# PERSPECTIVES IN CHANGE

ISSUES IN COMMUNITY SUPPORT FOR ADULTS WITH INTELLECTUAL DISABILITIES

Phase I – Highlights Report
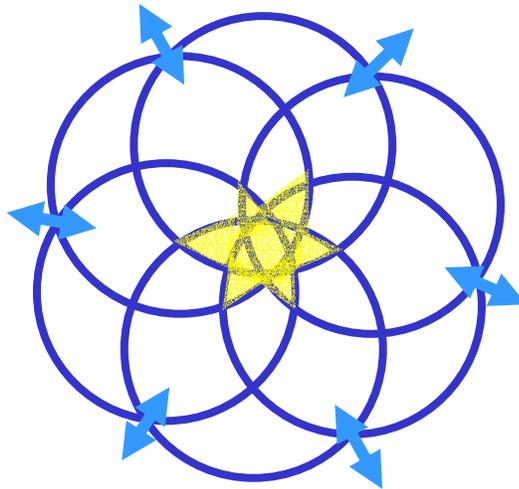
Participatory Action Research Partners

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.

Snapshot of themes and ideas …

"Relationships Are Most Important"
Adults with Intellectual Disabilities
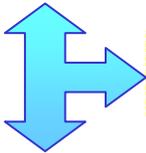
"Relationships and Access to Information"
Families
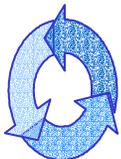
School to Work Transition "Not Just Protocol"
Families
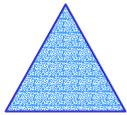
Creating a "Good Fit" Supports Success
Employers

"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**

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.

METHODS

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.

"Relationships Are Most Important"
Adults with Intellectual Disability

Community Connectedness

Feeling Valued

Relationships And Roles

Support
Internal (self)
External (others)

Daily Routine & Job Fit
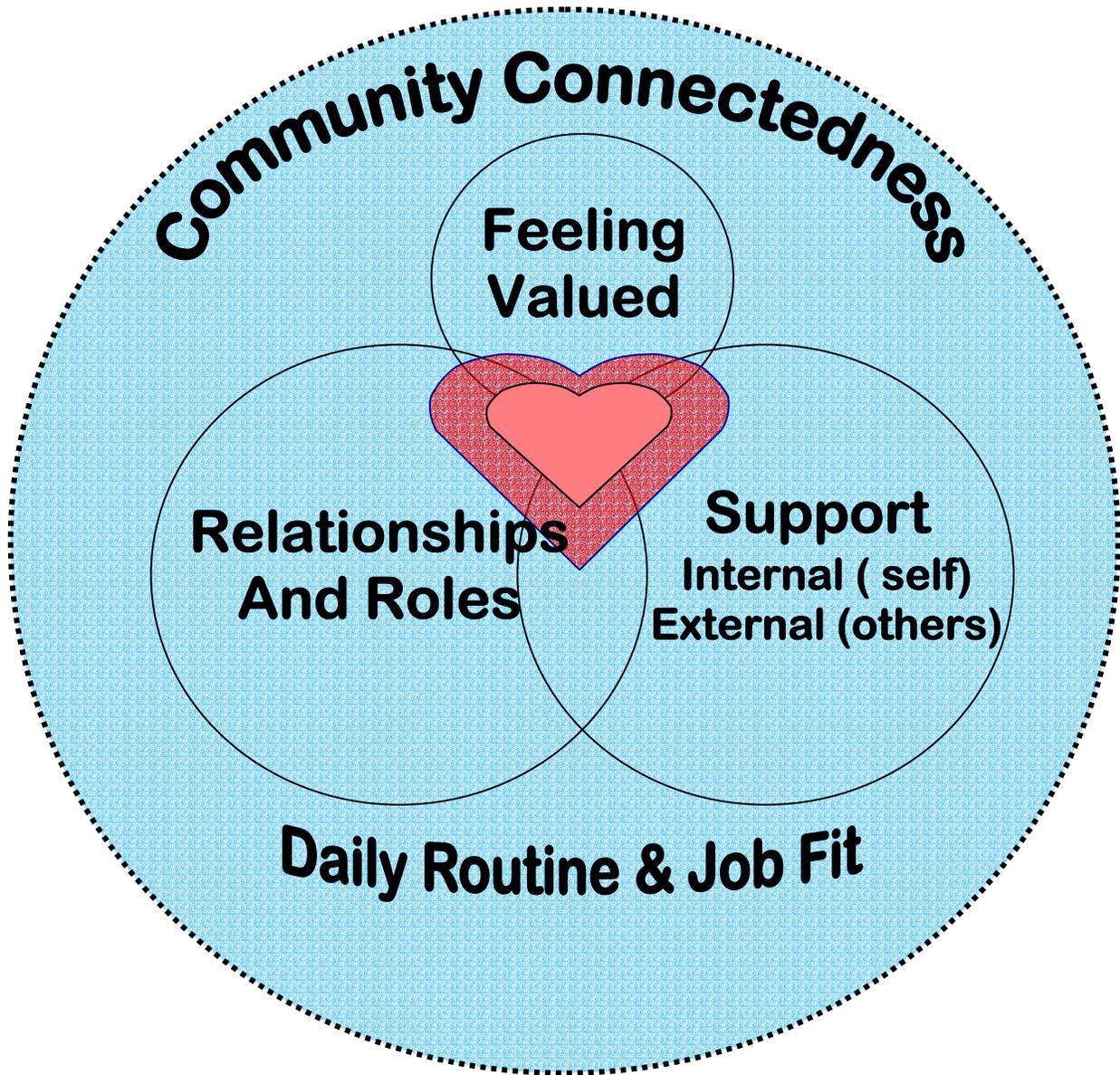
Interviews: Thirteen people from departments within Family Services and Education, as well as managers of support agencies.

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.


RELATIONSHIPS ARE MOST IMPORTANT

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."
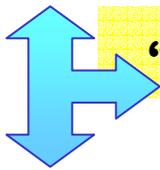
"Relationships and Access to Information"
Families

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
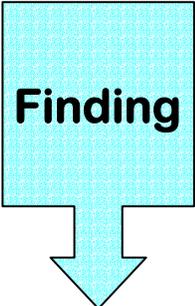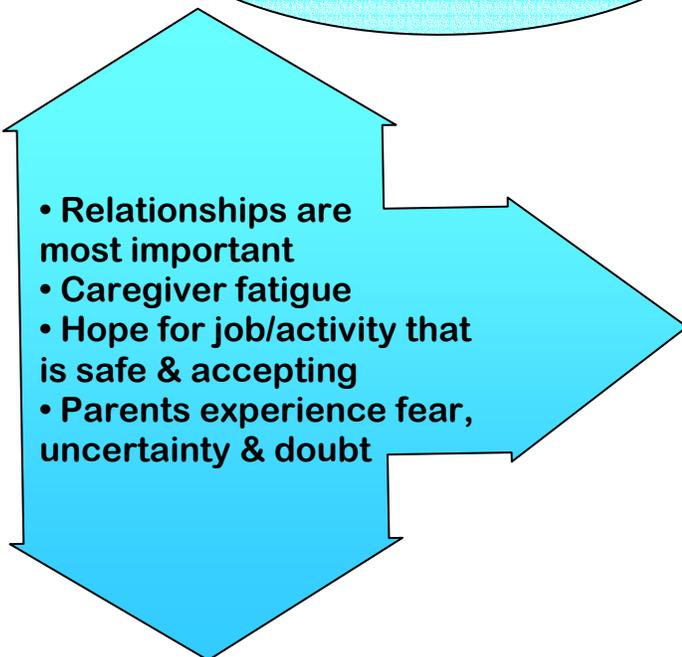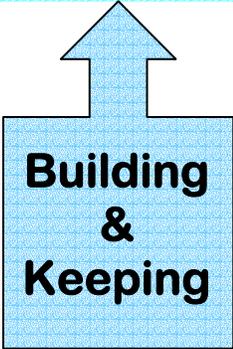
Generational Learners

FAMILIES OF ADULTS
"PRAGMATIC ACTIVISTS"
Focusing on
Later Life
Transitions

Finding

RELATIONSHIPS

Building & Keeping

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 *relationship*s – 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."

School to Work Transition – "Not Just Protocol"
Families

Early planning needed for an independent and integrated life

Job readiness skills and independence must be a priority within the school system

SCHOOLS

SUPPORT SERVICES

YOUNG ADULT

PARENTS

Parents must involve Family Services and initiate transition plan within the service and support system
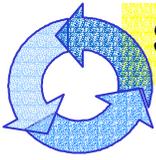
Parents must Initiate "PATH" Planning process
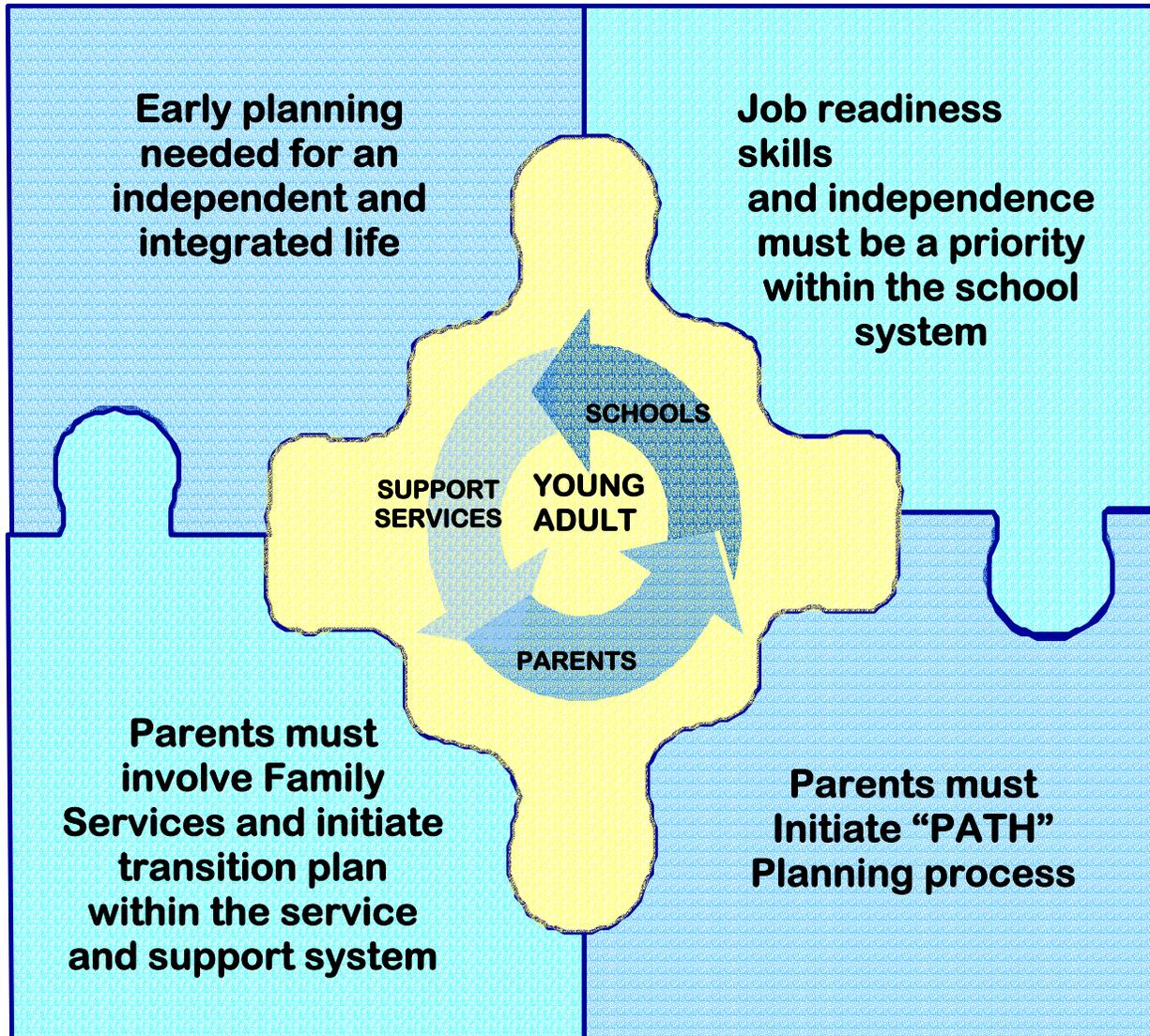
*Families want and need better access to information on the range of life options and opportunities*

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 or 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."

Employers: Creating a "Good Fit" Supports Success

Support Agency

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

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

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."
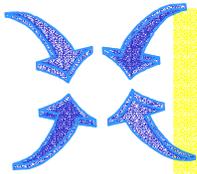
Role Clarity Issues are Complex
and can create confusion for Support Providers and others

Employing agency, other supporting agencies and support providers

Families

Schools

Community

Public Perception

Direct Support Provider

Government Services
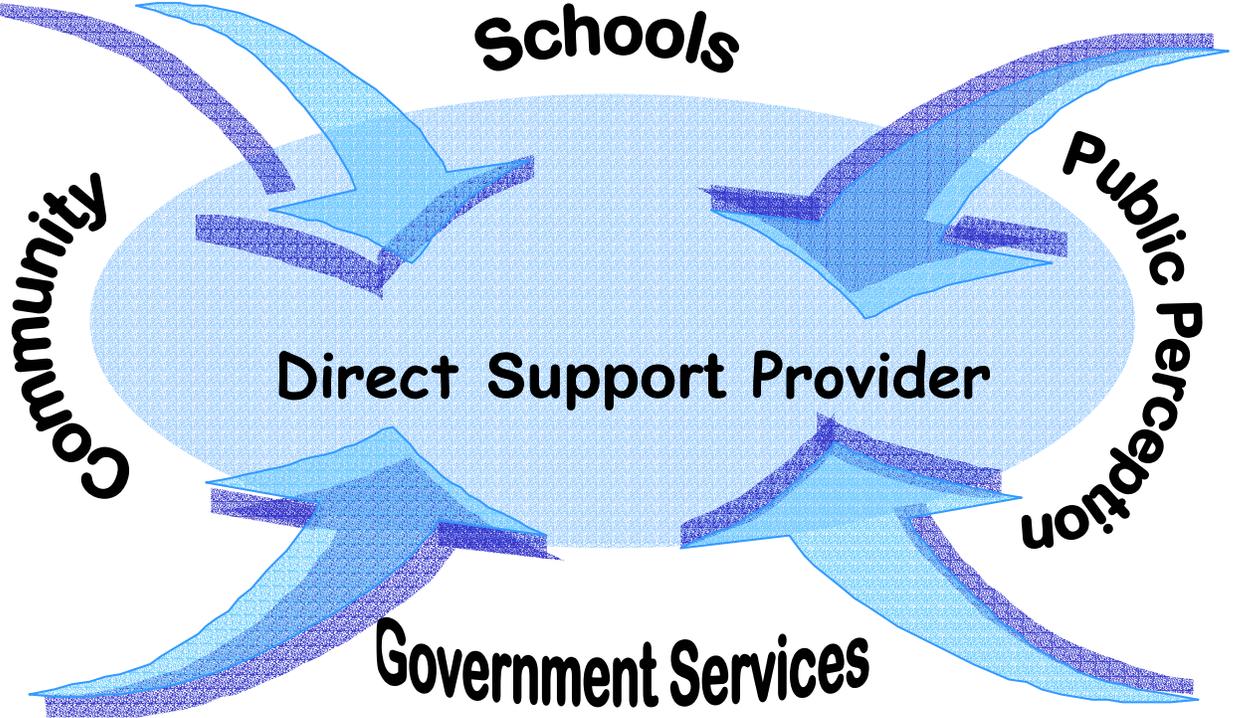
Employer (management, supervisor & co-workers)

Individual, Influential peers & other friends

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. R*ole 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."

COMMUNITY CONNECTEDNESS IS THE GOAL

The dynamic interplay of positive contributing factors and pressure points
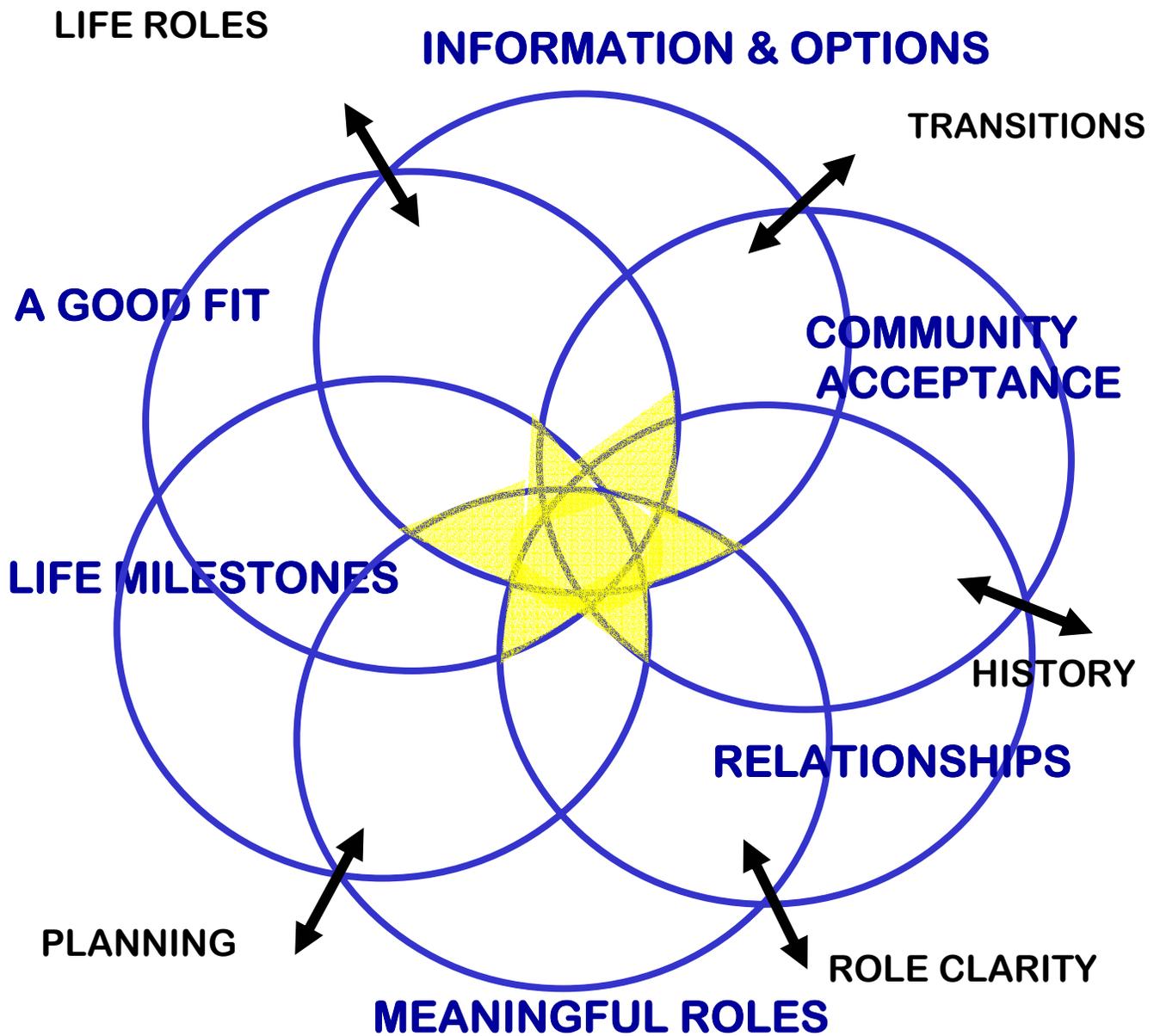
LIFE ROLES

INFORMATION & OPTIONS

TRANSITIONS

A GOOD FIT

COMMUNITY ACCEPTANCE

LIFE MILESTONES

HISTORY

RELATIONSHIPS

PLANNING

ROLE CLARITY

MEANINGFUL ROLES

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
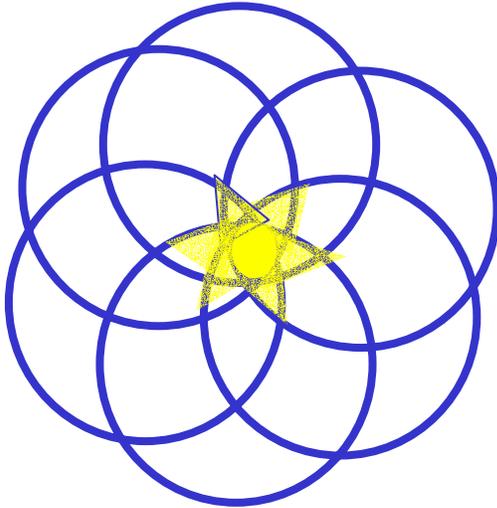
POSITIVE CONTRIBUTING LIFE FACTORS:
- **Relationships**
- **Meaningful Roles**
- **Life Milestones**
- **A "Good Fit"**
- **Information & Options**

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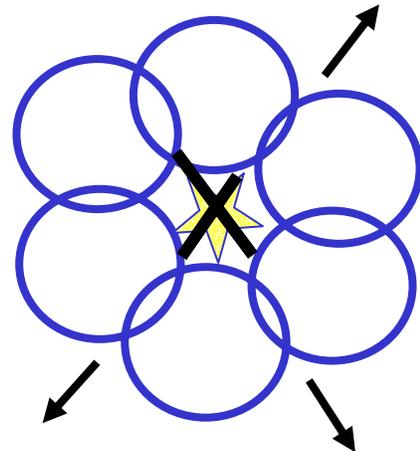
When the pressure points are not well managed, they pull the circles out of place and diminish the sense of "Community Connectedness"

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.

INTERVIEWS - 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.

Access to In formation, 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.

Perspectives In Change: Phase I Final Report

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.

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.