Together to Work

A Guide to Developing an Employment-Focused Family-Governed Group

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Using this Guide

This guide may be reproduced in whole, or in part for any non-commercial purpose related to providing information about services to people with disabilities.

Using the "InclusionWorks!" Name

We encourage individuals and families in similar circumstances to adopt the *Inclusion-Works!* model of collective family governance which focuses on community inclusion through the transition years from high school through young adulthood. If you wish to use the *InclusionWorks!* name for your family-governed group, it is necessary to seek permission to do so by contacting *InclusionWorks!* www.inclusionworks.ca.
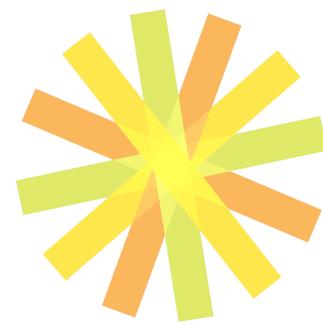
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Acknowledgements

An Introduction to this Guide

This guidebook focuses on the *InclusionWorks!* model of collective family governance and efforts by several groups of families in Victoria, British Columbia to support employment for their transitioning youth. Collective family governance, commonly called family governance, is a model of support in which individuals with disabilities, with the support of their family members, pool their resources (knowledge, networks, skills, funding, etc.) to provide services to a small group of individuals. This guidebook is the result of six years of learning about collective family governance and three years of piloting the delivery of employment services in partnership with the *Employment Program of BC* (*EPBC*—also referred to as *WorkBC*), with the support of a grant from *The Vancouver Foundation*.

This guide is designed primarily for families who are considering pooling their resources and who are interested in employment as a key goal for their family-governed group. It will be of use to others—people with disabilities considering developing user-led groups, service providers that are providing Host Agency services, micro-boards (person-centered nonprofit societies) looking at sharing resources, and policymakers concerned with innovation, user-led design, employment outcomes, and quality of services. Though set in the context of BC and the BC government's employment program and service delivery system for individuals with developmental disabilities, this guide may be of use in other provinces and jurisdictions where similar opportunities exist. It is our hope that readers learn from our experiences and are better able to develop self-determined supports for themselves and others, wherever they are.

Throughout this guide we use the term "family" to refer to the widest possible definition of family—people who self-identify as family. Most importantly, the word family puts the individual with a disability who ultimately must define and control his or her own life at the centre of the family. Where there is a need to distinguish "family members", we have typically used the term "parent", knowing that this term is also problematic. At times, siblings, grandparents, aunts and uncles, HomeShare providers, or others may act as the primary supporters of a person with a disability in a family. Our wish is that our wording is both inclusive and clear within the limitations of the English language. We acknowledge that more work is required to make our text more accessible. A Plain Language Summary of this Guide is available at www.inclusionworks.ca.

Throughout this guide, we make reference to a number of documents. In order to assist families in creating their own family-governed groups, we have included sample documents on our website at www.inclusionworks.ca.

The content of this guide is as accurate and applicable to other parts of BC as possible, recognizing that government, organizations, policies, and procedures frequently change and, that each community is different. We strongly recommend verifying the accuracy and applicability of the information provided in this guide directly with local sources.

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Section One—
The InclusionWorks! Model

Our Underlying Philosophy

InclusionWorks! is an innovative person-centred model of collective family governance providing support for youth living with the label of developmental disability during the transition years from ages 19 to 25. *InclusionWorks!* is facilitated by the availability of Individualized Funding (IF) through *Community Living BC* (*CLBC*). IF attaches dollars for services to individuals, allowing them greater choice and control in how to live their lives. IF is contrasted with the majority of *CLBC*'s service funding which, as of 2016, is attached to agencies and programs (referred to as global funding), not to specific individuals.

InclusionWorks! originated in Victoria, BC in 2010 when a small number of youth leaving secondary school and their families decided to collaborate to ensure quality community inclusion for themselves and their loved ones. The formative years of the late teens and early 20s are those in which all youth typically explore their life options—in particular school and work—and continue to learn and make new connections. Rejecting the traditional service provision of day programs, families following the *InclusionWorks!* model opted for IF and pooled their resources for greater self-sufficiency to prepare their young adult participants to become contributing members of Canadian society.

Since its inception, *InclusionWorks!* has been exceptionally well supported by its Host Agency of choice, *Community Living Victoria*, one of the keys to the model's success. Following the creation of *InclusionWorks! Victoria* in 2010, a second group, *InclusionWorks! Saanich*, was formed in 2012 and a third, *InclusionWorks! South Island,* in Fall 2014. Each group provides 35 hours per week of programming for 7 to 10 transitioning youth eligible for *CLBC* support. Currently, 25 families participate in *InclusionWorks!* in Greater Victoria. *InclusionWorks! North Shore* was formed in 2015 on the BC Lower Mainland and new *InclusionWorks!* groups are currently being considered in Victoria, Vancouver, and in the Interior and Northern regions of BC.

The original group of *InclusionWorks!* families spent considerable time and energy developing their collective values, programming principles and governance model. This included adopting an "Employment First" focus, believing that employment is a key means of contributing to society and of being truly included. Key Values and Principles were developed collectively and have changed slightly with each new group.

Key Values:

- Self-advocates and families are best positioned to make choices regarding their future and, with the appropriate opportunities, training, and support, can make a meaningful contribution.

- Canadian society is enriched by inclusion.

- The presumption of legal capacity of each individual should be upheld through supported decision-making.

- Everyone is entitled to have friends.

- Members of society are interdependent.

- We adhere to the principle of the "dignity of risk", recognizing that everyone has a right to undertake risks in pursuing life experiences and, that some of these risks will fail.

Programming Principles:

- Activities should be in community, challenging and age appropriate.

- Activities should be provided based on each participant's interests, strengths and capabilities.

- Each participant will have an individualized schedule. Some activities may be with other participants (experiential learning and peer support for example).

- Employment, independence, friendships, and life-long learning are key goals.

- Activities should embed learning opportunities for life skills and job readiness.

- Participants' physical and mental well-being is essential.

From the beginning, the *InclusionWorks!* groups placed a high value on inclusive and personalized programming over segregated and congregate programming. We challenged ourselves to be in community and to deliver individual or small group supports at least 80% of the time. When resources allowed, we moved from full group activities (useful for getting to know each other and necessary given our early resources) to activities in groups of three or less. We built in individualized activities for each participant as frequently as possible and enhanced them as paid and self-employment grew.

As mentioned, the first two *InclusionWorks!* groups embraced an "Employment First" philosophy, where sustainable employment was the primary goal. It is vital that the group of families buys in to this philosophy even if it takes time for their sons or daughters to engage in employment-related activities. Over time, this has helped the groups develop programming, where employment and employment-related activities take priority over other activities. This philosophy has influenced participants who have come to understand that a shift at work needs to take priority over a leisure activity that occurs at the same time. Other *InclusionWorks!* groups may choose other programming priorities.

In addition to using an "Employment First" philosophy to guide *InclusionWorks!*, the groups also determined that *InclusionWorks!* would be a transition program lasting five years. Families wanted *InclusionWorks!* to follow a typical life trajectory in which youth and young adults go to college or engage in other learning, have their first jobs, do apprenticeships, experiment and discover, and form important friendships. Families did not want traditional day programs where individuals enter and stay in for life. Rather, they wanted programming and supports that reflect participants' ages and interests with the belief that people change over time.

It is suggested that *InclusionWorks!* groups have no permanent "home" base, but makes use of community-based facilities. As much as possible, *InclusionWorks!* strives to use the same services as the general public, e.g., recreation centre programs, community based training courses, employment agency supports, community centres, etc. We have established on-going partnerships with a wide variety of agencies, organizations, businesses and service providers throughout the region. These partnerships are vital to the variety and quality in our programming, and ensure programs are tailored to our participants. One *InclusionWorks!* group has decided in its last year to rent a small apartment to work on programming goals related to independent living.

The *InclusionWorks!* governance model sees participants and their family members in control of how collective resources (including financial resources) are allocated and applied. From the groups' general direction to staffing and programming, participants and their families are the decision-makers on all matters.

Our Context

As *InclusionWorks!* developed, its participating youth and families, support workers, and partners learned much from their successes and mistakes. The initial two groups —*InclusionWorks! Victoria* and *InclusionWorks! Saanich*—were providing services to participants for several years and asked, "If we were to do it again from the start, what would we do differently?" A key part of that reflection considered how to create a family-governed group that, from the outset is focused on employment. A lack of initial resources meant that the structure of the groups—support worker roles, programming, partnerships, etc.—was not ideally set up to support the primary goal of employment. As a result, by 2013, few of their participants were actually working.

So began the exploration of how to change that. Working with a well-respected employment consultant, *InclusionWorks!* explored two options:

- Partnering with a *CLBC* employment service provider;
- Providing employment services itself.

While option one was viable, *InclusionWorks! Victoria* had previously established a partnership with a local employment service provider and experienced problems with relationships and outcomes. At that time, the service provider used traditional approaches to employment services and the organization's bureaucratic nature was not well-matched with the culture of a collective family-governed group. Similarly, several parents' independent experiences with other *CLBC* employment service providers had not resulted in sustainable employment for their youth.

As with many things, timing was everything. The *BC Ministry of Social Development* (now the *Ministry of Social Development and Social Innovation*) had recently overhauled the *Employment Program of British Columbia* (*EPBC*), consolidating hundreds of employment service agencies and establishing one *EPBC* provider per community. In Victoria, the *EPBC* employment services provider was looking for organizations to serve its "special populations", including individuals with developmental disabilities. Through early discussions, it was clear that the *InclusionWorks!* model offered an interesting opportunity to pilot a collective family-governed group as a fee-for-service provider to the new *EPBC* program. For *InclusionWorks!*, providing fee-for-service employment services offered several advantages:

- It allowed employment services to be directed by participants and their families in the same way community inclusion services were being provided.

- It embedded employment into each groups' overall programming and supports.

- It used the existing support workers' knowledge of participants to find and sustain employment.

- It used the generic employment service system that every British Columbian could access which aligned with *InclusionWorks!*' core principles.

- It provided additional resources to provide tailored employment services and build the capacity of the groups to further their employment goals.

- It allowed *InclusionWorks!* to use the specific, time-limited *EPBC* resources for employment services while using Individualized Funding for wrap-around and long-term supports.

The ability of *InclusionWorks!* to create such a partnership with the local *EPBC* program hinged on several things. First, it could only be done because the participants were in collective family-governed groups (as opposed to using IF independently). Secondly, the *InclusionWorks!* groups were using a Host Agency (a legal entity) that could support administrative and financial tasks associated with the work. Finally, the local *EPBC* office was willing to partner with an organization unlike traditional employment service agencies.

Collective Family Governance

> An issue for this generation is that many services provision models provided for adults with disabilities in Canada today, such as day programs, group homes, vocational services, and post-secondary options remain largely unchanged over the last 20 years and have not evolved to meet the assumed unique needs of this (current) transitioning group of young adults with disabilities.
>
> Rasmussen, Haggith & Roberts, 2011

What is Collective Family Governance?

Collective family governance, commonly called family governance, is a model of support in which individuals with disabilities, with the support of family, pool their resources

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(knowledge, networks, skills, funding, etc.) to provide services to a small group of individuals. Though it is currently used most often by people with developmental disabilities and their families, it is a model that can be used by others including those with mild dementia, physical or sensory disabilities, or others who would benefit from working in a small collective group with common needs and goals. Though we use the term collective family governance referring to youth with developmental disabilities and their family members, this form of sharing resources and supports can be used by various user-led groups in different forms. In fact, the *InclusionWorks!* model of collective family governance for transitioning youth seeks to shift to a more user-led approach giving greater involvement and control to the participants.

Families and individuals with disabilities have always been creative in developing new ways of doing things and groups of families have been forming collective family-governed groups for some time. There are situations, for example, in which a few parents from different families get together to buy a house, where their adult children can live independently with shared support or, parents in different families who together start a business to create employment opportunities for their sons and daughters. Unfortunately, these models are relatively rare in large bureaucratic service systems that are dominated by traditional providers of services (day programs, group homes, etc.). As well, until relatively recently, restrictive service funding from governments (i.e. global funding to agencies) meant that only families of means could develop and control such creative and individualized services.

Things, however, are changing. With the increased availability of Individualized Funding, existing family-governed groups are now examples of possibility. New family-governed groups are forming, and with the knowledge and support of professional allies collective family governance is emerging as a viable way to support individuals with disabilities to live meaningful lives as fully participating members of their communities. Individualized Funding and collective family governance, like micro-boards before them, represent a shift in power within disability service systems. Historically, professionals in government and service provider organizations have defined how services should be delivered and by whom. Individualized Funding, micro-boards, and collective family-governed groups put the power and control over services into the hands of individuals with disabilities and their families, where we strongly believe it belongs.

The term family governance is relatively new in relation to services for people with disabilities and has therefore not been clearly defined within the existing body of research. For the purposes of this guidebook, the concept of family governance is drawn largely from the work of Dr. Michael Kendrick who in 2009, facilitated a forum on family governance for *CLBC*. Dr. Kendrick has worked in various countries promoting collective family governance as one way to individualize services for people living with the labels of developmental disability. In *CLBC*'s forum summary report, *Think Tank on Collective Family Governance*, collective family governance is broadly defined as a way for "families to work together to identify and meet their needs" (*CLBC*, 2009).

The *Think Tank* report outlines a number of person-directed service options, including three collective models:

- Unincorporated/unaffiliated, collectively governed mini-projects to create individualized and other service arrangements

- Collectively member governed organizations to create individualized and other service arrangements (e.g., incorporated cooperatives and mini-agencies)

- Agency hosted, unincorporated, collectively member governed organizations to create individualized and other service arrangements.

CLBC, 2009, p. 5

As an alternative to traditional service provider-managed services as well as the typical use of Individualized Funding, each form of collective family governance offers advantages and disadvantages. The type of structure a group decides to use depends on the individuals being supported, the families involved, the types of funding used, available partners, the mechanics of the larger service system and its culture, and other considerations. It is important to distinguish between "family-governed" and "family-managed". Family governance means that families govern the group (i.e. make key programming, budgeting and personnel decisions). Those responsible for the day-to-day management functions can vary depending on the people involved and the structure selected.

The *InclusionWorks!* model of collective family governance is an autonomous unincorporated group working in partnership with a Host Agency. This guidebook speaks to the "unincorporated group" form of collective family governance. Many of the lessons we have learned over the last six years, however, also apply to other models and forms of collective family governance.

Family governance means that families govern the group (i.e. make key programming, budgeting and personnel decisions).

Forming a Collective Family-Governed Group

Opportunities

For many families of transitioning youth with developmental disabilities in BC, forming a collective family-governed group such as *InclusionWorks!* makes sense. Visits to many traditional day programs offering "Community Inclusion" services reveal mixed age groups in which 19-year-olds, the middle-aged and seniors are served together. They are most often in segregated settings and take congregate community outings, have routinized leisure-focused programming and schedules, and can have poor staffing ratios and supports. This fosters low expectations and a lack of focus on employment as an important part of being an adult in today's society. For the recent transitioning youth who have been included in regular classrooms in their neighbourhood schools throughout their education, these day programs are a step backward, not a step towards possibility. Indeed, there are many benefits to forming a family-governed group, including:

- **Participants and their families set the direction of the group,** from governance to programming and finances, and bring their diverse skills to the group.

- The economies of scale of families **sharing resources can leverage more and better services.**

- As users of services, participants and their families can create **person-directed supports that buffer against bureaucracy.**

- **Programming is flexible** and can shift quickly to meet individual and group needs and opportunities.

- **Participants of similar ages can foster a peer network.**

- **Families can hire or contract support workers and job coaches,** create their own partnerships, and determine how to use their shared resources.

- **Staff and contractors who can be similar in age to participants model young adult life** and provide access to youth culture.

- **Family members provide a network of support** to each other through the transition period and a close-knit safety net for each other.

Challenges

There are, however, some risks. Collective family-governed groups embody interdependence. The pooling of resources means that each individual is dependent on the success of others in the group and on each family's satisfaction with the group's programming and governance. If one family is dissatisfied and leaves, pulling out their resources, everyone is affected. This underscores the importance of members of a forming group to work through their vision, values, and principles—to ensure all involved are committed to the collective group and to problem-solving processes. Collective Family Governance is not a model of support for those concerned only about themselves or their loved one; It is a model in which everyone involved must care about the success of the group, as well as the success of each participant.

Grassroots Formation and Leadership

As families have developed the *InclusionWorks!* model, many *CLBC*-funded agencies have contacted us to learn more about how *InclusionWorks!* groups were formed and how the groups function in relation to our Host Agency. While we applaud their interest and offer assistance, we have observed that it isn't always clear who will be forming the family-governed group. **It is vital that youth and their families take the lead forming the group, as opposed to an agency or government placing individuals and families into groups.** To be successful, individuals and their families must develop relationships, explore their values and goals, and get a sense of whether they can organize together before committing to each other as a collective family-governed group. In our experience, if these steps are not taken, individuals and families will not be able to plan and work together, will not have a shared sense of identity, and will be unable to communicate and problem-solve when issues arise.

That is not to say, however, that service agencies and government can't play an important role in sharing information about collective family governance and bringing youth and family groups together—as enablers to group formation. True person-led and family-led service providers and government representatives who understand the

principles of self-determination will support the formation of family-governed groups rather than direct it. This is an important distinction that individuals and their families need to be aware of.

Starting a Family-Governed Group

Connecting with Other Families

How do you go about finding other like-minded families eligible for *CLBC* funding to explore forming an IF-based family-governed group? Depending on the nature of your community, you may be able to reach out through support groups, family-focused organizations, through transition resource fairs or directly to other families through social media. You can extend your search, with the co-operation of your local *CLBC* office. Privacy laws prohibit *CLBC* giving you the names of individuals or families directly. However, facilitators may tell other families about your initiative or the local *CLBC* manager may be willing to distribute a letter inviting families and youth in transition to discuss the model and to contact you directly. (See "Family Invitation" template in Sample Documents). Family-governed groups who choose to be ethnically and/or linguistically based can identify families with common interests through culturally-based organizations such as local First Nations or ethnic associations

Initial contact between families should happen in the last year of the youths' secondary school education. Optimally, the first meeting of interested families should take place by late fall. At this initial gathering, it is important to spend sufficient time getting to know each other and having a general discussion of hopes and goals for the next five years. Each parent should be prepared to give an update on their son's or daughter's eligibility for *CLBC* services and where they are in the planning process (unless already 19 years old most will likely still be in process). It is also important to discuss Individualized Funding and family governance, including the benefits and risks as described. At this point, the individual leading the meeting should create a list of interested families, contact information, basic information about the participating youth, and their current status in the eligibility and planning process.

The next set of family meetings should focus on youths getting to know each other, formulating a collective philosophy, and identifying shared goals for the next five years.

Whether meetings are conducted in a family home or a community space, we have found it useful to provide facilitated opportunities for the youth to get together without parents in the room. We have rented the Teen Centre in the local Recreation Centre which is an ideal space for activities and a good space for youth to get to know one another. Support workers can give parents a sense of how the youths got along together and any supports that were needed to promote engagement and participation. Not everyone has to be the best of friends, however, along with information provided by families, some potential relationships may begin to develop and common interests identified.

Subsequent meetings of families should begin with identifying shared values and goals. The first *InclusionWorks!* groups highlighted "Employment First" as a key shared goal. Other goals focus on friendships, ongoing learning, health and well-being, and increased independence. As the families begin to form relationships with one another, it is important to move to the commitment phase. Only when families have committed to being part of the family-governed group can the real planning of start-up begin, including choosing a Host Agency, assessing support needs, creating budgets, forming partnerships, developing programming and schedules, and determining how values and goals translate into practice.

Timing for Transitioning Youth

There is another important consideration at this preliminary stage of development. Based on the current *CLBC* transition process (at the time of writing), families will be developing or will have recently completed a Personal Support Plan with a *CLBC* Facilitator. In order to move forward on setting up an IF-based family-governed group, a specific request for Individualized Funding must be written into each Plan. Without this specific request, *CLBC* facilitators will often focus on assisting families who might receive service funding by identifying globally-funded programs for the transitioning youth. Under the current *CLBC* planning system, we have found it useful for families to use the same wording in each Personal Support Plan, indicating the youth is requesting Individualized Funding to set up an *InclusionWorks!* or collective family-governed group with other families. Also, name the group's Host Agency if one has been identified at this point. In order to create a family-governed group, all families will need to make the same agreement with the same Host Agency.

In order to get adequate initial funding to allow for successful implementation of the family governance model, families should present a collective face to *CLBC*. *CLBC* receives its annual budget allocation on April 1st each year and only after that can the local *CLBC* office make funding allocation decisions. Decisions are based on a number of factors looked at individually (i.e. level of need, health and safety, and prioritization) as well as the amount of funding available to the local *CLBC* office. The collective model of family governance is, therefore, a challenge to *CLBC*'s current funding allocation process, despite their support of a values-driven approach, cost-effectiveness, and ability to leverage additional resources. Practically speaking, this means the families in a family-governed group must speak to *CLBC* with one voice with the goal of sharing adequate resources. Families will have to sign a preliminary release form giving one or more families in the group permission to discuss each other's files with the selected Host Agency and *CLBC*.(See "Preliminary Release Form" template in Sample Documents).

Agreeing on the Family Leads

After a group of families has committed to being part of the family-governed group, they need to agree to a Family Lead and a Secondary Lead in order to ensure effective operation of the group. As families begin the process of exploring the potential of family governance, leaders typically emerge—someone who steps up to organize the next meeting, someone who communicates well in a group, someone who has a clear passion for the evolving vision of the group. Sometimes this person volunteers to take on the role of Family Lead, at other times this process is more difficult.

The Family Lead is the volunteer head of the group and the bridge between the Host Agency and other providers. They are the managing head of the group for day-to-day operations for at least the first period of operation. This is a key function, particularly once support workers are hired or contracted as they will need one person to be their key communications link. (See "Responsibilities and Characteristics of a Parent Lead" template in Sample Documents). The Second Lead has specific responsibilities (e.g., budget or human resources) and acts primarily as a support and backup to the Family Lead.

It is vital that these roles are filled. Even if the group delegates tasks, works in committee or the Host Agency plays a significant coordinating role, there is still a need to have at least two family members (a Lead and a Second) who become the main points of contact for the families, support workers, the Host Agency, and, when necessary, for *CLBC* and others. As with the group formation itself, leadership must emerge from the group and be supported by the entire group in order for it to succeed. As the group starts up, the Family Leads will put in a large number of volunteer hours. As the group becomes established, the weekly time commitment should diminish.

The Family Participation Agreement

Once the families have agreed on their shared values and goals and identified the Family Leads and a common Host Agency, they are in a position to sign a Family Participation Agreement to facilitate the smooth operating of the group.

Such an agreement serves a number of purposes, confirming:

- Each family's active participation in governance;
- Funding of the group including each family's contribution of *CLBC* Individualized Funding and other necessary funds;
- Agreed upon Host Agency and their protocols;
- Length of initial commitment to the group and conditions of withdrawal;
- Agreement regarding hiring or contracting workers;
- Agreement regarding hours and weeks of services;
- Other agreed upon arrangements regarding activities and finances;
- Responsibility regarding transportation; and
- A mediation and conflict resolution process, if required.

The Family Participation Agreement should also give the Family Leads permission

As families begin the process of exploring the potential of family governance, leaders typically emerge– someone who steps up to organize the next meeting, who communicates well, who has a clear passion for the evolving vision of the group.

to jointly sign agreements with the Host Agency, service providers and venues for *InclusionWorks!* administration and activities, and give them the authority to speak to *CLBC* and others on behalf of each member of the group and the group as a whole. (See "Family Participation Agreement" template in Sample Documents).

It is important to note that a family-governed group will be under the umbrella of a Host Agency; the group itself is not a legal entity. That is one reason the Family Participation Agreement is an important document. There will be situations when your Host Agency needs to sign on your behalf (i.e. a contract to book space, etc.) so your relationship and communications with your Host Agency are very important.

Host Agency and Contractual Agreements

A Host Agency is a *CLBC*-qualified organization that works in partnership with individuals and their families to assist in developing the desired supports, managing the funding and assuming all administrative responsibilities of the Individualized Funding contracts. The partnership with the Host Agency is key for the successful operation of a family-governed group and alleviates some of the major start-up and on-going operational requirements. In fact, it will be very difficult to pool resources and meet *CLBC* reporting requirements without a Host Agency.

Importantly, families and the Host Agency need to align their values and goals. In practical terms, among other things, the Host Agency must be comfortable with a small group of families making important decisions under their umbrella (i.e. who to hire or contract, which activities to undertake, etc.) and families must be comfortable with how the Host Agency deals with administration, finances, and risk.

Community Living Victoria became a Host Agency with *CLBC* in 2007 with several years' experience to draw on when the first *InclusionWorks!* group of families presented their request for affiliation. As *InclusionWorks!*' values and goals were well-matched with *Community Living Victoria*, it was good timing for the organization to explore different service models. *Community Living Victoria* had a strategic plan that included goals around supporting transitioning youth and young adults and was:

- Willing to be transparent regarding funding, budgets, and the sharing of information;
- Well-established in the community;
- An accredited organization;
- Willing to take risks and try new things;
- Interested in seeing *Inclusionworks!* succeed;
- Open and trusted the *InclusionWorks!* families.

Individualized Funding within a family governance model using a Host Agency involves four separate types of agreements.

1. The families sign a Family Participation Agreement among themselves. (See "Family Participation Agreement" template in Sample Documents).

2. Each family signs an agreement with *CLBC* for Individualized Funding, including naming the same Host Agency.

> The partnership with the Host Agency is key for the successful operation of a family-governed group and alleviates some of the major start-up and on-going operational requirements.

3. *CLBC* and the Host Agency sign contracts for the administration of Host Agency services for each participant in the group.

4. The Host Agency and the designated two Family Leads, on behalf of the group sign a Host Agency Agreement specifying the agreements between the two. (See "Host Agency Agreement" excerpts in Sample Documents).

The Host Agency receives the funds for *InclusionWorks!* participants and provides administrative and fiscal support to the group, including helping the group link with other resources (such as community behavioural support services). In Victoria, where there are multiple *InclusionWorks!* groups, *Community Living Victoria* maintains a budget for each group, and is also responsible to track each individual's service levels separately. The Host Agency receives a fee from *CLBC* for each of its Host Agency contracts so they can do the necessary administration and monitoring. This fee is over and above the direct Individualized Funding allocated to the individual.

The Host Agency:

- Helps families recruit, screen and train qualified support people;
- Provides fiscal management, including making payments, tracking budget funds, and reporting back to families and *CLBC* on budgets;
- Provides access to resources;
- Ensures required critical incident reporting takes place;
- Ensures the host agency support meets accreditation standards, if applicable;
- Assists families with human resource-related issues;
- Assists with on-going problem-solving, advocacy, and developing budgets;
- Works through any health and safety related issues;
- Provides liability insurance coverage;
- Provides *WorkSafe BC* coverage to support workers;
- Provides support for documentation and annual Person Centered Planning.

A key administrative function of the Host Agency is hiring or contracting and on-going administration of support workers and job coaches for the family-governed group. It is essential that the families maintain the responsibility for the selection and monitoring of the workers, however the Host Agency pays workers an hourly rate, reimburses them for travel and other expenses, as well as other HR-related tasks. From the Host Agency perspective, some of the lessons learned to date are:

- The Host Agency must have adequate resources at start up;
- There must be a willingness to respect the family governance model;
- There needs to be a good fit of participants and families (i.e. like-minded with similar goals);
- There needs to be an effective working relationship with the local *CLBC* Office;
- There will be an impact on Host Agency finance and administration departments.

Creating a Budget

In the *InclusionWorks!* model, individuals and their families pool knowledge, networks, skills, and funding. Funding includes:

- Individualized Funding from *CLBC*

- Personal or family contributions

- In-kind and financial donations (including space)

- Grants (in partnership with the Host Agency)

- Payments for employment services delivered through the *Employment Program of British Columbia (EPBC)* program.

Budgeting is primarily done by parents with this skill, with additional support from our Host Agency, *Community Living Victoria*. Depending on the skills of your group, you may use more or less of your Host Agency's support for budgeting.

The most important of the *InclusionWorks!* groups funding sources is Individualized Funding (IF) through *CLBC*. Depending on the individual youth, the majority of *CLBC* funding for *InclusionWorks!* participants has so far been allocated under three different *CLBC* direct service categories: Community Inclusion, Employment (a sub-category of Community Inclusion), and Respite. Individuals have received anywhere from $2800 per year up to 12, 17.5 or 23 hours per week of service funding based on their level of need (calculated through the Guide to Support Allocation).

In Victoria, families have been able to augment this funding with additional educational programming and services from the *South Island Distance Education School (SIDES)*. As a Distributed Learning Program, *SIDES*, part of School District 63, allows use of education resources to age 21 for eligible *InclusionWorks!* participants.

Through this project and over the last three years additional financial support in the form of fee-for-service *EPBC* payments have paid for employment services delivered by *InclusionWorks!*. It should be noted that double dipping is prohibited. That is, one cannot use the same *CLBC* employment services and *EPBC* employment services simultaneously.

Other financial support comes from families themselves, the amount determined by both group need and each family's ability to pay. As a group begins to form, a discussion about available financial resources must occur including what families can contribute. Financial resources need to be considered in relation to what will be needed to operate, particularly in terms of the number of workers required to adequately support participants. Careful consideration should be given to the best support worker to participant ratio to meet the specific needs of the participants, including addressing health and safety issues.

It has been our experience that, in some cases, parents presume their son or daughter needs much more one-to-one support than is actually necessary. Parents may, for example, be accustomed to having an Education Assistant in the school system so presume that this level of support is always necessary when in fact the participant

may well be supported in a small group of two to three people. These are some of the questions that need to be discussed by families as they establish their group's budget. With more information about individual participants, and their specific programming needs, budget projections will likely be revised several times.

In addition to direct service hours and dependent on available funding, *CLBC* has historically been willing to provide small amounts of money to provide some support for each individual participant's transportation and activity costs, planning and support coordination, and/or facility costs (our groups do some small weekly rentals of space in recreation and community centres). Resources made available to your group will depend on many factors. Unlike education services which all children are entitled to, *CLBC* services are not an entitlement. If you believe more resources are required for individual participants and your group, we encourage you to engage in discussion with your local *CLBC* office. We would note that none of the *InclusionWorks!* groups formed to date began with full service funding based on the participating individuals' Guide to Support Allocation (GSA) scores (these scores determine the number of weekly support hours an individual needs). Instead, groups have looked at overall financial needs and pooled whatever resources they can, working with the local *CLBC* office to gradually bring in additional Individualized Funding and lessen family contributions over time. As well, the existing *InclusionWorks!* groups have chosen to close for three weeks in August of each year, as well as two weeks during December holidays. The funding during this time stays in the *InclusionWorks!* budget and this has allowed budgets to stretch farther. Families should be aware that hourly pay rates for employees or contractors vary among regions and across agencies. Each Host Agency has its own funding template, which differs based on geographic location, whether the agency is unionized or not, the use of employees or contractors, etc.

Groups have looked at overall financial needs and pooled whatever resources they can, working with the local *CLBC* office.

Below is a sample budget, once *CLBC* funding is fully allocated (not including *EPBC* fee-for-service funds):

Monthly Revenues

Participant	GSA Score	Hours per Week	Support Coordination Hours per week	Transportation Costs per month	Activity Fees per month	Family Contribution per month
John	3	12	2	$50	$50	$100
Meilee	4	17.5	2	$50	$50	$50
Alicia	4	17.5	2	$50	$50	$150
Patty	3	12	2	$50	$50	$100
Greg	4	17.5	2	$50	$50	$100
Juan	4	17.5	2	$50	$50	$150
Danielle	5	23	2	$50	$50	$150
TOTAL		**117**	**14**	**$350**	**$350**	**$800**

Monthly Expenses

Expense	Hours per week	Hours per month	Average Expenses per month
Support Worker Hours ($20/hr)	96	403	$8,060
Team Lead Hours ($22/hr)	35	147	$3,234
Transportation			$500
Activity Fees			$500
Space Rental			$250
TOTAL	**131 hours**	**550 hours**	**$12, 544**

Weekly, monthly, and annual budgets will shift over time based on participants' needs, programming, partnerships, and your ability to leverage additional in-kind and financial resources. Our experience is that as we gained additional resources, we were able to increase individualized programming such as employment services. At the same time, some participants required less support over time as they gained independence and natural supports were developed. If you are able to form a partnership to offer employment services through the *EPBC* program, this fee-for-service funding will be time limited and needs to be factored in when budgeting for the longer term.

Tracking Your Budget

When selecting your group's Host Agency, it is important to find one that will assist you in tracking your funds and providing your group's Family Leads (or another designated person within the group) with a monthly statement of your group's accounts. Our Host Agency, *Community Living Victoria*, provides us with an Excel spreadsheet that shows how our group's funding decreases monthly over a year so we always know how much funding is available to the end of the calendar year. Additional resources are added to the tracking sheet, including payments from the *EPBC* program for billed employment services. Financial reports are given at each Family Meeting so that all participating families know how the group stands financially. Financial reports also allow families to determine how they want to use non-allocated funds from family contributions and other non-*CLBC* resources. With any remaining non-government resources, our groups have increased individualization of services, undertaken special activities, provided training opportunities to workers and gone on small outings such as overnight camping trips and conferences, among other things.

Your first year will teach you how to gauge your average monthly costs. We know for example, that our costs go up in the summer because we take advantage of the weather to participate in a number of special activities (i.e. trips to Salt Spring Island, Chemainus Theatre, overnight camping, etc.). We know that August and December are low-expense months because we shut down for several weeks. We also take advantage of programs and deals wherever possible. All of our participants have recreation passes, Recreation Integration Victoria and entertainment cards (allowing support workers free entry to recreation centres and movies), and IMAX theatre passes. In addition,

we monitor "Groupon" and other discount sites for discounts on activities. These all help reduce our programming costs and diversify our programming in inclusive environments.

Organizing Your Group

Relationships and Communication

As with any group or organization, success of a family-governed group is based on clear and open communication built on trust. This pertains to participants, family members, support workers, Host Agency staff, and partnering organizations. Central to this communication, however, are the relationships that families have with one another. Trusting relationships begin to be formed even before the *IncusionWorks!* group starts delivering the program, through initial meetings among families who are considering whether this is the model of support they prefer. Once a group is formed, meetings among families will likely take place every month or perhaps more frequently until the group has made most of its key decisions and, services are being smoothly delivered. Once that occurs, family meetings may be held every two months or less frequently depending on the group. Between meetings, electronic communications are frequent. In addition to regular internal meetings among families and with support workers, there will be meetings with external partners, which will also reduce in frequency over time. All of these meetings, especially family meetings, should be guided by agendas on which everyone has an opportunity to place an item, and where everyone has an opportunity to speak. The existing *InclusionWorks!* groups are consensus-driven; we talk through issues until everyone comes to a decision they are happy with. This may take some extra time at the beginning of a new group, however, once relationships are well established among families, decision-making becomes quicker.

Governance and Volunteering

It is the expectation that all families, including *InclusionWorks!* participants, are represented at scheduled family meetings. At these family meetings, information is shared and decisions are made about partnerships, the direction of programming, structure and practices, as well as use of resources. The goal is that *InclusionWorks!* participants take on more and more authority and decision-making roles in the governance of their *InclusionWorks!* group, from making decisions about programming and schedules, to interviewing and selecting support workers, and participating in family meetings. When individuals turn 19 they may not have the knowledge to manage a family-governed group, however, over time, as youth mature to adulthood and gain new skills, their roles should expand and support in decision-making should be offered if required. Our experience is that participants initially had little interest in attending family meetings, but as they matured and gained more skills, interest in attending increased.

Part of the initial Family Participation Agreement is an understanding that all families will play a voluntary role within the group, based on their availability and skill set. For the Family Leads there is a great deal of voluntary work, especially initially. For

other families, volunteering may be participating on an interviewing committee to select new support workers, researching opportunities for participants, or hosting a family meeting at their home. Whatever a family can do, it is important that everyone contribute as time allows. This helps build relationships and supports each family in becoming stakeholders in the group's success.

Coordinating the Team

With so many individuals involved and so many moving parts, along with the need to remain flexible and responsive to opportunities, it has been our experience that a relatively flat organization with a project team approach works best. *InclusionWorks!* operates with a project team model where all—participants, families, and workers have responsibilities.

InclusionWorks! operates with a project team model where all–participants, families, and workers–have responsibilities.

Each *InclusionWorks!* group is governed by its families who meet on a regular basis to set the overall direction and make the key decisions for the group. We also have a Steering Committee made up of Host Agency personnel and the Family Leads from each of the *InclusionWorks!* groups under its umbrella. This facilitates consistent policies across the groups that meet Host Agency requirements and promotes sharing resources, such as a common casual worker list.

On a day-to-day basis, coordination is done for each *InclusionWorks!* group by a Team Lead, a support worker position with additional coordination and communication duties. The Team Lead is responsible for, among other things, developing and distributing the weekly schedule to families and partners, liaising with community partners, bringing new programming ideas to fruition, acting as the main contact for families, and attending family meetings. (See "Team Lead Description" template in Sample Documents).

Staffing and Contracting

Depending on the families, the Host Agency, and the nature of their roles, support workers and other associated positions with a family-governed group may be employees or contractors. (See "Support Worker Job Description" template in Sample Documents).

The workers for the current *InclusionWorks!* groups based in Victoria are independent contractors. Contractors can set their own hours within the terms of the contract and are responsible for their own transportation and payment of taxes. This facilitates families making a choice of workers. Depending on the Host Agency, other staffing models may be appropriate depending on the terms of employee agreements.

Support workers provide direct participant support in the community, including job coaching. They may also be involved in specific activity planning and implementation and, curriculum development and implementation. In existing *InclusionWorks!* groups, support workers range from casual to full-time workers and include both support and coordination roles (Team Lead). Given that we have intentionally contracted with a group of young support workers who are close in age to participants, our *InclusionWorks!* groups try to be extraordinarily flexible. A given support worker's hours may change if they decide to go back to school, get a part-time job or need time off for a vacation or activity.

General Responsibilities of a Support Worker

Individuals attracted to the work of *InclusionWorks!* tend to be interested in flexible, creative, and innovative models of service delivery and can come from a wide range of backgrounds. In describing the role of the support worker, we ask that they:

- Relate to participants in a professional, caring and positive manner, which respects their personal worth, dignity and rights.

- Train, support and assist individuals in a variety of community, volunteer and work settings (including job coaching).

- Provide essential employment-related work with participants, including job discovery and job coaching.

- Bring programming and participant-related ideas and concerns forward in a timely manner.

- Develop and implement education and training plans as required, with the participation of individuals and team members, including employment skill development designed to meet the individual's employment goals.

- Provide opportunities for individuals to learn life skills (i.e. safety, financial management, nutrition and cooking) with an emphasis on increasing independence.

- Assist participants in developing interpersonal and social skills in the community, and act as an appropriate role model and facilitator.

- Communicate with community partners, educational staff, and team members via email, telephone, or in-person meetings as required.

- Work with individual community members, groups, businesses and agencies to foster opportunities for inclusion of individuals with diverse needs, including developing natural supports.

- Provide the Host Agency with goal updates for participants in consultation with families and individuals.

The Importance of Community Partnerships

Ongoing, mutually beneficial community-based partnerships are the backbone of *InclusionWorks!*. Partnerships may come in many forms, be of different durations and evolve naturally over time. Partners may be of varying levels of importance to the success of the family governed group. The core ongoing partners of *InclusionWorks!* have been our main funder (*CLBC*), Host Agency (*CLV*), our education provider (*SIDES*), and our *EPBC* employment agency, as well as the local university and college, which have provided both community space and practicum student support.

In addition, we have taken part in a variety of generic programs and activities in community, as well as contracted with a number of specialized service providers. With our goal of a well-rounded and reciprocal life in community, whenever possible, participants take part in the same activities and programs as the rest of the population and give back to community.

Programming

During the first six months of the groups' programming, there tends to be more whole group activities, allowing participants to be exposed to different opportunities and activities to gauge their interests, determine what types of settings work for individuals, and who in the group get along well with others, including which support workers fit best with which participants or given activities. Once support workers get to know each participant's interests, programming becomes more individualized, with the majority of activities taking place in small groups of two or three or one-to-one. (See "Sample Schedule" in Sample Documents). Our general areas of programming have included:

Paid and Self-Employment—This involves job discovery, developing job readiness, direct job skills training, job carving, coaching and maintenance (See Section 2 of this guide for further elaboration of these steps in the employment process). It should be noted that as we have moved towards an increasing focus on employment, all programming and activities are now viewed through an employment lens, from social skills to leisure skills.

Volunteerism—Participants actively volunteer in the community with non-profit organizations in the social, health, animal welfare, arts and environmental sectors. Volunteering promotes inclusion and provides opportunities for forming natural relationships and experience and skills for employment.

Education and Training—Based on a belief in life-long learning, participants' education and training is ongoing. For the first two years of *InclusionWorks!*, most participants are registered at *South Island Distance Education School* (*SIDES*) which provides an individualized program to accomplish specific Individualized Education Program (IEP) goals, including job and life skills preparation. *InclusionWorks!* also provides specialized education and training for each participant over five years—through outside providers and in-house delivered by our support workers. Educational topics include literacy, money management, environmental stewardship, community mapping, transportation skills and others.

Social Skills and Self-Advocacy—Participants have been involved in social skill development using and adapting the *Program for the Education and Enrichment of Relational Skills* (*PEERS®*) curriculum and the natural environments of the university and community. In our third year, we added self-advocacy and rights training, using facilitators and self-advocate trainers in our community. During election years we have provided training on voting, along with local, provincial and federal election issues.

Healthy Living and Leisure—Since *InclusionWorks!* began, there has been a focus on health and leisure, including exercise, sports, yoga, nutrition, arts, crafting, and dance. Most of these activities take place in recreation centres, parks, classes, and locations where other community members participate in the same activities. While we try to find generic providers of services whenever possible, for some individuals and in some situations, we contract with specialized providers with experience in modifying and adapting activities.

**Relationships**—Most of our participants have developed friendships with other participants (either within their group or in other *InclusionWorks!* groups) and we continue to work on supporting friendships outside *InclusionWorks!*. The hope is

> Once workers get to know each participant's interests, programming becomes more individualized, with the majority of activities taking place in small groups of two or three or one-to-one.

that the friendships formed among *InclusionWorks!* participants are genuine, based on shared interests as opposed to disability label. Several participants have social networks through a local non-profit organization, *Lifetime Networks*, that helps facilitate friendships between people with and without disabilities and some of our participants are connected with the *Best Buddies* program as well. The development of natural supports in the workplace, volunteer roles, and community activities has been essential to building relationships. After a couple of years of programming, it became clear that many of our participants needed support with developing intimate relationships and for the last several years we have provided education on dating, relationships, and sexuality for some of our participants.

Most of the activities in these focus areas are conducted or augmented through partnerships, which diversifies our programming, builds capacity in the community, and promotes inclusion.

Planning–Individual and Group

At various points throughout the *InclusionWorks!* groups' five year lifespans, we have found it useful to do a group *PATH* (*Planning Alternative Tomorrows with Hope*). A *PATH* is a person-centred planning tool that can be used for individuals and groups. We have been able to find locally trained *PATH* facilitators to support us in our visioning and planning and one of our family members has now been trained in the *PATH* method. In order to ensure our group *PATH* reflects the goals of participants, our support workers conduct abbreviated individual *PATH*s in advance of the group activity and bring them to the group *PATH* meeting.
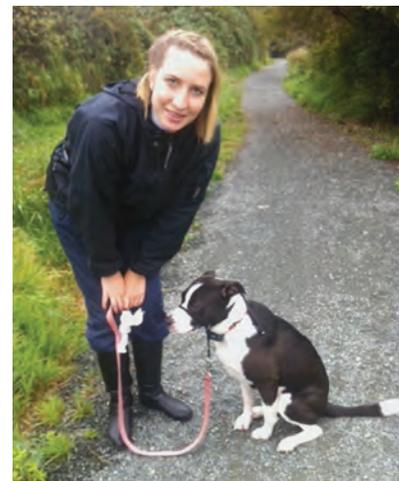
This group planning complements yearly person-centred planning with each of the individual participants, which is usually conducted by the Host Agency coordinator and the Team Lead. This is done with the focus person and their family and establishes desired short and long term goals.

We have also found the need to set aside time for planning among our contractors and with the Family Leads. We typically choose two to three days per year (one each in Fall, Winter, and Summer) for this planning. This is our opportunity to assess how each participant is doing, discuss changes in programming and supports, and explore creative new ideas.

Finally, each of our groups manages to carve out one afternoon per month and one hour per week when support workers and the Family Lead meet and plan. Quality, inclusive programming and supports can only happen when there is available collaborative planning time. Some groups have their weekly meeting within the programming day while others close early one day per week.

Policies and Practices

Over time, each of the *InclusionWorks!* groups has had to develop some policies to guide practice, though compared to formal service provider organizations, the number of written policies we have is relatively small. We also adhere to the relevant policies of our Host Agency. What happens when a participant communicates through behaviours that are unacceptable to the functioning of the group? Who is responsible for getting a casual worker if a regular support worker needs to take a day off? What

are the procedures when a participant shows up sick? What governs the use of cell phones throughout the day? What happens if there is an earthquake when everyone is in different places throughout the community? How will you handle petty cash? These are some of the questions existing groups have grappled with and for which we have created policies and procedures. There are also procedures for casual workers. Each casual worker receives a half-day orientation to each given *InclusionWorks!* group and must read the group's orientation binder, which provides basic information about participants, emergency contacts, etc. Policies, typically, come with time. (See "Sample Policy" templates in Sample Documents).

Group Dynamics and Problem-Solving

Like most groups, family-governed groups go through identifiable stages of development— forming, storming, norming, and performing. It's important to state this at the start, as well as during points of conflict. Working through problems together strengthens the group. As the group changes and develops, it will likely go through these stages several times. When you expect this process, it becomes less personal and the stress on the group is minimized. Our *InclusionWorks!* groups have intentionally included a commitment to problem-solving into our Family Partnership Agreements. On occasion, we bring in our Host Agency coordinator or others, to assist us with specific relationship issues. The key is that everyone is involved and working together to find solutions. Family members who are more individually focused may have difficulty with this. This is why it is so important from the beginning to have shared values and understandings and that those values and understandings be nurtured in your practices.

The key is that everyone is involved and working together to find solutions.

Maintaining Relationships

Group dynamics and relationships among participants, families, support workers, and partners will develop and change over time. Different groups take differing approaches to their relationships depending on their priorities. Among the existing Victoria-based groups, *InclusionWorks! South Island* has placed an emphasis on friendships among participants hoping these will be lasting. *InclusionWorks! Victoria* and *Saanich* have been less intentional about friendships, instead placing emphasis on employment and hoping relationships develop outside of the groups. All of the groups value friendships and employment, however, based on their own traits (participants, families, culture, resources, etc.), each approaches them slightly differently.

Likewise, family relations change over time. Our experience has been that once a group begins running smoothly, most families become less involved, re-engaging at different times over the five year lifespan of their group. As trust in the Team Lead, support workers, and the Family Leads increases, most family members feel less need to be involved in day-to-day decisions. This creates more hierarchy within the group in that the Family Leads typically have more information and tend to make most governance recommendations. As long as all families are aware of this dynamic and remain involved at the governance level, this arrangement seems to work. Conversely, all of the responsibility of the group cannot be placed on one or two family members regardless of their skills and abilities. The *InclusionWorks! South Island* group has been particularly good at engaging their families through a committee structure. Celebrations and annual barbeques have also been good ways to maintain connections.

Support worker cohesiveness and stability has also varied from group to group over time. Because *InclusionWorks!* is focused on supporting transitioning youth, we feel that the advantages to hiring or contracting young workers far outweigh the challenges. Young adults, often straight out of college or university, go on to graduate school, get better jobs, marry, have children and move on. We ask our workers to commit to at least a year and most do, (our longest term worker started as a practicum student four years ago). Be prepared, however, for some turnover and with it a re-forming of the group. Clearly, the Team Lead role needs as much continuity as possible, so we often move people from a support worker role to Team Lead when a Team Lead leaves. It is vital that the Family Lead and Team Lead work well together. The Family Lead needs to be someone who can strike the right balance between oversight of the team and giving them freedom to be creative and take on responsibility. The *InclusionWorks!* model does not lend itself well to micromanagement.

Finally, the relationship with your Host Agency will change over time as well. Hopefully trust and communication will increase and the Host Agency will support your group to build its capacity. There will likely be some healthy tensions—forces of professionalization and bureaucratization for example. Host Agencies are governed by legislation, regulation, policy and accreditation standards and there can be an expectation that family-governed groups manage themselves in the same way professional service providers do. Families may resist these forces. However, if you have a good relationship, these tensions can be discussed and resolved successfully for all parties.
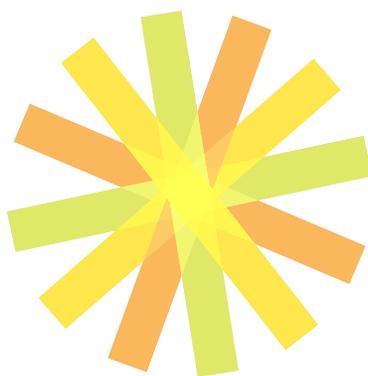
Section Two—Meeting Your Employment Goals

Focus on Employment First in a Family-Governed Group

There is a growing belief that to affect the persistently high unemployment rate of individuals with developmental disabilities, a paradigm shift from professional to self-directed services must occur. Using this approach, individuals will (a) have the knowledge they need to make informed choices and to direct the employment process, (b) choose from the full array of job and career choices available to other individuals in their communities, (c) receive individual and ongoing advice and support, (d) begin the employment service process by defining their career goals and paths, (e) have individual funding that reflects their unique career goals and paths, (f) determine the services and supports they will use their funding to purchase, and (g) contract directly with service providers. There are many unanswered questions about how a self-directed employment service system can most effectively and efficiently be structured and how it affects self-advocates, their families, providers of employment services, and government funding agencies.

Sowers, J., et al, 2002

As described in Section One, the original *InclusionWorks!* groups established employment as a priority from very early on, believing that employment is a key part of citizenship and inclusion. Like most individuals with disabilities and parents of children with disabilities, families experienced low expectations from service systems at times. The goal of employment, therefore, holds the same high expectations that society holds for all young adults.

Our work with a Customized Employment expert initially assisted our groups in clarifying our values and goals around employment. We determined that our work needed to become more outcome-focused requiring:

■ Real jobs (see definition below) where people have the opportunity to earn equitable wages and other employment-related benefits

- Development of new skills

- Social and economic inclusion

- Promotion of self-determination, choice and interdependence

- Enhanced self-esteem and,

- Increased quality of life where people are treated fairly and with respect.

Real jobs means that:

- Wages are paid at the going rate for the job, with the same terms and conditions as all other employees.

- The job helps the person meet their life goals and aspirations.

- Managers and colleagues value the employee role.

- It can be self-employment or resource ownership and,

- It does not include volunteering, work experiences, sheltered workshops, enclaves or work crews (except co-ops).

For our groups, this meant building our own capacity to deliver employment services—increasing our knowledge and skills around best practices in supported and customized employment. We endeavoured to become more knowledgeable as families, train our support workers, develop key partnerships, and importantly, create a culture in which employment is an expectation for everyone. While we have had the support of an Employment Facilitator through a *Vancouver Foundation* grant, the goal has always been to learn and share with others so that, even without additional short-term resources, other family-governed groups can successfully deliver employment services with their local *EPBC* program office.

Best Practices in Supported Employment

As with the formation of each of the *InclusionWorks!* groups, developing our capacity to deliver employment services required a set of values-based guidelines to govern our practice. For this, we looked to our expert consultant and her experience with customized and supported employment and her knowledge of the research literature. She provided us a summary of "best practices" that we aspired to and that set our direction.

1. **Choice and Control:** Employment support is guided by the job seeker to achieve his/her career aspirations.

2. **Paid Employment:** The job seeker receives the same rate of pay and benefits as other employees doing the same job. Individuals with competitive positions receive their paycheques directly from the employer.

3. **Partnership:** Job Seekers, employers, direct service providers determine the individualized strategies for providing support that will assist in career enhancement and ultimately facilitate long-term satisfaction for the job seeker and the employer.

4. **Full inclusion:** Socially and economically included in community.

> **We endeavoured to become more knowledgeable as families, train our support workers, develop key partnerships, and importantly, create a culture in which employment is an expectation for everyone.**

5. **Job Search:** Timely and appropriate support is provided to achieve successful employment.

6. **Individualized:** Negotiate to meet the unique/specific needs of the employer and skills of the job seeker, one person at a time.

7. **Natural Supports:** Employment supports are as unobtrusive as possible and (may) fade over time by building on community support and social capital.

8. **Long-term support:** Is available to all stakeholders to ensure people maintain employment stability and achieve career enhancement.

9. **Continuous quality improvement:** Stakeholders are involved in the evaluation of services and Service provider implements improvements.

Canadian Association for Supported Employment, 2016

Types of Employment

There are two general types of employment that are being pursued by and for *InclusionWorks!* participants—paid employment and self-employment. Which one of these is pursued depends on the individual and what is determined with them through the Discovery process. In some cases, participants have pursued one type of employment and as opportunities have arisen, and as their interests and skills evolve, or as we have understood them better, they have pursued a different type of employment.

"Paid Employment" is when a participant is paid an hourly wage by their employer. To date, *InclusionWorks!* participants have paid employment for between two and 20 hours weekly depending on individual circumstances and employer needs. Jobs have been in the health services, food services, and retail sectors, among others.

A number of *InclusionWorks!* participants have opted for self-employment. For *InclusionWorks!*, we consider our participants "self-employed" when they have their own micro-enterprise. A micro-enterprise is a very small business created based on a perceived community need or the passion of the individual (typically with five or fewer employees and often having only the self-employed owner). Generally, micro-enterprises need only a small amount of capital investment to start, and self-employed individuals need to be generating income for hourly wages. One of our participants delivers newspapers however, because he is paid based on the number of papers delivered, it is not considered a job under the *EPBC* program. Policies may vary between *EPBC* employment service providers. Please refer to your *WorkBC* office.

Within the field of employment for people with developmental disabilities, we speak of "supported employment" and "customized employment." Perhaps the best descriptions of these two models come from the Family Support Institute's booklet, *Employment Options for Individuals and Families in BC*:

> Supported Employment is a method of employment in which a service provider [or in this case, a family-governed group] works with an individual to obtain an existing job. The role of the service provider is to work with the employer to make modifications to the job which will allow the individual to be successful in their position. The service provider works alongside the individual as long as needed and can gradually fade their involvement as the individual becomes more independent, secure, and confident in their new role.

Over time, natural supports within the workplace (usually provided through co-workers or supervisors) may replace funded employment supports...

Customized Employment refers to a method of employment in which a service provider [or family-governed group] begins by first getting to know and understand the individual in a deep and meaningful way through a process known as Discovery. Discovery uses a person-centered approach to develop a profile of the individual by getting to know them and their unique skills and abilities rather than focusing on what jobs are available in the competitive job market. The process focuses more on observation and less on evaluation and assessment. For this reason, Discovery does not take place in the office but rather in the individual's home, preferred places, social settings, and community. The individual's family and network are engaged early and often, and the focus is on what a person can do, not on what they can't do.

Employers require many different skills sets from their employees. The role of the service provider is to explore these needs and develop a job which is of value to the employer and a good fit for the individual. Similar to Supported Employment, the service provider works closely with both parties to ensure that the individual is well supported and successful in their job. With time, supports can be faded and replaced with natural supports within the workplace. Customized Employment does not rely on competitive employment and instead seeks to place an individual in a job that is carved out specifically for them based on their preferences and strengths. Customized Employment is a set of techniques that can be used as the situation warrants. An individual is then systematically trained for the different tasks to achieve a real job for real pay. This approach creates more success for people with disabilities.

Family Support Institute, 2015

Terminology in the field and definitions used by the *EPBC* program differ slightly. As a fee-for-service employment service provider, *EPBC* definitions and terms need to be followed so that the work done by your family-governed group is aligned with their requirements and can be reimbursed.

Partnering with the Employment Program of BC (EPBC)

WorkBC is the provincial government's access point to the world of work in British Columbia. It was created with one key goal—to help all British Columbians to successfully navigate BC's labour market. *WorkBC* helps people find jobs, explore career options and improve their skills. *WorkBC* also helps employers fill jobs, find the right talent and grow their businesses.

WorkBC website, 2016

The *Ministry of Social Development and Social Innovation* (*MSDSI*) established *EPBC,* commonly known as *WorkBC,* in 2012 to better deliver employment services to all British Columbians. *EPBC* has offices around the province, some of which are managed by well-established organizations in communities, others are relatively new organizations. Some are non-profit organizations, others are for-profit businesses.

All *EPBC* offices have a variety of partnerships, some of which include subcontracting partnerships for employment-related services as well as fee-for-service contracting.

As BC's generic province-wide employment service, *EPBC* providers are mandated by government to service all BC citizens and funds have been designated to promote the employment of special populations. Special populations are groups facing particular barriers to employment, including youth, new immigrants, survivors of domestic violence, people with disabilities and others. Some *EPBC* offices, instead of providing employment services directly to these populations, work with organizations with expertise with these populations. Some *EPBC* offices provide services directly, and also partner with expert organizations to increase their capacity to serve individuals in their region. With *InclusionWorks!'* focus on employment first for youth with developmental disabilities, in addition to our meaningful relationships with our participants, a partnership with *EPBC* was a logical one. *InclusionWorks!* has been a fee-for-service provider for *EPBC*, providing each participant a full complement of employment services from discovery to job development, job coaching, and job maintenance, using a customized employment approach. This working relationship has provided us and our participants with additional resources to support skill development and employment, and assisted us in building our capacity and further individualizing our services. The *EPBC* program started just as the first two *InclusionWorks!* groups were looking to develop employment services and the local *EPBC* provider was looking for organizations to partner with to serve individuals with disabilities. Since then, however, additional community living organizations have entered into fee-for-service relationships with our local *EPBC* office. This holds true in other communities throughout BC.

In establishing your own relationship with your local *EPBC* office, we recommend:

Discussing the Idea with your Host Agency

Your relationship with your Host Agency is key to delivering employment services under the *EPBC* program. Because your group will be providing fee-for-service employment services, you do not receive payment until the service has been delivered. Employment services are very individualized. Discovery and job coaching, for example, require one-to-one support. Job development requires an individual to be in the community developing relationships with potential employers, negotiating customized jobs, etc. Consider if your Host Agency will allow you to use your existing funding to support such efforts, knowing that payment for the services will eventually come from the *EPBC* program.

As well, because you are not a legal entity, billing for services must come through your Host Agency. Consider if they are willing to invoice and track funds that can then be allocated to your family-governed group.

Developing a Working Understanding of the EPBC System

It has probably become clear that every local *WorkBC* (*EPBC*) office is slightly different in how it delivers employment services, reflecting the organization managing the program, the community, and available partners. Some factors to consider are:

1. Does the local *WorkBC* office have partnerships with fee-for-service providers and if so, are they also willing to work with a family-governed group?

2. Do they have service definitions, policies, and procedures they will share? Since the *EPBC* program remains a relatively young program, it has taken some time for local *WorkBC* offices to develop documentation for fee-for-service providers.

3. What does your local *WorkBC* office provide that can help your group understand the program?

4. Does the local *WorkBC* office case manage the individual and the employment services you will be providing? If so, they will likely be providing support and guidance along the way and ensuring that services delivered meet the requirements set out by the *Ministry of Social Development and Social Innovation* (*MSDSI*). Case management has been an important role in *InclusionWorks!'* relationship with its local *WorkBC* office.

5. Does the local *WorkBC* office have a user-friendly web-based system in place to document employment service activities or will you be required to input information directly into the Ministry's data collection system? Documenting activities is essential. It captures information about the individual and their employment services and supports and proves that the work was done in order for your group to be paid. Our local *WorkBC* office has developed a user-friendly, web-based system to submit client notes and upload documents. Not all offices, however, have such a system.

Assessing your Group's Capacity and Accessing Training

The *EPBC* system requires that organizations delivering employment services have the expertise to do so. Consider if your current staff or contractors have the skills to deliver employment services. Typically support workers receive little training around employment and in some cases, see themselves as caregivers as opposed to supporters. If your support workers do not have the training to provide employment services, what training is available? In addition to accessing training from our employment consultant, *InclusionWorks!* partnered with our local *WorkBC* office to conduct week-long training on Customized Employment. The course was offered in Victoria through Continuing Education at *Douglas College* on the Mainland. Another option for training is through the Employment Supports Specialty Advanced Certificate program at *Douglas College*, which is also available online. Other training opportunities, online and in person, exist throughout the province. Resources include *CASE* (*Canadian Association for Supported Employment*), *ASPECT* (*Association of Service Providers for Employability and Career Training*), and your local *CLBC* office's employment lead.

Determining Roles Within your Group

Aligned with training is determining worker roles. In our experience, it has been more effective to train all of our support workers in employment and assign each support worker responsibility for employment services for a specific individual(s). This does not mean others are not involved. It does, however, place responsibility for the entire employment process in the hands of a primary worker who is responsible for the

discovery process, working with the Employment Facilitator on job development, job coaching, job maintenance, planning, troubleshooting, and regular documentation. As we have transitioned from our *Vancouver Foundation* grant which had funded our Employment Facilitator position, each of the *InclusionWorks!* groups have assigned an existing support worker the responsibility for job development or contracted a new part-time job developer. Job development is a specialized skill that demands developing relationships with potential employers and marketing both your *InclusionWorks!* group and its participants. (See "Employment Facilitator Job Description" template in Sample Documents).

Working with the *EPBC* system

On-boarding

Before beginning to deliver employment services through the *EPBC* program, all staff and contractors who will be working with your participants need to be on-boarded. This requires all workers to provide a criminal background check done through the local police department or RCMP office (criminal background checks done through your Host Agency will not suffice), submit their personal information (name, address, etc), and provide an e-mail address to the *EPBC* program. This information is reviewed and must be approved before support workers can provide employment services and submit documentation on their activities. In addition to on-boarding support workers, we recommend the Family Lead or designate is also on-boarded in order to monitor employment service activities and documentation and to better facilitate communication with *EPBC* staff.

Intake

To start the process with *EPBC*, all of our *InclusionWorks!* participants had an initial meeting with their designated Disability Employment Services Advisor at our local *WorkBC* office. At this meeting, participants submitted various forms including a Disability Related Employment Needs Assessment (DRENA). Our local *WorkBC* office was very supportive of providing copies in advance so that families could provide the necessary information (i.e. their diagnosed disability) so our workers could better support participants to answer questions at the meeting. In one situation in which a participant had anxiety around meeting in the *WorkBC* office, the Disability Employment Services Advisor met her, the Employment Facilitator and her support worker in another, more comfortable location. Based on their *DRENAs*, all *InclusionWorks!* participants required Customized Employment Services and most were designated as Tier 4 (the highest level of support). We recommend staggering individuals' intakes into *EPBC* services based on their readiness—their understanding of what employment is, desire to get a job, and willingness to be trained and take feedback.

EPBC Services

Under *EPBC* supported employment, there are two forms of services offered. *EPBC* clients may access one or the other of these services, but not both.

Job Development (*JD*) services are provided to individuals considered "work-ready".

Job development is a specialized skill that demands developing relationships with potential employers and marketing both your *InclusionWorks!* group and its participants.

They have the ability to do a job with a typical job description, a job that already exists in the community. The individual might need help to do pre-work to getting a job, but they are ready to work and with support, can apply for pre-existing jobs. They may also need assistance when they start the job and some adaptations might be required to meet their specific needs on the job. Looking for a job, writing a resume, applying for a job, preparing for an interview, negotiating the terms of a new job and providing early support are services that can be provided to employment ready individuals who need job development services. Because the level of support for people who need only job development services is less, the amounts designated for payment for these services are less.

Customized Employment Development (CED) services are more intensive than Job Development services. They are for individuals who are not yet considered "employment ready" and who need more support. It also involves adapting or creating a new job (job carving) or a self-employment opportunity for an individual. The job is customized to fit the individual's skills, talents, abilities and passions in an environment that is a suitable for the individual. At the same time, the job fills the needs of an employer. The job is not applied for, it is adapted or created for the employee to meet their needs and the employer's needs.

The Customized Employment Development Process

All *InclusionWorks!* participants have accessed Customized Employment Development (CED) in one form or another. CED was developed to facilitate the support required when working with complex individuals who require extra support to find and maintain employment. It provides a personalized approach, allowing the restructuring of existing jobs and often brings together a combination of tasks that meet the needs of an employer while making the most of the skills, strengths and abilities of the worker.

What follows is more detail about each stage of Customized Employment Development process. The *EPBC* process is very linear, which has been one challenge that *InclusionWorks!* has come across with the *EPBC* system, as the lives of our participants are generally more complex.

Stage One: Discovery Process

The Discovery process determines an individual's strengths, skills, abilities, and unique qualities with consideration to the environments that are best suited to the individual. The Discovery process focuses on the positive qualities of an individual, what they're capable of, and how they can contribute. It is a time to discover an individual's diverse abilities, strengths, passions and what is motivating. For *InclusionWorks!*, the Discovery process is largely lead and completed by the *InclusionWorks!* support workers. Working closely with participants, support workers get to know each individual well and can provide great insight into the participant, which is critical to developing a job

that is a good match. The Discovery process involves meeting with others who are, or have been significant—in the person's life and can potentially give new information about the participant. For example, parents, siblings, respite care workers, home support workers, friends, former teachers, current teachers, past employers, and other natural supports can provide valuable information. A visit to the family home and the participant's personal space often provides valuable insight into the individual as well. Most of our support workers have been trained to complete the Discovery process by our contracted Employment Consultant. She provided us with an invaluable toolkit to better understand each individual, develop their employment themes, and develop ideas for potential jobs. (See "Discovery Tool" templates in Sample Documents). It should be noted that Discovery is typically a one-time service under the *EPBC* program. In theory, Discovery can go on indefinitely, as new information is gained about the job seeker but practically speaking, for the purposes of creating the Discovery profile and moving into job development, the Discovery process needs to end. The only time you would consider repeating a Discovery is when there is a significant change to the job seeker's life and the current Discovery no longer applies.

The completed Discovery profile is submitted to the *WorkBC* office. The document is extensive and meant to be used by anyone in the future who may be assisting the individual in finding employment. After submission, the individual together with their *EPBC* Case Manager reviews the document and develops an employment plan. Decisions are made on what employment services and supports are necessary to assist the individual in finding employment or becoming self-employed. In addition to the employment services delivered by *InclusionWorks!*, other services and supports may also include access to a bus pass, training courses, assistance purchasing work clothes and assistive technology, environmental adaptations, etc.

Stage Two: Customized Employment Development

Paid Employment

Once the Discovery process is completed, information from the discovery profile combined with conversations with the participant, support workers and parents, is used to look for employment that is a good fit for the participant. Working closely as a team at this stage is critical.

The employment facilitator uses the Discovery document, the three employment themes and 60 job ideas as a starting point to generating potential job leads. Using the networks of the employment facilitator, parents and other interested parties is critical. Any potential job leads generated, or contacts that have been initiated, are transferred to the employment facilitator who follows up with potential employers. Before meeting with a potential employer, the employment facilitator may create a profile of the participant. (See "Sample Profile" template in Sample Documents). The profile acts as an informal résumé. It outlines the person's strengths and experience relevant to the job and can include a photo. Depending on the relationship with the employer and how comfortable or experienced they are with employing a person with a developmental disability, the first meeting or two with the potential employer may be with or without

the participant. During the first few meetings, the employment facilitator gets to know the employer and their needs and works with them to address questions or concerns. Listening to the potential employer, the employment facilitator looks for tasks that are not currently being done or that are not being done effectively. With this information the employment facilitator can carve a new position that meets the employer's needs and the jobseeker's strengths. Some employers who have had no experience working with people with disabilities can have a harder time conceptualizing what a person could contribute to their business. The employment facilitator works with them to help them start to see and understand the strengths a person has and how they could contribute to the workplace.

Finding out the needs of an employer and making a good match between what they need and the skills, strengths and abilities of the participant is critical. The other factor that is equally important is the work environment. If a participant is very social, and they are put in an environment where there is very little opportunity to interact with others, it is less likely the job will be successful. The reverse is also true. If a participant has social anxiety and is better working on their own or with their job coach, a work environment with a lot of people will likely not work out.

The Employment Facilitator may have to make a business case for employment to potential employers. Luckily, there is strong evidence that individuals with disabilities make outstanding employees:

- 98% of employees with disabilities rate average or better in work safety.

- 90% rate average or better on job performance.

- Retention rates are 22% higher than the average for all employees.

- Customers show strong preference to spending their money in businesses that employee people with disabilities.

- There is a talent pool of 300,000 working-age British Columbians with disabilities.

> Minister's Council on Employment
> for Persons with Disabilities, 2007.

With the *EPBC* program, there are two funding points in the Customized Employment Development phase. Efforts to carve out a job must be well documented and, can be billed as CED Part 1. Then CED Part 2 can be billed once a job has been successfully negotiated and the participant has started their new job. All the details of the new job need to be documented and submitted to the *EPBC* program.

Self-Employment

For some *InclusionWorks!* participants, developing their own business and being self-employed is the best option. If self-employment is the better choice for the participant, a lot of additional support is needed. It is very important to make sure this support is available. For *InclusionWorks!* participants who have started their own business, the additional support has come in different forms. *InclusionWorks!* was able to partner with a local program, *EntreActive*, that works with people with disabilities to start their own businesses. It is our understanding that organizations like *EntreActive* exist in

Finding out the needs of an employer and making a good match between what they need and the skills, strengths and abilities of the participant is critical.

other parts of the province (e.g., *Community Futures*). In our case, *EntreActive* adapted their business development course for *InclusionWorks!* participants and over a 12-week period trained them and their support workers and our employment facilitator to develop a business plan. Laterally, for several participants, additional financial resources from *Inclusion BC'*s Ready, Willing & Able project allowed a person to be hired for additional hours a week to focus just on the development and support of the participant's business. In each case of self-employment, individuals needed a great amount of support from their family. The family needs to be invested in the business. One *InclusionWorks!* participant with a larger social network, reached out to her many friends who helped her and her business.

As with paid employment, individuals supported to pursue self-employment can access CED 1 and CED 2 funding. For the *InclusionWorks!* participants who developed their own business and received small business development training through EntreActive, the process was sufficiently documented in the *EPBC* system, including ongoing attendance at workshops and other self-employment-related activities. At this point, CED Part 1 could be invoiced.

The next stage is developing a business plan. The business plan must include the name of the business, estimated weekly hours the participant is working on their business, expected weekly income, the participant's position title, who is supporting the participant with the work, how necessary expenses are covered, and the (estimated) launch date of the business. Once submitted to *EPBC*, CED Part 2 funding could be accessed.

Stage Three: Job Coaching

To date, all *InclusionWorks!* participants have required job coaching to some degree. Job coaches play a critical role in helping the participant (new employee) adapt to their new job. The job coach plays an equally important role in helping the employer and co-workers get comfortable with the person and see them for their strengths. The job coach acts as a bridge, providing on-site training in job skills and work-related behaviour for employees with developmental disabilities. As the employee gains skills and confidence, and natural supports are developed, the job coach gradually spends less time at the work site, but remains available for retraining, assisting with challenges, and providing orientation and training for co-workers.

For *InclusionWorks!* the employment facilitator and support workers take on the role of job coaching. If the participant needs short term job coaching (6 shifts or less), the employment facilitator often provides the job coaching. If the participant needs ongoing job coaching, a support worker will be assigned. Providing job coaching support may also depend on the availability of workers and the employment facilitator as well. If there are challenges, the employment facilitator can assess and make suggestions or help develop a plan for fading out the job coach. Although the employment facilitator may not be regularly on the job site, she checks in frequently with the employees and job coaches to find out how things are going and if they (or the employer) need support with any aspect of the job. She also maintains communication with the employer and is available to assist the employer with any issue that may arise.

The *InclusionWorks!* support workers received training in job coaching although most is learned on the job. In some cases, the employment facilitator provides training/mentoring to new job coaches. With job coaching, the intent is to assist the participant to be successful in their job by encouraging and supporting the participant in their independence.

The job coach is not there to do the job. The goal of job coaching is to fade out, while helping to develop the natural supports for the participant that can come from work colleagues or a supervisor. Some participants will always need a job coach, others will rarely need one, and others will need a job coach off and on. Our goal is for the participant to become as independent of their job coach as possible, while still being successful at their job. Some experts argue that if a person continues to need a job coach then the job is not the right fit for them. We disagree. Some of our participants have high levels of need and may always require support. Because *EPBC* funding is short term, we have used *CLBC* Community Inclusion services as a way to continue support after *EPBC* funding is no longer available. That stated, our Employment Consultant believes that when job coaching it is better to fade in than fade out. That is, it is better to provide less job coaching than needed rather than more, which can create a dependency that makes it difficult for job coaches to leave.

With sufficient documentation, *EPBC* can be billed for on-site job coaching. All job coaching activities must be documented and funding for needed job coaching can be accessed a total of three times. Documentation needs to include a note that states the individual requires this support in order to maintain labour market attachment. The job coach then needs to document all relevant activities and supports in detail for each shift that is coached that includes work preparation, progress, issues, employer communications, training/teaching, transportation coordination, natural support development, and on-site support. For our *WorkBC* office, job coaching could be billed after 40 hours or when the participant becomes independent and no longer needs job coaching, whichever comes first. If more job coaching is needed, a rationale must be documented for repeating the service (e.g., 'required to maintain labour market attachment'). Policies may vary among *EPBC* employment service providers; please check with your local *WorkBC* office.

Stage Four: Job Maintenance

Once a participant becomes independent in their job and no longer requires job coaching, the next stage is to provide job maintenance support. Job maintenance support provides the participant and the employer with support needed to ensure that the job placement continues to go well for both parties. We have found that issues can arise after the job coach fades out, from either the participant's perspective or the employer's. Usually the employment facilitator provides support to both the employer and the participant to get things back on track. At times, this may mean adding job coaching supports for a period of time.

Job Maintenance support involves the employment facilitator checking in periodically with both the participant and the employer to assess the job placement. *EPBC* requires a minimum of a monthly check-in with employers. While employers and participants vary, for some employers, monthly check-ins are too frequent, so you need to find non-obtrusive ways to check-in, such as a quick e-mail. In our experience, employers will generally contact the employment facilitator if there is an issue that needs to be resolved. Regular and open communication with an employer builds relationships and can prevent problems before they occur.

We recommend frequent check ins with participants to see how their job is going. Since we work closely with our participants throughout each week, this is usually easy to do. Sometimes, however, an employee may be reluctant to discuss their less than ideal work with their support worker or employment facilitator. If workplace issues happen that the participant would like help with, the employment facilitator can assist by discussing the issue with the employer or helping the participant figure out a solution. When it is a bigger issue, the employment facilitator, team lead, job coach and parent lead and/or parents of the participant can become involved.

We have found that in most cases, when issues arise about the participant's performance at work, it is best that the employment facilitator works with the employer to determine the best way to address it. The employment facilitator or employer, or both can then address the issue with the participant. We have found that keeping employment issues separate from the rest of *InclusionWorks!* programming works best whenever possible. The employment facilitator is not with the participants as frequently as the support workers and team leads, so when performance issues arise, participants tend to listen more to the employment facilitator. When bigger issues arise at work, even though the employment facilitator is most often the first and main link to the employer, it is important to involve a job coach, team lead and the parent lead (and sometimes the parents) to help find a solution or resolution.

All relevant job-maintenance activities and supports must be recorded in sufficient detail to *WorkBC* twice monthly at a minimum. This documentation includes check-ins with the individual and the employer at regular intervals, client progress, etc. The check-ins with the participant should be at least twice a month and with the employer, monthly at a minimum.

Job Maintenance has two billing points. The first is at the 36-week point from the date the person started the job, or if there has been documented 30 hours of check-ins provided. The latter is less likely, as the check-ins do not usually take as much time. The second point is at 37-48 weeks and can be billed once the person has been in the job 48 weeks. All the rules that apply to Job Maintenance in the first 36 weeks apply. Sufficient documentation must be provided giving details about job maintenance support and check-ins with the participants and employer. However, if issues arise, if the job or management changes, it is possible to go back to job coaching for more training on-site if required. A rationale as to why the switch back to job coaching from job maintenance must be provided.

As already stated, for some participants, ongoing job coaching is needed and they may not reach the stage where they only need job maintenance support. For them, if all

of the job coaching billings have been used and they still require job coaching, then job maintenance can be used. If 40 hours of job coaching have been given, then Job Maintenance 1-36 can be used. Again, sufficient notes and a rationale for the service must be provided. Job Maintenance 1-36 can be billed two times. When both cycles of Job Maintenance 1-36 have been used, Job Maintenance 37-48 can be used. It can also be billed twice with a sufficient documented rationale for repeating the service provided to *EPBC*.

Tracking Participants through EPBC Services

In order to ensure that you are providing the necessary information and documentation to the *EPBC* program, it is useful to use a task completion checklist for each participant throughout the process from Intake to completion of Job Maintenance. This is useful for both paid employment and self-employment. (See "Sample Task Completion Checklists" in Sample Documents).

Relationships with Employers

InclusionWorks! has had a lot of success in finding employment for our participants. When we look over where our participants are working and who are their employers, it becomes apparent that most of our jobs have started with personal contacts of either the employment facilitators or families. Victoria is a small city and it does feel quite a bit like who you know is the key to finding employment, but this is likely true in many communities, even larger centres. It is said that between 50-80% of jobs are never advertised, and are found through networking and personal relationships. That seems to be even more the case when creating customized jobs for our participants.

We have found that finding employers starts with using our personal and professional networks. We start with thinking about all that has been discovered about the participant through the Discovery process. We brainstorm ideas about employment that would be a good fit. We think about who we might know that can provide us with an in to those potential places. Then, we start the conversation with them. The family governance model has the added advantage of being able to access a number of family networks.

It sounds easy, and sometimes it is fairly easy and works out better than we could have ever hoped for. One of our most successful placements started with a conversation that our employment facilitator had with a friend who is a physiotherapist. She thought that a certain participant might be interested in working in a physiotherapy clinic because of her interest in sports, the human body and her very social nature. She asked her friend if she could come with the participant and visit his clinic, so the participant could see what it was like and see if working at a physiotherapy clinic might be of interest to her. Fortunately, the clinic manager had worked at camps for people with disabilities and had seen what people with disabilities are capable of. In addition, he had a strong belief in inclusion. As well, the clinic's work was helping people take power back in to their lives after their injury and turning their disability or injury into
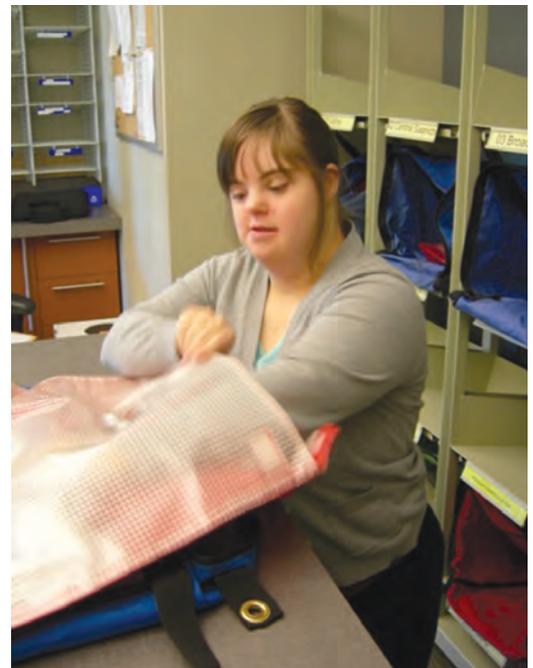
an ability, so hiring the participant fit perfectly with their philosophy. They promptly offered the *InclusionWorks!* participant a job.

The participant became fully involved in the clinic and her presence there was greatly valued. It was not without it challenges at times, but it was going so well that a manager at another clinic of the same organization hired another *InclusionWorks!* participant. And later, another clinic of this same national physiotherapy chain, hired a third participant.

One of the *InclusionWorks!* participants working at this physiotherapy clinic was featured in a CBC documentary about employment of people with intellectual disabilities, *Employment Matters*. The film, coupled with the success of the three *InclusionWorks!* participants working at these clinics led the employment facilitator to devise a plan with one of the managers to help promote hiring of people with developmental disabilities at other clinics within this national chain, starting with the Lower Mainland and Vancouver Island. At this time, at least one other clinic on Vancouver Island has hired a person with a developmental disability and a number of connections have been made for others in the BC Lower Mainland.

There are also times when it is very challenging to find a good employment opportunity for a participant. There have been times where we have found what seems to be a perfect fit, but the potential employer is reluctant. If an employer has not had a lot of personal contact with people with developmental disabilities, or has had a negative experience, trying to get them to see the benefits of hiring them can be a hard sell. In our experience, if an employer is very hesitant, it's best to plant the seed and move on without spending too much time trying to convince them that hiring a person is a good idea.

Networking, building relationships, making a great match, providing a great job coach, maintaining strong relations and support with the employer and the participant—all of these are keys to making the job match and maintaining the job. Simply put, at the core is building and maintaining good relationships with employers and participants. Both the employer and the participant need to know that you have their best interests at heart.

That might mean that sometimes you have to make it easy for an employer to let a participant go, which *InclusionWorks!* has had to do a few times. This might sound like that is only in the best interest of the employer and not the participant, but in fact it is not. If a job is not a good fit, it does not help the participant or the employer nor does it help our broader efforts for increasing community inclusion. At the same time, participants need to know that they can leave a job if it is not a good fit for them. Sometimes participants have been vocal about not liking their job. At other times, it is obvious that a participant does not like their job, even though they might say they like it. In these cases, the job coach, family, team lead and employment facilitator might need to work more closely with the participant to let them know it is okay to leave a job.

A Final Note on Employment

Delivering employment services might feel a bit daunting—after all you are a group of families, not a group of employment specialists. But the important thing is, like every other support a family-governed group might provide, family members know their loved ones best. It is the years knowing someone and the recognition and deep appreciation of an individual's gifts which lead to sustainable employment. Your relationship with your son or daughter informs all of the services and supports you design—and that includes employment. As you consider offering employment services through your family-governed group—either directly as *InclusionWorks!* has done or in partnerships with an employment service provider, remember that you and your son or daughter are in fact the experts.

We believe that Canadians have the right to work. We naturally define ourselves by "what we do". By pooling our resources and establishing community partnerships *InclusionWorks!* has been able to effectively support our participants towards full citizenship.
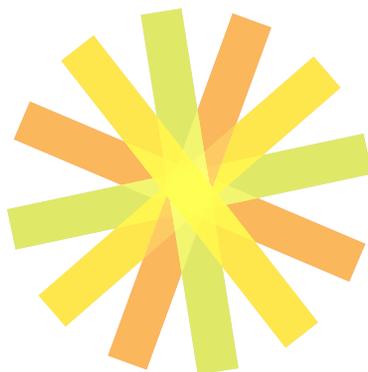
Section Three—Lessons Learned

Although *InclusionWorks!* is a relatively young model of family governance, focused on employment and community inclusion, there have been a number of lessons we have learned to date. Below are a few with very brief explanatory notes.

- The group must be based on values of inclusive community. Regardless of the pressures toward segregation, groups must constantly challenge themselves to be in community and as inclusive as possible.

- It is crucial from the earliest discussions that you have to work towards a shared understanding of values and principles among youth and their families.

- To ensure effective development and operation of the group, a Family Lead and Second need to step forward.

- A strong Host Agency is important. It's essential to seek out a Host Agency with like-minded values and one that embraces family leadership.

- As a group, there is a greater ability to leverage significant community resources not available to an individual.

- Keep the duration of your *InclusionWorks!* group to five years. Programming during the transition years should reflect participants' ages and interests and the belief that people change over time. It is important that *InclusionWorks!* groups don't become traditional day programs that continue beyond the transition period.

- You will benefit from not having a permanent physical space, particularly initially. Consider the natural trajectory of life and the goal of community inclusion. Use community spaces wherever possible. University and college-based spaces might be hard to find but are ideal for transitioning youth.

- It is essential to grow partnerships in community. Communities will be open and welcoming of partnerships when you approach them in a positive way emphasizing mutual benefits.

- Groups must have choice in partners. Partnerships will not work if the culture of the other partner is not consistent with the values of the *InclusionWorks!* group.

- In order to operate an *InclusionWorks!* group, families need to be creative and organized and work to solve problems quickly. Flexibility works in the participants' favour.

- Every family needs to volunteer. Volunteering makes everyone a stakeholder in the success of the group and increases the group's capacity.

- Collaboration and planning time are vital among families and workers. In addition to the Team Lead meeting regularly with families, support workers require sufficient time from providing direct support to participants to debrief and plan.

- When required, do not hesitate to access positive behavioural support services. Behaviour is communication and sometimes you will need help interpreting what a participant is saying.

- Families can provide employment services and supports towards outcomes equal to or better than traditional employment service providers.

- Employment is not only a goal. It is means to friendships, greater independence, pride and self-esteem, and the increased choices that come with money in your pocket.

- Resources from the *EPBC* are time-limited. This needs to be considered in terms of individualization in programming and supports as well as with regard to the longer term financial sustainability of the group.

- Risk-taking is safer when you are supporting each other as a group. The group can determine its own comfort level with risk always balancing safety with dignity of risk.

- An iterative approach to services and supports developed by and between individuals and their families and the community can over time create a more inclusive community.

- There is no cookie cutter *InclusionWorks!* group. Each group will develop its unique culture and ways of doing things.

We wish you the best on your family-governed journey!

Sample Documents

See Sample Documents on the *InclusionWorks!* website at www.inclusionworks.ca

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