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PERSONAL SUPPORT NETWORKS IN PRACTICE AND THEORY: ASSESSING THE IMPLICATIONS FOR SUPPORTED DECISION-MAKING LAW

Legal Capacity, Decision-Making and Guardianship

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EXECUTIVE SUMMARY

The concept of supported decision-making has been generating considerable debate. Many are drawn to the basic idea that decision-making rights – in areas ranging from health and personal care to finances – be delinked from particular levels of mental ability. The fundamentally hopeful premise of supported decision-making is that everyone can participate in personal decision-making if they have the right supports. Proponents of this approach, encouraged by the Convention on the Rights of Persons with Disabilities, say that traditional legal capacity laws that base decision-making rights on threshold levels of "understanding and appreciation" must be discarded, and a range of decision-making supports implemented in their stead. Others are concerned that traditional legal capacity laws, while perhaps imperfect, are necessary to safeguard vulnerable persons. They raise the possibility that giving legal status to ambiguous 'supported' decision-making process will only mask abuse.

As this broader debate continues unabated, many would agree on a narrower point – that is, that there is a lack of information about how *existing* supported decision-making mechanisms are working in practice, and indeed, that any attempt to legally formalize supported decision-making must build on such concrete experience. This paper takes this latter theme as its point of departure. Commissioned by the Law Commission of Ontario in the context of its inquiry into Ontario's legal capacity, guardianship, and decision-making laws, it steps back from the broader debate (about whether supported decision-making should be formalized in law at all), to instead examine one particular kind of decision-making support that is being used in British Columbia and Ontario: personal support networks. It considers: (i) how personal support

networks are operating in these two provinces; (ii) whether they are providing supported decision-making; and (iii) where they 'sit' within the broader legal context, including what it might mean to formalize them in law. In the context of this last question, it considers whether the law could, or indeed should, recognize the collective nature of 'network' decision-making as something distinct from individual one-on-one supports.

The paper is divided into ten parts. Part I locates this project within the Law Commission of Ontario's broader work, sets out the research questions, and explains the study's limitations, including the fact that it does not directly consider the perspectives of the individuals supported by personal networks. This means that this paper cannot speak to the more substantive and subjective elements of supported decision-making, for example, whether it is experienced as empowering. The short time frame for the study also made it impossible to fully canvass some other perspectives, such as those from government.

Part II sets out the project's three-step methodology. This included: (1) a survey of the literature relating to personal support networks to provide history and context for the entities under study; (2) a series of semi-structured interviews with persons with knowledge or experience relating to personal support networks; and (3) legal research into the laws and standards that currently apply to personal support networks, and the legal implications of varying options for formalizing networks in law. Of these three steps the interview stage was a central focus. This stage involved semi-structured interviews with 19 informants from a range of perspectives. Some had personally participated in personal support networks in either a personal or professional capacity. Others had not, and spoke to personal support networks

from the perspective of policy, academics, or other professional practice. In general, the objective was to determine how networks are working in practice, and what rules and safeguards are applied.

Part III is a short section on terminology; essentially, it explains that terms such as "Microboard", "Aroha entity", "support circle" and "personal network" are used in different ways by different people, and that in this paper the term "personal support network" refers to all of these types of entities. It sets out some minimal requirements (such as identifiable membership and the support of a single individual) for being called a "personal support network" for this paper. Part IV sets out some history and context for thinking about personal support networks. It explains that notwithstanding this paper's grouping of all networks together under a single term, they can be directed to different themes and purposes, including: (i) individualized funding and service delivery; (ii) friendship and community; and (iii) person-directed planning. While these themes often overlap, different networks emphasize them to varying degrees. And, supported decision-making may not be equally important to all of these goals.

Part V summarizes the results of the interviews. The lengthiest of the sections, it is intended to provide a relatively detailed description of informants' views on: network creation; principles of decision-making; interactions with government and private third parties; and the question of who is using personal support networks. There was a wide range of views in most of these areas. An exception was the uniform intention (at least among informants who had participated in networks) of providing supported decision-making. Another exception was informants'

experiences with private third parties. Neither the incorporated entities, nor the less formal networks, were able to interact with parties such as health care providers, lawyers, or banks, on the supported person's behalf.

Part VI briefly sets out some of the laws and non-legal standards that can apply to personal support networks. These vary by jurisdiction and the network's structure. Generally, however, incorporation brings with it a range of legal obligations, as does acting in an employer role. Incorporation also alters network members' (now directors') principles of responsibility and liability vis-à-vis third parties. Processes of decision-making in networks, on the other hand, are currently unregulated and unmonitored. Any standards that apply in this context are private and/or voluntary.

Part VII discusses the principles of supported decision-making, and asks whether the decision-making processes described by informants are consistent with these principles. It concludes that they are in many cases, but that one's answer will depend on the definition of supported decision-making that is adopted and on the particular network. It also discusses the skepticism that many people expressed about whether *all* networks engage in supported decision-making, or do so uniformly well.

Part VIII explores the policy options for recognizing personal support networks in law. It describes three possible approaches: (1) modest ones that largely rely on existing legal concepts (such as the duty to accommodate); (2) adoption of a supported decision-making law along the lines of British Columbia's *Representation Agreement Act*, which would not formally recognize networks, but could indirectly provide support for existing networks, and / or help to

create new ones; and (3) the more novel and contentious option of giving incorporated support

networks the legal authority to represent the personal decisions of a private individual. The

section ends with a discussion of the key factors that would need to be taken into account were

this final option to be taken forward. Part IX is an overview discussion the three legal options in

light of the twin concerns for protecting vulnerable decision-makers and ensuring adequate

clarity for third parties. It ultimately suggests that an expanded corporate model has some

potential to address these concerns in a way that the other legal options cannot; but that this

apparent advantage requires further examination alongside the range of factors, advantages

and drawbacks discussed in Part VIII. Part X concludes.

I.   INTRODUCTION

A. <u>Context</u>

This project arose out of a much larger investigation, being conducted by the Law Commission of Ontario (LCO), into Ontario's legal capacity, guardianship and decision-making laws.[1] The LCO's multi-year project is considering Ontario's *Health Care Consent Act[2], Substitute Decisions Act[3],* and certain elements of the *Mental Health Act[4],* with a view to determining whether, and if so how, Ontario's laws, policies or practices, or the practices of non-governmental parties, ought to change. A central focus of that project is the different possible approaches to legal capacity and assistance with decision-making, and the extent to which they are consistent with respect for the dignity and autonomy of older adults and persons with disabilities, as well as the importance of preventing and addressing abuse. More broadly, the LCO's project is informed by the principles identified in two earlier "framework" LCO projects on the laws affecting older adults, and persons with disabilities, respectively.[5]

One of the areas being examined in the LCO's project is supported decision-making. Although there is no single agreed-upon model or definition, supported decision-making models generally reject the basing of legal capacity rights on particular levels of ability, in favour of requiring supports and accommodation to enable the *exercise* of capacity. Rooted in a social model of disability, supported decision-making has found more recent support in the s. 12 equality guarantee of the Convention on the Rights of Persons with Disabilities (CRPD).[6]

In its discussion of supported decision-making in its *Legal Capacity, Decision-Making and Guardianship Discussion Paper* ("Discussion Paper"), the LCO observes that despite the

enthusiasm that many have expressed for supported decision-making, there remain some

challenges and concerns. Three of these are the importance of guarding against misuse or

abuse of the supporter role; the difficulty of making people legally responsible for decisions

they might not have fully understood; and the need for clarity and security for third parties who

need to know when they can rely on a decision as authoritative.[7] A further concern is the lack of

empirical evidence as to how supported decision-making is working in practice. As others have

observed, there is "almost no evidence" regarding the practical operation of supported

decision-making.[8]

Against the backdrop of these concerns, and drawing on the principle that any legal

implementation of supported decision-making should take into consideration local contexts and

experiences, the LCO determined the need for additional research into the decision-making

supports that currently exist in Ontario. Moreover, it identified "personal support networks"

(sometimes called "networks" in this paper) as one such support deserving greater scrutiny, and

commissioned this research project to take up this challenge.

B. Project purpose & research questions

The purpose of this project was "to consider whether or how 'personal support networks' as

currently operating in Canada, may or may not provide a practical foundation for formalized,

legally protected supported decision-making in Ontario".[9] More specifically, it addresses the

following research questions:

-   How are personal support networks currently operating in Ontario and British
    Columbia?

- Are these personal support networks providing a form of supported decision-making?

- Can personal support networks be understood as decision-making entities?

- If so, what would be the implications of formalizing, or building on, this approach in decision-making laws?

In answering these questions, I tried to pay particular attention to the importance of

protections for vulnerable decision-makers, and the needs of third parties.

C. <u>Limitations</u>

This study has several limitations. First, personal support networks as they are discussed here

arose largely out of the community living movement. Although some informants discussed

small pockets of use in other communities, the vast majority of the work pertaining to personal

support networks and decision-making appears to be directed to supporting people with

intellectual and developmental disabilities. While some informants expressed views about

whether this approach could be helpful for other vulnerable adults (such as older adults or

persons with mental health challenges), this study primarily addresses how personal support

networks are being used *now.* It does not consider to any significant degree whether networks

hold promise for a wider community.

A second significant limitation is that this study does not directly take into account the

perspectives of the individuals supported by personal networks. While informants – e.g.,

parents and other network members – sometimes provided third party accounts of the views of

some supported persons, and at least one supported person has publicly shared writing

describing some of his experiences, my understanding of this perspective is necessarily

limited.[10] The reasons for proceeding in this way were two-fold. First, the timelines for this study were short, requiring that the vast majority of interviews be conducted over the telephone. Second, the 'nuts and bolts' practical functioning and legal contexts of personal support networks were thought to be issues that could be adequately captured – at least in an initial way – by speaking with others involved in the process. The result of this approach is that this study provides some evidence as to how networks are operating in practice and the decision-making process in which participants are intending to engage. However, it does not fully assess (i) whether there are gaps between stated principles and practice; or (ii) the more subjective and substantive elements of supported decision-making – for instance, whether supported individuals experience personal support networks as empowering or whether they result in 'better' decisions.[11]

Finally, this study has a limited scope. It does not purport to consider all networks from all angles. I did not (and did not attempt to) consider every personal support network in Ontario and British Columbia. This would, after all, be impossible. First, there is no easy way to locate them all. There has been over 30 years of writing, thinking, and experimenting with these issues. While some of the people devising network supports for their loved ones have written books and founded organizations, others are quietly going about this work without websites or formal assistance. Second, even among the people identified (whether because their names and contacts were generously offered, or because they are associated with organizations with websites and telephone numbers) I was not able to speak with everyone. Some did not respond to my requests for an interview or were unavailable in the time allotted. In other cases there was simply insufficient time. This study can therefore only be illustrative. It provides a rough

picture of some kinds of personal support networks that people are using, and how they fit into the legal landscape.

II.   METHODOLOGY

The timeline for this project – from start to draft report – was approximately two and a half months. It took place in three broad stages, intended to locate personal support networks within the existing literature; provide information about how they are presently functioning in Ontario and British Columbia; and analyze their current and potential legal significance.

A. <u>Literature survey</u>

The first stage was a survey of the literature relating to personal support networks. The purpose of this step was to review some of the history and conceptual foundations of efforts to support personal support network creation in Canada (and particularly in Ontario and British Columbia) to provide a context within to locate the remainder of this study. This review did not substantially examine the broader literature relating to the importance of relationships, social inclusion and social capital to persons with disabilities (and indeed, to everyone).[12] Rather, it focused on literature relating to concrete attempts to support the creation and maintenance of personal support networks with some degree of formality – i.e., entities such as "Microboards" and PLAN support networks (see the definition of "personal support network" below). It examined formal academic literature relating to these attempts (of which there was relatively little) using academic search tools, as well as the more voluminous other writing such as

reports, websites, and 'blogs'. The results were primarily relevant to, and are described in, Section IV below.

B. <u>Interviews</u>

A core purpose of this project was to obtain information about the practical functioning of personal support networks as it relates to decision-making. To this end, the second stage of this project was a series of semi-structured interviews with persons with knowledge and/or experience with personal support networks ("informants").

1. *Who was interviewed*

There was a total of 19 informants, falling into four broad groups:

1. "Professional participants" (n=8; Ontario, 5; British Columbia, 3) defined as people who work with networks in a professional capacity – e.g., lawyers who advise on their structure and operation; professional facilitators; and employees of organizations directly involved in personal support network work.

2. "Lay participants" (n=4; Ontario, 3; British Columbia, 1) who were people participating in personal support networks in a voluntary, non-professional capacity – i.e. parents and non-parent members;

3. "Professional non-participants" (n=9; Ontario, 5; British Columbia, 3; Saskatchewan, 1) with expert knowledge of personal support networks – e.g., through policy work, advocacy, or academic study – but no direct personal experience with them; and

4. "Third parties" (n=1; Ontario, 1; British Columbia, 0), meaning government and private parties who interact in some way with the decisions made in personal support networks.

These are not neat categorizations. First, three informants self-identified as wearing several 'hats', and provided information from their experience as, for example, both a professional working with personal support networks and a lay member of a particular network. In these cases I tried to take into account the informants' views from both roles, meaning that they

were "double counted". (For this reason, the sum of the informants across the four categories is greater than the total number of persons interviewed.) There was also some subjectivity involved in allocating informants to these categories, for instance, in determining whether a person employed in a community organization was sufficiently directly involved to be called a "participant". Finally, the term "lay" in this context refers to participants' voluntary (non-paid or non-professional) participation in the networks on which their interviews focused. All of the "lay participants" were, however, long-time advocates with substantial expertise in the area of personal support networks.

2. Identification and recruitment of informants

The process of identifying and obtaining the agreement to participate of informants initially relied on existing relationships with the LCO. The LCO reached out to contacts in a number of organizations in Ontario and British Columbia. These individuals served as early informants through which the Conversation Guide was refined, and provided further information about whom to contact. At the conclusion of every interview I asked the participant whether they could identify anyone else with whom I should speak. In this way, there was a 'snowball' process of identifying and recruiting individuals. Where there were gaps in the perspectives I was obtaining, or where there were organizations or people known to me through my research but where I had no personal contact, I reached out directly. I attempted to ensure an adequate spread of informants as between Ontario and British Columbia, and between the categorizations described above. However, this was not always possible. At the point when I

had to conclude the interview process, there was only one lay participant from British

Columbia, and only one informant (from Ontario) had spoken to the third party perspective.

3. Interview process

In all but a few early exploratory interviews, I sent a preliminary introductory email outlining

the kinds of questions that I wanted to discuss. This email also explained that the interview

would be confidential (specifically, that that their names would be provided to the LCO, but

that neither names nor other identifying information would be included in any report); that I

would not be recording but would take notes; that I would use my notes for the purposes of a

report for the LCO; and that I would not include direct quotes unless I had express prior consent

to do so. Where I did not send an introductory email I conveyed this information at the outset

of the interview. All but three interviews were conducted over the phone. They ranged from 20

minutes to two hours. Several individuals spoke with me twice.

The interviews were semi-structured, meaning that I was prepared with a Conversation Guide

(attached as Appendix A) with a list of questions. However, I also indicated to each informant

that this was not meant as a 'script', and that they should feel free to redirect the conversation

as they deemed appropriate. The interviews were conversational in tone and many informants

were very frank with their experiences and perspectives. Finally, the informants – whether they

were parents, professionals, or academics – consistently spoke with remarkable energy and

enthusiasm about the creative design of supports and protections for persons with disabilities,

making the interviews both educational and a privilege.

C. <u>Legal research</u>

The final stage of this project required research into (i) the laws and standards currently applicable to personal support networks, and (ii) the possible legal implications of building on or formalizing this approach in decision-making laws. This required preliminary research into the laws and policies relating to government direct funding programs; the law governing non-profit organizations; employment law; and human rights law among other areas.

III.   THE LANGUAGE OF PERSONAL SUPPORT NETWORKS

A. <u>Terminology in the field</u>

As one informant emphasized, we are *all* involved in "personal support networks" in some way or another. Although the term has taken on a set of meanings with particular relevance to persons with intellectual and developmental disabilities and their supporters, it is important not to lose sight of the 'natural' basis for personal support networks, and the reality that everyone draws on a variety of personal supports in the making of personal decisions. Indeed, this kind of 'normalization' of supports is one of the core insights of supported decision-making models, and the approach to legal capacity in Article 12 of the Convention on the Rights of Persons with Disabilities. The principle often expressed by proponents of supported decision-making models is that nobody makes decisions independently; some people simply require more supports than others in order to exercise their decision-making capacity.

At the same time, terms such as "personal support network"; "circle of friends"; "support circle"; "Microboard"; "Aroha entity"; "self-directed support corporation"; and "person

centered society" get used to mean particular things (though not always in a consistent way), thus requiring some preliminary discussion of terminology. At the most general level, these terms can all be applied to groups of people coming together on a voluntary basis, with varying levels of formality, to in some way support a single individual through relationships of trust and intimacy. On the other hand, the details and precise purposes of these arrangements can vary significantly.

The easiest of the terms to define is "Microboard". Although the term originated in Manitoba, it was placed under copyright and trademark protection by the Vela Microboard Association in British Columbia. Although one occasionally sees other references to "microboards", the term has been legally reserved for use by organizations following the Vela Microboard model – that is, an incorporated not-for-profit organization to support a single individual and with certain features (e.g., a minimum of five directors). The Vela Microboard model has been adopted and promoted in some other jurisdictions, such as Tennessee (through the Tennessee Association of Microboards and Cooperatives[13]) and Texas (see the Texas Microboard Collaboration[14]). People wishing to incorporate a personal support network without following all required elements of the Vela model use a variety of other names, such as "self-directed support corporation" (common in the United States); "Aroha entity" (groups following a model developed in Guelph, Ontario); and "person centered society" (in use in British Columbia).[15] This paper sometimes uses the generic term "incorporated network".

Among incorporated models, groups may of course have different structures, practices, purposes and ideas of what is required to "support" the focus person. However, a commonality

is that they have greater legal powers and, in some jurisdictions, the ability to receive and manage funds. As one author puts it: "What distinguishes the microboard approach from… other individualized approaches to support is that the individual, through the microboard structure, receives and controls the dollars…"[16] Another explains that an Aroha entity is "the incorporated core of a person's circle of friends" with "the objects and legal powers to address the vulnerable person's planning and support needs".[17]

Unincorporated models are (by definition) less formal in their legal structure, but may still be more or less formal in their organization and functions. People sometimes use the term "personal support network" to denote a group with more structure and regularity, and the term "support circle" or "circle of friends" to mean a looser group of supporters that does not necessarily have defined membership or roles.[18] On the other hand, the terms are sometimes employed in precisely the opposite way. For instance, a group in the United Kingdom defines a "circle of support" as "a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life".[19] In a similar vein, the Ontario Ministry of Community and Social Services has defined "circle of support" as "a group of non-paid people who connect on a regular basis to help a person with a developmental disability to undertake a planning process… and spend social time together."[20] The Ministry says "this term is slightly different from a similar and commonly used term: personal support network", which is "generally considered to include a wider range of people" and "can extend to almost anyone that someone may know."[21] Other groups use the language of "networks" to refer to more defined groups intended to have stability and longevity. For instance, Planned Lifetime Advocacy Network ("PLAN") helps people to establish "personal networks" and commits to

providing lifelong supports to encourage network continuity. [22] Finally, the same or similar

groups may use different language over time. (For instance, an informant spoke of a group that

began using the language of "circles" but now prefers to speak about "networks".)

These are terms with a degree of malleability. However, irrespective of their precise usage, they

often refer to groups with shared values. For instance, they tend to emphasize "the critical

importance of relationships with friends", the value of "community allies", and the need for

effective planning to ensure a "more secure future."[23]

B. "Personal support networks" for this paper

In this paper, the term "personal support network" is used as an umbrella term capable of

encompassing *all* of the terms listed above, when they refer to intentional networks with

identifiable members. That is, it includes incorporated entities such as Microboards and Aroha

entities, as well as less formal (but still intentional) "circles of support", but does *not* refer to

the broader web of relationships in which a person might be located. Thus, for this paper, a

"personal support network" must:

- be a group of people (a minimum of 3 and usually more) generally including, but also often extending beyond, family members;

- who are in relationships of trust and intimacy with the supported person;

- who consciously undertake as a collective to support a single individual;

- who are not in paid relationships with the supported person[24]; and

- who meet and/or function with some degree of intentionality and regularity.

Notably, personal support networks may vary in what they understand to comprise their supporting role(s) (e.g., friendship, planning, practical supports), a point taken up below. Finally, there is a degree of tension between the core concept of "individualization" – a principle at the heart of many developments in deinstitutionalization, funding, service delivery, and principles of "normalization" – and efforts to define personal support networks. A number of informants emphasized that the power of personal support networks lies partly in their ability to be responsive to individual needs, and that we should be very cautious about either requiring people to have personal support networks, or requiring those networks to take a particular form. (For instance, one person emphasized that some people are more comfortable in one-on-one settings than in groups or "circles".) In defining personal support networks here, the objective is not to prescribe any particular form as ideal – rather, it is to identify the groups under study.

IV.   HISTORY AND CONTEXT: THREE THEMES IN PERSONAL SUPPORT NETWORKS

A point frequently made in the interviews was that personal support networks can be created for a variety of purposes. As one informant emphasised, it is important to always ask: "what are you hoping to achieve"? Personal support networks cannot be neatly categorized; there are nearly as many approaches to, and nuances among, personal support networks as there are networks. That being said, some common themes emerge. Three of these are: (i) individualized funding and service delivery; (ii) friendship and community (and, relatedly, security for when parents are gone); and (iii) person-directed planning and facilitation. While these themes or

approaches may (and often do) overlap, different networks emphasize them to varying

degrees.

A. <u>Networks to facilitate individualized funding and service delivery</u>

The first "Microboards" appear to have been created by David and Faye Wetherow, in 1984, in

Manitoba.[25] An important motivation for the creation of these early Microboards was

frustration with then-available funding and service delivery mechanisms. Indeed, establishing

Microboards was one part of a multipronged effort to transform support services for persons

with disabilities in Manitoba, which, at that time, were limited to residential services and day

programs provided by agencies. These efforts began with persuading the government to

provide some of the first individualized funding – that is, funding specifically based on a single

person's support needs, and segregated for those purposes – alongside development of both a

housing cooperative that was de-linked from services, and a services cooperative that could

help people manage their individualized funding and obtain the necessary services.[26]

Microboards then built on this model. The Wetherows explain that individualized funding and

the two cooperatives "paved the way for the creation of the first Microboards" in part because

of their shortcomings.[27] While they were an improvement over the older system (given that

everyone's funds were segregated and portable), having a single services cooperative

maintained some of the weaknesses of the traditional "agency model" – for instance, the

challenges of board members having to make decisions about when and for whom to advocate,

given that peoples' interests might not coincide. Microboards were proposed as a solution to

these problems, which would "bring the *structures* for providing supports more into line with person-centered and family-centered principles".[28] As the Wetherows explain:

> The structure of the first Microboards began with a simple question. We asked our friends in government, "what is the smallest unit of human organization that would be eligible to receive 'agency'-level funding?" The answer was 'a 3-person non-profit corporation which could be organized to support as little as one named individual'. Hence, the 'Microboard'.[29]

Beginning in 1990, Vela Microboard Association of British Columbia began to provide services to persons wishing to establish Microboards in that province, copyrighting and trademarking the term. Since 1990, Vela has assisted with the creation of over 900 Microboards, and interest in Vela Microboards is reportedly growing.[30] Eighty new Vela Microboards were established in 2013 alone, and a Vela employee indicated that more than half of the Microboards currently in existence were created within the last four years.[31] As in the Manitoba model, Vela Microboards may (but do not have to) receive funds earmarked for the supported individual, arrange for services, and act as employer of record. The idea is that a person with his or her Microboard can "create services that are creative, flexible and reflect the needs of the individual".[32] Some people in British Columbia have also created incorporated personal support networks (called "person-centered societies") outside the Vela model.[33]

"Probably the first Ontario 'microboard'" was created in 2002 around a man in Guelph.[34] The creators of that network decided to adopt a model different from Vela's, and replaced the word "Microboard" with "Aroha entity".[35] The path to this first Aroha entity was also somewhat different from the early Microboards, as there was already an active informal personal support network in place, along with a number of legal arrangements for individualized funding and housing through the Guelph Services for the Autistic (GSA) housing trust.[36] However, the group

formalized the "core" of the network as an incorporated entity in order to take on legal powers that it viewed as essential to continuity after the man's parents were gone. As an incorporated entity, the Aroha could receive and administer individualized funds, act as employer of record, and make contracts relating to housing. The creators of this model argue that Aroha entities have a greater ability "to address the vulnerable person's planning and support needs, to create solutions, and to manage resources in ways that are responsive and accountable".[37]

Incorporation and a desire to directly receive and manage funds often go together. Networks will not normally incorporate unless there is a reason to do so, and foremost among these reasons is recognition from government as eligible to receive funding, and from private third parties as eligible to enter into legally binding arrangements. However, individualized funding and incorporated networks are not always perfectly aligned.

First, incorporated networks sometimes have other purposes. While some people opt to create Microboards in keeping with the pure service-delivery model (sometimes alongside another network with social purposes), others have more social objectives. For instance, David and Faye Wetherow describe Microboards as a means of "engaging members of the larger community in purposeful personal support networks."[38] In setting out the qualities that "define the identity and purpose of a true Microboard", they emphasize values such as "[a]n unencumbered focus on the identity, needs and express wishes of the person" and maintaining an active and engaged "circle of support" more than they do services.[39] Similarly, Vela has broadened it mandate and, since 2009, has supported Microboards that do not receive funding or act as employer.[40] In these cases the Microboard is intended to provide advocacy and supports that

might include helping the person: "plan his/her life; brainstorm ideas; advocate for what they

need; monitor services and ensure they are safe; connect to his/her wider community; and do

fun things together".[41] Vela Microboards are also expected to participate in person-directed

planning, another of the themes discussed below.[42] Consistent with this, a scholar writing about

microboards suggests:

> [T]he microboard approach is much more than a funding arrangement and is concerned with much more than how support funds are channelled to the person with a disability and how these funds are spent. The microboard provides a circle of support that both forms a microcommunity for the person with a disability and opens the desired pathways to the community at large. In these ways, it works for empowerment-in-community.[43]

Second, there are instances of *unincorporated* personal support networks facilitating

individualized funding and supports. For example, Manitoba Family Services has a program

whereby it offers direct individualized funding to persons with disabilities on the condition that

they have a personal support network, which need not be incorporated. An organization called

LIFE provides assistance with creating a network to those who need it, and, with the help of the

support network the individual him or herself hires and manages staff.[44] Although Ontario does

not have a comparable program, one informant discussed an arrangement in which

unincorporated support circles in Ontario appear to be playing an active role in directing

funding and supports.[45]

These initiatives again reflect inevitable variability. However, the point here is that Microboards

and other incorporated network models have generally been organized around the central

motivating theme of individualized funding and service delivery.

B. Networks to support friendship, community and security

Another significant theme underlying some initiatives in personal support networks is the social isolation experienced by many vulnerable adults, and the belief that intentional network building can both improve people's quality of life in the present, and provide greater security for the future. For example, PLAN was created in 1989 in British Columbia out of "the conviction that isolation and loneliness were the biggest challenges faced by people with disabilities".[46] The organization works from the principle that "[c]aring relationships are the key to safety, security and a good life".[47] That is, caring relationships are essential to a person's quality of life (or the concept of "a good life"[48]) and, "the number of caring and committed family members and friends actively involved in their life" is also the "best guarantee of a safe and secure future".[49] PLAN provides fee-based services, such as a hired "community connector" to help with personal network creation. It also offers lifetime memberships, which bring with it a "promise to be there after the parents are no longer able to".[50] There are also PLAN Affiliate organizations (that follow the same objectives and values) in British Columbia, Alberta, Saskatchewan, Ontario, and several U.S. States.[51]

Other initiatives relating to personal support networks build on similar ideals relating to quality of life and security. The founder of the online tool Tyze Personal Networks (who was also a co-founder of PLAN) emphasizes the critical importance of social networks to "health and social outcomes".[52] Focusing on the 'security' side of the equation, the authors of a guide to Aroha entities in Ontario describe friends as "the greatest resource for a vulnerable person". They explain that "[t]he only real protection for our sons and daughters with a disability is with the

quality of the committed relationships they have" (and take an approach to succession planning

that pairs these enduring relationships with an incorporated structure).[53]

Numerous organizations, disability scholars, and others emphasize these themes of countering

loneliness and isolation; supporting meaningful connections and contributions within the

community; and providing greater security for the future.[54] These discussions sometimes take

place in the context of assessing service delivery models, with some expressing frustration with

the "confines of the disability services system".[55] For example, a Toronto organization states on

its website that "[p]eople who have disabilities are at risk of becoming isolated and surrounded

by people who are paid to be in their life".[56] Similarly, an informant took the view that

government policy in British Columbia supports a services model that can act as a barrier to

authentic relationships with unpaid persons.

Thus, although it is difficult to categorize personal support networks (they all invariably have a

range of purposes and underlying philosophies), one common theme is friendship and its

importance to well-being and security. And, some personal support network initiatives, more

than others, reflect this particular focus on "the social support that comes through having a

network of caring relationships".[57]

C. Person-directed planning and facilitation

Although it again overlaps significantly with the other themes discussed, the theme of person-

directed planning and facilitation deserves separate treatment. Newly a policy focus in Ontario,

Developmental Services Ontario describes "person-directed planning" as a process that "helps a

person with a developmental disability to find the tools and funding they need to live their dreams and meet their goals".[58] A guide published by the Individualized Funding Coalition for Ontario defines it simply as "an ongoing process that helps you think about the future".[59] A number of tools and techniques have been developed to assist with personal planning, usually with the assistance of a facilitator.[60] People may access these planning supports through a community agency that provides them, or by paying an independent facilitator.

Ontario policy allows persons receiving funding under the Passport Program to use up to $2,500 in Passport funds for person-directed planning.[61] Person-directed planning is also recognized under Ontario's new services legislation – the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* ("*Social Inclusion Act*"). The Act defines "person-directed planning services and supports" as those that "assist persons with developmental disabilities in identifying their life vision and goals and finding and using services and supports to meet their identified goals..."[62]

Regulations passed under the Act (though not yet in force) state that person-directed planning services and supports will qualify for inclusion in direct funding agreements.[63] The Ministry of Community and Social Services has also published a *Person-Directed Planning and Facilitation Guide* intended to "educate people about the value of well delivered person-directed planning and facilitation and establish key parameters surrounding best practice".[64] It discusses the numerous facilitators and facilitator networks now in Ontario, describing independent facilitation as an "emergent profession".[65]

Person-directed planning and facilitation does not automatically imply a personal support network, and even where a person has a network, he or she may choose not to involve it in the planning process. However, the two often go hand-in-hand. For example, a 2008 study by Lord and Hutchinson found that "[n]etwork building was an intentional focus" among families with access to both individualized funding and facilitation, with 54% of participants meeting "regularly" with "support circles" or "personal networks".[66] They found that participants often created networks before developing a support plan, and that facilitators "played a major role" in helping people to develop their support networks and to plan.[67]

The *Social Inclusion Act* also recognizes that persons may participate in person directed planning "with the help of their families or significant others of their choice".[68] The MCSS *Person-Directed Planning and Facilitation Guide* observes that this 'help' may come from a personal support network:

> Person-directed planning and facilitation intends to assist people of ALL abilities to create a better life. While in some cases the person may have the ability to "direct" the process, this will not be true in all cases. *In situations where people may need to rely to a greater degree on those around them the process may be initiated by someone other than the person. This may include involvement either of family, of [a] support network/ circle of support*, or in some cases a service provider. [Italics added.][69]

The planning and facilitation process itself may also involve the development or expanding of a person's support network. Ontario's Ministry Community and Social Services describes "relationship building" – "gathering people who will be involved in planning (sometimes known as the 'circle of support') and orienting the focus on the person, their dreams and goals" – as a typical step in the planning process.[70]

It is difficult to know how this is working in practice. Several informants suggested that notwithstanding Ontario's apparent policy shift towards individual choice, planning, and facilitation, this hasn't yet been implemented to a significant degree.[71] On the other hand, there are indications that a range of active facilitated networks existed in Canada even previous to Ontario's policy shift. A 2004 study observed "resilient and sustainable facilitated social networks across Canada", and predicted "ever-expanding numbers involved in this work".[72] The comments of some informants (to the effect that Ontarians are increasingly taking up facilitated planning within their personal support networks) provide some support for this prediction. On the other hand, an Ontario parent and independent facilitator said that parents are very often reluctant to set up sustained networks for their sons and daughters, and that networks set up specifically for planning purposes do not always last.

This section was intended to, first, provide some context and history to clarify the nature of the entities under study, and second, highlight the heterogeneity of personal support networks in both their practical operations (discussed further in the next section) and their basic premises and purposes. These different purposes are often rooted in common values, which values may also be consistent with supported decision-making. At the same time, in considering the potential of 'network approaches' for supported decision-making, it will be important to recall the variety of possible objectives and approaches, and to be clear about which ones (if any) should be formalized in law.

V. HOW ARE PERSONAL SUPPORT NETWORKS FUNCTIONING IN PRACTICE?

A. Introduction and scope of investigation

The informant interviews yielded substantial information relating to the practical operations of personal support networks.[73] The discussion below summarizes the interview results dividing them into four themes: personal support network creation; decision-making; interactions with third parties; and who is using personal support networks. In some instances the information obtained through interviews is supplemented with documents that informants provided, or with information from organization websites and published materials.

B. Personal support network creation

1. Identifying members

Every informant said the core requirement for membership in a personal support network is either a genuine relationship with the supported person, or a commitment to creating one. Indeed, a common theme across all personal support networks was 'friendship'. People involved in networks, whether in a personal or professional capacity, consistently identified as the most important factor that members know and understand the supported person well, and be committed to a trusting and respectful relationship (and in some cases, to spending time with the person). One informant referred to this as requiring friendship in the most profound sense. Several also spoke about the need for a shared philosophy, and one emphasized that members must view the supported person as an equal. A man supported by an Aroha entity states (in his 'blog'): "The most important qualifications for being director of my Aroha are:

knowing me, listening to me, caring about what matters to me, and sharing time and interests with me."[74]

Some informants said that it can be useful to include people with a range of ages and perspectives.[75] Several noted the need to guard against the tendency of some parents to choose members who can be *their* friends, rather than friends to their son or daughter. Without exception, informants speaking about incorporated personal support networks said that the supported person should ideally be a director of his or her own network.

2. Family members

Several informants spoke about the appropriateness of having a personal support network comprised only of family members. Generally, people said that it is better to have some members who are not family members, as they will bring different perspectives to the group, and will be disinterested in any family issues (such as inheritance) that might arise. However, informants had different views as to whether having non-family members should be a firm requirement. Some said there is a place for networks comprised only of family. On the other hand, a facilitator said we must distinguish between "family" and "support networks" as by definition the latter bring into play a broader group of people. Another informant, who is a parent and facilitator, said that it is important to have non-family members in the network because it is too easy for parents to interpret their sons' and daughters' expressions in particular ways, effectively 'putting words in their mouths'. She said having people who know the person from different perspectives can provide balance. Two lawyers commented from a safeguards perspective; they worried that having only family members present without

'outsiders looking in' might increase the risk of members imposing rather that supporting

decisions out of a desire to (over) protect.[76]

3. Network size

Informants indicated an enormous range in network size. One person referred to a "network"

with one active member. Another knew of a network with 25 to 30 people that met regularly.

The Vela Microboard model requires a minimum of five people, and recommends that boards

have between five and eight directors (including the supported person). The Ontario Adult

Autism Research and Support Network recommends that people creating Aroha entities have

as directors the focus person and four to five others "of different ages, abilities, and

interests."[77]

4. Skill sets

Informants also had different views about the relevance of particular skill sets. Two informants

(both professionals who do work relating to personal support networks, one in Ontario and one

in British Columbia) suggested that those setting up incorporated entities might seek out a

lawyer or a person with budgeting experience, while persons forming less formal personal

support networks might favour people close in age and temperament to the supported person.

In other words, a network intended to play more of a social role, and a Microboard that is

receiving funds and acting as employer, might be comprised of different people. On the other

hand, an informant from Vela said that in Microboards also, members should be chosen based

on the quality of the relationship, as any necessary skills can be learned. An Ontario informant

agreed, saying that particular skill sets like bookkeeping and accounting are helpful but not crucial. She again emphasized that the most important thing is having people who really know the person and will be a friend.

5. Geographic proximity

Not all personal support network members live in geographic proximity to the supported person. A parent noted that the members of her son's personal support network live across Canada, and that they don't see this as a problem; all of the members know her son well and are committed to him, even if they don't see him often. Another parent said that members should sometimes be physically present. A facilitator agreed, saying that if a member is physically present only once or twice a year they will have difficulty understanding what is happening. She said many people come to personal support networks with a variety of preconceptions about who a person is and what they need. Distance, in this informant's view, can exacerbate this problem and make it harder for the member to learn good discernment as to what a person truly needs and wants.

6. People in paid relationships

With the exception of one informant, everyone who spoke about network membership said that members should not be in any formal or paid relationship with the supported person. Some spoke about the potential for a conflict of interest. Others emphasized the importance of the network flowing from 'natural supports' that can be contrasted with (and be a buffer against) agency supports. One informant took the position that it can be good to include as

members people in paid relationships with the supported person. While she recognized some of the risks of this approach, and that paid people are not the same as 'friends', she said having them present helps them to understand what is needed to support 'a good life' for the person, and allows them to implement decisions with greater enthusiasm. One informant observed that in the PLAN model, people often include as network members former support workers, and that this can work very well.

7. *Process for establishing a network*

Informants generally recognized that personal support networks can be created in a variety of ways, and that some people start with many people in their lives, while others are more isolated and require more support. Thus, while some families may create networks entirely informally and independently, others seek out the assistance of an organization such as PLAN or of an independent facilitator. Families in British Columbia who want assistance creating an incorporated network have access to several organizations, of which Vela is most prominent. While there is no Ontario organization providing systematic support for incorporated networks, the Ontario Adult Autism Research and Support Network provides some information and guidance on its website (and there is also a published guide with information and sample agreements), and some people hire a lawyer to assist with the process.[78]

Facilitators take different approaches to finding network members. PLAN's approach is to hire a "Community Connector" who looks for potential network members based on previous relationships among family, friends, neighbours and others, and works to identify opportunities to meet new people.[79] PLAN materials emphasizes that this is about friendship, which "takes

chemistry and time".[80] An independent facilitator explained that she tries to develop the initial list of potential members with the supported person, and then takes it to the family for negotiation. She sometimes begins with a person's photograph book, going through it with the person and asking him or her to identify people. She said families are often surprised by the initial list (and skeptical that people will help) but that this can yield good results. This facilitator also described an initial process of meetings to bring potential members together, which might include social events like 'pot luck' dinners to gauge interest and comfort levels. Like PLAN, she emphasized that this process takes time, and that networks should ideally not be born from crisis – rather, people should begin creating their networks early, giving them time to become strong.

Every informant who spoke to the issue agreed that having access to professional assistance (whether through an organization or an independent professional) can be helpful, particularly for people who are isolated. However, not everyone viewed this as equally important. On the one hand were people who said that facilitation is essential. A parent said that creating a personal support network is extremely challenging, and that without a facilitator's help it is just too hard. She said parents often need help getting over the barriers – for example, the fear of asking others for help, and of 'letting go'. In a similar vein, an independent facilitator spoke about how difficult it can be for parents to give up control. She also emphasized that personal support networks are fragile and that facilitators can help with the constant tending that is required, particularly in their early stages.

At the other end of the spectrum, an informant in British Columbia expressed wariness about overly 'professionalizing' personal support networks. She took the position that if we had good education and supports, and legal tools like British Columbia's representation agreements, people would seldom need professionals. In her view it is the current 'systems' that discourage the natural formation of personal support networks. Other informants took a position somewhere in between, to the effect that facilitation is a useful resource that should be made available to those who need or want it.

8. Role of the supported person in establishing the network

It is usually the family that initiates the personal support network. As one person explained, occasionally the interest comes from the focus person, but usually not; most people don't know what these are until they are introduced to the idea. On the other hand, the man around whom the first Aroha entity was created explains that the impetus for his Aroha was his anxiety about what would happen after his parents were gone. His parents reportedly learned about and adapted the Microboard model in response to his concerns.[81]

Whatever the impetus, the supported person might have varying levels of ability to agree or consent to the network's creation. One informant, a facilitator, said that consent is essential, as there is risk inherent in opening one's most private details to group discussion; while this can provide support, it also brings a measure of accountability for decisions because the members are now 'watching'. She explained that before setting up a new network, she takes the focus person to another person's support network to help them understand what a network entails.

She also observes new networks closely for the first six months to a year to ensure that it is still working well for the person.

A lawyer observed that issues of legal capacity are rarely raised even in incorporated networks. However, he said that person must, at a minimum, understand in a general way what is being done (for instance, family members might explain, "we're creating an organization to support you"). On the other hand, one informant said that networks might appropriately be formed for persons who do not (at least initially) want one. She said that some people require gradual introduction to the idea of a support network because, perhaps, they don't like the idea of people talking about them. It might be that members gather and the supported person initially does not participate, but later becomes comfortable with the process.

With respect to selecting network members, every informant who spoke to the issue said that the supported person should be involved as much as possible. One person, a parent, said that the supported person must choose members, and cautioned that family members must be very careful not to impose their preferences about network membership. She emphasized that the focus person may have views that diverge from those of family members, and they may specifically want to ensure the presence of non-family members. Thus, in her view, family members must avoid being overly protective or prescriptive about the network's form, and must allow the supported person as much direction as possible. Other informants pointed out that many people are not able to 'choose' network members, but that it is possible to discern a person's comfort level in the presence of potential members.

9. *Network structures and degrees of formality*

People create networks with different degrees of formality. At one end of the spectrum are

Vela Microboards, which must comply with British Columbia's not-for-profits legislation and the

rules set by Vela. At the other end of the formality spectrum are very informal circles of

support. For instance, an independent facilitator in Ontario said she is cautious about

recommending "circles" in any defined sense, as these often don't work, either for the

supported person or for members. She said that expecting a group of people to come together

on a regular basis is often unrealistic, and many supported persons don't feel comfortable in

groups in any event. She suggested that a better approach can be to have a larger network as

well as a number of small circles, within that larger group, that can attend to particular kinds of

decisions. Other issues might also get worked out one-on-one over the telephone, and then

discussed with the supported person in private. She also suggested that some feel more

comfortable when group meetings are blended with social occasions that put the supported

person at the center. Many other informants also talked about the value of flexibility in

network membership and functioning.

Some people have several intersecting personal support networks with different purposes. For

instance, in the Aroha model in Ontario, the incorporated network (the Aroha) is seen as the

core, equipped with legal powers, of a larger circle of fiends. In British Columbia some people

reportedly have both a Vela Microboard and a PLAN support network.

C. __Decision-making__

It is hard to really get inside decision-making. This is particularly so without having personally observed network decision-making processes or communicated with the supported persons. Many people involved in personal support networks clearly have a strong commitment to principles of supported decision-making. At the same time, beyond the articulation of principle, it difficult to know what exactly people understand supported decision-making to require; how they implement it; and what is the experience of the supported person. Moreover, to a large extent, the parents and facilitators with whom I spoke are leading the charge around supported decision-making and personal support networks. I do not know how many others in British Columbia and Ontario are setting up personal support networks without this kind of commitment to philosophy and practice. This is, in part, a limitation born of the research methods used for this study; a 'call' to people to speak about personal support networks and supported decision-making will yield people who have thought about these two concepts as linked. While several informants alluded to 'other' personal support networks that are not engaged – or intending to engage – in supported decision-making, the recruitment phase of this project did not lead to the latter people coming forward.

1. *Do personal support networks make decisions and if so what kind?*

Personal support networks clearly participate in a range of decision-making. There is variability in the kinds of decisions made; the roles played by network members; the principles applied; and the conduct and legal positions of networks vis-à-vis third parties. (And, some informants did not think of their networks as engaged in "decision-making", preferring the language of

"planning".) In general, however, the informants agreed that networks are (or could be) involved in decisions relating to some or all of: where the person should live; whether the person should have a roommate; food; other matters relating to the home; budgeting; romantic and other personal relationships; what kinds of funding should be applied for; services; relationships with service workers; whether and when to initiate advocacy; work and volunteer life; health care; planning for when parents are gone; and any other issue that might arise in daily life or long-range planning.

There were important caveats. One informant, a parent, cautioned that support networks should not, and should not be seen to, be making decisions all the time. She emphasized that most people can live quite competently with supports and don't need a network to be constantly managing decisions. In her view, the support network should view its decision-making role as limited to 'major' decisions, relating to issues such as where to live, and health care. As these major issues had not yet arisen in her son's network, it was mainly providing advice, which she considers to be the appropriate role for a network most of the time.

Another informant had similar views, stating that networks should be concerned with the broad aspects of a person's life – for instance, their goals and objectives – rather than the day-to-day. Another, a facilitator, said decisions are about 'what is a meaningful day'. For instance, should a particular support worker be hired? Should the person work as a volunteer? A lawyer noted that the extent to which a network is helping with 'soft' decisions (such as helping with appointments) might depend on whether the person is also being supported by an agency. He observed that some networks choose to work with agencies, while others endeavour to

operate as much as possible outside the agency system. It was also apparent that the extent of a network's participation in decision-making might depend on the degree to which a parent is actively involved. For instance, the parent who said her son's network has not yet needed to make weighty decisions recognized that it will need to play a larger role after she is gone.

Another theme was privacy, and the idea that some decisions might appropriately be kept outside the personal support network. For instance, an informant noted that a Microboard might support health care decisions, but that often these kinds of deeply personal decisions are instead made with close family members. She explained that Vela recommends representation agreements for health care purposes. Another informant, a facilitator, emphasized that not everything is (or should be) disclosed to a personal support network. The supported individual may legitimately choose to keep some matters private. Other matters might be raised within a smaller subset of the network. For instance, questions about personal relationships or sex might arise and be more comfortably talked about in a smaller group or one-on-one.

2. Decisions relating to the employer role

In addition to the day-to-day decisions described above, incorporated networks can (in British Columbia at least) directly receive funds earmarked for the supported individual and make decisions relating to services and workers.[82] In Ontario, the ability of incorporated networks to directly receive funding as act as employer is less clear, but some groups have developed innovative ways to direct service provision (and some unincorporated networks may be directing services as well). The ways in which Ontario networks are doing this are discussed below, in section 'D – relationships with third parties'.

3. Decision-making processes and principles

How do decisions get made? What is the role of the supported person? Every informant who had directly participated in a personal support network, whether in a personal or professional role, said that the network was engaged in supported decision-making. At the same time, a number of informants expressed skepticism about whether *other* personal support networks necessarily do this, or do this well. Also while some networks had consciously elaborated a philosophy or set of principles related to supported decision-making, others were more vague about what supported decision-making entails. There is no single approach to (supported or other) decision-making, and decision-making processes are sometimes hard to describe. However, this section sets out some of the approaches to decision-making that were described by informants.

A parent's perspective: An unincorporated network in Ontario

A parent in Ontario explained that her son doesn't speak and cannot conceive of what a 'decision' is on a conceptual level, but that he has likes and dislikes like everyone and can express what he wants as situations arise. In this way, he can indicate his understanding. The network views its role as being to provide advice and to interpret the hundreds of decisions her son makes every day through expressions of his will. She said that the network knows her son very well and, like family, they know when something is right or wrong for him.

This informant explained that there are no formal roles governing network decision-making, but that it operates on the principle that decisions affecting her son's life must do no harm, and

hopefully, be to his benefit. The network also has a voluntary document that states that they will employ supported decision-making in accordance with Article 12 of the UN Convention on the Rights of Persons with Disabilities. It provides that they will treat her son "as an equal" and will "supply for him whatever is missing in his own capacity to maintain his own quality of life within the means, financial or otherwise, that are available to him". It also describes the network as "the embodiment" of her son's "supported decision-making capacity".[83] At the same time, this parent recognized that under current law, some of this is aspirational. For instance, when dealing with third parties, the network has no authority; rather, she participates personally (though often informally) or her son must act independently.

A parent's perspective: An Ontario Aroha entity

Another parent explained that the entire approach taken by her son's Aroha entity is grounded in the potential that he has shown for making good decisions. Her son and the Aroha directors start from the position that he has demonstrated capacity, but needs others to help him to carry out his wishes. Thus, while the Aroha has other purposes as well, supported decision-making is fundamental to what they do. This entails ensuring that her son's voice comes first and that directors listen, respect what they hear, and commit to carrying out his wishes. She emphasized the presumption of competence, that people have different ways of communicating, and that people who do not speak may have remarkable levels of comprehension and expressive abilities if they have the right supports.

This Aroha entity has elaborated many of its decision-making principles in writing. First, as an incorporated entity, it has corporate by-laws and objects. A sample Aroha bylaw includes provisions stating that:

- the supported person has "asked trusted friends to help him to manage the supports and services he needs for a good life in his community";

- the Aroha must "respond to the initiatives he expresses, and…ensure his wishes are heeded";

- the Aroha will receive and manage funds "upon receiving the appropriate authority" from him and "at his direction";

- directors must "understand and respect" his "life plan and priorities"; and

- "any new director must be well known and acceptable" to him.[84]

The person at the center of this Aroha also has a written "supported decision-making agreement", setting out relevant principles and providing at least moral authority for supported decision-making. A sample agreement includes:

- the names of the person(s) in the Aroha who will "support, guide, and/or represent the person in particular kinds of decisions";

- the supported person's statement: "I want the supporters to agree on their decisions. If there is a disagreement between the two supporters, there will be consultation among at least three supporters to make a decision that is acceptable to everyone present";

- an appendix setting out an "expression of preferences"; and

- space to attach a Ulysses agreement, which a person may want to create for times when he or she cannot consent, such as medical emergencies.[85]

Yet another written model agreement – an "Aroha Agreement" – states, among other things, that the directors will ensure that the supported person "has ways to understand options and

to make decisions about his life, using whatever communication works for him and maintaining

his supported decision-making agreement".[86]

An independent facilitator's perspective: Ontario personal support networks

An independent facilitator emphasized that not all personal support networks are providing

supported decision-making. Rather, some networks are set up for other purposes, such as

friendship. She said that supported decision-making is appropriate for people at all levels of

capacity, but that if this is to be an objective, it must be articulated from the start. Moreover,

building this process takes time. For instance, some people do not speak or are limited to

'yes'/'no' answers. Network members must learn to understand the person and the ways in

which he or she expresses will and intent. This may require modeling, as most people do not

start with a presumption of capacity, and many people do not know how to listen well. The

informant also explained that there must be a willingness on the part of the family to accept a

shift in power, as the family will not carry all the decisions as it might have before. To help

networks develop their capacities for supported decision-making, this facilitator might use tools

such as social occasions; informal spaces for relationship building; hospitality; and structured

planning processes. She described how, in the right circumstances, it is possible to observe the

person "relaxing into the wisdom of the group"[87].

This informant said the network must support the person to make his or her own decisions to

the extent possible, always guarding against "best interests" thinking. She emphasized that this

can be very challenging, especially when the network is created at a time of crisis. She also

talked about the importance of network members allowing the supported person to make

mistakes and to make choices counter to the network's advice. The network's role is not to tell the person what to do, but rather to help the person understand the ways in which he or she is vulnerable, and options for navigating those vulnerabilities. She clarified that none of the people she works with can make autonomous decisions without supports, as they don't have the critical analysis skills to understand their jeopardies. But by bringing knowledge of the person's vulnerabilities, the network can make it safer for the person to make decisions. On the other hand, this informant acknowledged that there might also be times when a person cannot decide for him or herself.

Finally, this informant indicated that the networks she works with do not generally follow any written agreement or statement of decision-making principles, but that facilitation is a safeguard. She said a facilitator can ensure that the network is set up for the 'right' reasons; that questions are asked appropriately; that the group remains focused on the supported person; and that members are not imposing their own views on the person.

A second facilitator perspective: Ontario personal support networks

Another person who had worked in a facilitator role appeared to take a looser approach to supported decision-making. She emphasized that networks *are* providing supported decision-making, but that this is not always done in a formal circle setting. Like the other informants, she explained that network members must listen deeply to really understand what the focus person is trying to say. However, she said that the 'messiness' of circles doesn't always get talked about. In her view, what is really needed is a core group of three or four people, who might be a subset of a larger group, who know the person well enough to deal with important decisions

as they arise. They can bring these decisions to the larger group for additional input and perspectives, but consensus (which she viewed as unrealistic) should not be required in her view. She also suggested that many decisions are, in any event, too personal to be aired in a group setting.

With respect to the role of the supported person, this informant said that the person is always the center of decision-making, but that this does not necessarily require him or her to be physically present or engaged at the time that the issue is discussed. For instance, in a discussion about a possible medical procedure, the supported person might not engage, or might fall asleep. In these situations the task of the network is to put themselves in the shoes of the person as well as they can and to think about what the different options would mean for him or her. This might also involve a preliminary conversation about *how* to discern what the person thinks and wants. If the supported person was not present, or was not engaged in the discussion, a family member might later talk to him or her on a one-on-basis.

Like the previous facilitator, this informant said the networks she works with do not usually have written principles for supported decision-making, but she considered facilitation to be a safeguard. In her experience it was the families who asked her to be present, as they wanted an outside person who would challenge them if they departed from the principles of supported decision-making. She said this kind of safeguard can be important, as families sometimes slip away from supported decision-making principles in the interests of 'getting the job done'.

A professional / director's perspective: Vela Microboards in British Columbia

An informant who was employed by Vela and had also sat on a Microboard in a personal capacity said that Vela Microboards are intended to provide a forum for supported decision-making. She acknowledged that there are likely Microboards that don't do supported decision-making, or don't do it well, but said Vela facilitators speak with directors about supported decision-making early on in the process. Ongoing Vela involvement in Microboards is voluntary, meaning that there is no current accounting of decision-making processes across the more than 900 Microboards that have been established in British Columbia. However, the informant indicated that the Microboard with which she had direct experience was following the intended philosophy.

One of the stated roles of Vela Microboard directors is to "help the individual plan his/her life".[88] Another principle is: "All people are assumed to have the capacity for self-determination", which capacity is to be "acknowledged, respected, and demonstrated in all of the dealings of the Microboard".[89] The informant explained that in the board she sat on they were not concerned with formal capacity – rather, they tried to understand how the person indicates her preferences, and how best to support her in understanding the consequences of her decisions. She said Vela facilitators teach this kind of lens – that is, of always asking how to maximize the person's capacity – to new directors. If the person can't articulate what they want, directors look to what the person has done in the past and other contextual information to help them make the best choice on the person's behalf.

This informant also emphasized that the Microboard belongs to the supported person. She

recalled a man who felt his Microboard wasn't listening to him. She reminded him that he could

fire his board – that this was *his* Microboard. She said the man subsequently confronted the

directors and that they agreed to listen better.

Microboards can specify some of their decision-making principles in their constitutions and by-

laws. Sample constitutions provided by Vela include statements:

- that the purpose of the society is "to solely meet the needs of" the person;

- that each society member must "make a personal commitment to establishing and maintaining a relationship with" the person; and

- indicating that the society will "plan, acquire, and/or deliver all recreational, educational, vocational, social and residential programs", specifying the involvement of the supported person in varying ways, depending on his or her level of ability. Thus, the board might do this:

  o "as indicated by" the person and regarding the "programs that s/he demonstrates need or interest in developing";

  o "with" the person, and "with consideration given to his/her interest[s] and strengths"; or

  o it might simply plan (without reference to the focus person's involvement) "with consistent respect for her wishes, interests and strengths".

This informant also viewed facilitation as important to the decision-making process. She

explained that supported decision-making represents a paradigm shift for many families, who

are not accustomed to truly respecting their relative's wishes. With respect to the source of

facilitation supports, she thought these could be provided by an organization or an

independent facilitator (provided they have the skills to provide guidance on both the

philosophical and practical matters like payroll) but that facilitation and services should never be provided by the same organization.

<u>Other themes and perspectives relating to decision-making</u>

Informants raised a variety of other themes relating to decision-making processes. One was the reality of varying levels of ability to participate in decision-making. An Ontario informant observed that directors must involve the person to the extent possible, and that irrespective of the person's level of participation, directors must have a genuine and supportive relationship with him or her, but that some persons will not be able to provide any actual input into decision-making. Another informant who is a parent and independent facilitator explained that supported decision-making is not as 'black and white' as following the person's wishes. She said her daughter's network follows a communal process that always keeps her daughter at the center, but that in addition to considering what she wants, they will consider her needs and what, from past experiences, makes her happy. She also acknowledged that in interpreting preferences, members will not 'get it right' all of the time.

Some informants spoke about the approach to conflict or disagreement between the network and the supported person. Generally, people said that ideally the supported person is never 'overruled'. However, most informants acknowledged that this will depend on the situation and the person's ability and understanding. One informant, a parent, said that if the members of her son's Aroha do not agree, they wait and try to work to a solution; they do not act counter to her son's wishes unless it is an emergency, or he is determined to lack capacity (e.g., for

medical reasons). Others said that the weight given the supported person's preferences might vary with the riskiness of the decision and the person's comprehension of that risk.

Indeed, safety and risk in general were common themes. Several people said that where safety is at issue – for example, a medical procedure or a particular living arrangement – the network must mitigate the risk, but that it should do so in a way that is as respectful as possible of the person's wishes. This could lead to a compromise decision; for instance, a person wanting to live alone might be allowed to do so on the condition that a 'panic button' is installed for emergencies. A facilitator in Ontario emphasized that parents sometimes need guidance on how to support their son or daughter's autonomy and right to take risks. On the other hand, a person who was resisting a medical procedure that he didn't fully understand might be required to undergo the procedure if the network thought that the consequences of *not* having it would be even more unbearable for him. In still other situations, a network might come to understand a decision to forgo a life-saving medical procedure as the authentic choice of the individual. Indeed, an informant in British Columbia talked about the powerful role that personal networks can have in supporting people through healthcare decisions and, in some cases, helping them to have a good death.

D. <u>Relationships with third parties</u>

For a network to move beyond 'advice-giving' to providing meaningful supports in the outside world, it must have some ability to interact with third parties on the person's behalf. The legal status of a supporter would ordinarily come from a supported decision-making law. The section below examines the extent to which different kinds of networks in Ontario and British Columbia

are already interacting with government and private third parties, focusing in particular on network relationships with (i) government funders and service workers; and (ii) private third parties such as banks and health care providers.

1. *Government funding & the employer role*

British Columbia

The Wetherows (who innovated the first Microboards in Manitoba) have suggested that the appropriate relationship between a Microboard and government is one in which "[t]he Microboard has the same standing as a provider agency – it *is* a provider agency, for one person".[90] This is essentially the model that has been adopted in British Columbia, where a number of government ministries have recognized the authority of Microboards to receive and manage a person's individualized funds and to act as employer of record for service workers. Funding may come, for example, from the Ministry of Children and Family Development, Community Living BC, the Ministry of Health, or from a trust or a settlement.[91] Where a ministry accepts a particular Microboard as entitled to receive funding, it will enter into a contract with the Microboard (similar to the contracts it uses for agencies) stating, among things, that the Microboard is the employer of record. Service workers, in turn, accept the Microboard's authority to act as employer by virtue of government recognition of this role.

A Microboard that is receiving funds and acting as employer is responsible for complying with the Ministry contract and all laws and common law obligations relating to the employer role, such as employment standards, human rights, workplace safety, and tax laws. Directors may also need to understand principles relating to contract, budgeting, and bookkeeping and

payroll. Vela recommends that Microboards purchase directors' and officers' liability insurance to minimize individual risk, and provides guidance to new Microboard members on how to minimize risk of liability.

Ontario: Incorporated networks

The ability of incorporated networks to receive and manage individualized funds is much less clear in Ontario. A lawyer indicated that he has set up 'Microboard'-type entities (or "self-directed support organizations") for Ontarians seeking to provide for long-term management of individualized funding. However, there is no Ontario law or policy that addresses the ability of incorporated networks to play this role. Indeed, notwithstanding this lawyer's experience, the informant interviews indicate that there is confusion and a lack of information about whether incorporated networks are eligible to receive funds in Ontario. Several informants said there is no reason to incorporate a support network in Ontario because the government will not allow it to receive funding.

Among Ontario networks that do receive and manage funding, they are apparently doing so as a result of creative arrangements with transfer payment agencies supportive of their objectives. The lawyer noted above explained that some transfer payment agencies agree to flow funds earmarked for individuals to 'microboard'-type networks. However, because there are no applicable laws or policies, any safeguards (for instance, related to use of funds or reporting) must be set out in the individual agency's policies, or by contract between the agency and the network. Informants whose networks directly receive funds confirmed this, also highlighting

that the lack of official policy means they are sometimes required to piece together funding from a variety of sources, only some of which might flow through the network.

For example, an Aroha entity has an arrangement with a transfer payment agency pursuant to which the agency directs funds earmarked for the supported person to the Aroha, and the Aroha provides the agency with monthly reports. On the other hand, this person also receives some Passport funding, which must be delivered directly to him (his mother co-signs in an informal capacity), as the Aroha does not have authority to receive these funds. The Aroha entity then uses the funds available to it to employ personal support workers.

In another example, a group of families has created several layers of structures to support their sons and daughters with disabilities. First, there is an incorporated support network that serves seven individuals and their families. Second, each individual has an unincorporated support circle. Funding flows to each individual in their family and circle on a monthly basis in at least two different ways: (1) The larger network has a contractual arrangement with a transfer payment agency that allows it to receive funding intended for the seven individuals, which it in turn allocates to each individual within their circle. (2) The network has another contract with the local Passport office granting it authority to receive Passport funds for specified individuals, which it again allocates among families. Families use these funds to purchase supports directly, using simple individual service contracts. Decisions relating to services and supports are made in the context of each person's support circle.

As in British Columbia, a person or corporate body that is acting as employer is responsible for complying with the laws (such as employment standards, human rights, contract, and tax) that

relate to that role. In the context of an incorporated network, directors might receive some protection through directors' and officers' liability insurance.

Ontario: Unincorporated networks

Generally, when people want their networks to directly engage in funding and employment decisions, they seek incorporation. It is precisely the legal powers associated with being an incorporated entity that attracts some people to this model.[92] On the other hand, an informant from a transfer payment agency in Ontario described an arrangement by which the agency receives the individualized funds for particular persons, and technically acts as employer, but takes direction on services and staffing issues from individuals' support circles. She also said that a person and his or her support circle could choose to use the agency as 'just the banker', and to contract for services directly.

On the other hand, this informant appeared to refer to "support circles" and "family" somewhat interchangeably. For example, a sample Employment Agreement used by the agency states that "hiring decisions are made by the family and person who is supported" and does not expressly recognize the support circle.[93] A parent whose son obtains services from this agency said that she makes decisions relating to staffing and services. However, she was confident that after she is gone the agency will take direction from her son's support circle, and said the circle will develop protocols so that agency staff know whom to contact for particular decisions. She thought that this agency might be unique in having a policy of working directly with support circles.

2. Interactions with other third parties: Banks, health care providers, lawyers

Informants' comments with respect to interactions with other third parties – such as doctors, lawyers, and bankers – were relatively consistent. In both British Columbia and Ontario, incorporated and unincorporated networks alike have no real authority in the eyes of these third parties. Neither banks, nor health care providers, nor lawyers, have any basis for accepting the authority of a personal support network member to represent the decisions of another. In British Columbia this is less significant given that a person can enter into an agreement under the *Representation Agreement Act,* giving named individuals (who could also be network members) legal status.[94] However, in the absence of such an agreement in British Columbia, and in Ontario, personal support network members have no such authority.

For example, a parent in Ontario said that neither she nor others in her son's personal support network have been able to help him open a personal bank account, as the bank requires a guardianship order or a power of attorney. Several Ontario informants said that personal support network members are often present during periods of hospitalization or other critical health care issues, but that medical decisions are generally made by family members included in the hierarchy of substitute decision makers in the *Health Care Consent Act*.[95] An informant in British Columbia confirmed that Microboards do not have authority to make health care decisions and said that, in any event, a representation agreement is generally the better approach. A single exception surfaced in the interviews; a lawyer described a situation in which the personal support network of an Ontario woman, who did not have family, was able to

petition the hospital to allow it to act as substitute decision-maker. This, however, was the exception to the rule.

Several informants described situations wherein third parties recognized an individual as legally capable when supported by his or her personal network. These cases represent more of an accommodation approach – that is, traditional legal capacity thresholds are applied, but with the understanding that a person might need assistance to reach that threshold. Thus, an informant explained that her son's lawyer, bank, and doctors all accept that her son has capacity when supported by his Aroha entity. Legal documents are in his name, and his mother co-signs as a kind of informal guardian. An informant who works as a facilitator similarly referred to a number of individuals who have been considered by banks as capable for purposes of opening an RDSP, when supported by a personal support network. Another informant described a woman who has significant health issues and is supported in medical appointments by members of her support circle. The informant said that this woman makes her own decisions; however, she and her health care workers know that she is more comfortable and can make better decisions with supports.

None of this changes for incorporated networks. Microboards and their ilk have authority to enter into the kinds of arrangements that are available to any corporate entity. For example, they can purchase or lease property, open corporate bank accounts, enter into contracts (e.g., with service providers), and purchase insurance. However, third parties do not recognize them as having authority to represent or 'act' for a supported person.

E. <u>Who is using personal support networks?</u>

Most informants did not know how many in Canada have established personal support networks, but thought that people with networks are likely in the minority.[96] Some people thought there might be growing interest in opportunities for network building. An informant said roughly 50 people have sought out information about Aroha entities, but did not know how many have gone on to create them. A facilitator said that people using support circles are still few in number but that these numbers might grow alongside the facilitation movement. A lawyer said that while incorporated networks are still uncommon in Ontario, many people are seeking out information. He speculated that their usage might increase as parents get older and seek out ways to ensure continuity in funding and services for their sons and daughters. Another facilitator said that there is a lot of 'talk' about creating circles and networks but that families often don't carry through, either because they have difficulty giving up control, or because they think there aren't enough people who will help. Another informant, a parent and independent facilitator, emphasized that many parents are reluctant to create personal support networks because their time is already overburdened and social network creation is a foreign concept. On the other hand, Microboards appear to be very well established in British Columbia. An informant indicated that about 900 have been created in total and that over half of the boards that exist today were created within the last four years. She also suggested that there is substantial overseas interest in Microboards.[97]

Nearly all of the personal support networks described by informants were created for persons with developmental disabilities. Indeed, most of the informants for this study came from this

perspective. Two exceptions surfaced in British Columbia: An informant said that approximately 55% of Vela Microboards are supporting persons with developmental disabilities, but that the other 45% are supporting persons with other disabilities. Another informant said that perhaps 10 per cent of clients supported by PLAN are seeking support for a mental health disability.

Several informants opined that personal support networks *could* be a useful resource for any vulnerable adult (and one person emphasized that they are important for everyone, whether or not they are 'vulnerable'). On the other hand, some cautioned that personal support networks might not work for everyone. For instance, one informant observed that people with fluctuating capacity due to mental illness might prefer a power of attorney approach. Another suggested that older adults might not be drawn to the personal support network model, either because they don't have enough people in their lives who can be involved to the required degree, or because they already *do* have these supports, informally, within their family.

VI.   LAWS AND STANDARDS APPLICABLE TO PERSONAL SUPPORT NETWORKS

A range of laws, policies, contractual terms and voluntary standards can apply to personal support networks. These vary by jurisdiction and a particular network's legal structure and relationships. An informal circle of support will be subject to little, if any, formal regulation. On the other hand, incorporated networks have a number of legal obligations.

1. *Standards relating to incorporation and corporate maintenance*

Incorporated networks – like every not-for-profit corporation – must comply with laws relating to incorporation and corporate maintenance. Organizations may incorporate federally or provincially. Those incorporating provincially will be subject to slightly different rules (and different terminology) in Ontario and British Columbia. Moreover, both provinces are the process of overhauling their laws in this area. In Ontario, personal support networks that choose to provincially incorporate currently do so under Part III of the *Corporations Act*.[98] However, the Ontario government has passed the new *Not-for-Profit Corporations Act, 2010,* which will come into force on a date to be named by proclamation (not expected before 2016).[99] In British Columbia, not-for-profit organizations are governed by the *Society Act*[100]. However, the Ministry of Finance is in the process of developing a new Act, and in August 2014 published a White Paper with draft legislation, inviting comments.[101]

As the laws currently stand, a number of the rules in the two provinces are substantially similar. Persons proposing to incorporate a not-for-profit organization (a "society" in British Columbia and a "corporation" in Ontario) must follow steps that include, in varying forms and stages:

- Obtaining approval of the organization's proposed name[102];

- Paying a fee and filing an application along with information such as: the purposes of the organization (called the "constitution" in British Columbia, and "objects"[103] in Ontario); the organization's head office address; and the names and addresses of the first directors;[104]

- Naming a minimum of three first directors[105] (and British Columbia also requires that there be a minimum of five initial "applicants" for incorporation[106]);

- Adopting bylaws that meet the standards set out in legislation[107].

Once established, the directors of the society or corporation must comply with laws governing corporate structure, maintenance, reporting and filing. For instance, they must hold annual general meetings[108]; have adequate financial arrangements and, if required, an auditor; keep certain records (for instance, relating to minutes, accounting and member lists)[109]; and file certain reports with the government with information about the corporation and its finances.[110] While not-for-profit organizations are not generally required to pay income tax, they must nonetheless file an annual Corporate Income Tax Return.[111] Some may also need to file an annual Non-Profit Organization Information Return with the Canada Revenue Agency.[112] Not-for-profits may also have additional filing obligations, depending on their activities and jurisdiction. Indeed, this area of the law is complicated and in flux. Incorporated networks must ensure that they keep apprised of their legal obligations, which may require time and jurisdiction specific legal advice.

2. *Duties and liability of directors of not-for-profit corporations*

The rules discussed above relate primarily to the organization's obligations to government. Importantly, however, incorporation changes the organization's status and legal obligations to third parties. In the case of a personal support network, it arguably also affects the legal relationship between network members and the supported person.

Directors are not generally liable for the actions of the corporation, such as contracts validly entered into, because the corporation has the status of a separate legal person (protection that is referred to as the "corporate veil"). Directors do, however, have significant duties and can be liable in a variety of circumstances. As a general matter, directors are responsible for managing

the corporation and for complying with its objects and bylaws, the relevant corporations

statute, any other applicable statutes, and the common law.[113] Directors owe a fiduciary duty to

the corporation that requires them to carry out these responsibilities with (i) the necessarily

levels of skill and diligence (in Ontario's new Act the standard is that of a "reasonably prudent

person"); and (ii) with loyalty, meaning "honestly and in good faith".[114] These duties are set out

in s. 43(1) of Ontario's new *Not-for-Profit Corporations Act, 2010*:

> 43. (1) Every director and officer in exercising his or her powers and discharging his or her duties to the corporation shall,
> (a) act honestly and in good faith with a view to the best interests of the corporation; and
> (b) exercise the care, diligence and skill that a reasonably prudent person would exercise in comparable circumstances. 2010, c. 15, s. 43 (1).

The duty of loyalty generally requires, for example, that directors attend meetings and be as

informed as possible regarding matters affecting the corporation. This "requires active and

concerted effort on the part of directors to be knowledgeable and ready to make informed

decisions affecting the corporation".[115]

A director may be held liable if he or she breaches any part of the fiduciary duty to the

corporation and this results in harm.[116] Directors can also be liable if they enter into a contract

without legal authority, or commit a tort (for instance, acting negligently), while acting as a

director.[117] There is also a range of specific statutory provisions that can make directors

personally liable. For instance, under s. 40(1) of the *Not-for-Profit Corporations Act, 2010,*

directors can be jointly and severally liable to employees of the corporation for up to 6 months'

wages and 12 months' vacation pay under the *Employment Standards Act*.[118] Indeed, Director

liability is a vast topic that cannot be fully canvassed here; these are only some possible sources of liability.

A corporation may indemnify its directors for costs incurred in the course of a legal action stemming from the execution of their duties as director.[119] Corporations may also purchase directors' and officers' liability insurance, and are generally encouraged to do so.[120] However, these protections may not extend to directors who have breached their fiduciary duty or acted illegally.[121]

It is unclear what directors' fiduciary duties mean for the relationship between directors and the supported person. The fiduciary duty is owed to the corporation. However, where the purpose of the corporation is solely to support the individual, arguably this could have the *effect* of also applying a fiduciary standard to relationship between directors and the supported person. On the other hand, the supported person is very often a director him or herself, creating the somewhat awkward proposition of a person having a fiduciary duty to support himself, and inserting a degree of ambiguity into the legal relationship with other directors. The supported person's dual roles – (i) as corporate director, and (ii) as beneficiary of some form of (arguably fiduciary) duty – do not sit together easily or intuitively. We can only speculate as to how these legal relationships might play out in the event of conflict, as there does not appear to be any case law on point.

3. Legal obligations relating to particular network activities

As noted above, an incorporated support network that is receiving and managing funds and employing workers will be subject to a range of legal obligations relating to that role.[122] These may include:

- contractual obligations, such as contracts with government ministries or agencies (in British Columbia), or with transfer payment agencies (in Ontario), relating to receipt and management of funds;

- federal and provincial tax laws; and

- laws pertaining to the employer role, such as employment standards legislation; occupational health and safety laws; and human rights laws.

Although unincorporated networks might participate in decisions relating to services and supports, they have no legal status to do so. (Indeed, there is no legal entity to which legal duties can attach.) As such, in these cases, the legal obligations relating to the employer role will fall on someone else, such as an agency that is acting as formal employer, a parent who is acting as 'informal guardian', or the supported person himself or herself.

4. Standards relating to the decision-making process

There are, of course, no laws governing a network's decision-making processes, whether supported or otherwise. However, as described above, networks can and sometimes do draft voluntary statements of their decision-making principles. Incorporated networks must also draft bylaws and corporate objects (or "constitutions" in British Columbia), and some use these instruments to expressly state their decision-making principles. The sample by-laws from Vela in British Columbia are an example of this approach. Finally, contracts between networks and

funders are another opportunity for decisions-making principles and standards to be set out in writing.

In none of these cases is there any assurance of consistency across networks or jurisdictions, nor of compliance with stated principles. And, of course, a statement of supported decision-making principles will not create any legal powers or authority for the network vis-à-vis third parties. (Indeed, it is these kinds of concerns that have led some to argue for comprehensive supported decision-making legislation.)

VII. ARE PERSONAL SUPPORT NETWORKS PROVIDING SUPPORTED DECISION-MAKING?

A. *What is* supported decision-making?

While there is no agreed-upon definition of supported decision-making, there are common themes. As the LCO points out, supported decision-making models generally aim to enable persons to "exercise control over decisions that affect them through supports… without any loss of legal capacity.[123] Indeed, a central intent of supported decision-making is to avoid any assessment of capacity or label of incapacity.[124] And, relatedly, most models specify that the supported person retains legal responsibility for their decisions, and that those decisions are legally binding (a point returned to below).[125] Most definitions also emphasize that supported decision-making should take place within "relationships of trust and intimacy".[126] Beyond this, however, there is more variability, particularly with respect to the degree of "control" or agency that the supported person must exercise, and the specific roles of supporters.

Some use the term "supported decision-making" broadly to encompass situations in which there is a process in place to discern the person's preferences. Thus, the supported person is the legal decision-maker, "but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behavior to determine his or her preferences".[127] For example, Bach and Kerzner and the Coalition on Alternatives to Guardianship recommend a "will and preferences" approach that requires that the person be "able to express their will and preferences in a manner that at least one other person can understand".[128] They suggest that supporters be subject to a standard of "best interpretation", acknowledging that there may be disputes over how to interpret a person's will and preferences.[129] They also argue that in some circumstances, the law should allow for individuals to have decision-making supporters appointed *for* them.[130]

Other writers appear to impose a more stringent agency requirement, both with respect to establishing and ending the decision-making process (for instance, ensuring that the person has "voluntarily entered into the arrangement") and the process itself.[131] Thus, some argue that the person must enter the arrangement freely and with consent.[132] Others emphasize that the person must "actively participate in decision making" and be able to "terminate the relationship at any point in time".[133] For instance, the Office of the Public Advocate in Victoria, Australia, states that "[c]onsultation, respect for a person's wishes and the promotion of a person's rights are not, of themselves, supported decision-making."[134] Rather, "any supported decision-making arrangement must have the free agreement of the person", and the person must be able to terminate the arrangement at any time.[135] Kohn, Blumenthal and Campbell also appear to be in

this latter camp of writers when they specifically consider what would be required for personal

support networks to qualify as supported decision-making:

> To the extent that a circle of support helps a person understand various life choices and
> choose among them, or that a microboard is structured to allow the person with a disability
> to direct its actions (e.g., such as by having that individual serve as the President of the
> Board), both approaches can be mechanisms for implementing supported decision-making.
> By contrast, if the members of a micro-board or circle of support ultimately make decisions
> on behalf of the person with a disability—even if they consult with that person and consider
> the person's wishes—then such arrangements should not be classified as supported
> decision-making. [136]

These different definitions of supported decision-making reflect a tension. On the one hand,

writers are aware of the need for clear indicia that a person is being empowered and permitted

autonomy to "make decisions for themselves" rather than being coerced in the name of

'supports'[137] On the other hand, many argue that supported decision-making mechanisms are

most needed by people who do not meet traditional, or even more flexible, capacity standards

and methods of participation. (For instance, some informants expressed concern that

supported decision-making under British Columbia's *Representation Agreement Act,* with its

continued use of a capacity threshold, "leaves people out".)

Finally, to assess whether personal support networks are providing "supported decision-

making", requires a position on what counts as 'support', and how narrowly we define the

decision-making process. Bach and Kerzner argue that "decision-making supports" for the

purpose of Article 12(3) of the CRPD should be interpreted to include "life planning supports"

(such as the person directed planning and facilitation tools discussed above[138]); advocacy; and

"relationship-building supports", among other things. [139] For example, they observe that "the

outcome of relationship-building supports is the development of relationships and support

networks which can provide representational supports at some point in the future".[140] This broad definition of "supports" would seem to require that all personal support networks be classified as supported decision-making because they are building relationships on which a person could draw in the future. The approach taken in this paper is, however, narrower. Recognizing that there may be many important background conditions for supported decision-making, to which networks might contribute, it nonetheless focuses on the more immediate process of decision-making at a particular time and place.[141]

B. **Are personal support networks playing this role?**

As noted above, every informant who was directly involved in a personal support network said his or her particular network *was* engaged in supported decision-making. At the same time, a significant theme among some informants was skepticism about whether all networks are providing supported decision-making, or at least, recognition that it might not be done uniformly well.

Some participants referred to personal support networks that are created without any intention of engaging in supported decision-making. For instance, a lawyer in Ontario said some families incorporate networks with administrative functions – such as managing funding – in mind. A lawyer in British Columbia said that he tries to talk to his clients about supported decision-making, but that sometimes people just want a result. An independent facilitator in Ontario said that that some networks are intended to address social ends, and do not make supported decision-making a central focus.

Others observed that networks and members intending to engage in supported decision-making have varying levels of skill and understanding, and that supporters may slip between supported and substitute decision-making. A lawyer said he was concerned that family members, while well meaning, sometimes favour safety and protection over autonomy and freedom. He cautioned that, without the necessary safeguards, giving sanctioned decision-making roles to networks could devolve into a means for families to reinforce each other and engage in substitute decision-making by another name.

Whether personal support networks are providing supported decision-making will obviously vary, both with one's definition of supported decision-making, and the particular network under study. However, many of the personal networks discussed by informants are, at least on the broader definition of supported definition described above, apparently engaged in supported decision-making. The discussion below briefly analyses the professional and lay participants' statements about network decision-making in the context of the following factors, drawn from definitions of supported decision-making: (i) concepts of capacity; (ii) the supported person's consent to create the network; (iii) whether networks members are in relationships of trust and intimacy with the person; (iv) the supported person's participation in decision-making processes; and (v) legal responsibility for decisions. As discussed above, the scope of this study was such that it can only provide some initial impressions. Further work could build on these findings, for instance, by asking the whether these processes are experienced as empowering.

1. Concepts of capacity

Every informant who spoke to the issue rejected traditional concepts of capacity, consistent with principles of supported decision-making. Indeed, the most common sentiment was that everyone can benefit from personal support networks and supported decision-making. Where capacity was referred to, it was in statements to the effect that there must always be a presumption of capacity; that a network can help maximize, or "supply… whatever is missing" in, a person's capacity; and that a person with capacity might need others to help him or her carry out wishes. One informant (whose son is generally recognized by third parties as having capacity with supports) said her son sometimes lacks legal capacity for medical reasons, and that in these situations it can be useful to pair supported decision-making with a Ulysses agreement. The majority of informants, however, preferred to avoid any context in which there might be a finding of legal incapacity.

2. Entered into freely and with consent?

If one were to make it a strict requirement that a person 'consent' (following the conventional meaning of that term) to network formation, most of the networks described in this study would fall short. This is not surprising, as traditional ideas of consent go hand-in-hand with traditional legal capacity. Only one informant discussed a network in which the supported person expressly chose to enter into a network arrangement, and that person apparently met conventional capacity standards when supported. One other informant talked about a supported person 'owning' his Microboard such that he was free to terminate the arrangement should he wish. The other informants described approaches ranging from: ensuring that the

person understands what is happening, to making sure the person is comfortable, to situations where a network might be created notwithstanding the person's initial objections.

In general, as with decision-making principles more broadly, network members appear to involve the supported person as much as possible. Informants recognized that some people will not be able to 'choose (or terminate) a network in the traditional sense, but took the position that people of all levels of abilities should benefit from personal support network arrangements. On the other hand, one informant cautioned that there can be slippage or confusion over *who* is choosing to create a network. This came through in several interviews, in which it was not clear whether the impetus for creating a network was the wishes of the supported person or his or her parents.

3. *Relationships of trust and intimacy*

Without exception, informants talked about the central importance of the network being comprised of people in relationships of trust and intimacy with the supported person. Some counseled vigilance to ensure people are chosen for the supported person and not the parents. Several also said relationships might vary with the purpose of the network (for instance, socializing versus hiring workers). Finally, some referred to other networks that might be set up without the real intention of being a personal support network. For instance, a network might be set up temporarily for personal planning purposes, with no intention of longevity. However, more than any other factor, the core focus on caring relationships was evident in every network in which informants had participated.

4. *Active participation in the decision-making process*

Not every definition of supported decision-making requires the active participation of the supported person. Like the requirement that the person consent to enter into the arrangement, there is a tension between requiring a particular level of ability to participate, and making supported decision-making accessible. And, whether a personal support network is seen to engage in supported decision-making will often depend significantly on the position one takes on this agency-related factor.

In general, informants took the position that the supported person should be involved in decision-making *as much as possible*. Many people spoke in terms of keeping the person 'at the center' of the decision-making process rather than any particular degree or method of participation. Thus, for a person capable of actively participating through assisted communication, it was seen as essential that network members take direction from him. In other situations, the person might not be physically present for decision-making. One person spoke of decision-making as a communal or collective process. She emphasized that supported decision-making for her daughter does not necessarily entail following her wishes in every case; rather, the important thing is to have a group of people make decisions based on a deep understanding of who her daughter is.

Many of these networks would not meet Kohn, Blumenthal and Campbell's requirement that the person "understand various life choices and choose among them" or that they "direct" the network's actions.[142] On the other hand, many would meet the standard recommended by Bach and Kerzner and the Coalition on Alternatives to Guardianship, that the person be able to

express their "will and preferences" in a manner that at least one other person can understand, subject to a standard of "best interpretation".[143]

5. *Legal responsibility for decisions and the corporate decision-making agent*

Decision-making rights and legal responsibility for decisions are usually corollaries. This makes the question of *who* is the decision-making agent important. Indeed, this is important both for the decision-maker (who may be legally responsible in the event of, say, breach of a service contract), and for third parties who require clarity about who is the responsible legal agent.

Few of the informants had thought about the issue of legal responsibility for decisions. In unincorporated networks, decision-making responsibility was sometimes perceived to reside with the supported person's family (even in the absence of any guardianship order or power or attorney). Incorporation, in turn, was often seen as a means of obtaining legal *powers* that might facilitate practical objectives like succession planning. Informants had not always reflected on the corollary, legal responsibility.

What, then, are the legal principles applicable to these networks, and what do these principles mean for concepts of supported decision-making? Generally, a legally responsible supported adult (i.e., who has not had his or her legal responsibility altered by, for instance, a guardianship order) will remain responsible for his or her decisions whether or not a network is providing support. Indeed, some view this maintaining of legal agency as integral to the very concept of supported decision-making.

On the other hand, where an incorporated network makes and implements decisions (for instance, to hire service workers or lease property) in its corporate capacity, it is legally responsible for these decisions. In these circumstances the network, not the person, is the decision-making agent. This is so because a corporate entity has the status of a legal person. As one plain-language guide puts it:

> A legally incorporated organization is a separate legal entity, just like a real person. The Society's existence does not depend on any one person remaining alive. Rather, the organization will "live" as long as it continues to meet the requirements set out by the provincial government. Consequently, an incorporated organization may enter contracts and/or sue other entities in its own corporate name.[144]

Thus, where a corporation has the legal authority to enter into a transaction (for instance, contracts with service workers or a residential lease), and it does so within this legal authority, it will be the legally responsible agent.

The fact of incorporation does not mean that a Microboard is the decision-making entity for all purposes. A Microboard will have the legal powers generally accorded at law and common law to corporations. A corporation has no legal authority to represent a person in health care (or banking, or lawyer's office) settings. Personal decision-making for another is not a power granted to corporations. Thus, while Microboard members might give informal guidance relating to medical care (and there could be a debate as to what directors' duties of care require in this context), the corporation is not a medical decision-making entity. In short, a corporation's status as decision-making entity is coextensive with its legal powers. Incorporated networks in British Columbia are recognized in government policy as eligible to receive funding and hire workers in accordance with their contacts with the ministry and applicable laws. And,

like most other corporations, they can do things like open corporate bank accounts, rent

property, and purchase liability insurance. Those in Ontario will also have these standard

corporate powers and can also enter into contractual arrangements with transfer payment

agencies, assuming those arrangements are not contrary to law. However, in neither province is

the incorporated network the decision-making agent for all purposes.

What does this mean for supported decision-making? The removal of legal responsibility from

the supported person for some decisions could be seen as a departure from ordinary supported

decision-making principles. Indeed, some informants viewed the removal of full legal agency

from the person as anathema to principles of supported decision-making and equality. On the

other hand, it could be argued that the corporate model is more consistent with the principles

of supported decision-making in that it expressly recognizes the interdependent, group nature

of decision-making, and matches legal responsibility to the locus of decision-making. Indeed,

although it identifies a new legal agent (the incorporated network), making this different from

most models of supported decision-making, it is not quite substitute decision-making either.

Most importantly, it does not require any finding of legal incapacity, and the person him or

herself is part of the collective that is the new decision-making agent.

In summary, it is impossible to make general or definitive statements about whether personal

support networks are engaged in supported decision-making. Some are (even on the strictest

definition) and some aren't (even on the most inclusive definition). Most informants

acknowledged that some people form networks that might technically fall into the definition of

"personal support network" used for this paper that are not intended to support decision-

making. On the other hand, in the networks in which informants had directly participated, the most common approach was to apply decision-making principles that are generally consistent with the "will and preferences" approach to supported decision-making. Finally, in the case of incorporated networks that make decisions in their corporate capacity, this could be seen as a distinct approach that lies somewhere between substitute and supported decision-making. While it removes legal responsibility for decisions from the supported person, it appears consistent with other key principles of supported decision-making. In particular, it seems to provide a means for some personal decision-making to take place in a way that maximizes the person's participation but does not require any legal capacity assessment.

VIII. POSSIBLE IMPLICATIONS FOR LAW

There are a number of opportunities for recognizing personal support networks in current, or potential future, law. The options set out below begin with the most modest (indeed, the first is arguably already law), moving on to opportunities for deeper reform. The first options largely rely on existing legal tools and concepts. These would give some recognition to network supports provided in particular cases, but would not formalize the network structure (although they could be paired with background supports for personal support network building). The second category of approaches would give legal recognition to *individual* relationships of support (like British Columbia's *RAA*), recognizing that individual relationships and personal support networks often go hand-in-hand, and that in using these tools people may both rely on and strengthen personal support networks. The final group of options explores the implications of building on the corporate model. These options take seriously the idea of *group* decision-

making supports, and the concept of a jointly created decision-making entity. The first of these – essentially, Microboards – is already law in British Columbia. The second discusses expansion of the Microboard model to other areas of decision-making, which would be a novel approach.

A. Opportunities for modest legal recognition (no substantial change to current laws or concepts)

1. Recognizing network support as part of the duty to accommodate persons in reaching traditional capacity thresholds

Arguably, this first 'option' is already legally required. Human rights legislation across Canada protects against discrimination on the basis of age and disability (among other grounds) in a number of areas. In Ontario, the *Human Rights Code* (the "*Code*") provides the right to freedom from discrimination in the areas of services, employment, accommodation, contracts, and vocational associations.[145]

Under sections 9 and 11 of the *Code,* the application of a facially neutral standard that adversely affects persons with disabilities can amount to discrimination.[146] Where there is *prima facie* discrimination, the burden shifts to the party relying on the standard to show that the person cannot be accommodated without undue hardship.[147]

The *Code* also specifically refers to a duty to accommodate in the context of allegations that a person is incapable of exercising a right because of disability. Section 17(1) provides that a right is not infringed "for the reason only that the person is incapable of performing or fulfilling the essential duties or requirements attending the exercise of the right because of disability".[148] Thus, it provides a kind of 'defence' to allegations of discrimination. However, section 17(2)

goes on to state that "[n]o tribunal or court shall find a person incapable unless it is satisfied that the needs of the person cannot be accommodated without undue hardship".[149]

Although s. 17 is not referring to "capacity" in the sense of legal decision-making capacity, arguably the section is broad enough to encompass legal capacity standards. On this interpretation, sections 9, 11, and 17 read together, would mean that a person providing a service (or other covered activity under the *Code*) could not withhold that service on the grounds that the person lacked the necessary legal capacity (a facially neutral standard), unless it were established that the duty to accommodate had been met. The content of this duty to accommodate could be debated, but might include, for example, allowing a support person, communication assistant, or personal support network member to be present where this allowed the person to reach ordinary legal capacity standards. Some scholars have advanced precisely this kind of claim, arguing that decision-making supports (such as personal support networks) should be recognized as a form of legally required accommodation.[150]

As the LCO notes, there does not appear to be any Canadian case law on point. However, the Commissioner for Human Rights for the Council of Europe has recommended that government and key institutions have an obligation to accommodate that would include: "acceptance of a support person communicating the will of the person concerned".[151] Although it has not been adopted as Ontario policy, the Ontario Human Rights Commission recently referred to (without endorsing) the argument that "providing supports as much as possible to help people make decisions should be recognized as part of an organization's legal duty to accommodate." It also observed that "Article 12 [of the CRPD] requires that appropriate measures be taken to provide

the person with the support they need to make decisions, *such as making sure a person has access to a network of people who can help.*"[152]

The informants' comments indicate that, in practice, some third parties are already providing this kind of accommodation. Informants described interactions with banks, health care providers, service providers, and lawyers, in which a person was viewed as legally capable when supported by one or more members of a support network. In some of these cases the person's capacity simply was not questioned when a supporter was present. In others, parents expressly appealed to the existence of the personal support network, successfully convincing the third party that there was (supported) legal capacity.

Recognizing decision-making supports as legally required accommodation does not specifically entrench any particular form of personal support network, or indeed, networks at all. The very idea of accommodation is that it is individual. As the Human Rights Commission has explained: "There is no set formula for accommodating people with disabilities. Each person's needs are unique and must be considered afresh when an accommodation request is made."[153] Thus, this approach would not formalize any particular approach to support networks in law. It also would likely not require that new safeguards be created, given that traditional capacity tests would apply. However, for the same reason, this approach will likely not satisfy those seeking meaningful alternatives to guardianship. Given that it would require people to "understand and appreciate" (with supports) it would continue to be inaccessible to many persons with disabilities.[154]

2. Network support as an alternative to guardianship – ss. 22 and 55 of the SDA

Sections 22(3) and 55(2) of the *Substitute Decisions Act* (*SDA*), dealing with guardianship for property and personal care, respectively, state that the court must not appoint a guardian if "it is satisfied that the need for decisions to be made will be met by an alternative course of action" that both "does not require the court to find the person to be incapable" and "is less restrictive of the person's decision-making rights than the appointment of a guardian" (the "alternative course of action" provisions).[155]

To date, it seems that in most of the cases applying these provisions, the 'alternative' under consideration has been a power of attorney. However, it could be argued that decision-making with the support of a personal network is an alternative to guardianship that should be recognized, in an appropriate case, under the alternative course of action provisions. Indeed, one Ontario case has (obliquely) suggested that supported decision-making could qualify under s. 55(2) of the *SDA*. In *Gray v. Ontario* (2006)*,* the Ontario Divisional Court heard a judicial review of the government's decision to close three residential institutions.[156] In the context of describing the government's process for planning and obtaining consent for individuals' new community placements (which did not require guardianship), the Court suggested that this process might be consistent with a "'supported decision making' process, which in many cases will be consistent with the words and the intention of section 55(2) of the Act".[157]

The Coalition on Alternatives to Guardianship has argued that the alternative course of action requirement "is not just a provision, but a process".[158] It explains that after the *SDA* was implemented in 1992 there was government interest in developing procedures for

implementing a supported decision-making system, but that "the promised process...never

materialized."[159] The Coalition recommends that this be taken up now, and that ss. 22(3) and

55(2) be used as the springboard for a new legislated supported decision-making process.

Again, this paper does not take a position on those recommendations for broader legal reform.

Rather, it considers the more immediate possibility that courts might recognize the supports

provided by personal support networks on a case-by-case basis – that is, examine all the facts

of a particular network arrangement, and if satisfied that "the need for decisions to be made

will be met", recognize the arrangement as an alternative to guardianship under ss. 22(3) and

55(2). The Court in *Gray* seems to have taken this approach, apparently viewing the alternative

course of action provision as requiring a case-by-case assessment rather than a set process:

> There are approximately 1000 individuals who will be transferred from these three institutions; their capacities and their needs in reference to the decision-making process will differ significantly. It is not possible to dictate a process for obtaining consent to community placements that will apply in every case. However, the objective will always be the same, which is to act in the best interests of the incapable person.[160]

Thus, while the alternative course of action provisions arguably open the door for a

comprehensive supported decision-making regime, they also do not preclude more modest

case-by-case recognition of decision-making supports in personal network context.

As with the accommodation approach discussed above, recognizing a personal support network

as providing adequate supports and protection in a particular case would not entrench any

particular kind of network, or networks at all. Rather, it would recognize that in that particular

situation, the network arrangement was working well and meeting the objectives of the *SDA*.

On the other hand, as with reliance on the duty to accommodate, there are significant

limitations to this kind of approach. First, in situations that are working well, it is unlikely that

anyone would be seeking guardianship to begin with. Persons seeking guardianship – a process

that entails significant effort and expense – will generally do so only where existing

arrangements are perceived as flawed, or where additional legal authority (for instance, to

interact with third parties) is required. Second, the court's authority to recognize networks is

extremely limited. Sections 22 and 55 give it the power to "not appoint a guardian" if there is a

less restrictive alternative that meets the requirements of those sections. This gives it the

power to leave the status quo in place; for instance, where the necessary decisions are being

made (perhaps because a parent is involved as 'unofficial guardian'), this would be permitted to

continue. However, a court considering a guardianship application under the *SDA* does not have

any authority to grant to a person's network legal status to, say, interact with third parties. Put

another way, the court can decline to appoint a guardian on the evidence of a network

arrangement working well, but it has no authority to help *create* the less restrictive alternative.

As the decision to grant a (corporate or individual) person legal status to represent another's

decisions can only be made by the legislature, this ultimately brings us back to the broader

debate over the desirability, and potential contours of, a new supported decision-making law.

B. Recognizing personal support network members within broader supported decision-making regimes

Any legally recognized supported decision-making regime that gives status to a person's

supporters could also, by extension, involve or strengthen a person's network. Indeed, unless

the network is recognized as a standalone entity (a possibility that is explored below) it may be artificial to separate 'network' supports from other (more individual) supports.

First, supported decision-making laws can give status to persons drawn from personal support networks. For example, under British Columbia's *Representation Agreement Act* (*RAA*), a person might appoint as a representative one or more persons from his or her Microboard or PLAN support network. An informant from a community organization in British Columbia said that many people ask members of their PLAN networks to be their legal representatives under the *RAA*. Second, as this informant also explained, the process of creating a representation agreement can help to establish a new personal support network. For instance, a person could appoint a 'team' of representatives, specifying how they are to work together on particular issues (such as through a 'telephone-tree' telling health care workers whom to call, in what order, in the event of a health-care issue). This informant acknowledged that representation agreements do not always work this way in practice. However, she said the advocates for representation agreements always perceived them as a means of both giving legal status to, and strengthening, a person's 'natural' personal support network.

The point here is not to advocate for British Columbia's approach to representation agreements in particular. Rather, it is that supported decision-making laws can promote decision-making within networks without expressly legislating a "network" approach. Appointing one or more representatives or supporters in their individual capacities can have the effect of strengthening previously existing networks, or of creating new ones.

Finally, while none of the policy options discussed above legally entrench the network form, all of them could be paired with a government commitment to providing the background supports (e.g., funding and programs) to help people to create and maintain robust personal support networks. As Kohn et al., observe:

> Policymakers can promote supported decision-making either by creating opportunities and mechanisms for formally recognizing an individual's decision-making supporter or by creating opportunities and mechanisms for providing individuals with such supporters. Both approaches may be necessary in order for supported decision-making to benefit both those with and without pre-existing support networks.[161]

These background supports would likely be important to any of these more modest proposals for recognition of personal support networks. For instance, an informant in British Columbia spoke about the power of representation agreements to foster network creation, but said that this potential has been limited by the lack of funding for programs that support network creation. She emphasized that any serious commitment to providing alternatives to guardianship must pay attention to the 'planning side', including the gradual process of building a network and the possibility that people will require help to do so. The Coalition on Alternative to Guardianship has made similar arguments, suggesting that the government should be required to take "proactive steps" to help people establish support systems.[162]

C. Options that build on the tool of incorporation

1. Why talk about incorporation?

Some have queried whether it is appropriate to make vulnerable persons fully legally responsible for the decisions made through a supported process, and whether the tool of incorporation could provide safeguards. The LCO raises this in its Discussion Paper:

A difficult question is the apportionment of legal responsibility for decisions made through supported decision-making. Responses are to some degree linked to the model of supported decision-making adopted, and the role that supporters are expected to play. One approach is to say that the decision is that of the person, and that therefore that person bears the full responsibility for the decision: critics argue that this approach can lead to troubling moral outcomes where some persons with significant levels of vulnerability may be liable to suffer substantial legal consequences despite not having understood the risks associated with the decision. Another approach is to emphasize the interdependent nature of decisions made through a supported decision-making approach.[163]

As the LCO notes, the Office of the Public Advocate for Victoria, Australia, has elaborated on

this second approach:

> [I]f decision-making is an interdependent process and if a person has a support network assisting them to make decisions, it can be argued that the members of the support network should bear at least some ethical responsibility for the decisions made, unless they formally distance themselves from the decision. The question of legal responsibility arises if decisions with legal ramifications are being made, for example decisions involving a financial contract, decisions requiring formal consent or decisions that may result in a person having a civil action brought against them. An alternative form of supported decision-making is to establish the support network as an Incorporated Association. Under this arrangement, all the members of the network take responsibility.[164]

Making a network a separate legal person achieves two main things, which are corollaries of

each other: First, it establishes a legal entity that can take on the legal powers ordinarily

available to corporations under the common law (such as the ability to enter into contracts)

and by statute. (As discussed above, corporations do not currently have the legal power to

represent the personal decisions of another; separate legal authorization would be required to

grant it these powers.) Second, a corporate entity is legally responsible for the acts and

decisions validly entered into by the corporation. This has implications for third parties who can

clearly identify the party responsible for any legal obligations. (A landlord who has leased

property to a corporation knows whom to turn to in the event of a breach, and the presence of

a corporate entity might lend some apparent stability to the transaction.) The presence of a

corporate entity also has implications for the supported person insofar as it is an alternative to having him or her personally lease the property and take on the associated legal responsibilities and potential liabilities.

Another possible implication of incorporation is the shifting of the legal relationship between supporters (now directors) and the supported person (possibly now also a director). As noted above, it is unclear what is the legal nature of this relationship where the supported person is both a director and the effective object of the corporation (in relation to which directors owe a fiduciary duty). Few informants had turned their minds to this issue, and there is apparently no case law on point.

The discussion below describes two ways in which Ontario law could recognize a 'corporate approach' to personal support networks and decision-making. The first is, essentially, the Microboard model. The second is to give incorporated networks a role beyond administering funding and services (which turn on ordinarily available powers of contract paired with government policy), giving them new legal powers to represent the personal decisions of a supported person. This is the far more radical of the two options, and it is in the context of this second option that the bulk of the discussion about protections for supported persons and third parties takes place.

2. *Making incorporated networks formally eligible to receive and administer individualized funds*

As discussed above, a small number of people in Ontario have incorporated personal support networks. The informant interviews suggest that where this is done, it is to (i) take on the legal

powers of a corporation (for instance, to own property) that can facilitate succession planning;

and (ii) enter into contractual arrangements with transfer payment agencies, allowing them to

receive and administer individualized funds. One policy option would be to regularize this

practice, expressly making incorporated personal support networks eligible to receive and

administer individualized funds, as is done in British Columbia. This would be one way to allow

for supported decision-making in relation to funding and services.

Does the *Social Inclusion Act* allow for Microboards?

While there is still no Ontario law recognizing the authority of an incorporated network to

receive and manage funds, the *Social Inclusion Act* does not appear to preclude it. The Act now

provides for direct funding agreements which, according to MCSS, will "give people with a

developmental disability and their families more choice and flexibility" by allowing families to

"buy supports themselves".[165] The direct funding agreement provisions (which are not yet in

force) state that an application for direct funding can be made by "a person with a

developmental disability, by a member of the person's family, by the person's caregiver or by

any other person."[166] Where a person is determined to be eligible for direct funding, the process

for assessing the person's needs "shall provide the person with a developmental disability, *and*

any person who submitted an application…on his or her behalf, an opportunity to

participate".[167] And finally, an "application entity" (meaning any of the nine Developmental

Services Ontario agencies across Ontario) "may enter into a direct funding agreement with a

person with a developmental disability *or with another person acting on behalf of a person with*

a developmental disability".[168]

It is unclear, however, how these provisions will be applied in practice. For instance, under the Passport Program, current policy is to require people to receive their funds either directly (in which case they are responsible for hiring support workers and complying with related legal obligations) or through a service agency.[169] There is no policy recognition of the third option of having funds flow through a personal support network.

Safeguards, training & resources

Recognizing incorporated networks as eligible to receive individualized funds and act as employer does not guarantee that decisions will be made in accordance with supported decision-making principles. Indeed, the informants' comments were to the effect that some incorporated networks are primarily intended to serve administrative functions; they are not always envisioned as forums for supported decision-making. Any safeguards in this respect, such as those relating to supported decision-making principles, the roles and duties of supporters, and monitoring, would need to be separately provided for in law or government policy (an issue that is taken up below).

Adoption of the Microboard model for funding and services would also require that supports be made available. The Wetherows emphasize this point:

> Because Microboards and unincorporated circles are small and citizen-based, they need reliable access to 'underlying supports' – organized sources for development, training, technical support and practical assistance in areas such as initial formation, planning, managing resources, recruiting, screening and training staff, handling difficult human resource situations, budgeting, evaluation, accountability, representing the person's needs to government, etc.[170]

In British Columbia, Vela Microboard Association plays this role for networks choosing to make use of its services. Their services are free of charge in British Columbia.[171] Were Ontario to go the route of formally recognizing and supporting the ability of incorporated networks to receive funding and act as employer of record, there would likely need to be some public or private equivalent.

Conflicting views about the benefits and drawbacks of Microboards

Impressions of Microboards appear to be mixed. Some praise Microboards for their ability to empower individuals and their families. For instance, following a review of models for service delivery, Pedlar et al. conclude:

> Of the various approaches to support that we observed, individualized funding along with a microboard service model seemed most promising in terms of fostering empowerment-in-community and the realization of texture in people's lives. We doubt that either one of these approaches, individualized funding or the microboard, would function particularly well without the other.[172]

They argue that the Microboard model is unique in its ability to vest "control to individuals and families" while being "grounded in openness to the larger community".[173] On the other hand, several informants expressed concerns about the Microboard model and its focus on funding and services. For instance, an Ontario facilitator thought that personal support networks should not be managing staff; she said that networks often talk about issues relating to support workers (such as whether to apply for particular funded supports or whether a particular relationship is working well) but that ultimately this should be limited to 'advice', so as not to confuse the roles of personal support networks and service agencies. Similarly, an informant in British Columbia spoke of tension between service delivery and natural supports. She said that

government policy and programs continue to be dominated by a traditional 'services' mentality, and that this can undermine authentic personal network creation. She suggested that policy makers ask *why* we want to emphasize personal support networks, as Microboards could be seen to be directed to effective navigation of the service system when, in fact, personal support networks could be doing more. On the other hand, an informant from Vela explained that the organization's mandate has broadened beyond service delivery and that about 25 per cent of current Microboards have chosen *not* to act as employer, instead providing informal support and advocacy based on relationships of trust and intimacy.

There are also alternative approaches to enhancing individual autonomy and control over services. For example, in British Columbia, some people pair direct individualized funding with a representation agreement under the *RAA*.[174] (In fact, where a Microboard is receiving the funds, this is understood as *indirect* funding – that is, something akin to having an agency-for-one – rather that direct funding.) Indeed, several informants thought that Microboards were very helpful and progressive when they were first introduced in British Columbia, but that they have been overtaken by representation agreements. Yet another approach to enhancing individual choice and decision-making in services is employed in Manitoba. Manitoba Family Services offers a funding model called "In the Company of Friends" (ICOF), which allows individuals to self-direct their funding on the condition that they have a personal support network (which is not incorporated). An organization called LIFE provides assistance to those who need help creating a network. The ICOF is described as an option for those who "want to self-direct and manage their own lives each day with help from friends and family, instead of receiving residential and/or day services from an agency". People use the funding to hire their own

support staff with the help of their support network. ICOF reportedly "works to empower each person to make his/her own decisions or minimally to participate in the decision making process".[175]

In the event that Ontario were to adopt a Microboard model, it would be important for this to remain voluntary. Several informants emphasized the difficulties that families can face when trying to set up Microboards (e.g., in identifying members) and that managing funding and services is time consuming and complex. For example, one informant said she preferred to give this role to a transfer payment agency (while still having effective choice in the services provided due to an arrangement with the agency). In general, informants wanted a range of options that could be adapted to individuals' particular needs, not a prescriptive model.

Finally, this option is discussed here as a possible locus for supported decision-making relating to services. Microboards represent one unique model for decision-making supports and, where some people in Ontario are already receiving individualized funding via incorporated networks, there seem to be compelling reasons for allowing and regularizing this role. At the same time, funding and service delivery obviously raises a whole host of complicated issues beyond decision-making that are not canvassed here. While the issues of supported decision-making discussed above should arguably be taken into account, the desirability of Microboards in Ontario should likely be treated as a distinct policy question, somewhat separate from how to more comprehensively allow for supported decision-making in law.

3. Extending the corporate model to other decision-making

The idea of having an incorporated personal support network manage funds and arrange for services fits fairly easily into the traditional service agency model. (As noted above, when the Wetherows innovated the first Microboards, they asked: "what is the smallest unit of human organization that would be eligible to receive 'agency'-level funding?"[176]) Having a Microboard-type entity make and represent the full range of personal decisions is quite a different proposition. It would also be a novel approach. As such, this section is something of a thought experiment. It provides a preliminary discussion of how this sort of model might be achieved in law, and some of the questions and considerations that would have to be considered, particularly in light of the overarching concerns about protecting vulnerable persons (both vis-à-vis supporters and from legal responsibility for decisions) and providing clarity for third parties.

<u>How could this be achieved?</u>

To build on the Microboard model for other personal decision-making would require a law (i) defining the network as a legal entity; and (ii) giving it particular legal powers to represent a person's personal decisions in defined circumstances, with appropriate safeguards. Existing Microboards meet the first of these requirements by using corporations law; as discussed, they are structured as not-for-profit corporate organizations with the sole objective of supporting the focus person. An expanded Microboard approach could similarly rely on incorporation, thus building on existing experience. Another possibility would be to create a new kind of legal entity for the purpose of decision-making law. This would have the advantage of not requiring

the parsing of existing not-for-profit corporate statutes for provisions that are or aren't appropriate to the supported decision-making context. On the other hand, it would also mean starting over; law-makers would have to provide for the full range of provisions (relating to membership, duties, responsibilities and potential liability, records, meetings, filing, and many other areas) currently set out in lengthy corporate statutes. This would be a considerable undertaking, particularly given that network decision-making would likely be only one of several approaches to decision-making offered to individuals and their families.

The incorporated (or otherwise legally recognized) network would also need to be given legal powers of representation. Incorporation by itself does not achieve this. Thus, to grant incorporated entities legal status to represent an individual's personal decisions vis-à-vis third parties would require that not-for-profit corporations law be paired with a new decision-making law. This legislation would need to set out the scope of the corporation's powers and responsibilities, and provide for any safeguards (an issue that is taken up below). This might look something like a modified version of British Columbia's *RAA*, which also allowed for the appointment of a *corporate* representative and, importantly, provided for legal responsibility for decisions to lie with the incorporated network.

While Microboards provide some preliminary indications of what this might look like, the full version of this approach is entirely hypothetical. Indeed, this is not really a single "approach", as it could take a variety of forms. While this makes it impossible to precisely analyze the model, it *is* possible to set out some possible contours and considerations. What follows is a discussion of

some of the factors, advantages, and disadvantages, which would be important to assessing the

viability and desirability of an expanded corporate approach.

<u>Key considerations for evaluating the approach</u>

Protections for vulnerable decision-makers – Legal responsibility for decisions: The most

obvious potential advantage of (and indeed the primary impetus for considering) an expanded

corporate approach is that it relieves vulnerable persons of responsibility for decisions that they

might not have fully understood, placing that responsibility on the corporation. This legal

allocation of responsibility would need to be specified in statute. For instance, British

Columbia's *RAA* does not assign legal responsibility for decisions to individual representatives,

and the presence of a *corporate* legal representative would not automatically imply that it

should be assigned legal responsibility; however, it would be possible to set this out in

legislation. Although I am using the term "representative" here, there is a degree of mismatch

between this term and the idea that the network would be the legally responsible agent. In

some respects, making the network the legal agent could be seen to be placing it in the role of

substitute decision-maker (it is not merely *representing* the supported person's decision, it *is*

the decision-maker). On the other hand, the fact that the focus person is member of the

network, and that the network would be following supported decision-making principles, make

this different from substitute decision-making also. Indeed, this kind of approach might require

new terminology.

It is difficult to know how this would play out in practice. None of the informants had

experienced, or even heard of, a situation in which liability for network decisions became an

issue. One can imagine situations – particularly where money is at stake, for instance, because

of breakdown of an employment relationship – in which having a corporate network as the

legal decision-maker might be advantageous for the supported person. Although the funds

available to incorporated networks are generally those available to the focus individual in any

event (for instance, individualized government funding), the network could collectively manage

the situation, and can also hold liability insurance. Moreover, having a group of people formally

engaged in decision-making might itself provide a measure of protection by ensuring a level of

reasoning and consideration before legally weighty decisions are entered into.

On the other hand, the advantages of the corporate approach are less apparent when we move

away from the employer role to more personal areas of decision-making such as medical care.

For instance, what would it mean, from the perspective of a supported person, for medical

decision-making to be legally placed with a corporation? Perhaps this might be significant if the

medical care somehow gave rise to a legal action against the supported person (or, against the

corporate decision-maker). But this is very much in the realm of speculation. Although people

very clearly benefit from supports in medical decision-making, and many informants said they

would like for Ontario to have something akin to representation agreements, it is not obvious

that anything would be gained – that is, that supported persons would be better protected –

from legally vesting medical decision-making responsibility in a corporation.

Protections for vulnerable decision-makers vis-à-vis supporters: Neither not-for-profit

corporations law, nor an individual corporation's contracts or corporate documents, can

provide adequate decision-making safeguards for vulnerable persons. Indeed, as Microboards

and other corporate networks currently operate, the safeguards relating to things such as use

of funds and decision-making processes, to the extent that they exist at all, are set out in

private corporate documents (e.g., the corporate objects) or in contract. However, the use of

only private and/or voluntary instruments means that there is no consistency across boards,

and in some cases, little or no monitoring or accountability to ensure that the objects of

supported decision-making are being met.

Any legislated system of supported decision-making would need to include adequate

safeguards. As Kohn et al. observe:

> One of the primary worries, even for those advocating supported decision-making, is the
> potential for coercion or other inappropriate influence by a representative or supporter.
> Exploitation and abuse certainly occur in guardianship context (although it is unclear how
> frequently), and supported decision-making arrangements create new opportunities for
> abuse. Indeed, when we turn to more informal arrangements such as supported decision-
> making, which may occur in private and with less accountability, the potential for financial or
> other abuse likely increases.[177]

Others have discussed possible standards and procedures for protecting supported persons

relating, for example, to: who can be a supporter; supporters' roles and the decision-making

principles to be applied; what is required of the supported person (e.g., capacity thresholds);

monitoring; and dispute resolution, among other things.[178] A discussion of these kinds of

proposals is outside the scope of this paper. However, whatever the appropriate standards and

safeguards, they would need to be spelled out in the statute granting legal powers of

representation to the corporation; the private law of corporations and contract law are

insufficient to the task. It would also need to clearly identify and resolve any conflicts between

the decision-making statute and corporations law, for instance, in the articulation of members'

duties of care.

Clarity for third parties: The LCO refers to this issue in its Discussion Paper:

> Concerns have been raised that supported decision-making, relying as it does on multiple
> persons, provides insufficient clarity for third parties, who must be able to easily pinpoint
> those persons who are authorized to enter into legally binding transactions.[179]

One of the possible advantages of incorporation is that there is a clearly identifiable legal entity

that is responsible for legal transactions. Indeed, several informants discussed informal

arrangements in which a support circle provided decision-making support, and a family

member accompanied the focus person in third party transactions as an "informal guardian".

These kinds of arrangements could indeed create ambiguity for third parties. Informants were

also sometimes unsure about exactly *who,* in a network decision-making context, is legally

responsible for decisions.

On the other hand, a network need not be incorporated to provide greater clarity. The

ambiguity arises because families in Ontario are creating informal supported decision-making

mechanisms without any legal context for doing so. This could be remedied by *any* law

providing legal status to decision-making supporters. Would a law granting representative

status *to a corporation* provide greater protections to third parties than a law granting this

status *to private individuals*? Not necessarily. Indeed, arguably it might sometimes provide *less*

clarity, given that it would insert another layer of representation. In the event that, say, a

medical decision was required, a physician would need to consult with a director with the legal

power to represent the corporation, which would in turn have legal powers to represent the individual.

For decisions for which there are financial consequences (such as personal banking), it might be argued that third parties have more financial protection where there is a corporation in play. On the other hand (unless the situation was one giving rise to personal director liability) third party protection in these circumstances is only as good as the funds available to the corporation, and in the case of Microboards, these funds are usually those earmarked for the individual in any event. In other words, the corporation's pockets might not be any deeper than those of the individual. (Although valid and applicable liability insurance might change this.)

In the end, it might be that from the perspective of third parties the choice between corporate representation and personal representation is relatively neutral. Indeed, a lawyer practicing in the area opined that third parties likely care little about what *kind* of legislation is passed, as long as it clearly specifies the lines of authority, so that they can limit their liability.

The safety of a group: A possible advantage of building on the incorporated model is that it takes seriously the notion of group support. Several informants talked about the safety inherent in of having more than one supporter. In the words of one informant, "the whole point is that there's more than one person". Another talked about the value of having people watch and balance each other, thus forming an informal system of checks and balances. Incorporation is not necessary to ensure the presence of a group. For example, several informants discussed the common practice of British Columbians appointing more than one representative under the *RAA,* sometimes specifying the ways in which representatives must cooperate or coordinate

tasks. On the other hand, giving the network separate legal status means that the network can outlive its individual members. This might have both symbolic advantages (the network is more than the sum of its parts) as well as practical ones, when it comes to tasks such as succession planning. Indeed, the creators of Ontario's first Aroha entity were motivated to incorporate by precisely these kinds of concerns about long-term planning and security.[180]

Complexity: A common sentiment among informants was that systems of support, and supported decision-making, should be kept as simple as possible. People discussed the multiple layers of bureaucracy that must already be managed in accessing disability supports, and emphasized the importance of not imposing unnecessary additional burdens on individuals and their families. In light of this, the work and formality of incorporation and corporate maintenance are a potential drawback. Families will often need to hire a lawyer, and will be faced with substantial work relating to meetings, bookkeeping, and government filings, among other issues. For already over-burdened families, this might act as a deterrent.

Formality vs. flexibility: A significant theme in the interviews was the need for flexibility. Again and again, informants emphasized that different people need different supports. They said not everyone is comfortable in a network or 'circle' environment, that those who are may require different kinds of networks and network practices, and that a person's needs can change over time. Many informants also talked about flexibility from the standpoint of supporters. They said that many parents are reluctant to help their son or daughter create a personal support network because they require significant time and energy, and can present a range of obstacles requiring flexibility and constant change. As one person put it, networks have a 'life' of their

own; without constant attention to shifting needs, they can become fossilized or die.

Informants also said that non-family network members have varying levels of time and energy to offer, and that requiring too much at the start is a disincentive to involvement.

In light of this need for flexibility, many informants were concerned about the possible effects of placing personal support networks within a legal framework. They emphasized that the law should neither require people to have networks (as this would, in any event, result in people having networks only 'on paper'), nor require personal support networks to take a particular form (for instance in the number of members or meetings). Many viewed incorporation as a threat to flexibility and to the dynamic process of strengthening 'natural' supports.

Concerns that legal roles will undermine natural relationships: A related issue is the possible tension between formality and natural relationships. Several informants talked about the challenges of keeping even informal groups of family and friends consistently involved. They said that people should be encouraged to contribute whatever they are willing and able to give, suggesting that a legal requirement to actively participate on a regular basis with legal duties attaching, might place the 'bar' too high, deterring less formal involvement.

People also worried that the formal tasks undertaken by incorporated networks might divert attention from relationships. For instance, an informant in British Columbia worried that the process of applying for and accounting for funds might make Microboards overly service-focused. Another informant was concerned that some people are interested in the Aroha model because they see it as a means to obtain legal powers, forgetting that the substantive core must be built around caring relationships. A lawyer in Ontario said that he often

encourages those interested in incorporating networks to consider their motivations, and to start by building a strong circle of support. In general, participants emphasized that whatever its legal structure, a deliberate and sustained focus on relationships is required to keep the network meaningful and alive.

Symbolism: Finally, some of the potential advantages and disadvantages of incorporation are rooted in symbolism. On the negative side of the ledger, people sometimes viewed corporations as cold, business-like entities that are likely to be 'legalistic', 'contractual', and 'mechanical', rather than conducive to caring and supportive relationships. On the other hand, these concerns must be viewed in context. While they might sometimes be born out, they may also stem from the *idea* of pairing a corporate structure with such a deeply personal role. In practice, there are indications that at least some people experience Microboards and Aroha entities as providing a meaningful circle of caring relationships.

A second set of concerns around symbolism relates to the 'social face' that might be presented by an incorporated network making personal decisions for another. An expanded corporate model as described in this section would go two steps further than, say, representation agreements in British Columbia, by (i) assigning not only representation power but also legal responsibility to another; and (ii) doing so to a corporation. There is symbolism in both of these steps. While giving up legal responsibility for decisions of course provides a measure of protection, it also arguably lessens the person's social agency vis-à-vis third parties. Even more, making a *corporation* responsible for decisions paints a potentially uncomfortable picture in which a corporation is legally making and representing deeply personal decisions relating to,

say, medical care. If, as some scholars have suggested, supported decision-making is "an opportunity to reimagine the disabled legal subject", we might wonder what sort of legal subject personal decision-making by corporation creates.[181] On the other hand, this might be partially remedied by employing different language. For instance, British Columbia's use of the term "society" for not-for-profit corporations might elicit fewer symbolism-based objections (though those who object in principle to the removal of legal agency would continue to be opposed to the model).

Some of the symbolism involved in an expanded Microboard approach might also be positive. By giving the network legal status, it takes seriously the idea that there is something different about, and valuable in, collective decision-making as distinct from one-on-one supports. Moreover, by making the supported person a director – a part of the legal decision-making entity – it gives distinct legal status to the intersubjective process of decision-making between the individual and the group. On the other hand, it is unclear whether networks are being experienced in this way. It was apparent from the informant interviews that many people do not think of incorporation as a tool to share responsibility; rather, the corporate structure is sought out as a means of achieving practical legal ends. As one informant emphasized, people will work with whatever model will help them to function in the community.

IX.   OVERVIEW AND DISCUSSION OF THE LEGAL OPTIONS

The evidence from the informant interviews suggests that personal support networks can be a powerful context in which to provide supported decision-making. Although not every network engages in supported decision-making, some clearly do; indeed, some of the networks

described by informants were based on incredibly thoughtful articulation of the principles of respect and support needed to enhance the focus person's autonomy and agency. Moreover, there is an apparent power to the group approach. Again and again, informants talked about something *different,* something that is *added,* by having a group of caring individuals who could bring a range of perspectives, check each other's biases and assumptions, and fill in for each other's inevitable absences. Many spoke of the group approach as providing safety.

Arguably, there is something in this approach that we ought to take seriously. The question is what it would mean to do so. One option is to provide background supports for networks – for instance, through programs and organizations that help people bring together networks of care – and to recognize these supports in particular cases through existing law. Thus, the law could expressly recognize decision-making supports (including those provided by personal support networks) as legally required accommodation where the person relies on these supports to reach traditional legal capacity thresholds. Courts could also consider, on a case-by-case basis, the possibility of a personal support network arrangement providing a less restrictive alternative to guardianship under ss. 22(3) and 55(2) of the *SDA*. Another option would be to move beyond current instruments and create a supported decision-making regime that recognizes *individual* relationships of support and representation (as does British Columbia's *RAA*). While this approach would not give particular status to networks, it would allow people to draw on their personal support networks and/or to create new ones by naming several representatives and requiring them to collaborate.

These options on their own, however, fall short when measured against the objectives of providing persons with meaningful participation in personal decision-making without any capacity requirement (thus providing an alternative to guardianship), while ensuring both adequate protection for vulnerable persons and clarity for third parties. Human rights accommodation and the alternative course of action provisions are unlikely to satisfy those wanting true alternatives to guardianship, as they don't solve the third-party problem; in the absence of a law giving legal status to supporters, parents will continue to act as 'informal' guardians, with uneven access to services, and third parties will face uncertainty about who is the legally responsible party. A new decision-making law giving status to individual supporters would solve the third party issue; but it would make supported persons legally responsible for decisions that they might not have fully understood, thus failing to address one of the difficulties raised by critics of supported decision-making.

So far, these options give personal support networks indirect support, without formalizing them in law. That is, where they are recognized (for instance as valid accommodation), it is because they are *in effect* providing necessary supports; neither the network, nor the 'network approach' to decision-making is given separate legal recognition or status. A second, and more radical, kind of approach would take the group form seriously, expressly recognizing 'network' supported decision-making through the tool of incorporation.

The fullest version of this approach would pair the tool of incorporation with a supported decision-making law. Together, these would make the network a legal person that is legally responsible for the decisions entered into by the corporation, thus addressing both the

difficulty of making vulnerable persons legally responsible for complex decisions that they might not have fully understood, and the need for clarity for third parties. The new decision-making law would also need to set out standards and safeguards for supported decision-making. Although individual networks might set out safeguards such as principles for decision-making in their corporate documents and contracts with third parties, these are private instruments that are both ill-suited to reproducing all of the subtleties of a supported decision-making legal regime, and unable provide the necessary protection. (For instance, there would be no consistency across networks, and no oversight.)

While this option offers potential advantages with respect to protecting vulnerable decision-makers from legal responsibility, and clarity for third parties, these advantages are not unambiguous. For instance, it is not clear how much these apparent benefits would accrue in practice. With respect to third parties, quite simply, they may not care *who* is the legal person responsible for decisions, as long as they can clearly identify the party that is legally authorized to make a decision, thereby limiting their liability. And, inserting a corporate person into the process could potentially create greater complexity in that a third party would need confirmation of two legal relationships – (i) between a director representing a particular decision and the corporation, and (ii) between the corporation and the supported individual. Vesting the legal responsibility for decisions in a corporation, on the other hand, might bring with it both advantages and disadvantages. For some decisions – for instance, those relating to funding and the hiring of service workers – it might indeed provide useful protection. Informants indicated that in many cases parents are, in any event, acting as *de facto* decision-makers even though the legal responsibility lies with their son or daughter, and it might make

sense to better align actual decision-making with legal responsibility. This could be achieved

through a Microboard approach such as the one used in British Columbia. On the other hand, it

is harder to see the benefits of removing legal responsibility for other kinds of personal

decisions, such as those relating to medical care. (And, if there are concerns about personal risk

taking in other areas, such as personal finance, there are other tools available such as trusts.)

Other factors discussed above, which are relevant to fully assessing an expanded incorporated

network approach, include: the safety in group approaches to support; the complexity of

incorporation; issues of formality versus flexibility; concerns that legalizing networks could

undermine natural relationships; and symbolism. For instance, there is a tension between the

formal structure of a corporation and the kind of flexibility and fluidity that many described as

essential to an effective personal support network. Although many informants were keen for

networks to receive greater recognition and support in law, they were also cautious,

recognizing that formalizing a particular legal structure could have the effect of dampening

creativity and entrenching forms and practices unhelpful to the real and changing 'life' of a

network. There are also potential risks in placing legal responsibility for personal decisions in a

corporation – namely, that the social 'face' of the person is a corporate entity.

This initial examination of personal support networks is not intended to be the basis for firm

policy recommendations. Rather, it aims to provide some preliminary data about how personal

support networks are working in practice, and to provide a road map for thinking about the

options for recognizing networks, and the decision-making supports that they provide, in law. It

assesses each of these options for their ability to address core concerns about protecting

vulnerable decision-makers and providing clarity for third parties, focusing in particular on whether the most novel of the options – granting legal powers of representation to incorporated networks – contributes anything on this front. With respect to this final option it also sets out (i) how this could look in law, and (ii) the key factors that would need to be taken into account were it to be taken forward. It concludes that while the approach appears to hold promise, particularly for its ability to relieve vulnerable decision-makers of full legal responsibility, and to match that responsibility to the actual (group) locus of decision-making, further research would be required to more fully assess the possible contours and implications of the approach in light of the factors identified above. Indeed, future projects might build on this work, and could include: (i) empirical research that more comprehensively examines Vela Microboards in British Columbia to determine, for example, whether they are engaged in supported decision-making beyond service delivery, the extent to which incorporation is perceived as beneficial or burdensome, and whether any liability issues have ever arisen; (ii) research into the perspectives of government third parties, for instance, the experience in British Columbia of working with individuals with Microboards, on the one hand, and those with Representation Agreements, on the other; (iii) a canvassing of stakeholders representing other communities typically described as "vulnerable", such as some older adults and persons with mental health concerns, to determine whether network approaches to decision-making are perceived as valuable beyond the developmental disabilities community; and (iv) theoretical research further assessing the compatibility of an approach that removes legal agency with theories of supported decision-making.

X.   CONCLUSION

There are apparently rich opportunities for supported decision-making within personal support networks. The question, however, is whether these should be formalized in law. Kohn *et al.* have opined that "it is simply too early to conclude that supported decision-making is an effective decision-making model, much less that supported decision-models should be institutionalized by state actors".[182] Consistent with these comments, it is likely too early to legally entrench 'network' forms of decision-making using a corporate model; it is not yet clear that networks should be given separate legal status to represent personal decisions. However, initial indications are that the approach, while not without difficulties, has the potential to address some of the concerns raised by critics of supported decision-making, therefore warranting further study in light of the factors discussed.

Finally, a call to further research does not preclude interim measures. Personal support networks could also be recognized *now,* through legal options that rely on existing laws and concepts, paired with government policy and programs geared to helping people create and maintain robust personal support networks. The evidence from the informant interviews suggests that networks can provide meaningful informal supports as well as a community of individuals who might step into the myriad legal roles that will exist in any legal regime. Supporting informal network building could therefore be a sound component of any legal approach, which might help provide security for persons with disabilities and their families.

APPENDIX A

Conversation Guide

Introduction

The Law Commission of Ontario is considering the potential of supported decision-making models, in the context of its broader investigation of Ontario's capacity, guardianship and decision-making laws.

In the context of this broader work, they have asked me to examine one particular kind of decision-making support – <u>Personal Support Networks</u>.

By "personal support networks" I mean both formal entities like "Microboards" and "Aroha entities", and less formal networks and "support circles".

I am trying to determine:

(i)   How these networks are operating, especially in B.C. and Ontario (although I'm open to information about other jurisdictions as well); and

(ii)   Whether they are a form of supported decision-making, and if so, whether we can learn anything from them in considering possible law reform.

Process

- I'm not recording
- I will take notes, which I may use in the context of a report for the LCO.
- I will not use direct quotes unless I have your express permission
- I will not attribute any comments to anyone. I may say things like, "a lawyer said…" and then paraphrase.
- The Law Commission will have the names of the people to whom I spoke, but these names will not be in any report. The report may include a list of the professions/ groups of people I spoke to – e.g., "a lawyer practicing in the field" or "a parent advocate".
- Any questions or concerns?

Questions

[Modified / selected from as appropriate]

1.   In what role(s) have you developed knowledge of, or experience with, personal support networks?

2. What (or what kind) of personal support networks do you know about?

3. How is the network formed? For example:

    a. How are members chosen? What is the procedure for joining or leaving the network?

    b. What is the role of the supported person in creating the network? Must he or she authorize its formation? Choice of members?

    c. Is it necessary for the supported person to have some level of decision-making capacity? If so, capacity defined how?

    d. What is the structure of the network? Is it legal in nature (e.g., incorporated)?

    e. Are there any written documents – e.g., bylaws, supported decision-making agreements, other – that are used to create the network or guide its work?

4. What kinds of decisions are made and how are they made? For example:

    a. What kinds of decisions are made within the network?

    b. What is the role of the supported person? (Does the network make decisions *for* the person, or *assist* the person to make his or her own decisions?)

    c. Must the network follow the wishes of the supported person?

    d. Must the supported person have capacity in relation to decisions made? If so, defined how?

    e. What does the network do when a decision is required and the network either cannot discern the person's intentions, or does not have direction as to how to carry out those intentions?

    f. How are disagreements managed? Instances where the network doesn't agree with the supported person? Where members don't agree with each other?

    g. Are the principles for making decisions set out in writing (e.g., in a supported decision-making agreement)?

    h. Where does the network look to for support and guidance (e.g. laws, policies, guidelines, community organizations, facilitator, etc.)?

5. Who is responsible for the decisions made in the network? For example:

    a. Who is held out as the decision-maker, especially if the network is dealing with third parties?

    b. Who implements decisions?

    c. Who is potentially liable? Does the network carry liability insurance?

    d. What is the relationship between the network and the supported person? Fiduciary?

6. What relationships, if any, does the network have with government? For example:

    a. Does it receive funding directly from government and act as the employer of record?

    b. Any other relationship to government?

    c. What does the government require in order to recognize the network (e.g., must it be incorporated and/or meet other requirements)?

    d. Are there any documents that govern this relationship (e.g., laws, policies relating to receipt of funding, other)?

7. What relationships, if any, does the network have with other third parties? For example:

    a. Do network decisions sometimes involve third parties (e.g., support workers, banks, health care providers)?

    b. What is the legal relationship between the network and these third parties? E.g., who is responsible to third parties for the decisions made? Who is liable if something goes wrong?

    c. What do third parties require in order to recognize the network (if they do)?

    d. How well are these relationships working? Are there challenges? Things that are working well?

    e. Are there any documents (e.g., laws, policies) that govern or guide these relationships?

8. Who is using personal support networks? For example:

   a. Do you have any information about how many people are using personal support networks?

   b. Do you have any information about who is using them?

9. Do you think personal support networks should be recognized / receive more recognition in law? How?

10. Do you have any other comments that you would like to share, e.g., about the limitations and/or potential of personal support networks in decision making? Anything else?

11. Is there anyone else you think I should speak to?

ENDNOTES

[1] Law Commission of Ontario, "Legal Capacity, Decision-making and Guardianship, Project Overview", online: http://lco-cdo.org/en/capacity-guardianship (last accessed 22 November, 2014).

[2] *Health Care Consent Act, 1996*, S.O. 1996, Ch. 2, Sched. A [*HCCA*].

[3] *Substitute Decisions Act, 1992*, S.O. 1992, Ch. 30 [*SDA*].

[4] *Mental Health Act,* R.S.O. 1990, CHAPTER M.7 [*MHA*].

[5] Law Commission of Ontario, *A Framework for the Law as it Affects Persons with Disabilities: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (Toronto: Sept. 2012), online: http://www.lco-cdo.org/persons-disabilities-final-report.pdf (last accessed 22 November, 2014); Law Commission of Ontario, *A Framework for the Law as It Affects Older Adults: Advancing Substantive Equality for Older Persons through Law, Policy and Practice* (Toronto: April 2012), online: http://www.lco-cdo.org/older-adults-final-report-framework.pdf (last accessed 22 November, 2014).

[6] *Convention on the Rights of Persons with Disabilities*, 13 December 2006, 2515 UNTS 3, GA Res 61/106 (entered into force 3 May 2008, ratified by Canada 11 March 2010), art. 12 [*CRPD*].

[7] Law Commission of Ontario, *Legal Capacity, Decision-Making and Guardianship: A Discussion Paper* (Toronto: May 2014), online: http://lco-cdo.org/capacity-guardianship-discussion-paper.pdf (last accessed 15 December, 2014) [LCO, *Discussion Paper*].

[8] Nina A. Kohn, Jeremy A. Blumenthal & Amy T. Campbell, "Supported Decision- Making: A Viable Alternative to Guardianship?" (2013) 117:4 Penn St. L. Rev. 1111 at 1114.

[9] Internal memorandum from the LCO to Sophie Nunnelley (September 9, 2014).

[10] Andrew's Bridges, online: http://andrewsbridges.blogspot.ca/p/aroha.html (last accessed: 19 November, 2014).

[11] E.g., the lack of evidence in this regard is discussed in Kohn et al., note 8 at 1129, 1155.

[12] See for e.g., George S. Gotto et al., *Accessing Social Capital Implications for Persons with Disabilities: A White Paper* (Kansas City: A National Gateway to Self-Determination Project, 2010), online: http://www.aucd.org/docs/Accessing%20Social%20Capital%20Implications%20for%20Persons%20With%20Disabilities,%20Final.pdf (last accessed: 27 November, 2014); Ministry of Social Development and Social Innovation, *Services to Adults with Developmental Disabilities (STADD): Support Networks – A Discussion Paper* (British Columbia, 2013), online: http://www2.gov.bc.ca/assets/gov/topic/D53478E6C207D4FEEE8B245A3994CA26/support_networks_framework/support_networks_framework.pdf (last accessed: 27 November, 2014).

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[14] Texas Microboard Collaboration, online: http://www.thearcoftexas.org/site/PageServer?pagename=partners_microboard (last accessed: 26 November, 2014).

[15] Information from an informant interview.

[16] Alison Pedlar, *A Textured Life: Empowerment and Adults with Developmental Disabilities* (Waterloo, Ont: Wilfrid Laurier University Press, 1999) at 126.

[17] Elizabeth Bloomfield & Gerald Bloomfield, *Creating a Home and Good Life of my Own: Formal Agreements Developed by Guelph Services for the Autistic in its role as a Housing Trust* (Guelph Services for the Autistic, 2012) at 42-3.

[18] For e.g., materials published online by the Ontario Adult Autism Research and Support Network describes three tiers of formality – from (incorporated) Aroha entities, to the less formal personal support networks created by the PLAN organization, to still less formal "circles of friends": Ontario Adult Autism Research and Support Network, "Aroha Entities for Personal Empowerment and Support", online: http://www.ont-autism.uoguelph.ca/entities.shtml (last accessed: 26 November, 2014) [OAARSN]. See also: Vickie Cammack & Kerry Byrne, "Accelerating a Network Model of Care: Taking a Social Innovation to Scale" (2012) Jul. Tech. Innov. Mgt Rev. 26 at 28: "A personal network is a group of individuals who come together to provide intentional and purposeful support for a person(s) facing a life challenge".

[19] Circles Network, online: http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent_id=115 (last accessed: 26 November, 2014).

[20] Ministry of Community and Social Services, *Person-Directed Planning and Facilitation Guide* (Toronto, Nov. 2013) at 4 [MCSS, *Person-Directed Planning Guide*].

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[21] MCSS, *Person-Directed Planning Guide,* note 20 at 4-5. See also, British Columbia Ministry of Social Development and Social Innovation, *Services to Adults with Developmental Disabilities (STADD): Support Networks – A Discussion Paper* (July 18, 2013), online: http://www2.gov.bc.ca/assets/gov/topic/D53478E6C207D4FEEE8B245A3994CA26/ support_networks_framework/support_networks_framework.pdf (last accessed December 19, 2014).

[22] PLAN, online: http://plan.ca/ (last accessed December 19, 2014).

[23] Bloomfield, note 17 at 46.

[24] Although most informants and most of the literature surveyed emphasized the importance of the members participating on a voluntary (unpaid) basis, and also having no paid role in the supported person's life (e.g., as a service worker) one informant offered the view that it is sometimes appropriate to include the latter kind of person in personal support workers. Her view was that people in paid roles both (i) can have a great deal of insight into the supported person; and (ii) can learn from participating in the network how to better perform the service role.

[25] David Wetherow & Faye Wetherow, "Microboards and Microboard Association Design, Development and Implementation" (revised August 2004), online: http://www.communityworks.info/articles/microboard.htm (last accessed: 28 November, 2014).

[26] These two cooperatives – "Prairie Housing Cooperative" and "L'Avenir Service Cooperative" – are described in Wetherow, note 25.

[27] Wetherow, note 25.

[28] Wetherow, note 25 [emphasis in original].

[29] Wetherow, note 25.

[30] Vela, "Our Work", online: http://www.velacanada.org/about-us/our-work-our-impact (last accessed 30 November, 2014).

[31] Vela, "Our Work", note 30; Informant interview.

[32] Vela, "About Microboards", online: http://www.velacanada.org/vela-microboardsn (last accessed 30 November, 2014).

[33] Two informants spoke of one or more organizations doing this. One mentioned the work of the Thompson Okanagan Community Services Co-operative (though suggesting that this might be more of a "service model", in which the organization that assists with incorporation also provides services).

[34] OAARSN, note 18; Bloomfield, note 17 at 42.

[35] According to the network's online materials, "aroha" is a Maori word that means "the various qualities and values that are needed in a caring circle of friends. Its meanings include affection, love, charity, compassion, empathy, concern, trust, pity, understanding and true friendship – all in active ways, not just ideas or feelings": OAARSN, note 18.

[36] Bloomfield, note 17.

[37] Bloomfield, note 17, 43.

[38] Wetherow, note 25.

[39] Wetherow, note 25.

[40] In these situations, people can separately receive individualized funding and arrange services, either directly or through an agency. Vela, "Our Work", note 30.

[41] Vela, "Our Work", note 30.

[42] Vela, "Principles and Functions for Microboards", online: http://www.velacanada.org/principles-for-microboards (last accessed 5 December, 2014).

[43] Pedlar, note 16, at 127-8.

[44] ICOF, "What is In the Company of Friends (ICOF)!", online: http://www.innovativelifeoptions.ca/icof/abouticof. html (last accessed 1 December, 2014) [ICOF].

[45] See notes 92 and 93 and accompanying text.

[46] Vickie Cammack, "Forward", in Nancy Rother, *Reaching Out: A portrait of Social Network Facilitation in Canada* (Vancouver: PLAN Institute for Citizenship and Disability, undated), online: http://institute.plan.ca/wp-content/uploads/downloads/2012/11/reaching-out__29373.pdf (last accessed November 21).

[47] PLAN, "Mission, Vision and Values", online: http://plan.ca/about-plan/what-we-do/mission-vision-and-values/ (last accessed 3 December, 2014).

[48] PLAN includes in its concept of "a good life": "Relationships with people who love and care for them; the opportunity to contribute; a home to call their own; supportive decision-making; and financial security: PLAN, "PLAN for a good life", online: http://plan.ca/about-plan/what-we-do/future-planning/ (last accessed 5 January, 2015). The concept of "a good life" is further elaborated in Al Etmanski, *A Good Life* (2nd ed) (Vancouver: Planned Lifetime Advocacy Network, 2014).

[49] PLAN, "Relationships", online: http://plan.ca/about-plan/what-we-do/future-planning/relationship/ (last accessed 3 December, 2014).

[50] PLAN, "Membership", online: http://plan.ca/member/ (last accessed 5 December, 2014).

[51] PLAN, "Affiliates", online: http://plan.ca/about-plan/plan-affiliates/ (last accessed 5 December, 2014).

[52] Cammack & Byrne, note 18 at 28.

[53] Bloomfield, note 17 at 37.

[54] For instance, see: Bloomfield, note 17 at 19: "Friends are the greatest resource for a vulnerable person, building community and inclusion by sharing parts of their lives and interests, and connecting with others who can offer friendship as well as opportunities for the person to contribute their gifts."

[55] Pedlar, note 16 at 119, and more generally at 119-20, 128-9.

[56] Nabors: A Community of Circles, "Circles of Support", online: http://www.nabors.ca/?q=node/8 (last accessed 5 December, 2014).

[57] Rother, note 46 at 6.

[58] Developmental Services Ontario, "Person Directed Planning", online: http://www.dsontario.ca/person-directed-planning (last accessed 5 December, 2014).

[59] Charlotte Dingwall, Kristi Kemp & Barbara Fowke, *Creating a Good Life in Community: A Guide to Person-Directed Planning* (Toronto: Individualized Funding Coalition for Ontario, 2006) at 6.

[60] For a description of some commonly used planning tools – e.g., PATH (Planning Alternative Tomorrows with Hope) and MAPS (Making Action Plans) – see MCSS, *Person-Directed Planning Guide* note 20 at 13-4; and Rother, note 46 at 17-18.

[61] Developmental Services Ontario, *Passport Program: Guidelines for Adults with a Developmental Disability and their Caregivers* (Toronto: Government of Ontario, October 1, 2014), at 6, online: online: http://www.mcss.gov.on.ca/documents/en/mcss/publications/developmental/passport/passport_guidelines_en.pdf (last accessed 18 December, 2014) [DSO, *Passport Guidelines*].

[62] *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008,* s. 4(2) [*Social Inclusion Act*].

[63] *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008,* O.Reg. 276/10, s. 5. (This section, and s. 11(1) of the Act (which provides for direct funding agreements) will come into force on a day to be named by proclamation of the Lieutenant Governor.)

[64] MCSS, *Person-Directed Planning Guide,* note 20 at 8.

[65] MCSS, *Person-Directed Planning Guide,* note 20 at 16, 31.

[66] John Lord & Peggy Hutchinson, "Individualized funding in Ontario: Report of a provincial study" (2008) 14:2 J. Dev. Disabil. 44 at 47-8.

[67] Lord & Hutchinson, note 66 at 48.

[68] *Social Inclusion Act,* note 62, s. 4(2).

[69] MCSS, *Person-Directed Planning Guide,* note 20 at 13.

[70] MCSS, *Person-Directed Planning Guide,* note 20 at 7, 13.

[71] See also the comments of the Select Committee on Developmental Services that some aspects of the DSO's operations are "still not fully operational", and that the provisions pertaining to direct funding agreements are not yet in force: Select Committee on Developmental Services, *Final Report – Inclusion and Opportunity: A New Path for Developmental Services in Ontario* (Toronto: Legislative Assembly of Ontario, July 2014) at 6, 10, online: http://www.ontla.on.ca/committee-proceedings/committee-reports/files_pdf/SCDSFinalReportEnglish.pdf (last accessed 5 January, 2015).

[72] Rother, note 46 at 7.

[73] Although this was an inquiry into networks' actual operations, as opposed to what works well, there are many organizations and publications that provide guidance on the factors that they see as important to network creation

and maintenance. See for e.g.: Rother, note 46 (setting out seven elements that the authors perceive as necessary for "nurturing and sustaining resilient social networks" (at 51)).

[74] Andrew's Bridges, note 10.

[75] See also Bloomfield, note 17 at 48.

[76] These comments are consistent with a survey of existing research conducted by Kohn et al., note 8 at 1134-5 (in which they state: "The existing information suggests that supported decision-making is likely to occur primarily within families and thus be subject to the attendant family dynamics—dynamics which may or may not be empowering.")

[77] OAARSN, note 18.

[78] OAARSN, note 18; Bloomfield, note 17.

[79] PLAN, "How does PLAN Create Networks?" online: http://plan.ca/about-plan/what-we-do/networks/personal-network/how-does-plan-create-networks/ (last accessed 10 December, 2014).

[80] PLAN, "A Note about Friendship", online: http://plan.ca/about-plan/what-we-do/networks/personal-network/a-note-about-friendship/ (last accessed 10 December, 2014).

[81] Andrew's Bridges, note 10; informant interview.

[82] People supported by Vela may also choose alternative approaches under which the Microboard does not act as employer of record. A person can receive services through an agency, or can directly receive individualized funds and hire services with the help of an agent (who may, in turn, be assisted by a Host Agency). With these latter options, the Microboard will provide advocacy supports but will not be directly responsible for managing funding or employment. See: Vela, "Microboards and Individualized Funding", online: http://www.velacanada.org/individualized-funding (last accessed 11 December, 2014). See also Vela, "What do Members Do?", online: http://www.velacanada.org/what-do-members-do (last accessed 11 December, 2014).

[83] Permission to quote these excerpts was granted by the informant.

[84] Bloomfield, note 17 at Appendix 2.

[85] Bloomfield, note 17 at Appendix 1.

[86] Bloomfield, note 17 at Appendix 4.

[87] Permission to quote granted by the informant.

[88] Vela, "About Microboards", note 32.

[89] Vela, "Principles and Functions for Microboards", note 42.

[90] Wetherow, note 25.

[91] Vela, "About Microboards", note 32.

[92] See, e.g., the discussion in Bloomfield, note 17 at 43.

[93] Excerpt from sample Employment Agreement provided by an informant.

[94] *Representation Agreement Act,* R.S.B.C. 1996, Ch. 405 [*RAA*].

[95] *HCAA,* note 2, s. 20(1).

[96] There is also very little evidence as to how widely supported decision-making mechanisms generally are being used in Canada. See e.g., the discussion by Kohn et al., note 8 at 1130-1.

[97] Representatives from Vela have reportedly advised and/or provided information to groups in Australia, England, Northern Ireland, and plan to present information to the United Nations. See Vela, "Our Work", note 30.

[98] *Corporations Act,* R.S.O. 1990, Ch. C.38.

[99] *Not-for-Profit Corporations Act*, 2010, S.O. 2010, Ch. 15.

[100] *Society Act,* R.S.B.C. 1996, Ch. 433.

[101] British Columbia Ministry of Finance, *Societies Act White Paper*: *Draft Legislation with Annotations* (August 2014), online: http://www.fin.gov.bc.ca/pld/fcsp/pdfs/SocietyActWhitePaper.pdf (last accessed 21 November, 2014).

[102] In Ontario applications for incorporation must include a Newly Updated Automated Name Search (NUANS) search to ensure the name is available, and ensure that the name complies with s. 13(1) of the *Corporations Act,* note 98 (i.e., that name not be "the same as or similar" to another organization in a way that would be "likely to deceive"). In British Columbia, the name must be approved and reserved in accordance with s. 3(6) of the *Society Act,* note 100 (which adopts the requirements of Division 2 Part 2 of the *Business Corporations Act,* S.B.C. 2002, Ch.

57) and the instructions provided by B.C. Registry Services: http://www.bcregistryservices.gov.bc.ca/bcreg/corppg/reg46.page? (last accessed 21 November, 2014).

[103] As currently drafted the new *Not-for-profit Corporations Act* no longer requires "objects", but the "articles of incorporation" (which replace the "letters patent" under the *Business Corporations Act*) must state the organization's purpose: note 99, s. 8(1).

[104] For Ontario, see the Government's *Not-for-Profit Incorporator's Handbook,* online: http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/nfpinc/Not_for_Profit_Incorporators_Handbook_EN.pdf (last accessed 21 November, 2014). For British Columbia, see BC Registry Services: *Incorporating a Society in British Columbia*, online: http://www. bcregistryservices.gov. bc.ca/bcreg/corppg/reg20.page (last accessed 19 November, 2014.]; See also: Gerald C. Scott et al., *Society Guide for British Columbia* (Vancouver: Community Legal Assistance Society, last updated July 2012).

[105] *Corporations Act,* note 98, s. 283; *Society Act,* note 100, s. 24(3).

[106] *Society Act,* note 100, s. 3.1.

[107] Schedule B to British Columbia's *Society Act,* note 100, includes sample by-laws that can be adopted without amendment. Vela recommends that persons adopting its Microboard model follow this approach (*Process for Incorporation of a Microboard under the Non-Profit Societies Act,* unpublished document obtained from Vela).

[108] *Society Act,* s. 56; *Corporations Act,* s. 293.

[109] E.g., *Society Act,* note 100, ss. 36, 70; *Corporations Act,* note 98, ss. 299-302.

[110] For e.g., a society in British Columbia must file an annual report with the Registrar within 30 days of its annual general meeting (*Society Act,* note 100, s.68). Ontario requires that an "Initial Return" be filed with Service Ontario within 60 days of incorporation (and that a "Notice of Change" be filed anytime that information changes), and that an Annual Return – with information required by the *Corporations Information Act* – be filed with the Canada Revenue Agency. (See the *Corporations Information Act,* R.S.O. 1990, Ch. C. 39 ss. 2, 3(1), 4.)

[111] Canada Revenue Agency, *T2 Corporation – Income Tax Guide 2013*, p. 7. Online: http://www.cra-arc.gc.ca/E/pub/tg/t4012/t4012-13e.pdf (last accessed 21 November, 2014). Registered charities are an exception to this rule. However, an incorporated personal support network will not generally qualify as a registered charity given its purpose to support only one individual.

[112] Government of Canada, "Canada Business Ontario" online: http://www.cbo-eco.ca/en/index.cfm/starting/getting-started/not-for-profit-guide/#Taxation (last accessed 21 November, 2014); Canada Revenue Agency, *Income Tax Guide to the Non-Profit Organization (NPO) Information Return,* online: http://www.cra-arc.gc.ca/E/pub/tg/t4117/t4117-e.html (Last accessed 21 November, 2014).

[113] See Ontario's *Not-for-Profit Corporations Act,* note 99, s. 21: "Subject to this Act, the directors of a corporation shall manage or supervise the management of the activities and affairs of the corporation."

[114] Jane Burke-Robertson, "Primer for Directors of Not-for-Profit Corporations, ch. 2: Duties of Directors" (Ottawa: Industry Canada, 2002), online: http://www.ic.gc.ca/eic/site/cilp-pdci.nsf/eng/cl00692.html (last accessed 13 December, 2014) [Burke-Robertson, "Primer for Directors"].

[115] Burke-Robertson, "Primer for Directors", note 114 at 3-4.

[116] Jane Burke-Robertson, "20 Questions Directors of Not-for-Profit Organizations Should ask about Fiduciary Duty" (The Canadian Institute of Chartered Accountants, 2009) online: http://www.cica.ca/focus-on-practice-areas/governance-strategy-and-risk/not-for-profit-director-series/20-questions-series/item12325.pdf (last accessed 13 December, 2014) at 20 [Burke-Robertson, "20 Questions"].

[117] Burke-Robertson, "Primer for Directors", note 114 at 2; See also: Vela, "Liability: How to Manage your Risk, Director's Liability: Plain Language Information" (last updated January 2013), online: http://www.velacanada. org/principles-for-microboards (last accessed 13 December, 2014) ["Liability: How to Manage your Risk"].

[118] *Not-for-Profit Corporations Act,* note 99, s. 40(1).

[119] In Ontario, see the *Not-for-Profit Corporations Act,* note 99, s. 46(1); See also the sample Aroha Bylaw included in *Bloomfield,* note 17, Appendix 2, for an example of such a clause.

[120] E.g., Vela encourages Microboards to purchase insurance. (See Vela, "Liability: How to Manage your Risk", note 117.)

[121] Burke-Robertson, "20 Questions", note 116 at 20.

[122] Developmental Services Ontario has published a booklet with guidance on hiring support workers: DSO, "Hiring a Support Worker: A Guide for Ontarians with a Developmental Disability" (Ontario: Government of Ontario, 2013), online: Ontario.ca/bxh1 (last accessed 13 December, 2014).

[123] LCO, *Discussion Paper*, note 7 at 122.

[124] LCO, *Discussion Paper*, note 7 at 122

[125] LCO, *Discussion Paper*, note 7 at 122; Leslie Salzman, "Guardianship for persons with mental illness: A legal and appropriate alternative?" (2011) 4 St. Louis U. J. Health L. & Pol'y 279 at 307. On the other hand, a report from the Office of the Public Advocate in Victoria, Australia, expressly contemplates the implications for personal support network approaches to supported decision-making for responsibility: Barbara Carter, "Supported Decision-Making: Background and Discussion Paper" (Melbourne, Victoria: Office of the Public Advocate, November 2009) at 20 [Office of the Public Advocate, Victoria]: "Responsibility for decisions made may lie with the person with a disability or with the group, depending on the areas of decision and the arrangements agreed to".

[126] LCO *Discussion Paper*, note 7, at 123; see also: Coalition on Alternatives to Guardianship, "The Right to Legal Capacity and Supported Decision Making for All: A Brief to the Law Commission of Ontario" (Toronto: October, 2014), at 2, 22.

[127] Kohn et al., note 8 at 1120.

[128] Michael Bach & Lana Kerzner, "A New Paradigm for Protecting Autonomy and the Right to Legal Capacity" (Prepared for the Law Commission of Ontario, October 2010); Coalition on Alternatives to Guardianship, note 126 at 15, 22.

[129] Bach & Kerzner, note 128; Coalition on Alternatives to Guardianship, note 126 at 4.

[130] Coalition on Alternatives to Guardianship, note 126 at 22.

[131] Kohn et al., note 8, at 1120.

[132] See the discussion in LCO, *Discussion Paper*, note 7 at 123 (discussing but neither adopting nor rejecting this element).

[133] Salzman, note 125 at 306.

[134] Office of the Public Advocate, Victoria, note 125 at 20.

[135] Office of the Public Advocate, Victoria, note 125 at 20.

[136] Kohn et al., note 8 at 1123.

[137] Kohn et al., note 8 at 1157.

[138] See Section IV C, "Person Directed Planning and Facilitation".

[139] Bach & Kerzner, note 128 at 79-80.

[140] Bach & Kerzner, note 128 at 80.

[141] For example, Pedlar has discussed Microboards in terms of their potential for enhancing empowerment and control for supported persons. Pedlar, note 16 at 122.

[142] Kohn et al., note 8 at 1123.

[143] Bach & Kerzner, note 128; Coalition on Alternatives to Guardianship, note 126 at 4, 15, 22.

[144] Gerald Scott, revised by David Mossop, Karen Mountifield, James Pozer, Renee Matthews, "Society Guide for British Columbia" (Community Legal Assistance Society, last revised July 2012), online: http://d3n8a8pro7vhmx.cloudfront.net/clastest/pages/79/attachments/original/1401252010/Revised_Society_Guide_%282012%29.pdf?1401252010 (last accessed 17 December, 2014).

[145] *Human Rights Code,* R.S.O. 1990, Ch. H.19, ss. 1-9.

[146] *Human Rights Code,* note 145, ss. 9, 11; see also: Human Rights Commission, "Policy and guidelines on disability and the duty to accommodate", online: http://www.ohrc.on.ca/en/policy-and-guidelines-disability-and-duty-accommodate/3-prima-facie-discrimination-because-disability (last accessed 17 December, 2014) [HRC "The duty to Accommodate"].

[147] *Human Rights Code,* note 145, s. 11; HRC, "The Duty to Accommodate", note 146.

[148] *Human Rights Code,* note 145, s. 17(1).

[149] *Human Rights Code,* note 145, s. 17(2).

[150] The LCO discusses this point in its *Discussion Paper*, note 7, at 40; Bach and Kerzner are two Ontario scholars who make this kind of accommodation argument: Bach & Kerzner, note 128.

[151] LCO, *Discussion Paper*, note 7 at 40.

[152] Ontario Human Rights Commission, *Minds that Matter: Report on the Consultation on Human Rights, Mental Health and Addictions* (Toronto: 2012), 92.

[153] HRC "The Duty to Accommodate", note 146.

[154] To clarify, the duty to accommodate is not specific to a particular program or policy option – rather, it is a continuous obligation on those offering services, employment and the other areas listed in ss. 1-9 of the Code. And, some people have made stronger arguments than the one described in this section, to the effect that the duty to accommodate requires a system of supported decision making for persons who cannot meet the "understanding and appreciation" test (or Bach and Kerzner's "legally independent" group). Where this kind of argument to be accepted, however, it would require the implementation of new decision-making laws (such as those recommended by the Coalition on Alternatives to Guardianship, note 126). The purpose of this section is to describe more modest policy opportunities for recognizing personal support networks, which would not require an overhaul of the law. Opportunities for deeper reforms are described in the sections below.

[155] *SDA*, note 3, ss. 22(3), 55(2).

[156] *Gray v. Ontario,* [2006] O.J. No. 266; 264 D.L.R. (4th) 717 (Ont. Div. Ct.), para. 47 [*Gray*].

[157] *Gray,* note 156 at para. 47.

[158] Coalition on Alternatives to Guardianship, note 126 at 4.

[159] Coalition on Alternatives to Guardianship, note 126 at 8-9.

[160] *Gray,* note 156 at para. 47.

[161] Kohn et al., note 8 at 1154-5.

[162] Coalition on Alternatives to Guardianship, note 126 at 18.

[163] LCO, *Discussion Paper,* note 7 at 125.

[164] Office of the Public Advocate, Victoria, note 125 at 24.

[165] Ministry of Community and Social Services, "Legislation", online: http://www.mcss.gov.on.ca/en/mcss/programs/developmental/improving/legislation.aspx (last accessed 18 December, 2014).

[166] *Social Inclusion Act,* note 62, s. 13(2).

[167] *Social Inclusion Act,* note 62, ss. 17(1)(2).

[168] *Social Inclusion Act,* note 62, s. 11(2) (italics added).

[169] DSO, *Passport Guidelines*, note 61.

[170] Wetherow, note 25.

[171] Vela, "How we can help you", online: http://www.velacanada.org/ (last accessed 19 December, 2014).

[172] Pedlar et al., note 16 at 124.

[173] Pedlar et al. note 16 at 127.

[174] Those who request more than $6,000 in direct funding are in fact required to appoint a representative (or "agent" for purposes of the funding) under the RAA. See: Community Living BC, "Individualized Funding Policy" (June, 2009), online: http://www.communitylivingbc.ca/wp-content/uploads/Individualized-Funding-Policy.pdf (last accessed 18 December, 2014). Two informants also talked about the BC Ministry of Health's Supports for Independent Living (CSIL) program. This program provides self-directed funding to eligible adults with physical disabilities wishing to hire their own home care supports. The program allows those needing assistance managing the funds to either create a society (effectively, a Microboard) or appoint a representative under the *RAA*. Both informants thought that the *RAA* provides the better route. One informant thought that more people in the CSIL program are in fact choosing this latter route. (The other did not comment on rates of usage.)

[175] ICOF, note 44.

[176] Wetherow, note 25.

[177] Kohn et al., note 8 at 1137.

[178] See e.g., The Coalition on Alternatives to Guardianship, note 126; Bach & Kerzner, note 128.

[179] LCO, *Discussion Paper,* note 7 at 133.

[180] Andrew's Bridges, note 10.

[181] Terry Carney, "Participation and Services Access Rights for People with Intellectual Disability: A Role for Law?" (2013) 38 J. Intell. & Devel. Disabil. 59, 62; Kohn et al., note 8 at 1127.

[182] Kohn et al., note 8 at 1155.