

## Toolkit: Networks of Support February 24, 2021

It is important for individuals to have a network of support around them. Social supports enhance our health and wellness. Ensuring **sustained support**, as needed, is integral to an individual having opportunity to live the life they enjoy. The approaches described in this Toolkit offer some emerging strategies and resources. All of the suggestions take time to examine and implement.

### Background

Research has shown that individuals in the autism and intellectual disability communities have a range of personal relationships. They can sometimes face barriers in becoming involved in their communities. Accordingly, these individuals can often struggle to find an organic network of support.

But there are a number of ways an individual can find support to build a life-long support network. If you are someone, or know someone, who may be interested in looking to build a formal network of support, this Toolkit might be helpful.

There are many options to consider. Some options have strange names and sound complicated. We hope that this Toolkit can help simplify the range of information. You may also want to contact your regional advocacy office such as the Autism Society or Intellectual Disability Advocacy office in your area. The key here is ensuring a strong commitment to, and plan for, supporting the individual to live the life they choose, and thus, coming alongside them to ensure that this aim indeed is achieved.

This Toolkit discusses three different kinds of *formal support networks supporting someone's care*. At the most basic level, these are networks made up of people who come together on a voluntary basis, with varying levels of formality, to support someone through meaningful relationships. The details and purposes of these formal arrangements can vary significantly.

Beyond providing information, this provides information on organizations that may be helpful.

The Toolkit will cover:

1. Circle of Support/Circle of Friends
2. Personal Support Network/Lifetime Network
3. Microboard™ (and Aroha Entity)

**DISCLAIMER:** COST – It is important to note that some of the organizations listed in this Toolkit charge for services. AIDE Canada is not endorsing any particular organization or support structure; we solely aim to present options for someone interested in forming a formal support

network. It is also important to note that the personal support networks covered in this Toolkit are not about legal capacity for decision-making, and instead are focused on care planning.

## **1. Circle of Support/Circle of Friends**

The first form of a personal support network is called a Circle of Support or Circle of Friends. This is the most informal kind of structure covered in this Toolkit.

### ***What is a Circle of Support?***

A Circle of Support or a Circle of Friends takes an old and lasting concept of building community relationships, and locates it in a modern context. It is more informal than the Personal Support Network or Microboard concept discussed later in this Toolkit.

Circles of Support tend to be more informal than the other structures discussed in this Toolkit because they often are made up of a looser group of supporters who don't have defined membership or roles. This is more informal than, say, the role of a Microboard member (discussed below).

Accordingly, a Circle of Support is a group of citizens who come together to support and share relationship with the person with a disability. This group of people knows and cares about the individual, and is in place to ensure that the individual feels supported and safe. Members of a Circle of Support are not paid. They are people who an individual likes and trusts. Members of a Circle of Support meet regularly to socialize and enjoy each other's company. People in an individual's Circle of Support are there to spend time with the individual, and support the achievement of personal goals, overcome barriers, and plan for the future.

A Circle of Support is very similar to the Personal Support Network discussed next, though it is more informal. In other more formal structures, individuals often work with staff or other facilitators to help identify members of their network. In these other structures, often times members have certain roles to play in the arrangement. A Circle of Friends is more casual, and does not need the constant guidance of a facilitator.

### ***Finding assistance to set up a Circle of Support***

Some provinces have specific organizations who can help an individual set up a Circle of Support:

- Ontario
  - a. [NABORS \(Toronto\)](#); 416-315-0095 ext. 210
- Quebec
  - a. [Friendship Circle](#) (Montreal); 514-735-8725
- New Brunswick
  - a. [New Brunswick Association for Community Living](#) ; 1-866-NBACL-4U

In addition to these organizations, anyone can facilitate a Circle of Friends/Circle of Support development process by using [these guidelines](#) (Inclusion Press), which are available to anyone in Canada.

## **2. Personal Support Network**

The second kind of formal network covered in this Toolkit is more formal and is called a Personal Support Network. There are organizations whose sole purpose is to help individuals and/or families establish a Personal Support Network.

### ***What is a Personal Support Network?***

A Personal Support Network is a group of people who are brought together in a formal structure to support an individual with disability. Members of a Personal Support Network provide the individual with advice, support, companionship, and decision-making assistance. Each Network is uniquely created for the individual, and is focused on their goals, needs, interests, and lifestyle.

Members of a Personal Support Network could include family members, friends, neighbors, loved ones, and professionals, such as counsellors or financial advisors. Some people choose to have legal advisors in their Personal Support Network. First and foremost, these people care about the individual's safety and well-being. They are not paid.

Members of a Personal Support Network carry out roles and responsibilities that are difficult for the individual with a disability to carry out on their own. This will vary depending on the person. Some people may need assistance with housing, employment, or recreation, for example. Others may simply want help developing closer ties to neighbors and the community.

Personal Support Networks can do the following:

- Provide links to others in the community
- Secure and monitor supports and services
- Spend time with the person
- Plan, dream, socialize and have fun
- Provide security and a sense of relief for the individual and/or family
- Act as a resource for executors and trustees
- Provide potential executors and trustees
- Keep key players well informed
- Act as representatives and support decision making
- Provide a forum for Network members to support one another.

There are a few organizations in Canada that help individuals establish a Personal Support Network. These organizations charge for services, with fees dependent on an individual's circumstances. We encourage you to follow the links below for more information on each organization.

### ***What does the network development process look like?***

These organizations will begin by looking at an individual's gifts, interests, health and safety considerations, and current routines. Most often, this work will be done with an individual called a *Community Connector*. The individual with a disability could work closely with the Community Connector who tends to be a paid employee of the organization. They would get to know one another with the aim of supporting the individual with a disability in identifying a strong network of relationships.

### **The role of a Community Connector**

Community Connectors are facilitators. They help the individual at the centre of the Personal Support Network – the individual with a disability – nurture existing relationships in their lives while adding to their group of friends. They coordinate activities with family and friends. They attend events in the community alongside the individual to help with introductions to others in the group. They also facilitate introductions to new people, and can help an individual manoeuvre through awkward social situations.

A few times a year, Community Connectors will bring the Personal Support Network together for a planning meeting to ensure that the person at the centre is recognized and feeling heard. It is important for the individual at the centre of the Personal Support Network to feel empowered in their decision making, have a place to call home, and have financial security and a well-planned future.

You can find more information by clicking the links below.

### ***Where can you find assistance setting up a Personal Support Network?***

- British Columbia
  - a. [Planned Lifetime Advocacy Network \(PLAN\)](#) (Vancouver); 604-558-2055
  - b. [PLAN Okanagan](#) (Kelowna); 250-860-2080
  - c. [Lifetime Networks](#) (Victoria); 250-477-4112
- Alberta
  - a. [PLAN Edmonton](#) (Edmonton); 780-488-2422
  - b. [Inclusion Lethbridge](#) (Lethbridge); 403-327-2911
  - c. [PLAN Calgary](#) (Calgary); 403-263-8226
- Ontario
  - a. [Thunder Bay Family Network](#) (Thunder Bay); 807-577-0034
  - b. [Partners for Planning](#) (Toronto); 416-232-9444
  - c. [Able2](#) (formerly Citizen Advocacy) (Ottawa); 613-761-9522

Note, if you live in another province or territory, we recommend reaching out to [Planned Lifetime Advocacy Network \(PLAN\)](#). Although they are based in Vancouver, BC, they may be able to help you no matter where in Canada you live.

### **3. Microboard<sup>™</sup>**

The third and most formal network is called a Microboard™. Microboards are more formal than both Personal Support Networks and Circles of Friends, as they actually involve incorporating as a not-for-profit entity with the government. This means they can be more involved in the day-to-day finances of the person at the centre.

### ***What is it?***

A Microboard is made up of a small group of family and friends who join together with the individual with a disability to create a simple incorporated not-for-profit organization. This small group of people works with the individual to help create their desired life.

The term comes from the words “micro,” meaning small, and “board,” reflective of a non-profit agency. The term “Microboard” is trademarked by an organization from British Columbia called Vela Canada. They are one of the original founders of this concept.

Through incorporating as an official not-for-profit organization, a Microboard formalizes someone’s personal network. The Microboard system is intended to ensure that individuals are supported throughout their lifetime, not only by family members, but also by their communities.

A Microboard must have at least 5 people, including family or non-family members. Most say 5-8 is the optimum number of members in a Microboard.

Members are also known as Directors, because of the Microboard’s official legal status. Not-for-profit organizations must have a Board of Directors to oversee the organization, and a Microboard is no different.

Members can include:

- Parents
- Siblings
- Aunts and uncles
- Cousins
- Friends of the family
- People who have worked with the individual and bonded with them, and shown an interest in their life
- People the individual meets on a daily basis and are interested in their well-being
- Current staff from the agency or school that supports the individual.

Members should be people who know and care about the individual with a disability (who is at the centre of the Microboard). Members are likely a supportive part of the individual’s personal network. They may or may not have expertise in a specific area of disability or support services, but they importantly bring a strong relationship and commitment to the individual’s well-being.

### ***What do Microboard members do?***

One of the most important roles of Microboard members is that they spend time with the individual in whatever way is most natural for them. They can help the individual with the following:

- Support personal and life planning
- Brainstorm ideas for the future
- Advocate for what the individual needs
- Help with daily or regular tasks, like doing laundry or grocery shopping
- Monitor services and ensure the individual is safe
- Employ or communicate with support workers
- Connect to the individual's wider community
- Do fun things together.

There are two types of Microboards. The first type is a Microboard that manages finances for the individual. For individuals who receive government funding to support them with their needs, the Microboard would receive this money directly.

With access to these funds, Microboard members become responsible for dispersing them. Alongside the individual with disability, Microboard members hire and oversee staff, and set up and pay for the supports that are required by the individual. Microboard members become the “employer” of the people hired to support the individual. Together, Board members can set up services that are creative and flexible, and reflect the needs of the individual. Much like a typical employer, Microboard members handle payroll, bookkeeping, reporting, regulations, and other required processes. These members are mandated to always act according to the wishes of the individual for whom the Microboard was created.

The second type of Microboard is one that does not have responsibility for an individual's finances. It is simply a formal entity brought together to support someone in decision-making and advancement toward their goals.

It's important to note that this process is meant to be collaborative between the individual with a disability and Microboard members. Microboard members work with the individual to make decisions that are desired by the individual, and nurture well-being. Microboards are *not* about legal capacity for decision-making, and are more focused around care planning.

### ***How can a Microboard be established?***

A Microboard is established by federal or provincial incorporation, which can be a complicated process. There are a few organizations across Canada that can help with the process, including Vela Canada, the original founders of the Microboard concept.

### ***Where can you find assistance setting up a Microboard?***

British Columbia

- [Vela Canada](#) (services free in BC; consulting provided to families across the country); 604-539-2488

#### Ontario

- [Microboards Ontario](#)
- [Pooran Law](#); 416.860.7572

If you live outside of British Columbia or Ontario, we encourage you to reach out to [Vela Canada](#). They have a lot of resources on their website and offer consulting services to families across the country. Note: Vela Canada’s consulting services do cost money, and the specific cost is dependent on an individual’s circumstance and the province/territory in which they live.

#### **A similar model: Aroha Entity in Ontario**

Because the term Microboard is trademarked by Vela Canada, other groups and individuals adopting a comparable format have called it something different. The University of Guelph and the Ontario Adult Autism Research and Support Network (OAASN) have developed such a service, entitled an Aroha entity. More information on Aroha entities can be found below, but it is important to note that the model is relatively limited in regional scope. The University of Guelph and OAASN are the primary sources.

- [OAASN About Aroha](#)
- [OAASN About Entities](#)
- [OAASN Questions and Answers on Aroha](#)
- [OAASN Guide to Incorporating an Aroha: Models: Strategies, Objects and Bylaws](#)
- [Story of Ontario's First Aroha](#)  
Book by Andrew Bloomfield, Aroha pioneer: Ontario’s first Aroha was incorporated around Andrew Bloomfield. He wrote a book about how his life has been transformed by his Aroha. The book is titled: ***Bridges over Barriers in my Life with Autism***.

#### **Some Final Advice from Parent to Parent...**

“Considering and investigating these issues take time and patience. If your child has had an opportunity to meet lots of people in school, she/he may have developed a sense of who is genuinely supportive, and who might be a friend or advisor. It may take many introductions after school age to get a good fit between a support person, your child, and perhaps yourself as well. Developing a pool of *resource friends* while still in school, may help long term.

Larger organizations, such as Inclusion Alberta (in Alberta), or organizations which are more umbrella-like than disability-focused, often have very useful annual meetings, with a wide variety of subjects discussed that are helpful to parents. These meetings may also help to introduce caregivers/parents and siblings to similar households, who can guide the search for sustainable supports through their own experience.

Unfortunately, you cannot always depend on your physician, lawyer or social worker to be aware of methods, organizations, or provincial/territorial funding sources to help in your quest for planning long term. Share with them and others any insights you discover. Both you and these others will be helped by the work you have put in.”

### **From a Parent well over 60...**

“Let’s say you as a parent, guardian or sibling of an intellectually disabled individual, now an adult, are approaching retirement. Most of your close friends are probably of the same age. Much advice is given to you as you approach retirement. This will include the suggestion to make friends and connections beyond the workplace (for which you may not have had time during your working years), and to include younger people as well. Deliberately searching for younger acquaintances helps make retirement as interesting and long lasting as possible. These younger friends and acquaintances also may prove to be the bulwark of a sustainable network supporting you, as well as possibly your now adult family member.

Making new friends and a network at age 60 is a challenge. Think about mixed age groups found in sports leagues, religious organizations, musical groups, continuing education, language classes, cooking classes, and volunteer work, as examples. You should have some fun too!”

## **Appendix: Worksheet to Identify Existing Support Networks**

As discussed above, there are many different ways to develop a support network. There are several organizations and lots of online resources that can help.

A good first step is to recognize the supports that are already present in your life. This includes friends, family members, teachers, neighbors, etc. Each person in your life can bring you a different kind of support. Sometimes these people are closer than you think.

We've created a simple worksheet that might help with this process. Mapping out these existing supports, and areas in which more support would be beneficial, can help form the basis of a more formal structure later on.

**WORKSHEET: SUPPORT NETWORKS**

<b>People you already know:</b>	<b>What strengths do they have that may be helpful?</b>
<i>Example: Neighbor Jane</i>	<i>Jane works in Human Resources. She could help with writing a resume.</i>
<i>Example: Uncle Bob</i>	<i>Uncle Bob is a great listener. He could help with clarifying goals.</i>

***Are there any strengths or supports you feel you could benefit from? Who might be able to help you with these missing supports?***

<b>People you want to meet:</b>	<b>Strengths they have that might help you:</b>
<i>Uncle Bob's friend Nancy is a chef.</i>	<i>Maybe Nancy can help me learn how to cook.</i>