greater extent.’

Board member and parent:

‘It’s very new to me to suddenly not know, suddenly I’m informed that (board owner) is going to visit (board member) without me having heard anything about it. Or when on a visit to hospital, and suddenly someone else is sitting there, also visiting. Without me knowing about it. That's nice.’

Board member and parent:

‘I think it has changed. Us being able to ask. Everyone is so busy. They all work, but this has resulted in them taking the initiative in relation to us. Instead of us having to ask. They suggested doing things together.’

Board member and parent:

‘For the first time, they have invited him to take part in activities without us adults.’

## The board's awareness is raised

Guidance and training is important in order to ensure that this model does not develop into a new guardianship regime where board members make decisions on the board owner’s behalf. The Canadian model focuses on person-centred thinking. Uloba has worked to raise awareness of topics related to self-determination, CRPD, the Independent Living ideology and person-centred thinking. A lot of it is about sharing experience, reflecting on dilemmas that could arise and discussing possible ways of dealing with them.

One dilemma that was raised in a board concerned short-term wishes versus long-term needs in relation to soft drinks. The board owner is very fond of cola, but will find it very complicated and challenging to visit a dentist. One of the board members, who is not a parent, raised the issue of whether the parents may nevertheless have instructed the people who assist the board owner on a day-to-day basis to enforce too strict limitations on his consumption of cola. Uloba does not take a stance on what the correct course of action is in different cases, but encourages the boards to raise such dilemmas and consider whether they should change their decision. We would also like to remind them to revisit dilemmas later so that rules are not set for the rest of the board owner’s life.

Read more about dilemmas in the chapter ‘Dilemmas related to self-determination’.

Several of the boards have commented that they have learnt a lot from hearing about the above-mentioned topics, and they have found examples from Canada and the exchange of experience between boards to be particularly instructive.

### Awareness is raised outside the board

Uloba has observed an interesting trend in several boards that have brought the board owner's own perspective to the fore in encounters with the public administration, for example the school system or municipal authorities. One board owner was involved in a process with the municipal authority about opportunities for work and more BPA hours. The meeting with the municipal service manager took place in the board owner’s home, with most of the board members present. One of the board members, who had attended similar meetings in the past, described the atmosphere as uniquely open and respectful. The board member believes that this occurred because the board attended the meeting and so obviously listened to the board owner’s thoughts, and that this in turn influenced the service manager. Another board reflected on the same issue in relation to the people who assist a board owner who uses an implicit form of communication on a day-to-day basis.

Board member 1:

‘(...) and I also think that the fact that we have these meetings makes us more focused in our follow-up of the people who work with him. They have to report and we keep an eye on the financial situation, activities, and in the next meeting we are going to ask them **“how did it go?”** Things they were to plan and do. So I think it’s a good thing to have someone who sort of keeps an eye on things or perhaps contributes ideas. Many residential facilities probably just deflate. No one is paying attention or making demands.’

Board member 2 and parent:

‘And I feel that it carries more weight, when we’re a board. There are more people than these two old parents.’

Board member 1:

‘It’s not easy to come up with new activities, but just the fact that we request them helps to keep activities going for him. Simply that we're keeping an eye on things.’

In another board, a parent and board member describes feeling that the board owner’s needs are met with more respect and taken more seriously by the authorities when there is a board compared with when they were ‘just’ two parents. This echoes similar experience from Canada.

Parent and board member:

‘After 17 years! Finally we don’t feel steamrollered. We’ve always been told that a nursing home or an institution is next. It’s always there in the background. They didn't think BPA was a possibility. (...) We’ve been doing this for two or three years without being aware of it, really. Talked to siblings. **Do you think this is okay? Should we hire them or them? Where to go on trips?** But now it’s all been put into a system, which makes it more inclusive for the siblings. It's real, what we have felt all these years. People are used to communicating with parents, exhausted parents who aren't able to fight for their child.’

The same parent describes an eternal tug of war between the county and municipal authorities about insufficient assistance at school when their son finished lower secondary and started upper secondary school. He describes how much more weight the board owner's wishes carried when there was a supported decision-making board.

Parent and board member:

‘I haven’t worked since autumn. I accompany my child to school. We have to be serious in dealings with heads of units and sections. Not just exhausted parents or parents who want (...) Finally we have found something that “gets through to them”. They reply and make proper formal decisions. They don't just throw something out there.’

Others, however, have found that public authorities do not acknowledge the board because it has no basis in law. Yet others have been afraid to even mention the supported decision-making board because the board owner doesn’t have a guardian. They have worried that even mentioning the supported decision-making board could make the board owner a candidate for guardianship. The board members have therefore used roundabout and surreptitious approaches, painful though it may be.

### Ensure that board owners can live their life the way they want – without this being dependent on individual people

Parent and board member:

‘Lived life, language and quality of life cannot rest solely on the parents’ shoulders. It is a precarious situation. It is hard. And there is no safety net.’

Many next of kin find that they alone bear full responsibility for ensuring that the board owner can live a good life on his or her own terms. Several parents describe having fought for and helped to develop a network of services around the board owner, whether in terms of access to an appropriate environment for communication, living arrangements in a flat or house of their own, BPA or other services. They express fear about what will happen to the board owner's possibility of making decisions for themselves and living the life that he or she wants when the parents are no longer there. They hope that a supported decision-making board with more people involved can function as a safety net for self-determination.

One parent describes a lot of unhappiness when the board owner had no BPA and the municipal authority controlled the services.

Parent and board member:
'For us, this is primarily a safeguard for the day when we are no longer here. Someone will be ready to take over. (...) It's better to have a supported decision-making board than two parents in declining health who will not be around forever.(...) The most important thing is that nothing dramatic happens when we die. That is definitely the most important thing to us. (Board owner) shall continue to live in the house with staff and BPA.'

One parent of two grown-up children who are board owners tell us that they think a lot about how the third child will be able to cope with everything alone when the parent dies.

Parent and board member:
'I have thought a lot about (brother). He is a brother, but has two siblings. He'll never be able to manage to say that the municipality will have to sort things out – and for that he needs the help of someone his own age. I think about that. We can't hide from him the fact that the municipality doesn't sort things out.'

All of the parents hope that the supported decision-making board can function as a safety net to ensure that the board owners' will and wishes for their own life are respected and that they will have the opportunity to continue to live the life they want after their parents are gone. In Uloba's view, this is precisely what the supported decision-making board can contribute to. This model can ensure that the board owners' will and preferences are heard, understood and realised throughout their life. Their situation is less vulnerable when more people are involved. Vela Canada's experience is that even though some members leave a board, temporarily or permanently, other members will keep the board going.

## Challenges associated with the model

This chapter describes some of the challenges we have encountered during the project period.

### Small network and no board chair

Eight of the nine boards have appointed a chair who is responsible for convening and chairing the board's meetings. The board owner with no chair also has a small board, and none of the board members have wanted to take on the role of board chair. This has hampered progress in the board's work. The board in question has only met three times during the project period, and the meetings were initiated and chaired by Uloba. The board owner had no other natural candidates for new board members, but Uloba has, in consultation with the board owner, found another board member who could potentially also take on the role of chair, thus ensuring continuity in the board's work.

One reason for the slow progress of the above-mentioned board is probably that it needed close follow-up during the project period, while Uloba has been involved in several processes at the same time and had limited resources. Another reason is probably that the board owner's first board members were appointed later than those in the other boards, which means that they missed the joint training. Uloba believes that the board would have made more progress with closer follow-up, which it would have received had the project period not coincided with a pandemic.

Experience from Canada shows that it varies a great deal how long it takes to get a board up and running. Some get there quickly, while others need time and close follow-up. It is absolutely possible to set up a board even for people with a small or seemingly non-existent network. In fact, the microboard model was developed based on a group of people with small networks. Vela Canada was established when the big institutions were closed down. Many of the people who lived in these institutions had lost their entire network, but we have all come into contact with different people through the life we have lived. Part of Vela Canada's job is to find people who have had a close relationship with the microboard owner. It could be an old teacher or, as in one example from a Canadian microboard, a bus driver who had driven the person in question to a weekly activity. The two had established a close relationship because they sat next to each other on the bus and talked on a weekly basis. It took a while, but this bus driver became the person's very first board member.

### Teething problems

As in Canada, the boards in our project developed at different paces. Some quickly established regular meetings with set agendas, while others had more sporadic meetings over a longer period of time. Several found continuity to be a challenge initially, but things improved when the boards had a chair who took charge. It appears that boards with frequent meetings provide more support than boards with more infrequent meetings.

It took some boards years to get properly up and running. This was probably primarily due to the pandemic, but the project period has also entailed a great deal of learning for all parties involved – including Uloba.

Several parents have commented that finding board members who wanted to contribute was less challenging than expected.

### Dilemmas related to self-determination

There are several dilemmas related to supported self-determination. It is about understanding the nature of self-determination and what self-determination is based on. Such as the possibility of being able to understand and be understood, and of experiencing making choices and living with their consequences. It is important that the people providing decision support employ person-centred thinking. The simplest way to explain it is to focus your thinking on the person you support, not yourself.

Larry Tebrake, Person-centred trainer, Minnesota Department of Human Services:

I've now had the opportunity to work for the last three–four years as a trainer in helping people understand what is important to others and how should we be treating each other. And it's not only people with disabilities, but it's each other, it’s within organisations, and it's across any interaction that you have. And that’s what I think is so important about it. It's not only for a certain set or group of people. It’s for all of us.’ (RTC Media, Research & Training Center on Community Living, University of Minnesota, 2016)

It is important that the people providing decision support are aware of dilemmas such as risk assessment, long-term values versus short-term wishes, sensitive topics, natural resistance etc. Sometimes, we stop the people we love from doing what they want, because we don't want them to experience problems. Maybe we are more realistic or fear the worst. Below, a board owner shares his reflections on how it feels to face what may perhaps be described as natural resistance from a board member. The board owner wants to move out of the institution.

Board owner:
'I know that (board member) is happy that I live here. (Board member) believes that I would never have received the help I need if I had continued to live in (the home municipality). That I would never have received the same help. That I should be very glad to live like this, but at the same time, I also think, sometimes I think that I would have liked to live close to my family too, in a way. Then I'm not always so pleased that people are delighted with the choice I made. (...) I plan to move out from here in a year or two, but my (board member) and others may say **"You'll have to shelve that idea. You can't sit here thinking about what sort of home you want, or the flat you want, just yet. You have to take things as they are. One thing at a time."** Argh. That word. One thing at a time. Sometimes it annoys me when I want to talk about the things I would most like to do. (...) **"Now you have to take it easy with everything you want".** (...) You're sort of held back. (...) I want a bigger flat, a bigger place where I can get to a shopping centre or something. (...) And that I have to take it easy, for example about wanting to move. Take things as they come. Yes, of course I understand. I must be allowed to have wishes.'

The boards have provided feedback on Uloba's focus on the above-mentioned topics, in combination with the fact that they have been given the opportunity to reflect on the topics, raises awareness and helps them to better support self-determination. The board member in the above quote was one of the people who entered the project late and missed the training provided by Uloba. The board member has therefore not had the same opportunity to learn what the other have learnt. This illustrates how important it is to have training about the role of board members, self-determination and dilemmas.

Uloba assumes that some board members may, for various reasons, be unable to support the board owner's self-determination regardless of what training is provided. In such cases, other board members have a responsibility to speak up. If the person in question is someone who is very important to the board owner, an advisory role in relation to the board may be more appropriate. Uloba would like to follow up these topics further.

There is general consensus among the boards that discussing concrete examples is very instructive, and Uloba will focus on doing so in its training.

An example from Canada that Uloba has used to explain person-centred thinking concerns a microboard where the person supported stated that she wanted to become a doctor and work in a hospital. The board knew that it would be difficult for her to achieve this, but they didn't say so. They had been trained in person-centred thinking and knew that their understanding of her statement is not necessarily the same as hers. Person-centred thinking is also about responding to statements with interest and curiosity. Consequently, the board asked her why she wanted to become a doctor and work at that hospital. She replied that she wanted to help people and wear a white coat with a name tag, and that she liked the hospital. That gave them very different frame of reference to work within to support her. The woman eventually got a job at the hospital. The job involved helping people to find books in the library. The work uniform was a white coat with a name tag.

Another example we have presented to the boards in the context of person-centred thinking and risk assessment is a board owner in Canada whose greatest wish is to stand between the lanes of a motorway. It is of course not possible for them to fulfil this wish, as we have to assume that the person in question does not wish to die. They did, however, try to find out what it was that was so special about standing in the motorway, which the person had actually done on some occasions. They found out that it might be the feeling of the cars whizzing past on both sides. They then thought that he might experience a similar feeling in a trampoline park that had trampolines on the floor, walls and ceiling. That was a way of taking the board owner, and what he was expressing by seeking out the motorway, seriously. They accommodated his wish, but in a safe setting. The next dilemma is of course what is sufficiently safe and for whom. Again you have to focus on the position of the person you support.

**'... I want to be in control.
I'm the boss.'**

Board owner

### Board members who fail to attend

A couple of boards experienced board members not attending board meetings. This was particularly challenging since a family relationship was involved, and the board members, and perhaps also the board owner, were very disappointed. Being a board member is a commitment. If you cannot follow through with it, you should not be a board member. Uloba nevertheless asked the board to consider whether the person in question could have an advisory role instead. The possibility should be considered that people who matter to each other could provide important input to the board's work, even if they are not comfortable with the formal role of board member with all that it entails.

## Discrimination in society remains an obstacle to self-determination

This chapter presents the most illustrative examples our project has encountered of how the paradigm shift hampers the board owners realising self-determination.

The project has found that disabled people who need decision support currently have limited opportunities to realise their right to self-determination in Norway. This is not only about the absence of a system and legislation that allow for supported decision-making. We live in a society where disabled people encounter discrimination and obstacles at every turn because Norway has yet to undergo the paradigm shift in terms of thinking and policy that is required in order to implement the CRPD.

> A paradigm shift would entail a shift in understanding from an individual pathological perspective where individual differences are considered to be the cause of marginalisation and lack of participation, to seeing society's shortcomings and prejudice as the cause of marginalisation and discrimination. We have a long way to go to achieve a paradigm shift. The consequences of the traditional attitude that disabled people are primarily hampered by their own individual impairments and not by prejudice and structural discrimination are reflected in policies and terminology. (Equality and Anti-Discrimination Ombud, n.d., Funksjonsevne, paradigmeskifte)

## Communication

Communication, the possibility to understand and be understood, is an important key to self-determination. There are many different forms of communication and communication aids. Disabled people are entitled to receive training in the form of communication, or the combination of forms of communication, that they need. Several board owners appear not to have received such training or skills maintenance. One board stated that the board owner received augmentative and alternative communication (AAC) training in school, but it was not followed up later. During the project period, the board has arranged for the board owner's environment to resume AAC, but they say that they were planning to do this anyway.

We have both specialist environments and various forms of communication aids in Norway, but it is not a given that people are able to access what they need. Parents of adults as well as children who are board owners confirm this. The mother of one of the children in the project described having fought for years for access to the appropriate communication environment for her child. Once that was finally granted to the family, it was like getting a magical key to communicating with the child. One of the people she was most impressed with was communication expert Gunnar Vege, whose background includes experience from special needs teaching, the resource system for deaf-blindness, and the educational and psychological counselling service (PPT). Uloba hired him to give a talk at a supported decision-making board gathering already in 2019 as part of the training provided. The title of the lecture was: See me so that I can see myself. Validate me so that I can believe in myself.

Communication is an important topic in Uloba's training because understanding and being understood is such a crucial prerequisite for self-determination. We hope to raise the boards' awareness so that they seek out appropriate specialist help if the board owner needs it.

Jan Tøssebro, reference group member and professor at NTNU:

'To me, communication is about a lot more than training for the person concerned. It is just as much about teaching their surroundings to interpret implicit language and individual (often referred to as idiosyncratic) language. This, in turn, can be linked to framework conditions, such as those who provide services being sufficiently familiar with the person concerned, and it can have a bearing on personnel policy (small groups) and work rotas to ensure that the person is surrounded by people who are capable of interpreting him or her.'

As Tøssebro points out, the possibility to understand and be understood is about much more than training for the board owner – the people around the board owners in their everyday life also need training.

## Prejudice

Disabled people are a group at particular risk of suffering the consequences of prejudice.

Parent on how differently a board owner with an implicit form of communication is treated by public authorities compared with the board owner's non-disabled siblings.

'You can only see it if you're up close. (...) I have to fight for her to be able to do what the others have done. (...) Says something about how little dignity you're treated with without a voice. (...) Feel that I encounter a lack of dignity again and again. She's worth so little. It's not that important. When you have three girls the same age. Seeing the difference in how they are treated at the dentist's. By the same systems.'

We are all influenced by the society in which we live. Those of us working on the project have focused on that in an effort to notice our own ingrained ideas. Prejudice that limits people and hinders their self-determination can be found in us, in the public administration and also among family members.

At the beginning of the project, all board owners had a contact person in relation to Uloba. They were selected by the board owner, either alone or with the support of board members. One of the board owners had selected a contact person who was employed at the board owner's place of residence. When the contact person changed jobs, the board owner was left without a contact person. Uloba's project manager went to visit the project participant – in part to become better acquainted, as the project was fairly new, and in part to find a new contact person for the board owner. After a long conversation, the project manager asked the board owner who they wanted as their new contact person. The second she had asked the question, she realised what she had just done. Would she have asked a person who did not need decision support the same question? Of course not. The person she was talking to would then automatically have been her contact person. So why did she ask the board owner? Well, because she assumed that the board owner could not be her main point of contact. This was an early lesson in the importance of adopting a self-critical and open approach in order to realise one's own ingrained prejudice in this work.

Uloba immediately started work to put things right. In the cases where communication allowed, Uloba's primary contact was from then on with the board owner. When good communication required knowledge of the board owner's form of communication and life story, the board members were the main point of contact. The project manager also contacted the board owner to apologise. The board owner then reflected on how it feels to be met with such prejudice.

Board owner:
'I have never considered myself to be in need of a contact person. I can speak for myself and think for myself. I don't need someone close to me there to understand the conversation between us, but I have no difficulty understanding that some people may need that. (...) I understand that we face such prejudice. Not being allowed to decide for oneself. Having others in control. Even if that's not how it should be. I want to be in control. I'm the boss.'

An adult board owner has wanted to work with children and young people ever since she was young. She has no challenges being understood when she communicates her wish to representatives of various public authorities, but nevertheless encounters attitudes and prejudice that prevent her from achieving her dream.

Board owner:
'So, I really enjoy working with children and young people, but I've always been told that "(...) **I don't think that education programme is right for you. I think you would do better in a different programme."** The one I've wanted to work in. Childcare and youth worker. Which I've wanted since I was a teenager, but then people come along and try to tell me what's right and what is really the right choice for you. What can you say?

I had a meeting some years ago with (name of county authority) where they told me that I need really good... I hate it when people say things like **"If you think about it for a moment, do you really think that childcare and youth worker is the job for you? You need (description of the person's functional impairments as an obstacle to being able to work with children and young people)."** So I had to stop and sort of shelve it. I had to choose a new direction, and that was... There was someone here at work who said that "(...) **I want you to think about something. What if you can take an education in sales and service?"**, as another alternative. Instead.

Then I told the woman we were meeting that I had been advised to consider sales and service. And she said **“Yes, that might perhaps suit you. Working in sales and service.”** So now they’re working on me becoming a sales and service training candidate. (...) I’ve experienced this twice. I was living in (...), and there was this person, who I believe worked for the municipal authority, who was working with me. Also said (...) **“Are you sure about childcare and youth worker..?”** Then I stuck to my guns. Didn’t want to give in. But then having to face such opposition again. From (...) county authority itself?! What can I say?! I encounter the same prejudice again and again, (...) **“Are you sure about this? Sure that you’re doing the right thing?”** And even when you say “yes”, then they say **“How about sales and service, (...) maybe you should think about how that could be better?”**

This is just one of many examples of board owners’ experience of navigating their own life when they are dependent on different services from and contact with the authorities – that are supposed to assist them, but instead becomes obstacles to their self-determination and self-realisation.

Board owner:
‘When others say you should do this and that. Where are you supposed to be treated with respect then? By others? When others have to speak on your behalf? (...) If a person is struggling, cannot speak or is deaf or whatever, then I think that I have to understand the person with the problem. I have to think “What can I do to make it possible for that person to understand what I’m saying? What must I do to show the person that respect or show that I want to work to ensure good chemistry between us and demonstrate that – how do you want us to communicate?”’

### The absence of a system and legislation that allow for supported decision-making is an obstacle to self-determination

The fact that Norway has no legislation and system for supported decision-making capable of accommodating this model, has imposed limitations on the supported decision-making boards. It has limited what can be discussed in a board meeting and how they can actually contribute.

Board member:

‘It was difficult to know what we were getting into when we first started. Some practical issues at first, and then all this legal stuff. I thought perhaps that there would be more room to help more than we have been able to do. We have become supporters, but perhaps not been able to contribute very much directly.’

Board member, parent and guardian:

‘The most demanding tasks are probably the work leader function (BPA) and financial matters. But the board cannot help with these things at present. But you have provided input on aspects of work leadership other than personnel matters. That helps too. Maybe another board member could take on the work leader function! What is so good about a supported decision-making board is that there are more of you and you can lean on each other.’

A board member who is also a parent is concerned with ensuring a good and open information flow between different services and the supported decision-making board, and believes that a basis in law could guarantee this, in the best interests of the board owner.

Board member and parent:

‘The duty of confidentiality. That is a real nightmare. I have the impression that the municipality is using the duty of confidentiality for all it's worth to keep us at arm’s length. It’s brutal how they don’t tell us about the child’s situation when the child is under their care. The parents are not supposed to know anything, but that shouldn’t be the situation when you have BPA and a supported decision-making board. Information flow should be possible and not prevent you from being involved in the child’s life, even if someone else takes over their care, the formal care.’

In Canada, the system is that in cases where the board owner does not express an explicit decision on a given topic, there will be a vote. In the event of disagreement, the majority decides. We have not been able to test this, as the supported decision-making boards lack a legal basis. No concrete disagreements have come to Uloba’s attention, but a board member who is also a guardian and mother has informed us that disagreement has occurred.

Board member, mother and guardian:

‘Yes, there have been occasions when we have definitely disagreed. Formally speaking, I have legal responsibility for things, so then I've just said that that will be for me and him to decide.’

Some boards have found that the public authorities have shown more respect for the board owner’s wishes when board members tell them about the board. However, others have found that the supported decision-making board has not been taken seriously precisely because the model lacks a basis in law.

Board member: ‘Our greatest fear was of course the possibility that (board owner)’s care could revert back to the municipal authority when we are no longer able to run it (BPA). A supported decision-making board gives us more strength to resist the municipality that is ready to take over and more or less encouraged it.’

Uloba: ‘Have you told the municipality about the board?’

Board member: ‘Yes, and they told me bluntly. They don’t care about the supported decision-making board. It was dreadful. (...) I can understand if formally, since the supported decision-making board has no legal platform. It’s a club. A group of volunteers. Under the current legislation. (...) Our greatest fear is that the municipality comes to take over. That would make (board owner) feel unsafe and act out.’

# The way forward

Being in control of your own life is a fundamental human right. The CRPD acknowledges that some of us may need a formalised form of decision support in order to make decisions for ourselves. This means that Norway must offer a variety of models for supported decision-making to choose from for disabled people who want such support. The current status is that there is no such system for disabled people who are in need of decision support, and their human rights are thus being violated. According to up-to-date figures for 2023 from the Norwegian Civil Affairs Authority, 33,500 people fall within the scope of CRPD are under guardianship. These people ought to have the option of supported decision-making. This means that a large number of people in Norway are victims of this human rights violation.

The Guardianship Act will have to be amended for Norway to fulfil its obligations under the CRPD. The reason for this is that the CRPD does not allow people to be deprived of their legal capacity and put under guardianship on grounds of functional impairment as set out in the Guardianship Act Section 20, Section 22 and Section 33 second paragraph. Section 33 second paragraph is the provision most commonly used in relation to people with intellectual disabilities, and we can refer to this as 'deprivation of legal capacity by stealth'. Under this provision, no legal decision is required to deprive a person of legal capacity, but the right to self-determination can nevertheless be lost simply by a doctor writing a simple certificate declaring that the person does not have the capacity to give consent. This is where Norwegian law is in conflict with Article 12 of the Convention. The Norwegian Civil Affairs Authority does not know how many people are under guardianship pursuant to Section 33 second paragraph. Many people with intellectual disabilities have close family members as guardians, or other people close to them who want to help. Others have guardians who they do not know and who receive significant income from serving as a guardian for several people.

The Norwegian Association for Persons with Developmental Disabilities (NFU), the Equality and Anti-Discrimination Ombud (LDO) and the Storting's advisory body, Norway's National Institution for Human Rights (NIM), all share Uloba's view that everyone who wants it must have access to supported decision-making instead of being forced into guardianship. We will therefore continue our work to promote the introduction of a law and a system for supported decision-making in Norway.

Experience gained from the project shows that board owners achieve a higher degree of self-determination. Uloba therefore wants to offer more people the opportunity to set up a supported decision-making board. It is a CRPD requirement that disabled people who want supported decision-making must have several models to choose from, and Uloba looks forward to other organisations beginning to develop other models. In any case, it is a prerequisite that a legal framework for supported decision-making models must be established.

All the supported decision-making boards we have followed during the project wanted to continue to work in this way – even now that the project has been concluded. The boards deserve ongoing follow-up. We also consider follow-up and adapted training on various topics an important contribution to ensuring well-functioning supported decision-making boards that can guarantee the board owners' self-determination.

The right to self-determination has become one of the causes that Uloba is most committed to. The organisation has therefore established a team dedicated to spreading knowledge about the model and developing it indefinitely in cooperation with the boards from this project. We will also continue our work to ensure that Norway incorporates the CRPD into the Norwegian Human Rights Act and establishes a law and a system for supported decision-making.

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