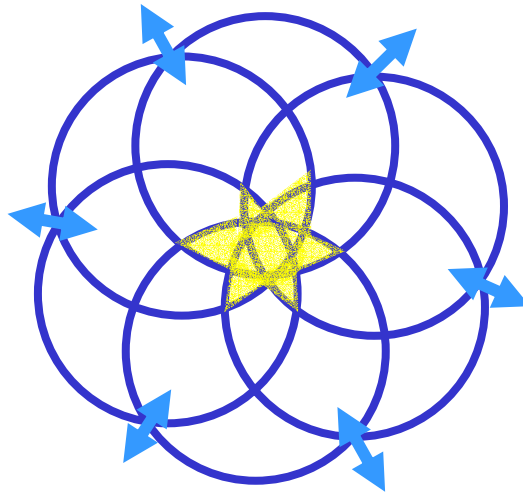


# PERSPECTIVES IN CHANGE

## ISSUES IN COMMUNITY SUPPORT FOR ADULTS WITH INTELLECTUAL DISABILITIES

### *Phase I – Final Report*



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## ACKNOWLEDGEMENTS

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Additionally we wish to acknowledge our enlightened and supportive funding agent who in the true sense of philanthropy wishes to remain anonymous.

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## HIGHLIGHTS REPORT

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Perspectives in Change is a grassroots participatory action research project that includes Continuity Care Inc., ACL Winnipeg, SCE Lifeworks Inc, Network South Enterprises Inc. and the University of Manitoba Health Leisure and Human Performance Research Institute and Faculty of Education. This study is privately funded by an anonymous foundation seeking to further the enhancement of lives of adults with intellectual disabilities through action research and community based change.

The research *focus* is on issues and opportunities supporting broader participation in work, life and community for adults with intellectual disabilities. The Research *purpose* is to identify key issues that affect the provision of community-based supports and services to adults with intellectual disabilities in work and community participation, and to develop an action plan for addressing these issues—fostering positive change. Of particular interest is the identification of factors that determine successful employment for adults with intellectual disabilities, and how this knowledge could result in more successful marketing of supported employment in general, as well as more successful supported employment experiences in particular.

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## METHODS

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More than 70 people participated in focus groups and interviews, including adults with intellectual disabilities, families, employers, support providers, and people from government departments within Family Services and Education, as well as support agency program managers.

**Focus Groups:** Participants were referred from the project partners, and invitations were also advertised in organizational newsletters asking interested people to call the project coordinator for further information. Focus groups were professionally facilitated by an external firm, with transcriptions and tape recordings.

**Adults with Intellectual Disabilities:** Two focus groups of adults with intellectual disabilities reflecting a wide range of employment experiences, representing the full continuum of support needs. A total of nine participants were recruited; five females ranging in age from 22 to 42 years and four males ranging in age from 22 to 35 years. These focus groups were facilitated by core team members and graphically recorded, tape recorded and transcribed.

**Families:** Two focus groups were conducted; eleven participants in families with youth ages 16 – 18 years and eleven participants, representing seven families with adult members with an intellectual disability.

**Employers:** Twelve participants attended one of two sessions held mid-day over the lunch hour at a downtown office.

**Support Providers:** Two focus groups (total of 17 participants) – with representation from direct service providers, supervisors and management. Both the full spectrum of support needs as well as day service options were represented.

**Interviews:** Thirteen people from departments within Family Services and Education, as well as managers of support agencies.

**Verification and Analysis of Data:** The core team analyzed the data from each focus group separately, identifying the key ideas within that group. Cross group analysis looked at ideas and themes common or different between the focus groups. Two data check sessions were conducted – one for adults with intellectual disabilities and one for families, to provide feedback on the summary of the data and verify the accuracy of the analysis and interpretation. All interviewees received a copy of their full transcript and opportunity for comment or feedback.

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### RELATIONSHIPS ARE MOST IMPORTANT

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For adults with intellectual disabilities the data shows three core values: the importance of relationships, feeling valued and the right supports- both internal and external. Adults see the relationships with the people in their lives as central- as depicted by the double heart at the centre of the diagram. Everything else in life is viewed through those relationships – good or bad. Their daily routine and job fit or activity fit is the context in which they experience *community connectedness*. Depending on how well the daily routines, job fit and the three core values mesh together determines how *community connectedness* is enhanced or diminished.

- Adults with intellectual disabilities express their perceptions of work, life and community participation in terms of the *relationships* they experience, and the people they interact with.
- Adults were very clear on their role in asking for assistance from their *external supports* and relying on them in times of difficulty or stress. The job coach or support provider in the employment site is a very important person and a positive and trusted contributor to their daily experience.
- Internal support is the importance of staying positive, persevering and using positive self -talk to work through life’s challenges.
- Feeling valued as a real contributor in relationships or roles is important; it is about recognition for a job well done.
- Daily routine and job fit is representative of the day-to-day context in relationship to achieving broader participation in the community – achieving *community connectedness*. Creating a good job fit and series of daily routines around the core values as described above enhances the overall opportunity for broader participation in work, life and community.
- Having meaningful daytime activities is very important, often expressed as a combination of paid and unpaid work, volunteer, full time or part time and recreational or leisure pursuits.
- The importance of meaningful daily routines and a good job fit or activity fit is directly proportional to the extent that it offers meaningful relationships; a sense of feeling valued with the right supports contributes to enhanced community connectedness.

“Yeah, they, like say “Hi” to you in the morning, they give you claps, they give you hi-5’s, they give you a hug in the morning, they like when you’re there. But when you’re not there, they miss you. They say “Oh, so-and-so, I missed you, how you doing?” and like that, they’re like, they want you to be there.”

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### FAMILIES VALUE RELATIONSHIPS & ACCESS TO INFORMATION

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Families with youth and families with older adults are represented by the top and bottom of this diagram respectively. The arrows in the middle represent common perspectives for both groups. The “parental pipeline”



is a both a need and an opportunity, whereby parents expressed how they value learning from one another but need to get more connected with other parents for the purpose of learning or mentoring. Both groups of families identify access to information as an issue and acknowledge that families learn well from the experience of other families. The relationships their family member experiences are also most important.

- Families identify three main challenges: the challenge of accessing information on the range of options and opportunities, navigating the whole transition timeframe for school to work and child to adult services, and making plans for the transitions of later life.
- Families of youth are concerned about the issue of *finding* positive and meaningful *relationships* – both paid as support and unpaid as friends, co-workers or community people. For families of adults who are involved in work or day activities, the focus is building and *keeping* the *relationships*.
- Frustration is caused by not knowing where to go for information within the “systems” of support and service providers, as well as the quality of response from information providers.
- Parents rely on, and prefer to learn from other parents and would welcome more networking or structured ways to connect with other parents more easily.
- Parents feel strongly that work is more than a job. The dreams and realities of work and *career* cover a wide range of job types; full time, part time, paid or unpaid, volunteer, combinations of jobs and recreation are all acceptable and desirable if the experience supports positive relationships and happiness.
- Parents value the personal growth achieved by broader participation in the community.
- Families are very aware of the necessity for improved community awareness and acceptance, which they see as directly linked to achieving greater inclusion and opportunity for their kids.
- Parents see access to support, services and funding as one of their greatest challenges.
- Parental advocacy is critical; older parents worry that the younger generation should be more active lobbying for supports and services – especially for later life planning.
- Parents see opportunity for improvement in many areas – but particularly later life planning, partnering with business and strategies to improve public awareness and acceptance.

“It is case of deciding what the priority is – what is frustrating parents- access to information and finding the direction and looking for answers. Let’s eliminate that problem and get on with answering the real problems – not finding the information. Our kids do not need the extra baggage of our frustration.”

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### SCHOOL TO WORK TRANSITION IS FRUSTRATING FOR FAMILIES

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The timeframe of *school to work transition* is a major area of concern and frustration for parents. This topic also relates to the issues of access to information on the range of options and opportunities and how well, (or not) the school and family services system is doing at guiding parents through the complex maze of transition. The *school to work transition* process is often described as a set of protocols that are anchored within the school system, but it is really much more. *School to work transition* is a five to seven year journey of planning and decision-making, crossing the boundaries of different school and government authorities. Parents need to drive this process, but often lack the information and the roadmap, as well as the consistent support of all involved.

- Planning for natural supports and community integration means fostering relationships and activities in the neighbourhood that can last a lifetime.
- While in school, preparing for job readiness is a critical skill development goal that requires focused activities and usually includes a variety of work experience situations.
- Parents should proactively communicate with their community services worker to ensure a smooth transition to adult services between ages 16 and 18 years. Additional discussion is needed to plan for

appropriate funding after graduation at age 21 for supported employment or day support as well as community living plans.

- Parents have the right to request several “PATH” (“Planning Alternatives for Tomorrow with Hope”) sessions between the ages of 14 and 21 while in the school system. PATH planning is an important person centred visioning process looking at possibilities for the future.

“Schools did not have an understanding of the work force or the agencies that supported individuals. They only had a very narrow focus, and that was the sheltered workshops and they still do, they have no ideas what agencies are out there, if you, as a parent, come in and say to the school “you’ve known my son for 12 years, what would you recommend?” They say “we can’t make a recommendation because that would favour one agency over another.” And then they can’t tell you anything about the system, if you go from the school system to the social service system, they can’t tell you how to do that either.”

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### EMPLOYERS VALUE SUPPORTED EMPLOYMENT AND A GOOD FIT

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Employers value creating a good fit for supported employees which includes the employer culture, the supported employee and the agency job coach or liaison person. A good fit is achieved by focusing on the relationship, the task, the training, time for on-going training, job support, direction, a safe and positive environment, job growth opportunity, clearly defined roles – especially for the on-site job coach, and a real and valued contribution.

- Senior management talks about productivity, morale contributions and public perception or marketing as being real benefits of participating in supported employment.
- Front line supervisors and co-workers talk about the initial investment of training time, but derive personal satisfaction from the relationship with the supported employee and how they could not imagine their workday without the individual.
- Benefits of supported employment are perceived differently by senior management and the co-workers.
- Supported employees offer real contributions from both an economic and humanistic perspective.
- Some employers were at times frustrated or confused by the role of the agency liaison person and/or the on-site job coach.
- For the on-site job coach, clearly defined roles and expectations as well as on-going communication are especially critical to resolving *role clarity* issues.
- Employers see the benefits of supported employment as hiring someone with an incredible work ethic who is a role model to others, and freeing up other staff for other duties, as the right thing to do, as good for the corporate image, and an important positive morale builder within their workplace.
- Employers feel that many entry level or menial jobs can be staffed more easily with supported employees at the entry-level pay scale.
- Challenges for the employer relate to finding the right combination of job tasks in a supportive environment with good training as well as on-going re-direction and establishing a relationship with both the employee and the job coach.
- Employers typically get involved with supported employment because of awareness resulting from having a family member or friend with an intellectual disability, experience working with people who have intellectual disabilities or awareness of other employers who are involved with supported employment.
- Employers who are currently involved with supported employment feel strongly that they could assist with the recruitment of other employers for new supported employment positions.

“His attitude is incredible, and it’s infectious. He is certainly a positive influence on the other staff members, because he’s always smiling, always happy, always enjoying himself.”

“You wonder is there like hundreds of people that are just standing there waiting for a job, an opportunity and what can I do about it? Well, I can show that I have one person I work with and it works extremely well for 10 years and there’s other people now that I’ve met that are in exactly the same case as me.”

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### ROLE CLARITY ISSUES ARE COMPLEX FOR SUPPORT PROVIDERS

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Role Clarity complexity is the issue that support providers and others experience as they balance the perspectives of many people in support of an individual with intellectual disabilities. Support providers recognize that they need to have the supported adult’s best interests focal to all they do. *Role clarity* in this diagram shows the support provider as central and the arrows pointing inwards represent the influencing people or organizations that impact how the support provider does their job.

- Support providers see themselves as an intermediary between all the people in an adult’s life; as a social convener, an educator, an advocate, an employment specialist and a coach for developing self-advocacy skills.
- Front line support providers answer to many people- supervisors, other support providers or agencies, families, employers of supported individuals, co-workers and the individual they support as they try to do what they think is best.
- Support providers recognize that some employers are confused about the role of the on-site job coach or agency contact person.
- From a personal perspective, *role clarity* frustration for the support provider is living with the issue of entry-level wages, growing educational requirements and a job that requires complex relationship management skills. High turnover is a natural occurrence among support providers.
- Some support providers feel that they had to educate young adults and their families about the range of options and services after graduation from school.
- The *role clarity* issue in relationship to graduation comes from needing to assist training for skill development that should have happened while in school and not on the limited funding or support available for locating a job once the individual has graduated.
- Support providers are frustrated by the ignorance and perceived injustices their clients may encounter in the work world or in the community.
- One of the biggest challenges for support providers is striking the balance between caring and coaching: allowing enough emotional investment to be a good support while maintaining enough emotional distance to manage the day to day pressures of the job.

“Not everybody’s reality’s the same, so in giving support, you’ve got five people giving support to the same individual, sometimes the individual can get confused. You know, they’ve got Mom’s perspective, sister’s perspective, Dad’s perspective, my perspective, my employment professional’s perspective, voc rehab worker, too many people sometimes involved and they can get “I don’t know what to do anymore.”

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### ACROSS ALL FOCUS GROUPS –COMMUNITY CONNECTEDNESS IS THE GOAL

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*Community connectedness* is the extent to which an individual is involved and participating in a wide variety of community based activities and relationships. Across all the data from focus groups there were many common threads relating to the positive results achieved and meaningful experiences shared when adults with intellectual disabilities participate in a wide variety of community based activities and relationships. When all the circles of positive contributing factors overlap in connected harmony then a star is created at the centre. This star represents the individual and the strength of *community connectedness* that they can experience. Pressure points

are those factors that pull away from the positive contributing factors and diminish the experience of *community connectedness*.

#### POSITIVE CONTRIBUTING FACTORS FOR COMMUNITY CONNECTEDNESS

- **Relationships** are one of the most significant motivators or positive contributors in life for adults with intellectual disabilities. Adults with intellectual disabilities perceive life through the quality of relationships they experience.
- **Meaningful Roles** have adults with intellectual disabilities contributing to the best of their potential and being appreciated and valued for that contribution. The contribution is real and may be in an economic sense or a humanistic sense as described by employers, or it may be as one or more of the many roles we all have and experience in life.
- **Information and Options** represent access to the range of services and supports as well as access to funding to receive the actual services and supports. For families this was one of the most frustrating challenges, but by being more aware of options and opportunities families and individuals can make more meaningful life plans.
- **A good fit** is the term representing the positive characteristics and qualities that contribute to meaningful supported employment or day activity program and the relationships, as well as being valued for a real contribution.
- **Community perceptions** about adults with intellectual disabilities are an important indicator of the potential for *community connectedness*. As community members become more aware of the valuable contributions made by adults with intellectual disabilities, more opportunities will be available and therefore easier to achieve *community connectedness*.
- **Life milestones** are the significant events that take place in life as one ages such as starting school, completing school, starting work, progressing through work life, births, deaths, marriages and completing the life cycle with retirements and changing health or ageing. These milestones are an important part of *community connectedness* as experienced and celebrated by people with intellectual disabilities. Because some of these milestones are perhaps stressful or negative or bring risk, some adults may be sheltered from experiencing these milestones for themselves or sharing them with others. Participating fully in life and community includes participating in natural life milestones in ways that are meaningful for all people.

#### PRESSURE POINTS ON COMMUNITY CONNECTEDNESS

Pressure points are the situations or factors that need to be well supported, with good communications in order to achieve *community connectedness*. When pressure points are not well managed they pull the circles of positive contributing life factors outwards, and diminish the sense of *community connectedness*.

- **Life roles** refer to how well adults with intellectual disabilities are able to live and experience natural life roles and relationships that occur in their circle of family, friends and community. This includes roles and relationships such as son or daughter, sibling, adult- no longer in a child relationship with parents, co-worker, tax payer, voting citizen, and even employer when one takes into consideration the various people earning their livelihood as they support this individual. Life roles for many people with intellectual disabilities can become pressure points as they are managed, controlled and planned by the supports around them. The degree to which these life roles are able to evolve naturally becomes the degree to which enhanced *community connectedness* can be better achieved.
- **Role clarity** is complex and a major pressure point. Role clarity, if not well managed with effective communications and shared priorities, can cause frustration and confusion for all involved. There seems to be issues of conflicting philosophies, priorities, areas of responsibility, defining best interests – all in support of one person's life. Ensuring that everyone who cares for and supports an adult with

intellectual disabilities has a similar outlook and understands how their interaction contributes to the holistic life perspective is an important contributing factor to achieving *community connectedness*.

- **History** is the continuity through a person's life; understanding and learning from the experiences that have already occurred. History is a pressure point when the same things are tried over and over, each time called something new and different. History is a pressure point when learning from the past is ignored and not acknowledged. To achieve *community connectedness* it is important to always strive for improvement and this is sometimes best achieved by learning from what has worked well in the past and what is best to avoid.
- A meaningful **life plan** that helps us to achieve our goals and objectives is important but the reality is much of what happens in our life is the product of serendipity or chance. For adults with intellectual disabilities there is very little opportunity for serendipity or chance, because there are so many people involved and so many plans – some of which have little to no input from the adults themselves. Planning is a pressure point because so many adults with intellectual disabilities experience life only as defined by one or more of the many plans and people around them. Ideally adults should experience life as natural life milestones happen and plans would be invisible and holistic, understood and supported by all involved. *Community connectedness* requires both a plan and serendipity.
- **Transitions** are defined as the system imposed processes that align in a rather un-natural way with some life milestones. A natural and happy life milestone is high school graduation. The school to work timeframe is a frustrating and challenging transition, as system-imposed rules do not always align with the life milestone.

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## INTERVIEWS - SUPPORTING PERSPECTIVES

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**Relationships and Community Participation:** The concepts of relationships and community participation were raised by many of the interviewees as an area of importance in the lives of people with intellectual disabilities. However, there were differences of opinion as to how to help foster relationships and what might help or hinder true participation and involvement.

**Access to Information, Services and Supports:** Access is another prevalent theme that emerges from the interview data. The data illustrates that access to information is problematic due to the number of systems involved in supporting people with intellectual disabilities and the unfamiliarity of each of these systems with the others.

**School to Work Transition:** Analysis of the data revealed that life transitions were seen universally as pivotal points in an individual's life. Many transitions were mentioned including transition into school, transition from school to adult life and transition to retirement and senior years. However, the transition from school to work was seen as a particularly trying process for individuals and families.

**Role Clarity:** The theme that has been identified by the core team as role clarity was less of an issue for these informants. However, role clarity remains a subject that requires further analysis. There continues to be a discrepancy between the focus group participants and the roles of direct support providers. Thus the core team feels that further analysis must be completed at the next level.

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## CONCLUSIONS ON PERSPECTIVES IN CHANGE

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Perspectives in Change has identified many issues and opportunities in support of broader participation in work, life and community for adults with intellectual disabilities. The data findings as gathered from the focus group and interview participants clearly identify the value of connecting with the community in meaningful activities, work and relationships with as much opportunity for integration and participation in the community as reasonably possible.

Perspectives in Change has been about finding ways to better understand issues in community support for adults with intellectual disabilities. Participatory action research was used as a means to garner inclusion and input from the community of stakeholders and interested participants. Through this research, many valuable ideas and suggestions were identified from the focus group and interview participants, generating considerable interest and energy within the community of interested people, organizations and employers.

Key findings from Phase I include the identification of an overarching theme of *community connectedness* as a positive goal for adults with intellectual disabilities. Enhanced *community connectedness* is a goal for adults with intellectual disabilities shared by the people who care for and support them. *Community connectedness* is a dynamic interplay of positive contributing life factors and pressure points.

This research found that relationships are most important for adults with intellectual disabilities, while relationships and access to information on the range of options and opportunities is most critical for families. For the family group it was also concluded that the school to work transition process is far more than just a “protocol” and individuals and families need the knowledge and skills to co-ordinate years of planning and decision-making. Employers described how creating a *good fit* for work opportunities supports the success of the employee, the employer and the support provider. In the support provider group *role clarity* issues were identified and recognized as creating confusion and frustration for support providers and others.

The focus of the Phase II recommendations is the creation of sustainable processes that further enhance opportunity for broader participation for adults with intellectual disabilities. It is important to note that the five Phase II projects also intend to use participatory action as the means to engage the community in developing sustainable activities and processes to support broader participation in work, life and community for adults with intellectual disabilities.

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## ACTION STEPS – PHASE TWO

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### **Project One: Options and Opportunity Forum for Parents and Youth**

- Engage community stakeholders in planning and implementing a sustainable annual options and opportunities event for adults with intellectual disabilities and their families.
- Focus on helping families to learn about philosophical perspectives of inclusion, life planning, day programs, supported employment options and community living options.
- Provide networking opportunities and facilitated discussions so individuals and parents can learn from one another.
- Look for ways to evolve this event to possibly include potential employers, job prospects and profiles of successful supported employment situations.



**Project Two: School to Work Transition**

- Identify the perspectives of educators regarding their role in the preparation of children and youth with intellectual and other developmental disabilities for valued participation in community life. This project represents the continuation of research and analysis into the activities around transition and how to enhance the process for families and youth.

**Project Three: Campaign to Increase Public Awareness of Supported Employment**

- A communications strategy that will help to bring together employers and their supported employees with positive profiles targeting professional and trade publications as well as the broader community. The benefit is increased general awareness and acceptance of adults with intellectual disabilities in the workplace as recognized and valued contributors and employees.

**Project Four: Employer-to-Employer Outreach Program for Supported Employment**

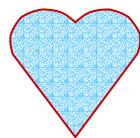
- Based on suggestions from the employer focus groups, this project will create a sustainable employer-to-employer presentation and profile program, building on the successes of current employers involved with supported employment and encouraging the recruitment of new employers. This effort is also supported by Project Three, coordinating the communications strategy of with the launch of the Employer program and increasing the overall awareness and potential benefit.

**Project Five: Identifying and Assessing the Impact of Role Clarity Confusion**

- Recruit key community stakeholders to further assess the complexity of *role clarity* issues, identifying systemic opportunities for awareness, education and information that help to mitigate the frustration felt by front line support providers. Through further data collection and analysis with an expanded group of key stakeholders this project hopes to foster positive change through increased awareness, understanding and communications.

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# Snapshot of themes and ideas ...



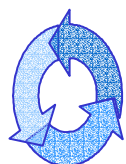
**“Relationships Are Most Important”**

Adults with Intellectual Disabilities



**“Relationships and Access to Information”**

Families



**School to Work Transition “Not Just Protocol”**

Families



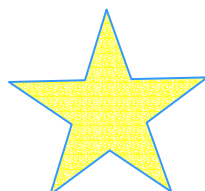
**Creating a “Good Fit” Supports Success**

Employers



**“Role Clarity” Issues are Complex**

Support Providers



**“COMMUNITY CONNECTEDNESS  
IS THE GOAL”**

Enhancing Community Connectedness is a dynamic  
interplay of positive contributing factors  
and pressure points



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## EXECUTIVE SUMMARY

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Perspectives in Change is a grassroots participatory action research effort on the part of a core research team comprised of community-based advocacy groups, support agencies, and researchers from the University of Manitoba. This study is privately funded by a foundation seeking to further enhance of the lives of adults with intellectual disabilities through action research and community-based change.

The research focused on exploring issues and opportunities that promote broader participation in work, life and community for adults with intellectual disabilities. The purpose of the research was to identify key issues affecting the provision of community-based supports and services to adults with intellectual disabilities in work and community participation, and to develop an action plan for addressing these issues in order to fostering positive change. A sub-purpose was to explore and document those factors that support and encourage businesses currently employing people in competitive and supported employment settings, in order to expand supported employment opportunities.

Over the past two years more than 70 people participated in focus groups and interviews, including adults with intellectual disabilities, families, employers, support providers, individuals representing the government departments of Family Services and Education, as well as support agency program managers. The core research team completed the data collection, validation and analysis summarized in this Phase I Final Report.

The major result of the Phase I research was the identification of an overarching theme of **community connectedness** as the goal for adults with intellectual disabilities. Enhancing **community connectedness** is also a goal shared by the people who care for and support these individuals. **Community connectedness** is defined as the dynamic interplay of positive contributing life factors and pressure points and is more fully described in the body of this report.

The core team was also able to distill one or two major issues from the data of each focus group. These are depicted in Diagram #1 on the facing page. The resolution of each of these issues leads to the overarching goal of **community connectedness**. The research data showed that creating and maintaining relationships is the most important issue in ensuring a feeling of connectedness for adults with intellectual disabilities. Families felt that relationships for their family members and access to information on the range of options and opportunities available were most critical. The school to work transition process was identified as being far more than just a **protocol**. Thus the issue for families is being able to more easily identify the ways and means of accessing information in order to co-ordinate transition planning and decision-making to secure the best life possible for their family member. Being able to access more information and plan better will result in an increased feeling of **community connectedness**. Employers revealed that the issue for them was being able to assist in creating a “**good fit**” within the workplace to help ensure the success of the employee, the employer and the support provider. A “**good fit**” in an employment setting will help people with intellectual disabilities feel better connected to the community. The data for the support provider group indicated an uncertainty about the exact nature of the support role. **Role clarity** issues were therefore identified and recognized as creating confusion and frustration for support providers and others involved in the supported employment process.

Proposed recommendations for the implementation of five initiatives in Phase II are summarized at the end of this report and more fully in the Phase II Proposal document. The focus of

# What are the issues and opportunities relating to effective supports for adults with intellectual disability to work and participate in the community?

## FOCUS GROUPS

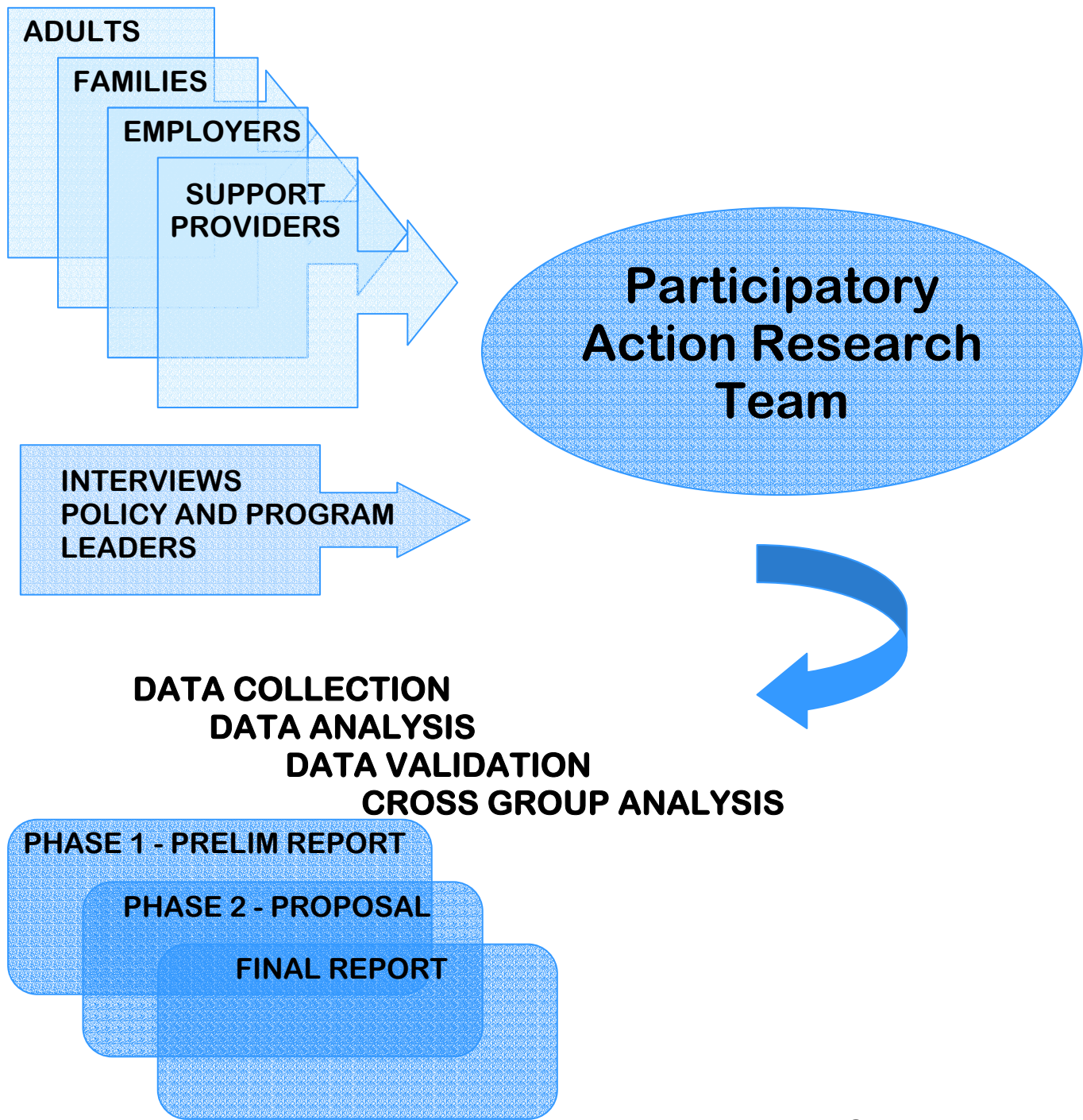


DIAGRAM # 2

the Phase II recommendations is the creation of sustainable processes that will further enhance opportunities for broader participation in work, life and community for adults with intellectual disabilities. It is important to note that in the five Phase II initiatives, participatory action will also be the means to engage the community in developing the final outcomes.

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## INTRODUCTION

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Phase I of Perspectives in Change represents a multi-stage process to address the complex issues of broader participation in work, life and community for adults with intellectual disabilities. The first phase of this research project utilized participatory action research methods, involving more than 70 stakeholder participants including adults with intellectual disabilities, families, employers, support providers, individuals representing the government departments of Family Services and Education, as well as support agency program managers. This study is privately funded though an organization representing anonymous philanthropic interests. The impetus for this project comes from the community of support providers committed to the principles of inclusion for adults with intellectual disabilities.

Through an intensive review of the data, the core research team of Phase I of Perspectives in Change has identified some key issues that must be addressed in order to broaden and encourage the ultimate goal of community connectedness. It has also developed an action plan with that aim. The Phase I Preliminary Final Report, Phase II Recommendations and Actions Steps have been completed for distribution to the funding agent. The Phase I Final Report has now been completed and will be distributed to the partners and all stakeholders.

Diagram #2 on the facing page depicts the research question and process employed.

### RESEARCH QUESTION:

**What are the issues and opportunities relating to the provision of effective supports for adults with intellectual disabilities that promote or discourage fuller participation in the community?**

Supports and services that are required for full community membership are not available to adults with intellectual disabilities - particularly those with intensive support needs. This “gap” is especially evident in employment sectors, where community-based (non-sheltered) opportunities are insufficient to meet the demand of students moving from educational settings to employment settings. Therefore, the sustainability of community-based supports and services are at-risk because of limited financial resources such as government funding, and community-based opportunities.

### PURPOSE:

- To identify key issues affecting the provision of community-based supports and services to adults with intellectual disabilities in work and community participation.
- To develop an action plan for addressing these issues in order to foster positive change.

A sub-purpose is to explore and document those factors that support and encourage businesses currently employing people in competitive and supported employment settings, in order to expand supported employment opportunities.

## INTENDED OUTCOMES:

- A comprehensive analysis of the issues related to providing individualized supports to people with intellectual disabilities within work and community settings, with particular emphasis on individuals with intensive support needs.
- The development of recommendations to address these issues in consultation with various constituency groups such as families, service providers, employers, and individuals with intellectual disabilities.
- The enrolment of stakeholders in taking action through the Phase II implementation of the Recommendations and Action Plan.
- The preparation of a Phase I Final Report in which the issues and recommendations are summarized; and the preparation of a Phase II Proposal for Implementation and Evaluation.

## CORE RESEARCH TEAM

The core research team members are involved in various capacities in promoting and supporting adults with developmental disabilities to work and participate in the community. The team includes the following members:

### University of Manitoba

Dr. Jennifer Mactavish, Health Leisure and Human Performance Research Institute  
Dr. Zana Marie Lutfiyya, Faculty of Education  
Dr. Christine Blais, Health Leisure and Human Performance Research Institute

### Community Partners

Oly Backstrom and Colleen Isfeld, SCE Lifeworks Inc.  
Shelly Ferec-LeGall and Krista Bissett, Network South Enterprises Inc.  
Janet Forbes, ACL Winnipeg  
Bob Manwaring, Continuity Care Inc.

Further information on Core Research Team members can be found in Appendix 1.

The existing supports and resources for adults with intellectual disabilities are at a point where strategic initiative is required in order to ensure continued progress. This is why the core research team has dedicated time, effort and energy to tap into the community of concerned participants to clarify and better understand the issues and foster positive action through “Perspectives in Change” research and recommendations. The project partners gratefully acknowledge and give thanks to the enlightened support of their funding agent.

### Setting the Context

The impetus for this research evolved as a result of discussions with two managers of supported employment agencies and Dr. Jennifer Mactavish of the Health Leisure and Human Performance Research Institute. A social marketing campaign was initially discussed as a means of profiling and promoting supported employment. Dr. Mactavish suggested a participatory action research (PAR) approach that would bring all stakeholders together to explore the issues and collaboratively identify actions that might increase participation of people with intellectual disabilities in all aspects of community life, with particular emphasis on employment.

PAR is based on the notions of cooperation and consensus and therefore offers a successful way of “setting people on the common path” without the divisiveness that may accompany efforts to reconcile multiple interests and needs. The process involves including individuals, who have traditionally been the subject of research studies, as full partners in the research process (Oliver, 1997). One of the defining elements of this approach is the participation of all stakeholders in identifying the issues that define a topic or problem with the intention of translating this knowledge into action (Stringer, 1996).

An opportunity to acquire private funding for research aimed at improving the lives of marginalized people was identified. This resulted in the creation of “Perspectives in Change”, a collaboration of a committed team of volunteer participants, referred to as the Core Research Team, to steward the project and facilitate the participatory action process. A project co-ordinator was hired to bring organizational skills and data and document management to the project.

The first phase of the project was undertaken to identify the issues related to supporting adults with intellectual disabilities in the community and to develop a strategy to address these issues, using the PAR method. The aim of the research was to assist in implementing a strategy to strengthen and further evolve community-based supports and supported employment.

Because this research is privately funded and not accountable to any one specific agency or organization, it is especially important to generate the interest, energy and enthusiasm of the community in order to successfully implement the project’s recommendations.

### STRATEGIES AND PROCESS FOR INVOLVING FOCUS GROUP PARTICIPANTS

The process of identifying potential focus group participants was a combination of referrals from the core research team members, as well as open invitations advertised in newsletters from various organizations asking interested people to call the project co-ordinator for further information. Letters were sent to potential participants, outlining the project, explaining confidentiality issues and highlighting the focus group process. Once a participant confirmed his or her interest, a letter and a copy of the consent form was sent confirming the date, time and location. Each focus group participant was offered a \$25 stipend and assistance with transportation if required. When the participants arrived at the focus group site, they were asked to sign the consent form and a receipt for their stipend.

### *Adults with Intellectual Disabilities*

For adults with intellectual disabilities, several different actions were undertaken. The core research team generated a list of potential participants who offered a range of perspectives, experiences and degrees of ability and/or support requirements. The goal was to create two focus groups of adults with intellectual disabilities that reflected a wide range of supported employment experiences and who represented the full continuum of support needs.

The nominating core team member made the first contact by way of a letter of introduction and invitation or personal phone call. Approximately 20 first contacts were made with individuals and, in some cases, their parents or care provider. Once the first contact was responded to in a positive way, the project co-ordinator followed up with a phone call to confirm participation. In a few cases, a written invitation was extended. Once a participant was confirmed, the project co-ordinator arranged to meet with the individual at their home in order to complete the consent form and explain what was involved in being a focus group participant.

The initial meetings were an important part of establishing a rapport and introducing the participant to the topic of discussion. The project co-ordinator was able to review the list of questions, complete the consent form, and help each participant to feel comfortable with the upcoming process.

Of the 15 invitations extended, nine participants were recruited: five females ranging in age from 22 to 42 years and four males ranging in age from 22 to 35 years. Further details about the participants are included on page 20.

The focus group sessions were held at the Winnipeg Centennial Library on two different evenings. The sessions were facilitated by two core team members experienced at leading group discussion with adults with intellectual disabilities. The facilitation team used a discussion leader as well as a graphic recorder who charted the group's responses on a large wall of paper across the front of the room. The project co-ordinator, who met participants during the initial meetings, acted as greeter, hostess and note taker. The focus group sessions were tape recorded and transcribed.

### ***Families***

Two focus groups were conducted with families: one group having a family member with an intellectual disability aged 16-18 years (families of youth); and the other group having an adult family member with an intellectual disability (families of adults). The families of youth were recruited through a general letter of introduction sent by Special Olympics to those families on their database who had a family member in the required age bracket. Families were invited to contact the project co-ordinator to indicate their interest in participating. In addition, newsletters from the agencies involved in the project included a general notice requesting volunteers. Eleven participants were recruited for the families of youth focus group. On the day of the focus group meeting, two participants did not attend; one family was represented by both parents; and one mother chose to bring her daughter so she could speak for herself.

For families of adults, a general introduction and invitation was extended through four different newsletters and membership mail-outs to people affiliated with the support or advocacy agencies partnered with the project. People were again invited to contact the project co-ordinator directly to express an interest in participating. Additionally, the support and advocacy agencies sent general letters of introduction and invitation directly to selected members of their organizations.

Through self-identification, seven families were recruited with a total of eleven participants. Further details about the participants are included on page 24. Two evening sessions were conducted back to back at a market research office downtown and were led by a professional focus group facilitator. The sessions were tape-recorded and several core team members observed the groups through privacy glass with prior disclosure to all participants.

### ***Employers***

The process of nomination from various core team members was used to identify potential participants for the employer focus groups. Letters of introduction and invitation were sent, indicating that the project co-ordinator would call directly to follow up. If an employer chose not to return the project co-ordinator's phone call, it was accepted as a decline. Twenty-one letters were sent to employers and 12 participants were recruited. Two participants did not attend on the day of the meetings. There was a choice of two session times, both held at a downtown office. A professional facilitator, who made full disclosure to participants that the sessions were



being tape-recorded and observed, led both sessions. Further details about the participants are included on page 31.

### ***Support Providers***

Two focus groups were created to represent support providers: one was comprised of front-line or direct support providers and the other was comprised of supervisors or mid-level managers. In the participant selection process, the core team endeavoured to ensure that participants supported people who were involved in the full spectrum of daytime options. Once the source organizations were identified, the project co-ordinator called the director or senior manager, in order to introduce the project and ask for support in identifying potential participants for the focus groups. For potential participants employed by the relevant core research team member, a private letter was sent asking for their participation, and requesting that they contact the project co-ordinator if interested. The project co-ordinator provided further information only to those people who called to express an interest in participating. Using this process, 23 people were recruited for these focus groups and six did not attend on the day of the meetings.

The focus group sessions were held back to back in the evening at a downtown office. Professional facilitation was used and sessions were tape-recorded and observed. Further details about the participants are included on page 37.

## **PROCESS FOR IMPLEMENTING DATA COLLECTION STRATEGIES**

During the focus groups, a semi-structured question guide was applied across all the groups with only minor adjustments relevant to each of the groups. Table #1 below shows the types and examples of questions used. For the adults with intellectual disabilities, the same question flow was used with fewer follow up probes, as the group spent more time articulating their thoughts. The graphic recording was a valuable tool as it allowed the facilitator to verify the accuracy of the data with the participants and to clarify inaccuracies.

Table # 1      Typical Question Flow in the Perspectives in Change Research Project

Question Type	Example of the question and follow up probe
Introductory	Tell us about ... (your family member, your work, your supported employee, your role as a support provider)
Transition	What factors support broader participation in work, life and community? What is the connection between the activities and participation?
Key	What are some of the obstacles, barriers or issues related to participation? What is working well, what is not working?
Summary	What is most important to making this work – broader participation? What are the critical success factors?
Closing	Any other thoughts or ideas on things you wish to share today?

## **PROCESS FOR COMPLETING VERIFICATION AND ANALYSIS OF DATA**

The core research team members reviewed all data independently and then participated in a group discussion. Each focus group session was analyzed separately for the purpose of identifying key ideas. Overarching themes were noted for further follow-up during the cross-group analysis. During the analysis discussions, the core team began by sharing initial reactions or comments to the transcripts. Then a structured group process technique was used whereby each person wrote their thoughts or ideas on large “post it” notes. The notes were then placed on a visible wall and the group proceeded to work collectively through a sorting and thematic exercise. This technique is referred to as “build the wall”, and allowed for both the creative energy of independent analysis and the capturing of new ideas through participation in group discussion. The team was able to visually reflect on the analysis and create diagrams for each of the focus groups. The team then used the intensive approach of a full day session to complete the cross-group analysis. All meetings were recorded and transcribed, with detailed summary notes documenting the build the wall “post it” notes and any other visuals created.

Additionally, two data check sessions were conducted – one for adults with intellectual disabilities and one for families. The purpose of these sessions was to provide an opportunity for participants to offer feedback on the summary of the data and verify the accuracy of the analysis and interpretation. Three people attended the adult meeting and eight people attended the family session. In both sessions, the participant feedback validated the interpretations of data and analysis. It was anticipated that data check sessions for employers and support providers would not be well attended as significant effort was involved attracting participants for the original focus groups. For this reason, and because of the strength of the validation experience with families and adults, it was determined that additional data check sessions would not be conducted with the employers and support providers. The team was also cognizant of the fact that all participants would be invited to a presentation of the Phase I Final Report and Phase II recommendations. Core research team members felt that this final presentation meeting would be more successful in attracting employers.

## **INTERVIEWS**

Interviews proved to be important for data collection and validation, as well as for recruiting key stakeholders from managerial and governmental positions. Thirteen interviews were conducted with people from the Department of Family Services and the Department of Education, as well as managers from various support agencies within the community. The purpose of the interviews was to look at how the perspectives of the focus group participants - adults, families, employers and support providers – are being supported by the systems and organizations that serve them. The analysis of the interview transcripts focused on how the perspectives of the interview participants supported or differed from the various focus group perspectives.

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## **FINDINGS**

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This section contains a detailed description of the research findings from each the focus groups. A cross-group analysis follows and provides a summary of the core research team’s interpretive perspective on how the focus group data and analysis link together in support of the overarching goal of community connectedness. The interviews are discussed following the cross group analysis.

During the analysis process, the core team created a simple graphic to depict the findings from each group of participants. The graphic is a summary of what was heard from the participants and includes interpretative analysis of the data. The narrative write up is a description of the graphic and the analysis. Supporting quotes from the data follow.







# **“Relationships Are Most Important”**

**Adults with Intellectual Disability**

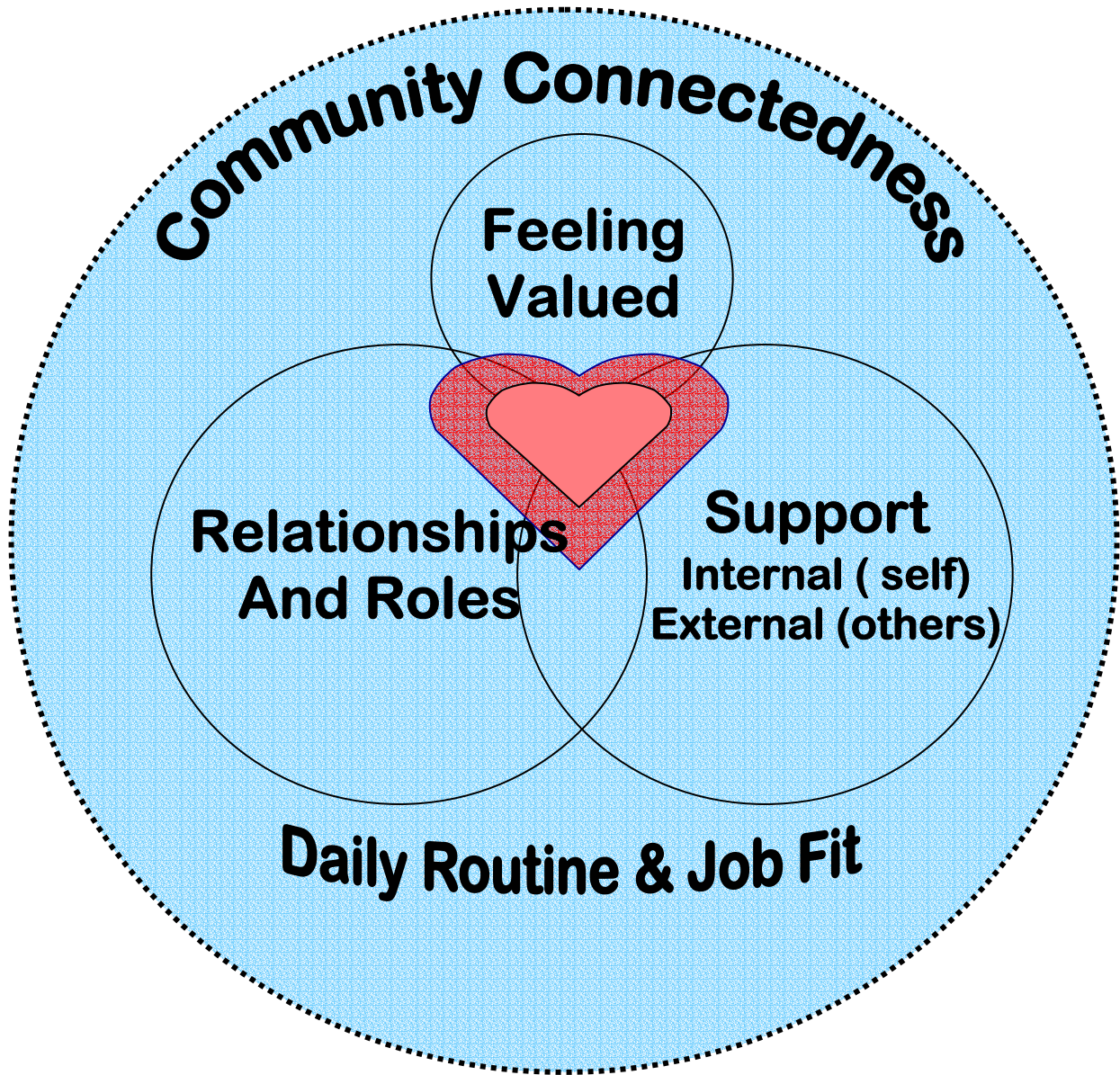


Diagram # 3

## **1. ADULTS WITH INTELLECTUAL DISABILITIES**

### **INTRODUCTION- SETTING THE CONTEXT**

Two focus groups for adults with intellectual disabilities were held on June 24<sup>th</sup> and 27<sup>th</sup>, 2002 at the Winnipeg Centennial Library. Nine participants attended for one of two sessions for approximately 90 minutes of discussion.

The participants ranged in age from 22 to 42 years and all had completed some form of high school, progressing onto an assortment of work and volunteer opportunities. With the exception of one individual, all the participants are affiliated with a supported employment agency. Some people are employed at a competitive wage while others are looking for paid employment and currently volunteer. Some adults live at home and others live independently with support. Some adults can work independently whereas others require individualized support.

As depicted in diagram #3 on the facing page, three prevalent themes emerged from these groups: having valued relationships and roles, feeling valued, and having the right supports, both internal and external. Community connectedness is enhanced or diminished based upon how well the daily routines and job fit mesh together. Community connectedness is identified as the ultimate goal for all adults with intellectual disabilities and summarizes the themes expressed by the focus group participants.

The following headings provide a description of what each theme represents to the focus group members. A selection of supporting quotes follows.

### **PERSPECTIVES ON RELATIONSHIPS AND ROLES**

Without exception, the adults with intellectual disabilities express their perceptions of work, life and community participation in terms of the relationships they experience, and the people they interact with. This perspective is central to their being and central to their perception of a good life. The situations described centre around people, relationships, and feeling valued by others. A sense of being able to contribute and belong is a powerful motivator and life enhancer.

As the core team progressed through the focus group dialogues, it was very evident that adults with intellectual disabilities perceive themselves and their activities in direct relationship with the people around them. All of the experiences described and situations encountered came from the perspective of interactions with others.

“Yeah, they, like say ‘Hi’ to you in the morning, they give you claps, they give you hi-5’s, they give you a hug in the morning, they like when you’re there. But when you’re not there, they miss you. They say ‘Oh, so-and-so ... I missed you, how you doing?’ and like that, they’re like, they want you to be there.”

“Yeah, the customers are nice, too, like there’s nothing like saying ‘Hello, Good Morning’ or ‘How are you’ and ‘How’s your afternoon’, that makes the customers very happy. Yep.”

“Employees make you, like make you want to be at that job.”

“I love it ... Nice people work there.”

“I love talking to people ... I like going out with people for lunches ... Yeah, and people at Special Olympics. I go out for lunch with them, or we go out at night some times ... Once a week, if there’s time ... Yes, and I like e-mailing people.”

## SUCCESSFUL SUPPORT IS INTERNAL & EXTERNAL

### *External*

External supports are those supports that come from support providers, co-workers, supervisors, friends, family and schools. Focus group participants were very clear and articulate on the role and value of the support provider as a job coach. They described the support providers as very important people, and positive and trusted contributors to their daily experiences. Participants were also very clear when they discussed asking for assistance and relying on the people supporting them in times of difficulty or stress.

“Talk to somebody about what, when you leave high school, talk to, get somebody to come to your school and talk to them, and ... Yeah, they have two people coming to your school and they talk to you about which, what organization you want to go into, and then you can talk and phone them and talk to them ... I picked Lifeworks because I thought that organization would help me find a job, but I got my job before I graduated high school. I got a part time job before I finished”.

“Well, first thing in getting a job, I guess you have to know certain people who will help you find a job and keeping a job, well, um, I guess it’s doing it well.”

“The people I work with ... Um, well, um, sometimes I talk to all of them, and it makes my job easier ... Because like if I have a problem or something, then I talk to the foreman about it and then they tell me to work.”

“She’s easy to talk to and she sits down and she listens to me, when I have problems at work, and she says ‘Okay, this is what I’ll talk to the supervisor and I’ll tell her this problem and this problem’ and she gets back to me, tells me ‘Okay, you have this problem and you could just get along with your people that you’re working with’ and stuff like that.”

“Basically, someday I’ll basically phone my parents, but I don’t always have to phone them, I can phone like other people that are on the support network, like sometimes I can phone like my staff members and talk to them and talk to other people that are involved.”

“I have a job coach, and I have any problems my job coach comes and helps me at the job ... I see her once a week and we go for coffee, and we talk about the problems at work, and she deals with them, and then she calls my supervisor and she talks to them about problems sometimes at work.”

### *Internal*

Internal supports are defined as the wisdom of learned experience and the development of coping strategies to deal with life’s many challenges. They include knowing the importance of staying positive, persevering and using positive self-talk to work through issues. Group members seemed willing to share their own experiences with others during the session. It was difficult to determine whether or not these internal supports stemmed from an emphasis on staying positive that is enforced by the school system, as the age range of participants would have encompassed a variety of educational approaches over time.

“Respect the person, believe in yourself, don’t be scared. Sometimes get frightened that is the nature of it, stand up for yourself, hang tough, don’t be nervous, don’t panic, do what you can, that sounds good.”

“Give them a chance to learn and grow with job.”

“Have patience ... Because I know patience is welcome when you’re looking for a job.”

“Just take it easy, and not get so frustrated, like go to where you need to find a job and just search on the computer or find it in the paper or something like that.”

“Or just stay in your job and be good to the employees and not get frustrated and not talk back to your employees and if they want you to do something or go upstairs to the lunch room, just be in your job and have fun in your job and not get frustrated and not .”

“It’s probably good advice. There you go, so that’s what you do when people nag at you. Keep smiling.”

“Just think if you’re frustrated, and we know frustrated with the people and the people are gonna get on your nerves and just go outside and calm down for a while. You don’t get mad at them, you know, make a scene in front of the customers.”

“You have to enhance, reach a goal, work hard, go out into the real world, real job, go to a place with a job coach and resume.”

“Give a chance, see what you are able to do, patience.”

Participants spent a considerable amount of time talking about internal and external supports. They tended to see themselves as a part of the solution for frustrations they encountered and were open to seeking guidance and support from others. The positive comments regarding the role of external supports also confirms the research findings that relationships are very important to adults with intellectual disabilities.

## **FEELING VALUED**

Feeling valued is the sense of reciprocity in a relationship and represents the quality of that relationship. Relationships make people feel valued because they are being accepted for who they are and what they have to offer others. Having a variety of relationships is important, but it is also important that some of those relationships contribute to a sense of feeling valued as a real contributor. During the focus group sessions, the discussion focused on feeling valued in the daily work setting. Participants valued both the sense of personal achievement and accomplishment, as well as the recognition from others of a job well done.

In terms of feeling valued at work, participants did not distinguish between paid work, volunteer work, full-time and part-time work. Doing a good job, fitting in and knowing how to manage the day-to-day job, all contributed to a sense of being valued at the workplace. Financial compensation was not found to be a primary motivator for people, but participants recognized that getting paid is another way to feel valued and appreciated.

“Sweeping and taking out the garbage and vacuuming, that’s the three jobs I like to do. That’s very important, like taking care of the floors and then mopping and washrooms and stuff. And plumbing, I used to do that, because I remember, and you use a plunger and say if the toilet got blocked up, you got to use a plunger and put it in and you know what? I did it, eh, and I did it some other time. So I put the plunger in, bingo, I got it going.”

“I love, my job for me is ... um hm. It’s a perfect job ... I look forward to it.”

“When I get to work, I see a big mess and then ‘oh good, time to get to work’.”

“And I can trust a person, too. I’ve got Vaughn, who works with me, and I’ve got a guy, name’s Fred, he’s my biggest boss and I can trust him and he can trust me ... Because I’m a good worker and that’s why I’ve got to keep the place clean, or clean up.”

“That’s what I feel a little bit important.”

## **DAILY ROUTINE AND JOB FIT IN SUPPORT OF COMMUNITY CONNECTEDNESS**

Daily routine and job fit is not the language of the participants, but is representative of the day to day context in which relationships manifest themselves to achieving broader participation in the community – community connectedness. In the analysis of the data, both within these focus groups and across focus groups, there was evidence to indicate that creating a good job fit and series of daily routines around the prevalent themes as described above, enhances the overall opportunity for broader participation in work, life and community.

“I’m looking for a job because basically I can’t live independently without having a job. Basically I need from In The Company of Friends, which that, basically I get my money from, but basically I also need money so I can fend for myself.”

“Well, sometimes I wake up happy sometimes, it’s a very nice day out and I guess, it’s the way I feel. Sometimes I feel happy, like you’re happy, I go to work.”

“They’re always nice to me ... And they help and I like the team.”

“No, I like the whole, I love the whole thing. I just love the whole thing.”

“I am doing my dream job.”

“On the weekends I bowl ... And I love gardening, too ... I like going to the cabin ... Since my Dad passed away, I don’t go nowhere (camping).”

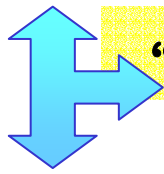
“Yeah, and I’ve got a nice place to live and I’m glad I got one. I live right now on >>> and I got my own place now.”

“Yeah, they have a party, they have parties like with their birthdays, they invited me or they go places if they have private parties, they invite me, too.”

## **DISCUSSION**

Focus group data for people with intellectual disabilities clearly demonstrates the importance of having relationships with others and of feeling like a valued and contributing member of the community. Participants acknowledged the role of internal and external supports in their lives. Having meaningful daytime pursuits was very important whether it was paid or unpaid work, volunteer opportunities, full or part-time jobs or recreational activities. Being able to participate and feel included was more important than the nature of the pursuit itself. These factors all contribute to an enhanced level of community connectedness.





## **“Relationships and Access to Information” Families**

### **Information Seekers**

#### **FAMILIES OF YOUTH “GREAT EXPECTATIONS”**

Focusing on  
School to Work  
Transition

**PARENTAL PIPELINE  
of information**

- Relationships are most important
- Caregiver fatigue
- Hope for job/activity that is safe & accepting
- Parents experience fear, uncertainty & doubt

**Finding**

**RELATIONSHIPS**

**Building  
&  
Keeping**

### **Generational Learners**

#### **FAMILIES OF ADULTS “PRAGMATIC ACTIVISTS”**

Focusing on  
Later Life  
Transitions

Diagram # 4



## 2. FAMILIES

### INTRODUCTION – SETTING THE CONTEXT

#### *Families with Youth*

The ten participants in this group were all parents of youth with intellectual disabilities who will be leaving the school system within the next five years. The teenagers attend both integrated and non-integrated programs and range in age from 16 to 19 years. All teenagers are in transition to Adult Services and are eligible for support from the Department of Family Services. One participant brought her 18 year-old daughter with her to participate in the discussions.

The focus group discussion led the core research team to characterize the families with youth as “information seekers” with “great expectations”. One of the most pressing concerns for this group is accessing information on the range of options and opportunities available to their family member, as well as navigating the transition process from school to work and from child services to adult services. Generally, the participants felt that relationships and happiness are most important for their family member.

#### *Families with Adults*

Ten participants ( including six couples) took part in this focus group, representing seven adult family members ranging in age from 25 to 42 years. These participants spoke from their personal experiences as driving forces behind improvements to integration in education, and as founding members of advocacy groups or support agencies. They acknowledged the significance of being knowledgeable and being an involved advocate.

The core research team characterized the members of this focus group as people who are able to offer the strength and wisdom of “generational learning”, and who approach challenges from the view of “pragmatic activists”. This group focused on the “big picture”, or community perspective, and how their family member participates and contributes. As with the previous family group, these participants saw relationships as the key to community connectedness and inclusion. They felt that the focus must involve building and maintaining relationships and finding the right combination of work and day opportunities that foster community participation.

Diagram # 4 on the facing page summarizes the data gathered from both family focus groups and shows some common perspectives. Both groups identify access to information as an issue and acknowledge that families learn well from the experiences of other families. The relationships that their family member experiences are also of primary importance. They recognize that throughout life, they will continue to face the challenge of helping to find and foster relationships for their family member.

The following material in this section provides a description of the focus group results and analysis. Each key theme is followed by a selection of supporting quotes.

### RELATIONSHIPS

As with the adult focus group participants, parents also identified relationships as the most important factor in creating a feeling of community connectedness. For the families with teenagers, the focus was primarily on finding and fostering positive and meaningful relationships – both paid (support providers) and unpaid (friends, co-workers or people in the community). For families with adult family members who are involved in work or leisure opportunities, the focus was on building and maintaining relationships. The focus group families saw community-based relationships as instrumental to achieving happiness, a sense of feeling valued and being connected with others. They also acknowledge that it cannot be assumed that all families

understand how critical community-based relationships are, or that all families know how to go about fostering these relationships.

“Isn’t our goal in life to be happy, and to enjoy our life and to be of service to other people? Well, our kids like that too.”

“Relationships are core to the whole thing.”

“We need a ‘how to’ – how to set up lifelong relationships. This needs to be talked about because we can not assume that families know this is so important or know how to do this.”

“We need the paid relationships but especially the not paid relationships. Our children need to meet lots of people in the community.”

“While they are in school relationships are much easier, it just happens. When they are out of school the hardest thing to do is to find relationships and how to integrate. All their friends from school have moved on.”

“The most important thing is happiness, feeling valued as part of the community- who cares if they get paid or not- I don’t think money is as important as happiness.”

## **ACCESS TO INFORMATION AND OPTIONS**

Families spent a considerable amount of time talking about their frustration with the challenge of accessing information on the range of options and opportunities available for their family members. The frustration relates to being unaware of where to go in order to get information within the “systems” of support and service providers. They felt that many of the typical information providers, such as educators, schools and the Department of Family Services, do not have a full appreciation or awareness of the available options and opportunities, how to access them, and what supports and services are most appropriate for the individual in question.

Parents were also quick to acknowledge that they would prefer to rely on and learn from other parents who have been through similar experiences, and would welcome more networking opportunities or structured events to connect with other parents. Access to information and the ability to translate that information into an action plan for their family member, are critical to improved participation in work, life and community for people with intellectual disabilities.

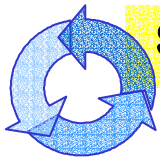
“Why is it so tough to get information? Why do we have to go through a maze of government offices?”

“We all experience difficulty in accessing information – wondering where to go, what is the path. It is not just families with youth- but also us older families with adults with intellectual disabilities.”

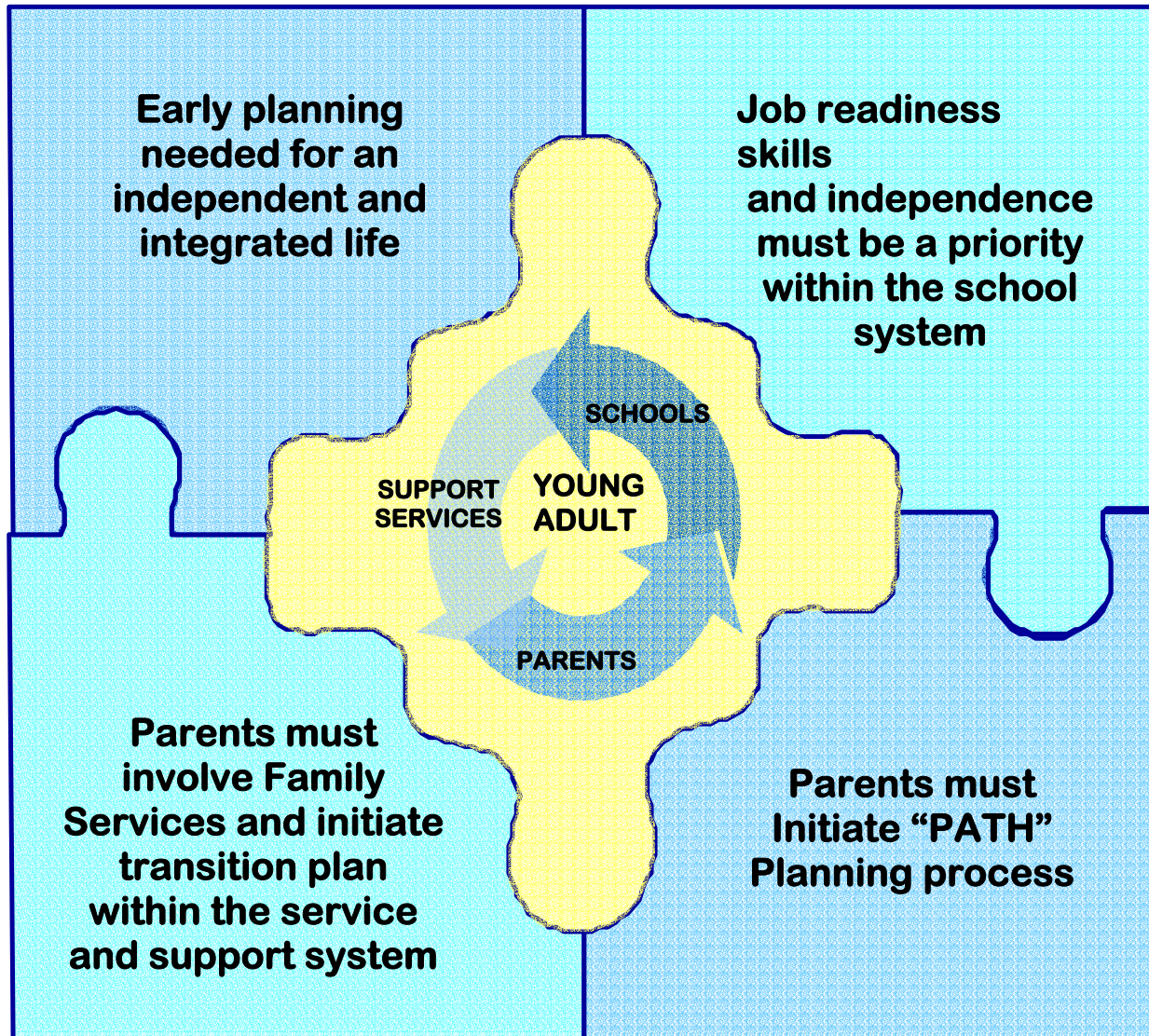
“We need realistic information, not pie in the sky. Some theories are unrealistic and our children can not be lumped as all the same in a category.”

“It is case of deciding what the priority is – what is frustrating parents- access to information and finding the direction and looking for answers. Let’s eliminate that problem and get on with answering the real problems – not finding the information. Our kids do not need the extra baggage of our frustration.”

“We need to further develop that after school years networking opportunities - it is not well developed.”



## School to Work Transition – “Not Just Protocol” Families



*Families want and need better  
access to information on the range of  
life options and opportunities*

Diagram # 5

## **SCHOOL TO WORK TRANSITION**

The school to work transition is a major area of concern and frustration for parents with teens, especially as it relates to the issue of access to information on the range of options and opportunities. Diagram #5 on the preceding page depicts the complexity and inter-connectedness of people and organizations involved in the transition period, as well as the topics that need to be understood and addressed by parents. The school-to-work transition process is often described as a set of protocols that are anchored within the school system. In reality, however, the school-to-work-transition process is a five to seven year journey of planning and decision making, crossing the boundaries of many different educational and governmental systems. Parents need to drive this process, but often lack the information, the roadmap, and the support of all parties who are involved.

“I have one son who is, I guess you would say, mentally challenged. He is 16 years old, my husband and I really don’t know what to do, where to turn. He is at school and they can’t figure out a grade that he could possibly be in, so he sort of had to individualize by phone call between me and somebody who arranges his work and he may spend some time in some classroom, that sort of stuff. But about jobs, what he can do, we don’t know...”

“Yeah, and I had the same experience with K, and I said ‘it’s mandated here, you have to start transition by the age of 16’ and just stayed in their face, was very persistent, nicely, but I didn’t go away. And finally at 17 they started to do some planning and the resource teacher just didn’t believe that K could be a part of the work force in any capacity, um, and I just was really insistent, I just didn’t go away, I just kept saying ‘yes, you know, we’ll do a path, I’ll bring people in’ and I think they finally did it, just thinking if they did it they’d get rid of me.”

“Schools did not have an understanding of the work force or the agencies that supported individuals. They only had a very narrow focus, and that was the sheltered work shops and they expressed complete, and they still do, they have no ideas what agencies are out there, if you, as a parent, come in and say to the school ‘you’ve known my son for 12 years, what would you recommend?’ They say ‘we can’t make a recommendation because that would favour one agency over another.’ And then they can’t tell you anything about the system, if you go from the school system to the social service system, they can’t tell you how to do that.”

## **CAREER - THE GOAL AND THE REALITY**

Parents felt strongly that work is more than a job. Some parents spoke of a “career and all that it implies”, meaning the broad spectrum of work-based opportunities that offer a meaningful connection with other people and a sense of being valued. The dreams and realities of work and career span a wide range of possibilities, as long as the experiences promote and foster positive relationships and personal happiness.

Parents spoke of progressive opportunities for learning and growth, including participation in a variety of tasks, flexible scheduling, and the possibility of trying different jobs to see what fits best. Some parents shared concerns that their family members were being encouraged to choose the first available opportunity and were therefore not allowed or encouraged to explore a variety of personal interests and work situations.

Notwithstanding the challenges they face, parents expressed considerable pride in their family member’s accomplishments.

“... to stay in school until he’s 21. Next year he will be going to work experience and working part-time. But our goal is, and his goal is to continue his education and the ultimate goal is a career.”

“So our vision is to have our son to be, first of all, a productive human being and that career means, cooking is a career as long as you do the best you can at it. It gives you warmth, it gives you feeling, it gives you growth, it gives you education, you get to fraternize with your peers, you’re on the ball team, you’re on the golf team, you’re asked to go out, the social aspect. So I think jobs suggest six months here and a month there.”

“I think our hopes are just that he would have a job at something consistent, meaningful for him.”

“Somewhere he, where the job is fulfilling, um, where there’s going to be growth and where he would have socialization, where there would be people to talk to and interact with. He would need to be quite supported.”

“She’s going to have to try a number of things to find where she can fit in, and she needs one-on-one support. ...Does it have to be same job five days a week? It could be two or three jobs in that week. She likes to socialize with people so giving her that opportunity, it would be beneficial to have more than one place to go to during the week. Certainly having her integrated within the community, working at an established business, getting paid for it, is an objective. But again, if she’s happy working at a place that is less integrated, that wouldn’t bother me a whole lot. Again, it is the happiness, the fulfilment that she experiences that’s the most important thing.”

## **BENEFITS OF COMMUNITY PARTICIPATION – WORK AND ACTIVITIES**

### ***Community Involvement Fosters Awareness and Acceptance***

The participating focus group families were very aware of the need for improved community awareness and acceptance, which they saw as directly linked to achieving greater inclusion and opportunity for people with intellectual disabilities. When families first spoke of the benefits of community-based employment, recreation and leisure opportunities, they made it clear that they saw their son or daughter’s inclusion and participation as a role model for increasing public awareness. By being present in the community, they can demonstrate the range of abilities and contributions that people with intellectual disabilities have to offer.

“... [my child] is bringing awareness to the rest of the community that mentally challenged people can function in our society. I have nothing against sheltered workshops, if the kid’s happy and enjoying what they’re doing, great. But I question how much knowledge the rest of the community’s given about what’s going on in that business.”

“I would say that, as a society, we’d be better off knowing that mentally challenged people can function in society.”

“He took a public bus and like you say, the public exposure and the back and forth, the bus driver knew him very well. ... to having his little bit of money put in Astra Credit Union so he got to go there, got to know the girls there, withdrawing money and so on, they talk to him by name and make a fuss over him – it’s just great. He had to go to the post office and buy his own bus pass, same thing there. He was interacting with people and he gained a great deal.”

## ***Community Participation Fosters Personal Growth***

Families spoke at great length about the examples of personal growth and development their family member has achieved by working and participating in the community. Individuals demonstrated new skills and abilities that some parents had not seen before. These comments demonstrate the importance of focusing on the potential abilities of people with intellectual disabilities, rather than dwelling on inabilities. Opportunities to grow and extend oneself help to achieve community connectedness through broader participation in work and life.

“It gives purpose to his life. It gives him a reason to get up in the morning, and even when our son is sick, for example, he doesn’t quite understand why he can’t go to work. He loves to go to work, it’s good for him physically, socially.”

“I think the thing that’s important to him, that takes a lot of responsibility as to getting himself there on time and I think he feels good about what he accomplishes and things are a challenge. He comes home and talks about things the challenge and how, you know, they’ve had a tough day and what happened and all that kind of stuff. I think it gives him a sense of purpose and it makes him feel valued.”

“It’s amazing, absolutely amazing! Everything that everybody else said is true of K as well and she used to be called KK, but we can’t call her that, not at work anyway, she’s K at work. And she’s just matured, just incredible.”

“And she’s just so confident and the language that she’s developed, she comes home with different words every day, because she has cerebral palsy, she has what I call the cerebral palsy accent, her speech isn’t always clear and she used to communicate, she’d try to pick out the key word and use one or two, now she comes home and I have to tell her to please be quiet. [laughter] It’s just incredible and using not simple words. Really extensive language.”

“If you had asked me three years ago what my son would be doing today, I would have shrugged and said I just don’t know. But all through high school he did work experience so had two years of training and now he works in a personal care home and delivers trays and folds towels and I would never have seen him doing all that. But he is lucky – he has a job coach and that has helped him to have the opportunity to learn.”

## **CHALLENGES & ISSUES**

### ***Support Issues***

The family participants acknowledged that although government cannot take the sole responsibility of providing for people with intellectual disabilities, there must be some level of expectation for basic supports and services. Funding for individualized support was a major focus of discussion as an announcement to cut funding for individualized support had just been made by the government.

“She’s 18 in September, she’s mentally challenged, non-verbal. She will definitely need one-on-one support when she’s out of the school system. We have concerns about how she’s going to get that one-on-one support.”

“No one would dream of telling a person with a physical disability ‘you have to share your wheelchair with two other people,’ but I mean that’s what they’re saying about individuals. That blows my mind.”

“I think transportation’s a barrier. I think getting around is a barrier. I think transportation is a barrier to go from ‘A’ to ‘B’. A child at 16 gets his license. T, at 16, it was a big event to take a bus.”

“He has to be supported in his activities, otherwise it’s difficult for him to participate. So that’s always the challenge, it’s not so much the activity, it’s finding the right kind of support, and finding the people to do it. Sometimes we, as his parents, are getting to an age where it’s very difficult for us to do the sport that he’s doing, or that we’d like him to do.”

### ***Parental Advocacy Challenges***

The families involved in the focus groups were very aware of their role as advocates and the power that advocacy can have. Many of the families are involved in board level positions in advocacy or support agencies, some were the founding members. The parents of teens tended to be somewhat less experienced. Parental fatigue was a common problem, with many parents feeling tired of having to fight for information, services and supports with many different organizations and governmental departments. Despite the fatigue, parents recognized that the need for advocacy is critical and never-ending.

“It’s going to require advocacy, both by individuals and business, institutions, whatever. It is going to require money, funding, whatever you call it, by government AND businesses.”

“There’s some horror stories out there that shouldn’t exist but you have to be right on top of it. You have to go in and lobby at your school, we’ve been through it lots, but after a while you get tired of it.”

“You don’t feel like this confrontation all the time. It’s not part of your life, it takes the harmony out.”

### **PARENTS IDENTIFY OPPORTUNITIES AND OPTIONS**

Overall, the families who participated in focus groups offered very positive perspectives. Where they encountered challenges or issues, they also identified opportunities, which have been grouped into planning, partnering with business, and public awareness. The following quotes support each of these opportunities.

#### ***Planning***

“And it’ll be a big problem because as of now those [residential] homes are staffed on the basis of them being at a day program, and when they are no longer able to be at that day program, that requires 24 hour staff and that’s money. Where it’s going to come from, we don’t know.”

“I think that’s definitely necessary when our children don’t work any more is that there’s enough recreation services available for them, so they don’t sit in front of the TV from morning to night and then get all sort of health issues. They have to be taken out and have physical activity, just outings and stimulation and I think that is a very, very important part of this.”

“Probably the other thing that these parents need to do is to plan for our ultimate demise and the old age of our young people.”



### ***Partnering with Business***

“If you could, you know, make it something for the business community to aspire to, to have um, some people with special needs on staff and to support them and make it a symbol of prestige within the community to be doing those sorts of things, I think over time it might help to make it more part of the overall community.”

“We need a really good marketing plan and strategies to introduce our children to the community.”

“... some kind of advocacy that goes around to all companies so that they’re aware that these people can be good.”

### ***Public Awareness and Acceptance***

“I think we have to do a much better job of public awareness, pointing out that our children do have values, they do have skill and they should have equal rights in society, just like anyone else. And it seems that whenever there’s budget cutbacks, the cuts are made on the backs of our children.”

“I think a major factor is acceptance, or if you wish right now, many of our problems are due to a lack of acceptance. I think if there’s acceptance of our children, this opens doors, it creates awareness. Politicians then recognize a need, educators say ‘hey, let’s look at the ability here, not the disability,’ employers say ‘these people can do a job just as well as the others, maybe better in many instances.’ So I think acceptance, awareness is very significant.”

### **DISCUSSION**

Members of the family focus groups agreed on a number of points. Firstly, they stated that relationships are the most important key to community connectedness. Secondly, they found the lack of accessible information to be very frustrating. Finally, they felt that community participation brings many benefits, both in terms of broader awareness and acceptance by the community, and in terms of personal growth and development for their family member. The transition processes, particularly from school to work, are not well planned and are difficult to understand and navigate, given the fact that each organization and department has only a small piece of the overall puzzle.

The family focus group participants were very action-oriented and brought forth many ideas and suggestions for improving outcomes for people with intellectual disabilities.







## Employers: Creating a “Good Fit” Supports Success

### Employers (Senior Management)

- Where “buy in” is initiated
- Motivated by benefits and increased productivity
- Respect testimonials from other employers

### Suggestions:

- Parade successes
- Make participation easy
- Celebrate with public recognition
- Anticipate issues
- Explain roles of agency and job coach
- Encourage direct communication with employees

### Support Agency

#### Both employer groups value:

- Morale boost
- Strong work ethic
- Positive public image
- Increased productivity & economic value

### Employers (Supervisors & co-workers)

#### Value:

- Employee relationship & social interaction
- Sense of feeling good
- Agency follow-up – customized to the situation
- Ownership of situation

### Supported Employee

#### Both employer groups suggest what is required for success:

- Adequate training time
- Positive relationships
- Strong supervision
- Save environment
- Job tasks are enjoyed by employee
- Opportunity for growth in position
- Employee’s sense of feeling valued

### Employer

### Supervisor & Job Coach

### A “good fit” should exist in terms of:

- Tasks
- Relationships/personalities
- Training & Support
- Environment (physical, social & cultural)
- Opportunity for growth

### A good fit should exist between:

- Supported Employee and Employer/work environment
- Agency/job coach and Supported Employee
- Agency/job coach and Employer/work environment

Diagram # 6

### 3. EMPLOYERS

#### INTRODUCTION – SETTING THE CONTEXT

##### *Employer Groups*

The employer focus groups were represented by both senior management and front-line supervisors or co-workers. In the first group, six senior management participants represented a courier company, a hotel, an automotive dealership, a sporting goods store and a mailroom. The companies have been involved with supported employment for periods ranging from four to ten years, and employ anywhere from one to three people at their site. Experiences with supported employment were mixed in the early stages, but all participants reported being pleased with their current supported employment environment.

The second employer group was comprised of four participants in direct co-worker or supervisory roles in the areas of office assistance, mailroom/courier services, retail and hotel housekeeping. Supported employees worked independently and were either supported as individuals or in small groups. Focus group participants spoke very positively about their personal relationships with the supported employees. While both groups spoke in glowing and positive terms there was a slight distinction between the first and second group, which may also be reflective of the senior management versus front line employee perspective.

The management group discussed supported employment in terms of productivity, morale contributions, and public perception or marketing benefits. The front-line supervisors and co-workers related their day-to-day experiences and personal relationships with the supported individuals. Although the initial investment took time, training and patience, these participants said they could no longer imagine their workday without the supported individual.

The following material in this section provides a description of the focus group results and analysis. Each key theme is followed by a selection of supporting quotes.

#### CREATING A GOOD FIT SUPPORTS SUCCESS

Overall, several themes emerged from the employer groups. The main theme is the need to create a “good fit” between the supported employee and the support provider, on the one hand, and the work environment, on the other. This is depicted on Diagram #6 on the facing page. A good fit incorporates a number of components, including: a positive relationship between the employee and the supervisors and co-workers; an enjoyment of the tasks being performed; sufficient time to train, as well as time for on-going training as necessary; proper job support and direction; a safe and positive learning and working environment; the opportunity for job growth; clearly defined roles – particularly for on-site support providers; and the opportunity to provide a real and valued contribution. Although this definition is complex, focus group employers were easily able to identify the components of a good fit and indicated that this could be achieved with reasonable effort and focus.

Some employers were at times frustrated or confused by the role of the support provider. This can have a significant effect on the supported employment situation because this role is critical in establishing a good fit. Focus group participants said that the support provider needs to understand the company culture and needs to be an effective communicator with the company management at all levels. For those support providers who follow up with the supported employee periodically, it therefore becomes important to determine the best follow-up process, and to recognize that support provider turnover can complicate relationships within the employing organization. Participants also felt that the on-site support providers require clearly defined roles and expectations, both for their own understanding as well as the understanding of the employers and co-workers. It is also critical that there be open lines of communication between support providers and employers and co-workers. Employers sometimes felt a level dissatisfaction with the high turnover rates of support providers as well as with the approach of some support providers towards the supported employee.

“They’re wonderful, you know we were talking about it today that they show up for their shifts, they have dedication, they are better than some of these 15, 16, 17 year olds on the streets that don’t care about the job. They really care, which is really good. I mean, that’s what we need in a service industry.”

“They add a lot of value to our dealership, customers enjoy seeing them working and often kid around with them and often take them for coffee as well. So they really, they communicate well with our customers and our staff.”

“They’re a small but very valuable part of our staff. P does maintenance tasks and duties with support and V does the more product preparation.”

“She works 9 to 3, 5 days a week, and she loves her job. She hates being away.”

“They do general janitorial work in our warehouse and they’re really well liked, especially Y. He’s been around for a very long time, so he’s got a lot of relationships with the different people that we have. We have over 300 employees, so there’s a real fondness for some of these individuals.”

“He works with the maintenance department, he does general janitorial duties, sweeping the stairwells on a daily basis. His attitude is incredible, and it’s infectious. He is certainly a positive influence on the other staff members, because he’s always smiling, always happy, always enjoying himself.”

“I found that the only problem I had was the turnaround with the job coaches. We’ve gone through a lot of job coaches. If I’m not mistaken, sometimes we would have one for two, three weeks and then it would be someone else and then another someone else. And, you know, this person would pop up out of nowhere and say “I’m here”, you know “who are you?” Seriously, that kind of thing, and they’d say “I’m Jim’s replacement, I’m C’s job coach.”

## **BENEFITS OF SUPPORTED EMPLOYMENT**

Senior management focus group members identified many tangible benefits to supported employment, from both a direct economic perspective, as well as a social environment or work culture perspective. Although direct supervisors and co-workers recognized the productivity contributions, their discussions focused more on the relationships that supported employees enjoyed with their employers, fellow staff and customers.

The employer groups reflected on the major benefits of hiring an individual with an intellectual disability through supported employment: supported employees model a strong work ethic; other staff are free to do other duties; supported employment is the right thing to do and is good for the corporate image; and it is good for morale.

Some employers spoke in terms of dollar savings and having the benefits of supported employment agency training. Employers recognized that because many entry-level positions are difficult to staff and require the payment of premium wages, it is wise to hire a capable and trusted supported employee to fill these positions.

### ***Economic***

“I didn’t think I did anything and like they think it’s the world. You give them an inch and they think it’s a mile and other people laugh at you, you know, if you want them to work overtime. They actually take pride and care in their work, whereas quitting time comes, everybody else just runs for the door, so it’s a win/win for both sides.”

“I would say that they’re one of the most reliable employees that we have, they’re always there, they’re always on time, always early. They know what they’re doing, um, and they’re fun, we’re always laughing down there.”

“She works harder than a lot of people I know, honestly.”

“She starts when she’s supposed to start, she works through her break, like she works the 8 hours that she’s supposed to work. If you do the math, the person that, you know, fools around a bit and slacks off 5 minutes extra here, quits early, at the end of the day she accomplishes more or an equal amount. You kinda can see when people are brought in and they’re working, you know, everybody else is stopped and she’s working away and they’re kinda looking and they go ‘well, I guess we should be working,’ it helps in that aspect.”

“You have to break the job down into simple steps and explain it to them. And in doing that, you learn something about the company, too ... But so often with supposedly normal people, you assume they can hit the ground running and you don’t take the time to explain it right, where, and then you run into problems later on; with these individuals, you take the time, you actually build a better employee in them.”

“When you have to break it down, you find shortcuts, you save money, you better organize the job and you train employees better. So again, it’s a win/win for both sides.”

“Says a lot about your company and your business and your ability, your willingness to try different techniques and different ways.”

### ***Work Culture/Social Environment***

“His attitude is incredible, and it’s infectious. He is certainly a positive influence on the other staff members, because he’s always smiling, always happy, always enjoying himself. I think he just gets off hanging around with the maintenance guys, more than anything else. He has lunch with them and hang around, be one of the boys and you know, it’s a great boost for not only our staff, but our guests and everybody who has the opportunity to see him in action. He never fails to tell me every day how much he loves being there.”

“Aside from the obvious with the economic position it puts us in and value that it adds to our business, you see everyday the encouragement and the happiness that these people get out of coming to work everyday and numerous times our managers have said, coming out of a stressful meeting or budgetary times, month end, you look in the office and see this person sweeping or cleaning or vacuuming and just getting so much charge out of it, that you just, it puts life in perspective. We all really value that.”

“The mailroom is a whole different place with her in it, we joke and we laugh, she goes out for lunch with us all the time and she takes part in everything we do – all kinds of functions that we have.”

“H or K or E coming through and just breaking the ice, telling us a joke, that normally you’d be, you’d snap at, but then the customer and the staff member both look at it and go ‘you know what, life isn’t that serious, let’s deal with this,’ and it brings them down to a level where, I’ve witnessed it many times, you just sort of giggle and walk away and go ‘jeez, I’m glad they’re here’, you know. They’re an ice breaker.”

“Just how that rubs off on the other people when they’re grumbling about it and here’s somebody just loving the opportunity. It affects the other employees, you don’t have to say anything, you can see it’s rippling through, so that’s a definite benefit.”

## CHALLENGES AND ISSUES WITH SUPPORTED EMPLOYMENT

The challenges and issues of supported employment relate back to finding the right fit for all the individuals involved in the process. The employers acknowledged that employing individuals with intellectual disabilities was an investment of time and effort, and that not every supported employment situation was successful. Focus group participants suggested that the situations that have been the most beneficial to all parties have been those where people have clearly defined roles and there are open avenues of communication between the employers and the support providers. Another challenge was working through behaviours that are not appropriate at the work place. Having a reliable support provider helped employers and employees deal with these issues more effectively.

“Let’s not fool ourselves, they can’t do everything, there are certain limitations, but I don’t think there’s a lot of limitations. There’s a lot less than most people think.”

“I’m finding it’s really crucial, more so than the individuals in the program, it’s the people that are supervising – they really need to fit into your management structure and there has to be some good communication that way. If it’s strong and positive there, everything else sorta seems to fall into place. If it’s not, if that relationship’s not really developed, then I find that everyone sort of suffers.”

“It’s not just the task that they’re going to do, because everyone’s got tasks that seem simple enough, I think it’s the environment in which they’re in that plays a great deal of, has a great impact on whether or not they’re successful.”

“Because there are two or three people, maybe like the situation you have that could be integrated with less effort, and I sound kinda harsh when I say that, but the reality is, would you rather have 3 or 4 people completely integrated in the work force or supported 1/4 of the time or supported 1/5 of the time, or are you going to use all of your resources and support one-to-one, over and over and over.”

“I don’t think a lot of people also know that this service even exists ... there’s this service out there that, there’s people out there that are willing to, you know, help out, do a lot of tasks, for these companies that need it.”

## WHY EMPLOYERS GET INVOLVED WITH SUPPORTED EMPLOYMENT

Focus group data demonstrated that there are many reasons why employers become involved with supported employment. The most common reasons are: a personal awareness of the abilities of people with intellectual disabilities; a previous experience working with people who have intellectual disabilities; or awareness of other employers who are involved with supported employment. Although some employers were contacted by way of “cold calls” or letters, many participants commented on the fact that supported employment agencies are not well known or utilized as sources of employee recruitment.

Being a good corporate citizen and promoting a positive public image are motivating factors for initial involvement in supported employment, but these are not motivators for maintaining involvement. Employers spoke of the importance of learning about supported employment from other employers and saw this as a powerful and convincing way in which to involve others.

The employers in the focus groups felt that prospective employers need to hear how the supported employment agency will support both the employer and the employee, identifying issues and concerns in advance. It is important for the employer to know that it is easy to get involved and that individuals with intellectual disabilities can contribute to the business in a positive way.

“I thought it would be good for the company, I thought it would be good for morale, I thought it could be a win/win situation which ultimately, after a few growing pains, it turned out to be.”

“From a marketing standpoint if nothing else, it looks good on our business, people think positively about us because of that, it’s selfish but it’s true.”

“We actually got involved from a customer of ours ... and then all the managers of our dealership did a tour of the facility. We noticed that they had a lot of people doing a lot of tasks for them and we started asking questions and that’s how we got involved. They have about 20 individuals working for them, and they said it proved well for them. So we got involved at that time and never looked back.”

“They’re integrated ... they’re completely integrated in the fabric of what we do. Everyone knows them, everyone’s involved with them, everyone understands their needs and I think if we stopped being involved, I think we’d have a backlash, actually. Our employees would be wondering why we discontinued this, it just makes so much sense for us.”

“These people come in, just cherishing the fact that they have an opportunity to do something, feel part of the community and, I guess it’s a selfish reason, but it feels good.”

“I think it’s more personal. The fact that the parents want to thank you for all the stuff, I think that’s thanks enough, you don’t really have to get recognized. It’s, I don’t know, it’s good for the hotel, or for the company you work for recognition, but something like that should be done for everybody, it doesn’t matter. It’s just too bad that not everybody does it.”

## **SUCCESS INDICATORS FOR SUPPORTED EMPLOYMENT**

Success indicators refer to factors that contribute to a positive supported employment experience and help to maintain employer involvement. One of the most significant characteristics is the strength of the relationship between the supported employee and his or her co-workers or supervisors.

Participants felt that on-going positive contact with the supported employment agency is important to maintaining long-term employer relationships. The contact needs to be meaningful in both content and process.

Recognition in the form of certificates, plaques or awards dinners were acknowledged as meaningful to the business from a public relations perspective, but not as a motivator to maintain supported employment relationships. One of the biggest motivators for continued involvement is the ability of employers and co-workers to feel good about supporting another person who, with some help, can make a valued contribution to the workplace.

“The ability to communicate both directions, right, communicate with management, communicate with people that they’re there to support, um, that’s number one for us.” (Referencing the job coach or on site agency support staff.)

“They may be really good, like you were saying they could only do certain skills, or they could only do certain tasks, well let’s try something else. I think us, as employers, are willing to let them try. I mean ‘OK, you know what, you don’t fit here, let’s put you here,’ and we’re willing to help them or work with them or work with their agencies and I think that is a big thing.”

“She came down and we met a couple of times and then the worker came with her for the first few days, but we had a good crew that worked closely with her and helped her and trained her along. It didn’t take her long to catch on and, you know, be up to speed where she could basically be left on her own at times.”

## EMPLOYERS OFFER RECOMMENDATIONS FOR ATTRACTING NEW JOBS

The employer focus group members offered a number of suggestions as to how to improve supported employment and attract new employers. They felt that there were three issues that need to be addressed: fears, awareness and successes.

Potential employers may fear that people with intellectual disabilities do not have the capacity to legitimately make a contribution; they may be concerned about inappropriate behaviours or the ability to communicate; and they may feel that the process of training is too onerous, given the return.

There is always an issue of employers being unaware of the abilities of individuals with intellectual abilities to contribute in a meaningful way. There is also the added problem of the relative invisibility of supported employment agencies as providers and trainers of entry-level employees.

Promoting success is a means of profiling positive examples of supported employment. Because employers said that they learn best from other employers, they were able to suggest concrete ways in which they might educate other employers and encourage them to become part of the supported employment process.

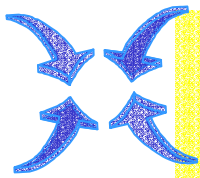
“You wonder how well they’re doing placing people and how many, is there like hundreds of people that are just standing there waiting for a job, an opportunity and what can I do about it? Well, I can show that I have one person I work with and it works extremely well for 10 years and there’s other people now that I’ve met that are in exactly the same case as me, some with more than one worker, six or seven ...”

“I think the agencies should be looking at marketing the fact that people from their agencies are placed within certain businesses. The public responds, like you say, positively to that, but if Network South, for example, was to provide me with a decal for my door or a poster or something that just said ‘Community Supported Employment Assistance In This Store’ or something, come up with a catch phrase and say ‘look, this is a store or this is an organization that cares about the community because they’re supporting.’ So it’s kind of like marketing your people. Saying ‘well, they’re in our store, or they’re in this business,’ that’s a good thing, but how do you communicate that to the community. If more businesses saw that, we could get more businesses to sign up.”

“I was sort of tossing an idea around – rather than bringing you to the marketplace and going to the marketplace, why not bring the decision makers to you in a forum and advertise it that way. Bring a group of leaders together into a room and sort of parade different success stories across and advertise it that way. A business convention or a lunch or something like that.”







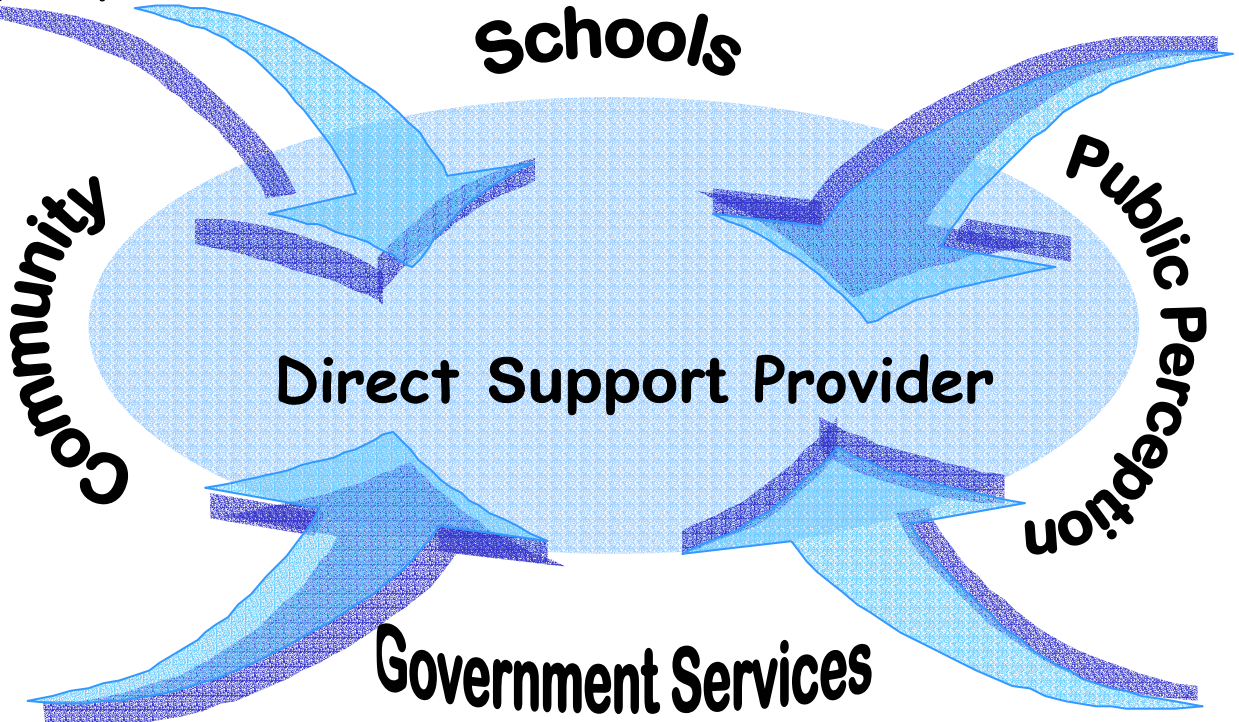
## **Role Clarity Issues are Complex**

and can create confusion for Support Providers and others

**Employing agency, other  
supporting agencies and  
support providers**

**Families**

**Schools**



**Employer (management,  
supervisor & co-workers)**

**Individual,  
Influential peers  
& other friends**

Diagram # 7

## 4. SUPPORT PROVIDERS

### SETTING THE CONTEXT – INTRODUCTION

#### *Focus Group Participants*

There were 16 focus groups participants in the support provider category, six in the first group and ten in the second group. The first focus group was comprised of people in front-line or direct support roles from a variety of daytime and residential support programs. Participants in the second group held supervisory or a mid-management positions for agencies providing support, although more than half the group also had direct contact with adults with intellectual disabilities. The types of organizations represented included sheltered workshops, supported employment agencies and residential homes. Focus group members assisted people in a number of situations including individualized support at work or in a residence; supervision of a large group of adults in a workshop; employer recruitment; job readiness skill development; resume preparation; job location support; program management for individualized support; and administration within an agency. The supported individuals spent their day in a variety of situations, including paid employment, unpaid employment (both full and part time), and in volunteer positions.

#### *Role clarity– A complex issue*

The diverse perspectives of participants, coupled with the wide range supports provided, presented a challenge in finding common themes in the data analysis. The participants encountered numerous issues and spoke of their frustrations in dealing with all of the people involved in the lives of individuals with intellectual disabilities. After some reflection, it became apparent that “role clarity” was perhaps the common theme in focus group discussions.

Support providers face the complex task of supporting one or more individuals in accordance with the wishes and desires of many. They recognize that they need to focus on the best interests of the individuals they support, but they must also meet the expectations of a number of other interested parties, including: their own employer, the supported individual’s employer, supervisor, and co-workers; family; other support providers and agencies; the adult themselves; close friends or influential peers; the school system; and the public perceptions of the community at large.

Because they spend most of their time working directly with the people they support, support providers face the additional pressures of isolation as they have limited opportunity to connect and network with colleagues.

Diagram # 7 on the facing page shows the support provider as the central figure. The arrows represent the many pressures on the support provider as he or she attempts to manage the position. The support providers also have some internal conflicts in finding the optimum balance between caring and coaching. The challenge is how to be invisible as a support but present enough to mentor.

A fuller summary of the support providers’ quotes can be found in Appendix 4.

### SELF PERCEPTIONS OF DIRECT SERVICE PROVIDER ROLE

Despite the service provider’s actual job description, focus group data revealed that he or she perceives the role of service provider as an intermediary between all the people in the supported individual’s life. Balancing so many competing interests can lead to challenge and frustration, which can affect how well the service provider performs his or her job. This, in turn, can influence the extent to which the supported individual feels connected to the community.

“Not everybody’s reality’s the same, so in giving support, you’ve got five people giving support to the same individual, sometimes the individual can get confused. You know, they’ve got Mom’s perspective, sister’s perspective, Dad’s perspective, my perspective, my employment professional’s perspective, voc rehab worker, too many people sometimes involved and they can get ‘I don’t know what to do anymore.’”

“So that’s a big part of our job, is to get out there and really, you know, inform parents, inform sometimes even the teachers what’s out there, what options they have and let the parents and the students make an educated choice as to which agency they want.”

“A social life because a lot of people don’t have that, at all. With the social workers, our position, there is such a big turnover that they’re constantly facing a loss, you know, because they don’t have any friends so they consider us their friend. Sometimes that line is thin because the turnover is so high that they’re always, there’s nothing constant for them.”

“A lot of employers don’t understand people’s roles or whatever. Just say you’re a job coach “oh, that’s fine” but they don’t know what ... they don’t know what it is. When I got this job I realized there’s a textbook written about the actual dealing with.”

“A huge percentage of the individuals that I’ve worked with do not know of things out there. It’s my, our responsibility, I find, since I’ve been in the field, that I need to educate the people I’m working with.”

“But teaching the paid people in their life right now how to teach them to be their own self-advocate, which in turn will get them new friends, which in turn will get them better treatment at work, that’s crucial. So I guess the support and education of the people who are supporting the individual is crucial. Pretty much your frontline workers. It’s the direct service staff because they’re there – they’re the ones that are going to see the people every day, they’re the ones that work for the people, so they’re the ones that need to be educated on how they teach the individual how to support and advocate for themselves.”

## **Perceptions of Employers**

Support provider focus group data showed a discrepancy between the senior management perspective on supported employment and the perspectives of the co-workers and employees. Participants also questioned the motivation or acceptance by some employers. They felt frustrated by a general lack of awareness on the part of employers about the abilities of people with intellectual disabilities to contribute to the workplace. There was also significant discussion about the continued confusion surrounding the role of the support provider at the workplace.

“I think a lot of employers think, because we come in there, we can provide the training for the employers, it doesn’t cost the employer anything for training, so that’s incentive for them right away.”

“I think most situations that have a good support there from co-workers that you work with and then they really, you know, part of the team more or less and then they’re not isolated at lunch time or whatever, you know, situations like that. I think any situation where the person’s really sort of part of what everybody else can do, seems that everybody else works best.”

“Employers being afraid to hire somebody with a disability. Like the unknown factor.”

“Some employers think that the clients might be more intrusive than they are helpful in the workplace.”

“It’s hard to say, for people with more severe disabilities, it could work a lot better. You have to have more employers who are open to paying people, you know, who need a lot more support. For them, I’m not sure, you know, working as well as it should.”

“It’s just the stereotype, stereotypical images that employers have about people with disabilities, just getting around that, get past that, and really show employers that this support really can contribute and can be a very valued members of the workforce.”

“Sometimes employers feel that they are doing a great favour to a person with a disability, because they’re providing them with employment. And these guys are doing the work of everybody else, there’s that attitude that “oh, you know, we’re doing them a favour.”

## **PERCEPTIONS OF FAMILIES**

Although many support providers have only an indirect relationship with families, they still felt that families have a significant potential to impact upon their role. They recognized that families are also conflicted as they try to decide what is best for their family member. Again, the issue of communication arose as an area that could be better utilized to open dialogue and ease tension.

“But I would say 50% of our phone calls likely come from parents that aren’t happy that the child is working Monday to Friday. Why can’t he work Saturday and Sunday, too? I mean it’s just ‘get him out of the house’ type of thing. We have some real issues.”

“These parents, they don’t realize what they’ve actually created is some, their child is dependent on somebody always being with them.”

“I tell his parents ‘well, geez, this guy’s capable’, like if he was in my group he’d be working on his own, you know if you have a job coach with you the person sticks out like they’re not normal.”

“Parent responsibility really doesn’t change that much, they’re always worried about their child and they’ll either underestimate their abilities, overestimate their abilities, shelter their child too much, expose their child too much.”

“Parents don’t understand how it works at the high school level, when the kid’s going to graduate. They don’t know what agencies are out there, what they do and, agencies are on a continuum.”

“... a client was starting his job and a couple of weeks after they started a new job the parents want them to go away to the lake with them for a couple of weeks.”

## **PERCEPTIONS OF GOVERNMENT SERVICES**

Support providers feel the impact of government services and supports in a very direct way. They often have to advocate for clients who may or may not have the government funding for supports they perceive as important. Conflicting government policies tend to put additional stresses on support providers as they attempt to find employment opportunities. Support providers also see and feel the pressures experienced by their supported employment agency as the funding support for programs changes or shifts. And from their own perspectives, they must deal with issues such as entry-level wages, a lack of benefits, growing educational requirements and a job that requires complex relationship management skills.

“I think the process that we do is working. I think what works against us is basically things like social assistance. Obviously some people have figured out that they can make the exact same amount on social assistance as working minimum wage job.”

“To look at this group of people as a good group to hire and to maintain, advocate for the government to set aside more funds for it so that we can all do more of what we do and we can do it better.”

“And what do I need more of? More support in my group, which again goes back to the funding and the money issue, to allow myself and my team within my group to develop skills for the individuals within my group.”

“People fall through the cracks. Push them all through school and then, maybe a high school teacher got them their first job and kinda set them on their way and then they lost that job.”

“A lot of them they don’t even have a community service worker or a rehab worker who are just out there. I mean they have to be referred to us by one of the two, so if you don’t have one of those two you don’t have access to anything.”

“Some of our guys if they get sick during the day, they don’t have the option to go home because they’re in a group home and they can’t go home. Or if they have a holiday day and they want to take it off, well they can’t stay at home because they can’t be there by themselves, so if they’re sick they have to come to our offices, sit in our board room or a spare office.”

## **PERCEPTIONS OF SCHOOLS**

Support providers are part of the school to work transition process as young adults move from the education system to adult life. They had many thoughts on the “employment readiness” skills of young adults as they begin to look for employment. They commented on the limited development of basic interpersonal skills, life skills, hygiene skills and job readiness experiences. Support providers were concerned about how the range of support options and opportunities is communicated to families while their teenager is still in school and felt they were having to educate young adults and families about what was available after graduation.

“Some of the schools, the students are being almost herded, depending on their use of advisors or a special-ed teacher. They’re really being steered in a certain direction and the students and the parents aren’t being educated at all the options that are available to them.”

“You know, nobody has a clue. The kids don’t have a clue, a lot of the teachers don’t have a clue, you know like the schools that we’ve been doing on an on-going basis have more information and access.”

“We need the students to have the skills when they come out of school, to have lots of skills, training, whichever, operate a cash register, work in a restaurant, whatever, just, so when you go to an employer, they already have the skills there. That would make our job easier, of course, to find someone employment because they already have the skills. I think schools should focus more on work.”

“... it’s important that their work experiences in high school be geared towards some of what they’re interested in, not just plunked in for two weeks at the same work site that they use every single year to put the same people through.”

“The fact that some teachers are trying to do good deeds in class. You know they’ll get that the client that first job, but after that job they kind of fall through the loop and who knows where they end up. Making sure that that client gets hooked up with some kind of Social Service, Voc Rehab or what have

you, because once they're out of the school system, they're gone. They're off on their own, they may have left there in a positive way, but who knows what happens later on because in my experience once you've got that client, they're going to come back again. Two, three years and lose my job and start over again."

## **COMMUNITY AND PUBLIC PERCEPTIONS**

Because there is a general lack of awareness about the abilities and contributions of people with intellectual disabilities, support providers said they felt a responsibility to act as advocates for the people they support and to help people develop the skills to advocate for themselves.

Support providers also discussed struggling with providing individuals with enough independence to grow and experience community connectedness, while providing enough protection to those who are traditionally vulnerable.

"This may be a little pie in the sky, but the community as a whole, including the business community, really needs to be educated on the issues and the whole, everything that involves the population that we support. There's just a lot, I hate to say, ignorant people out there, but there is. You see it on the buses, I mean just everywhere you see it and so people in general just really need to be educated on all the issues, the barriers, and just need to know more about the people we support and what they have to offer."

"I don't think supportive employment is that well known even just to the general public. I knew absolutely nothing about it before I started working there."

"I think they eventually need to be part of society where the person that they're with isn't paid to be with them. They have to have real friends and it's not at that point, yet, I don't think. You know, most of their support is paid to be there and work is like a situation that's a natural situation. These people aren't paid to be with this person, so the more they can work the better, more natural it is for them. So I think a situation where everything is natural is better."

## **PERCEPTIONS OF SUPPORT AGENCIES**

Focus group participants saw agencies as positive contributors to sustainable supported employment situations. The role of agencies was clearly understood and articulated as a positive contributor in finding and maintaining good working situations for adults with intellectual disabilities. In cases where re-training is required or re-employment becomes necessary, employment agencies are available to offer support, advice, or direct assistance.

"I really see a lot of my employers retaining employees longer because of services that are there. So if a minor problem that can be worked through on their level it's worked through, but yet it later on resurfaces and our company comes in and reinforces."

"I have a situation where someone's at a job for 6 years, all of a sudden they run into a bad spot and either they're not motivated or they're, they've got personal problems, and then the employer can come to us and they'll just phone because we used to be associated with them, and get someone to go in and drop in a couple of times a week and just talk to the person, check the job situation, see if there's any problems they're having with co-workers or maybe sometimes a new manager or whatever the situation is."

"Well, no what you have to do is go in and sell your clients for what they can do and not," you know as an individual, but how they can help the employer, what they can do for the employer and the benefits that the employer will gain. As opposed to selling them from a social service aspect. We have to look at it a different way."

## **PERCEPTIONS OF ADULTS WITH INTELLECTUAL DISABILITIES**

Support providers indicated that one of their biggest challenges is striking the balance between caring and coaching: allowing enough emotional investment to be a good support while maintaining enough emotional distance to manage the day to day pressures of the job.

Support providers discussed a number a of additional problems such as dealing with the peers of the individuals they support, who may be trying to influence employment decisions, and helping individuals establish social relationships at work. For many people, it is difficult to establish and nurture friendships with co-workers that extend beyond the workplace.

"Most people, I find, that we work with, will show up every day, they are very productive and take pride in their work and they want to do a good job, so I think the quality of work will improve for the employer. So, yeah, it is a good investment and I think some see that."

"One girl, actually it will be 5 years at the end of October she's been there, and she is so reliable. The employer can phone her - anytime somebody phones in sick, he'll phone her, she'll just be there. She never says, 'No, I can't make it,' she'll move all mountains to get there, so I mean those are, if he could have 10 people like that, he would love to. But I mean she does have her problems, and if you read back in her file, they've been ongoing, but I mean they're not, she's bossy and she sort of talks too loud sometimes, but I mean those are things that you can overcome ... Sounds like most of the people I work with."

"Outside influence like a roommate or a boyfriend. You know there's a couple of examples that we've had. You're at a dead-end job, and our clients are not developmentally challenged enough ... and someone criticizes them and says, 'Oh, you know you're never going to go anywhere. You're washing dishes or you're working in the food court,' so I mean there's outside influences there too."

"I find that some of my clients almost put up their own barriers without realizing it. They can do a job beautifully, have no problems with co-workers, do the job wonderfully, and then something will happen, whether it's outside influences or not. Where suddenly a barrier goes up. I have one client right now; she was doing absolutely wonderful where she was. She sabotaged herself, you know, she actually ultimately kind of shot herself in the foot and it took probably, it's been a month now, and we're just starting now to see a turnaround. And that, ultimately, has helped with that because she's had to work on her own, repairing the damage that she's done."

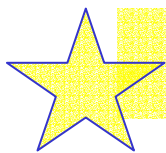
"We're finding there's an ageing population and there really isn't a lot of options for people who are getting older, whether that be having flexible hours. For example, working two times a week instead of five times."

## **DISCUSSION**

Role clarity is the term used by the core team to describe the many uncertainties that service providers face when providing assistance to people with intellectual disabilities. The challenges of balancing multiple perspectives and varying philosophies all in support of one individual's life can cause confusion and frustration.



Support providers in front-line positions are somewhat limited in their ability to influence systems and organizations that define the rules of engagement for them and the people they support. The complexity of role clarity is a reality for people providing support to others. More clearly understanding of the role of direct service providers will help ensure that people with intellectual disabilities receive the best support possible with the fewest conflicts and tensions. In this way, they will be able to better experience community connectedness.



## COMMUNITY CONNECTEDNESS IS THE GOAL

The dynamic interplay of positive contributing factors and pressure points

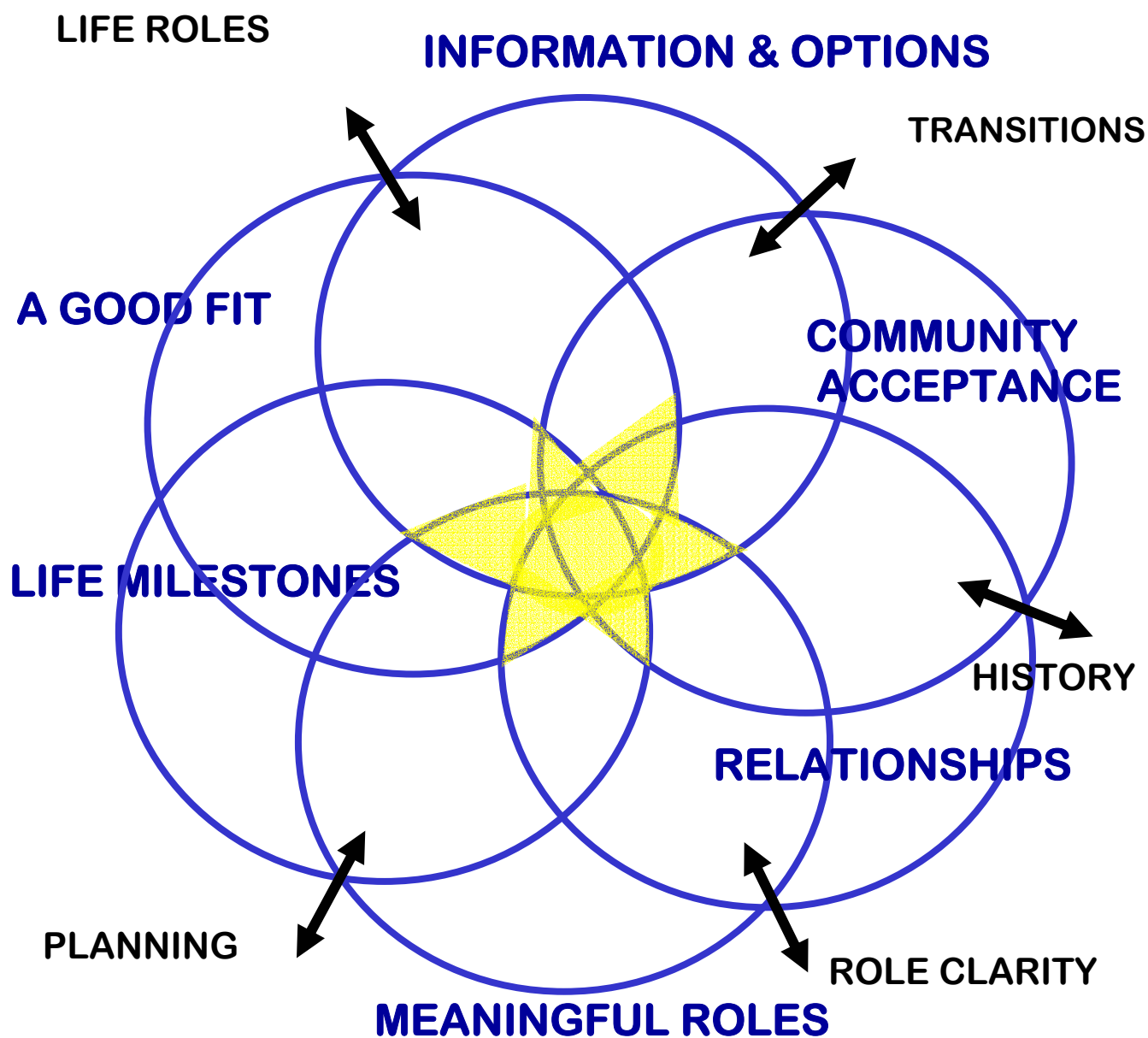


Diagram # 8

## 5. CROSS GROUP ANALYSIS

### SETTING THE CONTEXT –INTRODUCTION

The cross group analysis was completed after the data from each of the focus groups was reviewed and analyzed. This analysis provides a summary of the core research team's interpretive perspective on how the focus group data and analysis link together in support of the overarching goal of community connectedness. Community connectedness represents most of the ideas and themes generated by this research.

### BALANCING POSITIVE CONTRIBUTING LIFE FACTORS AND PRESSURE POINTS

Community connectedness is the extent to which an individual is involved with and participating in a wide variety of community-based activities and relationships. For adults with intellectual disabilities, enhancing community connectedness involves the dynamic interplay of positive contributing life factors and various pressure points. In the cross group analysis, the following key concepts were identified as positive contributing life factors:

- Finding and maintaining relationships in the community
- Having meaningful and valued roles
- Accessing information and options
- Finding a good fit in employment and other opportunities
- Experiencing community acceptance
- Experiencing life milestones

The first five concepts have been discussed at length above. However, in addition to these, many of the participants spoke of natural life transitions that need to be planned for. These transitions are referred to as “life milestones”. They are an essential part of living and include school experiences, beginning and progressing through jobs and careers, making and maintaining significant relationships, marriages, births and deaths of loved ones, retirement and changing health. Adults with intellectual disabilities progress through these life milestones, often in the context of “transition planning”. For the purposes of analyzing this research, life milestones have been identified as positive contributing life factors, while transitions have been referred to as pressure points. It is the quality of the transitional experience that potentially enhances or detracts from the positive experience of the life milestone, which will occur naturally, whether or not a plan is in place.

Pressure points are described as:

- Failing to experience natural life roles
- Difficulties in clarifying support provider roles
- A lack of continuity in life
- Excessive planning
- System-imposed (unnatural) transitions

When the pressure points are not well facilitated or managed, they interfere with positive life experiences and diminish the sense of community connectedness, as depicted in Diagram #8 on the facing page. The positive contributing life factors and the pressure points are closely linked in a dynamic interplay of choices and opportunities, leading to either positive or negative experiences. When the focus group participants spoke of challenges or frustrations, it was evident that they were referring to some of the pressure points in life. While not all the pressure points listed above are in the language used by the focus group participants, the cross group analysis uncovered common ground between the groups, resulting in the identification of these points. The

following information provides a more detailed description of the positive contributing life factors and pressure points that people with intellectual disabilities can experience.

### ***Positive Contributing Factors***

#### ***Relationships***

As discussed above, relationships were identified by all the focus groups as one of the most significant motivators or positive contributors in life for adults with intellectual disabilities. Having valued relationships increases the feeling of being connected to the community.

#### ***Meaningful Roles***

Meaningful roles mean that adults with intellectual disabilities are contributing to the best of their ability and are being appreciated and valued for that contribution. Individuals may make their contribution in many ways, including economic, social and cultural. The more meaningful roles an individual has, the more accepted and connected he or she feels.

#### ***Information and Options***

Information and options refers to two issues. Firstly, it involves accessing information about the range of services and supports available for people with intellectual disabilities. Secondly, it involves accessing funds in order to receive services and supports required to lead a full and meaningful life.

Knowledge is a powerful tool for enhancing broader participation in work, life and community for adults with intellectual disabilities. It is therefore critical that relevant information be easily accessible to everyone involved in the process.

#### ***A Good Fit***

The definition of a good fit includes having those characteristics and qualities that contribute to meaningful supported employment or day-time opportunity; enjoying relationships within the community; and being valued for making a real contribution. The concept may be perceived differently or have different implications, depending upon the perspectives being offered.

#### ***Community Acceptance***

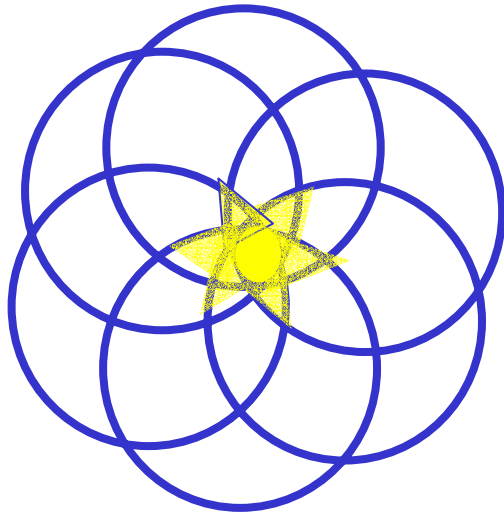
Enhancing community acceptance and perceptions about adults with intellectual disabilities are important components of achieving community connectedness. They also form a reinforcing pattern. As community members become more aware of the valuable contributions made by adults with intellectual disabilities, more opportunities will become available and therefore community connectedness will be easier to achieve.

#### ***Life Milestones***

Life milestones are the significant events that take place in life. Participating fully in life and community includes participating in natural life milestones in ways that are meaningful and safe, rather than being sheltered from them. Life brings challenges and risks for everyone, and facing new experiences is an opportunity to



## COMMUNITY CONNECTEDNESS IS THE GOAL



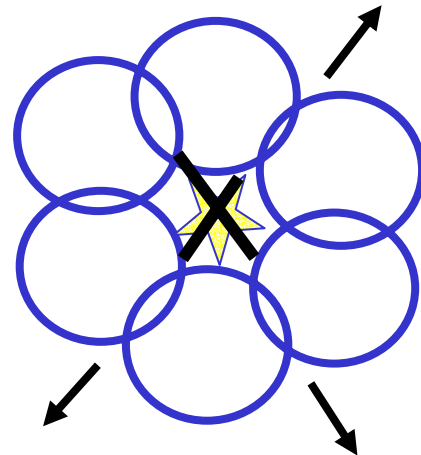
### POSITIVE CONTRIBUTING LIFE FACTORS:

- Relationships
- Meaningful Roles
- Life Milestones
- A “Good Fit”
- Information & Options

When the circles are connected and overlapping the centre creates a “star” and this represents successful **“Community Connectedness”**

### PRESSURE POINTS:

- Life Roles
- Planning
- Transitions
- “Role Clarity”
- History



When the pressure points are not well managed, they pull the circles out of place and diminish the sense of **“Community Connectedness”**

Diagram # 9

participate and grow. Life milestones were recognized in the cross group analysis as a positive contributing life factor. However, how people react to life milestones can be a source of pressure as well.

## **PRESSURE POINTS**

Pressure points are those factors that negate the positive contributing factors and diminish the experience of community connectedness. It is therefore important that they be well thought out and properly managed. The following information describes each of the pressure points.

### ***Life Roles***

The term “life roles” refers to how well a person with an intellectual disability is able to live and experience natural life roles and relationships that occur in their circle of family and friends. This includes roles and relationships as a son or daughter, a sibling, an adult, an aunt, uncle, or cousin, a niece or nephew, a friend, a loved one. Life roles may also include community-based roles such as co-worker, taxpayer, citizen, voter and employer. Life roles for many people with intellectual disabilities can become pressure points as they are managed, controlled and planned by the supports around them. This planning and management can lead to a loss of spontaneity. Therefore, the degree to which these life roles are able to evolve naturally reflects upon the degree to which community connectedness is achieved.

### ***Role clarity***

As discussed in the findings and analysis from the support provider focus groups, the issue of role clarity is complex and a major pressure point. Role clarity, if not well managed with effective communications and shared priorities, can cause frustration and confusion for all those involved in supporting people with intellectual disabilities. A key factor for ensuring a sense of community connectedness is the ability of an individual’s entire support system to come to a similar understanding in promoting the best interests of the individual being served.

### ***History***

History is the sense of continuity throughout a person’s lifetime. It involves understanding and learning from the experiences that have already occurred. History and continuity are particularly important for adults with intellectual disabilities because throughout their lives they encounter so many people providing support and assistance. History becomes a pressure point when the same things are tried over and over again, and there is no acknowledgement of what simply does not work. To achieve community connectedness, it is important to strive for improvement and broader participation.

### ***Planning***

For people with intellectual disabilities, planning is a pressure point because so many adults with intellectual disabilities experience life only as defined by one or more of the many plans made for them. Because so many people are involved in providing support, assistance and opportunities for adults with intellectual disabilities, plans are a critical communication tool and provide some measure of accountability for success. The system serving people with intellectual disabilities requires planning, but it is important to distinguish between planning for the individual and planning to serve the needs of the system. It is also vital to recognize that often the individual gets left out of the planning process and therefore loses a voice in the direction his or her life will take. Community connectedness requires both a plan and an opportunity for chance to prevail.

## ***Transitions***

Transitions, as defined by this research, are the system-imposed processes that may or may not align with some of life's natural milestones. One of the major transitions that was a focus of this research is the school to work transition. The transition becomes a pressure point for a number of reasons. Access to supports shifts from a child-oriented system based on entitlement, to an adult-oriented system based on availability. Therefore, there is a need to navigate new processes while attempting to access funding.

Although most teens leave the school system at age 18, funding is often not available for young people with intellectual disabilities until age 21, so decisions must be made as to whether to graduate with peers or remain in school until adult funding is in place.

While the school to work transition is a difficult one, it is not the only transition in the lives of people with intellectual disabilities. The need to address planning for later-life transitions is also a pressing one for individuals and families.

## **GROUP ANALYSIS CONCLUSIONS**

Perspectives in Change has identified many issues and opportunities in support of broader participation in work, life, and community for adults with intellectual disabilities. The focus group data clearly shows the value of connecting with the community in meaningful activities and relationships with as much opportunity for integration and participation in the community as is reasonably possible. The analysis across the groups leads to the conclusion that community connectedness is the ultimate goal for adults with intellectual disabilities.

## 6. INTERVIEWS

### SETTING THE CONTEXT – INTRODUCTION

The informants involved in the individual interview process are all people who work or have experience in providing services and supports to people with intellectual disabilities. As such, they can be described as providing services or access to services, in terms of how these services will be provided or used.

Some informants work for the government and thus have at least some opportunity to influence policies or programs or support the implementation of policies or programs. Other informants work for non-profit organizations, as managers or CEO's, providing services and supports to people with intellectual disabilities.

The basic question for all interviewees was:

**“What are the issues and how can we improve participation in work, life and community for people with intellectual disabilities?”**

It is important to note that each interview was a unique conversation or dialogue with the interviewee and elicited perspectives particular to each person's work or background experience.

The data collected from these interviews is distinct and individual and not representative of the group or collective. In analyzing the data, ideas and themes were uncovered that were both consistent with focus group analysis and unique.

#### **findings - Supporting perspectives**

#### ***Relationships and Community Participation***

The concepts of relationships and community participation were raised by many of the interviewees as an area of importance in the lives of people with intellectual disabilities. However, there were differences of opinion as to how to help foster relationships and what might help or hinder true participation and involvement.

Some interviewees felt that people with intellectual disabilities living independently within the community experienced feelings of loneliness and isolation, whereas individuals living in a group situation with their peers were more involved and experienced more socialization in their lives. This data reflects a tension between community inclusion and relationship building. Mention was also made of the problem that some people's main relationships are with paid staff members. This demonstrates the need for informal support systems within the community to allow people to become more connected.

“When I look at who is having a more active person-centred life, it's individuals who live in groups ...”

“Well, I think it's very helpful to be socially connected to other people with disabilities.”

“... I think it makes for a well-rounded life for the individual ... having things that they can choose to do in the evenings that involve their peers ...”

In terms of community connectedness, there were also some differences of opinion as to community acceptance of people with intellectual disabilities. Some interviewees believed that the community was not sufficiently accepting of full participation, while others felt that there was still untapped community capacity.



“I think better connections within the community, I think more natural connections within the community...”

*Other areas of concern were sentiments that working in an integrated setting does not guarantee relationships and that activities can be merely a means of keeping people busy and not necessarily of being involved.*

### ***Access to Information, Services and Support***

Access is another prevalent theme that emerged from the interview data. The data illustrates that access to information is problematic due to the number of systems involved in supporting people with intellectual disabilities and the unfamiliarity of each of these systems with the others.

Family mentoring and networking were seen as positive ways to access information and get a better understanding of the processes and procedures. However, differences of opinion arose as to who bears the responsibility of easing access issues, depending upon each interviewee’s background and perspectives.

Another very prominent issue for interviewees is the problem of limited resources and funding. This difficulty came across as manifesting itself many forms: poor wages and benefits for support providers, which in turn can lead to high staff turnover; an inability to access one-to-one support; a mentality encouraging the slotting of people into day-time activities based on availability and funding and not necessarily based on the wishes, gifts or abilities of the people for whom the services and supports are being provided.

Other thoughts that emerged include a lack of information on options available; transportation difficulties that may preclude people from fuller participation; and a lack of awareness and/or acceptance by both potential employers and the community at large.

“As a society we have not set ourselves up to make sure those supports will be there and so then – so the message almost from the beginning is you are going to have to temper your dreams ...”

“I think that there’s a community capacity issue.”

### ***School to Work Transition***

Analysis of the data revealed that life transitions were seen universally as pivotal points in an individual’s life. Many transitions were mentioned including transition into school, transition from school to adult life and transition to retirement and senior years. However, the transition from school to work was seen as a particularly trying process for individuals and families to navigate through. Many interviewees felt that awareness is a vital piece in making this transition smoother. Awareness includes knowing what options and alternatives are available as well as involving all participants in the process: various government departments, educators, families, support providers, and self-advocates. A general lack of transition planning at an early enough age was identified as a major barrier to a smoother transitional process.

“The school division ... also has an obligation ... there are critical partners in this. They are a part of the team of information that comes together ...”

### ***Role Clarity***

The theme that has been identified by the core team as “role clarity” was less of an issue for these informants. However, role clarity remains a subject that requires further analysis. There continues to be a discrepancy between the focus group participants and the roles of direct support providers. The meaning for this

discrepancy remains unclear. Data from the support provider focus groups, which were comprised of different types of providers, did not give the core team any means with which to reconcile these various perspectives. Thus the core team feels that further analysis must be completed at the next level. This would involve a research process where interviews would be conducted on an individual level with attention focused on the role that the particular individual plays when providing supports to people with intellectual disabilities. In this way, different support roles will not confound role true role clarity issues.

“... I sort of think of there being a bit of tension between day and residential ... almost a competitiveness at times ... So when it works well it's great to see, when everybody is sort of working in cooperation and there's good communication so that hopefully we have an interest in the person's whole life.”

## CONCLUSIONS

When the core research team analyzed the interview data, ideas and themes were uncovered that were both consistent with focus group analysis and unique. Interviewees recognized that for people with intellectual disabilities, it is important to have relationships and participate. However, not every person interviewed saw relationships and community participation in the same way. Similarly, participants had differing views on who should be providing information and how services and supports should be offered. However, all those interviewed believed that there was a need to better co-ordinate information dissemination and all recognized the limitations on service provision due to funding and resource allocation.

Whatever the differences of opinion were, the core team was able to use the interview data to corroborate those issues that were important to focus group participants. The interview data also helped to define the issues standing in the way of improving participation in work, life and community for people with intellectual disabilities.

In the following section, entitled Action Steps, the Phase Two recommendations for implementation are identified and described briefly.

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## ACTION STEPS – PHASE TWO

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In addressing the issues and opportunities identified in Phase I of Perspectives in Change, the following five key initiatives are proposed for the Phase II implementation of sustainable actions in support of broader participation in work, life and community for adults with intellectual disabilities.

### **Project One: Options and Opportunity Forum for Parents and Youth**

- Engage community stakeholders in planning and implementing one or more sustainable annual options and opportunities events for adults with intellectual disabilities and their families.
- Focus on helping families to learn about philosophical perspectives of inclusion, life planning, and valued daytime opportunities for their family members.
- Provide networking opportunities and facilitated discussions for parents so they can mentor and learn from one another.

### **Project Two: School to Work Transition**

- Gain the perspectives of educators on their role in the preparation of children and youth with intellectual disabilities for valued participation in community life. This project represents the continuation of research and analysis into the activities around transition and how to enhance the process.

### **Project Three: Campaign to Increase Public Awareness of Supported Employment**

- A communications strategy to profile successful supported employment situations by targeting professional and trade publications as well as lifestyle publications. The benefit will be an increased awareness and acceptance of adults with intellectual disabilities in the workplace as recognized and valued contributors both by potential employers and by the community at large.

### **Project Four: Employer to Employer Outreach Program for Supported Employment**

- Based on suggestions from the employer focus groups, this project will create a sustainable employer-to-employer presentation and profile program, building on the successes of current employers involved with supported employment and encouraging the recruitment of new employers. This effort is also supported by Project Three.

### **Project Five: Identifying and Assessing the Impact of Role Clarity Confusion**

- Recruit key community stakeholders to further assess the complexity of role clarity issues by way of further data collection and analysis with a select group of participants. This project hopes to foster positive change through increased awareness, understanding and communications.

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## CONCLUSIONS

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Perspectives in Change has been about identifying the key issues affecting the provision of community-based supports and services to adults with intellectual disabilities in work and community participation, and developing an action plan for addressing these issues in order to fostering positive change. Participatory action research was used as a means to promote inclusion and gather input from the community of stakeholders and interested participants. Through this research, many valuable ideas and suggestions were identified, generating considerable interest and energy within the community of interested people, organizations and employers.

Key findings from Phase I include the identification of an overarching goal of community connectedness for people with intellectual disabilities. This goal is shared by those who care for and support them. Community connectedness has been defined as the dynamic interplay of positive contributing life factors and pressure points. Data from each focus group produced one or two major issues. The resolution of each of these issues leads to the overarching goal of community connectedness.

The research data showed that creating and maintaining relationships is the most important issue in ensuring a feeling of connectedness for adults with intellectual disabilities. Families felt that relationships for their family members and access to information on the range of options and opportunities available were most critical. The school to work transition process was identified as being far more than just a protocol. Thus the issue for families is being able to more easily identify the ways and means of accessing information in order to co-ordinate transition planning and decision-making to secure the best life possible for their family member. Being able to access more information and plan better will result in an increased feeling of community connectedness. Employers revealed that the issue for them was being able to assist in creating a “good fit” within the workplace to help ensure the success of the employee, the employer and the support provider. A “good fit” in an employment setting will help people with intellectual disabilities feel better connected to the community. The data for the support provider group indicated an uncertainty about the exact nature of the support role. Role clarity issues were therefore identified and recognized as creating confusion and frustration for support providers and others involved in the supported employment process.

The focus of the Phase II imitative recommendations is the creation of sustainable processes that further enhance opportunity for broader participation for adults with intellectual disabilities. It is important to note that the five Phase II initiatives also use participatory action as the means to engage the community in developing the final outcome.

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## APPENDIX 1 PARTNER INFORMATION

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### **SCE LIFEWORKS INC.**

SCE LifeWorks is a non-profit, community-based organization that provides support to individuals with mental disabilities to work and participate in the community. LifeWorks was established in 1987 by concerned parents who were dissatisfied with existing adult service options for their young adults, upon graduation. This parent group had a clear vision of an alternative program which would not only provide opportunities for participation in mainstream community life, but which would support people in contributing their own skills, abilities, and resources to society.

SCE LifeWorks now provides services to approximately one hundred and thirty - four (134) individuals with mental disabilities, along with their families and employers. As a result of the demand for these type of services, in 1991 a parent group formed to develop a satellite program now known as Network South Enterprises Inc. The demand for this type of service and supports are increasing, as more young adults are exiting an integrated school system and are seeking supports to continue an integrated lifestyle.

Initially, SCE LifeWorks began by providing supported employment for adults with developmental disabilities in community based work placements. SCE LifeWorks is not only involved in providing person-centred services, but also research, community development, information dissemination, and training. We continue to strive for advancement of our mission "To support adults with mental disabilities to work and participate in the community."

In 1998, the Board of Directors along with LifeWorks' Membership changed SCE LifeWorks' name from Sturgeon Creek Enterprises Inc. The new name better reflects the services and mission of the organization while at the same time reduces confusion regarding location, relationships to other similarly named organizations and the organization's non-profit status. LifeWorks continues to be an organization which is driven by the community and strives to meet the needs of the community.

For more information about LifeWorks please visit our website at [www.lifeworks.mb.ca](http://www.lifeworks.mb.ca)

### **NETWORK SOUTH ENTERPRISES INC.**

Network South Enterprises Inc. (NSEI) is a not-for-profit community-based employment agency for adults with mental disabilities. NSEI assists people to obtain and maintain employment. NSEI's goal is to identify and create opportunities for employment and to encourage the full participation of persons with mental disabilities in our community.

NSEI and LifeWorks share the same philosophy and mission statement, which are as follows:

Mission: To support adults with mental disabilities to work and participate in the community.

Philosophy: All people deserve the opportunity to work and participate in the community where they are respected and rewarded for their efforts, skills and accomplishments.

NSEI was founded in 1990 by several parents who were concerned about the quality and availability of appropriate employment opportunities for their adult sons and daughters. In 1992 NSEI was incorporated and it currently provides employment services to approximately 130 adults with mental disabilities.

To learn more about Network South Enterprises Inc. please visit their website at [www.networksouth.mb.ca](http://www.networksouth.mb.ca)

## **HEALTH, LEISURE & HUMAN PERFORMANCE RESEARCH INSTITUTE**

The Health, Leisure and Human Performance Research Institute is housed within the Faculty of Physical Education and Recreation Studies. The Institute was first constituted as The Sport and Exercise Sciences Research Institute until 1992 when it underwent a name change to become the Health, Leisure and Human Performance Research Institute. This change was a reflection of the broadening research foci within the faculty and is truly reflective of one of the most diverse research institutes at the University of Manitoba.

The goals of the Health, Leisure and Human Performance Research Institute are:

- \* To create an environment which promotes and supports research in health, leisure behaviour and human performance.
- \* To conduct original scholarship and basic and applied research of the highest quality in the areas of human movement and leisure behaviour.
- \* To disseminate research findings through traditional academic means and a variety of other activities designed to serve the broader community.
- \* To provide opportunities for undergraduate and graduate students to participate in research activities related to health, leisure and human performance.
- \* To promote collaboration and interdisciplinary activity with other University faculties and departments and the external community.

To learn more about the research institute please visit their website at <http://www.umanitoba.ca/faculties/physed/research/index.shtml>

Dr. Jennifer Mactavish

Since the early 1980's, Dr. Mactavish has worked extensively with individuals with intellectual disabilities and their families. This experience has fostered research interests in the social-psychological outcomes associated with participation in recreation and sport across the lifespan, and factors (individual, family, systemic, and programmatic) that support and constrain these involvements. More recently, these interests have been extended to include issues broadly related to quality of life (e.g., social integration, independence, later life planning), and methods for enhancing the direct involvement of individuals with intellectual disabilities in the research process (e.g., participatory action research). To learn more about Jennifer Mactavish please visit her webpage at <http://www.umanitoba.ca/faculties/physed/research/people/mactavish.shtml>

Dr. Zana Marie Lutfiyya

Zana is in the Faculty of Education at the University of Manitoba. Her interests include the facilitation of personal relationships between people with and without disabilities, social policy, qualitative research methods, advocacy, and inclusive education.

Dr Christine Blais

Christine is in the Faculty of Physical Education and Recreation, specializing in Disability Studies. She received her BSc and MSc in Kinesiology from the University of Ottawa, before completing her Ph.D. in Educational Psychology. Previously, as Chair of the Department of Child and Youth Studies at Brock University she helped develop the Child Health Program in partnership with the Department of Community Health Sciences. Dr. Blais' research interests focus primarily on issues related to the ability of people with disabilities to perform complex motor skills as they age. The ability to perform complex motor tasks (i.e., focus attention, make decisions, perform accurately, and task share) is directly related to issues of quality of life and independent living

#### **CONTINUITY CARE INC.**

Helping families plan a future for their family member with disabilities. Continuity Care has been established by a group of dedicated parents, siblings and citizens who wanted to assist Manitoban families in planning for their future of their relative with a disability. They are concerned about the alarming number of families that have not taken the time to develop a plan. Continuity Care works effectively in partnership with families, community, government and service providers. Many families falsely believe that if they identify a portion of their estate and rely on the other siblings to look out for their brother or sister with the disability, that everything will be taken care of. Good intentions based on the wrong information can put people at risk. Some siblings tell us that they are uncomfortable with the responsibilities that the parents are expecting them to undertake. Others find that improper wills and estate planning can result in loss of government income supports, medical and dental benefits and access to many government programs.

Continuity Care has identified key areas for families on which to base their future planning on. It has developed a framework called the Family Future Planning Program that uses individual consultation, formal presentations, hands-on workshops and person-centred planning tools to lead families through the process.

Continuity Care is committed to ensuring that the families future planning will become a reality. It has identified key roles that Continuity Care might assume. These roles may include an appointee to a trust, a visitor that checks in with the person on a regular basis or as a broker for services and supports as identified in the planning. To learn more about Continuity Care please visit their website at <http://www.crm.mb.ca/lifestyl/advoc/contcare/>.

#### **ASSOCIATION FOR COMMUNITY LIVING - WINNIPEG (ACL - WINNIPEG)**

ACL-Winnipeg is a not-for-profit organization working for a community where each individual is cherished. ACL is involved in the following:

- Provides education, advocacy, service development and community development on behalf of children and adults with mental retardation and related disabilities.

- When requested, ACL staff and volunteers provide support and advice to families of children with newly-discovered disabilities, families wishing to see their school-age children in integrated education, and families wishing to develop circles of support for themselves or their children.
- Emphasizes family-directed solutions in the areas of relationship building, housing, employment, and continuity of care.
- Individual planning and consultation
- Organization planning/consultation
- Education and training
- Vipond Family Resource Center
- Open Access Resource Center
- Respectful advocacy

For more information about ACL-Winnipeg please visit their webpage at [www.aclwpg.ca](http://www.aclwpg.ca).





