

The Key Role of Independent Facilitation in Supporting Adolescents who have a Developmental Disability to Prepare for and Build a Meaningful Adult Life

We are all “social beings” who make meaning with and through others by telling stories about our lives. As children and adolescents, we are accustomed to others being the narrators of our story. Parents, teachers and siblings defining our potential, who we are and who we are to become, until at last, we reach adulthood and see the necessity of narrating and shaping our own story.

1. Introduction

For the past eighteen years in Ontario, Families for a Secure Future has been innovating with the role of Independent Facilitation in supporting adolescents who have a developmental disability to transition out of secondary school into a meaningful adult life.

While there are many transitions that each of us go through and embrace throughout our lifetime, the passage from adolescence to adulthood is clearly one of the most necessary and difficult ones. For every person, it signals a shift in our relationship to others. We must consciously become aware of what it means to take responsibility for our lives and at the same time recognize what we rely on others for and how we want to contribute to the lives of others. Adolescents with developmental disabilities are no different, they yearn to find places in the world where they belong so that they can gladly make their contribution to others, build relationships and take up their adult lives. As an Independent Facilitation organization, Families for a Secure Future has had extensive expertise in supporting adults (18 years and older) with developmental disabilities and their families, to prepare for and manage change as they work their way through the numerous transitions that are part of a typical life.

Independent Facilitation is fundamentally committed to ensuring that adults who have a developmental disability have the right to take up their citizenship and be supported to fully participate in life alongside others in their community. While those we serve may choose a wide range of community experiences and adult roles, it is this vision of community inclusion that sets Independent Facilitation apart from other person-directed planning models. As a principle, we and all other Independent Facilitation organizations in Ontario ensure that they remain independent, unencumbered and free of conflicts of interest by not offering any residential or day services. As

well, we do not manage people's funding allocations or have any responsibility related to assessment, eligibility, service provision or funding determinations and oversight¹.

As Independent Facilitators, we have the privilege of standing alongside people as they begin envisioning and making changes in their lives. These are changes that they have willfully chosen. We bear witness to these changes. We see how these changes begin to re-shape their sense of self as well as how they transform the lives of everyone who is woven into their lives. We help people to imagine more boldly or creatively and better adjust to the newfound expectations and demands brought about by these changes and help them to consider and take their next steps day by day.

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There is now extensive research and evidence in the area of 'youth to adult transitioning' to suggest that adolescents with disabilities who are leaving and/or preparing to leave secondary school, benefit greatly from receiving a range of supports to assist them in taking up their adult lives. These supports, when offered to them through Independent Facilitation within the context of their family or others of their choosing, increase the chances for them to become more productive and lead richer, more inclusive adult lives in the community, as citizens. Most importantly, supports that aim at helping youth to transition into valued adult roles are more likely to expand their social connections so that they feel a true sense of belonging and satisfaction (see KING et al. 2005).

2. The Broken Promise of Inclusion

At this point in Ontario, some 35 years after Bill 82 introduced the principle of 'universal access' to public education, guaranteeing the right of all children to be enrolled in a publicly-funded school and provided suitable educational programming, many of today's secondary schools seem to merely tolerate the presence of adolescents with developmental disabilities in their school. Families tell us they turned to Independent Facilitation because of how exasperated they were with school boards that do not invest financially and morally in creating an inclusive culture in their schools. Many families share with us how demoralized they become as they witness schools relegate students with more complex disabilities to custodial modes of education where they are put "out of sight and out of mind" in self-contained special education classes that are found on the periphery of school life.

¹ There are currently several Independent Facilitation Organizations in Ontario. For more information visit the website for the Ontario Independent Facilitation Network oifn.ca and familiesforasecurefuture.ca

Over the last 18 years of collaboration with many school boards we have experienced a steady erosion of the promise of inclusion and the current reality is both disappointing and damaging. We have come to believe that many secondary schools in Ontario today have lost the moral conviction that was once apparent. Schools are no longer driven by the belief that ‘each belongs’ and that we are all strengthened and made better by the gift of inclusion where diversity is encouraged and acknowledged as something that brings more spirit and life to the school. This lack of moral imagination in finding ways to support each student to be engaged and participating alongside their age peers has become a serious impediment to inclusion. School inclusion has unfortunately, in practice, been reduced to a series of legal and rights based obligations. While these obligations are essential, and critical for families to understand and apply in their advocacy, they are often undertaken by secondary schools in such a way as to simply ‘play by the rules’ rather than set out to create a rich and vibrant learning environment for all students to flourish regardless of their abilities. It seems that the moral arguments for school inclusion too often get lost in the shuffle of litigation-averse school boards who seem to have come to view special education as an added pressure rather than a moral obligation to do right by students.

While some exemplary school boards in Ontario have shown superior leadership and maintained their commitment to inclusion and ensuring that students with disabilities are welcomed and given a highly individualized curriculum that helps prepare them for adulthood, they are, from our experience, clearly the exception to the rule.

Rather than schools ensuring a quality education, students who have a disability experience being viewed as ‘second class students’ and sometimes not even as students at all. Students report being unwanted because they are taken from class to class by their Educational Assistants and treated as visitors. This ‘visitor status’ is reinforced as they are continuously asked to leave classrooms and wander the halls if they are seen in any way to disrupt the work of the ‘real students’.

This experience of being relegated to an inferior education that provides little hope for a future, affects a growing contingent of students, and not just those who have a developmental disability. It impacts all those who have for some reason been marginalized by society. Those who are poor, who struggle to maintain adequate housing, who identify as LGBTQ², find it difficult emotionally to cope with the demands of secondary school, who are considered behavioural problems, who do not speak English as their first language, and most importantly and finally, those who belong to racialized minorities.

When we first begin supporting these students it takes a lengthy process of building trust and recovering from the status of social outcast before they are ready to participate in regular community settings again.

² LGBTQ stands for Lesbian, Gay, Transgender, Bisexual and Queer.

3. The Inevitability of Adulthood

Adolescents in our culture have an ever-present expectation placed on them to consider their future and how they feel they can best contribute to the world. They are given a whole range of resources to sort through the various options and gain experience in making decisions related to their future. While it is clear, that this transition is tumultuous for all adolescents, there is some solace in each of them knowing that they are not alone and that this transition is experienced by everyone. They accept and acknowledge that there will be certain formative events or thresholds that will mark and signify the shift from one phase of life to another, including:

- leaving secondary school
- securing paid work
- starting college or university
- moving out of the family home
- dating and courtship
- travelling places with others who are not family
- making autonomous decisions about key areas of their life

For any or all of these seminal events to happen in the lives of adolescents who have a developmental disability, it requires extraordinary and intentional effort and planning. It necessitates that parents know their rights and the rights of their child when it comes to getting relevant educational programming and transition planning.

Many of these events or thresholds that typically signify the transition to adulthood cannot be simply taken for granted or regarded as inevitable. For the most part, they are seen as ‘against all odds’ or unrealistic for youth with developmental disabilities. Parents are painfully aware that for their sons or daughters to reach these goals it will take a tremendous amount of belief in their young adult and persistence on their part. They feel discouraged as they come up against the broader society’s view that people with disabilities belong in segregated, sheltered settings where they can be given ‘special’ care and where they will essentially be placed out of sight and out of mind. For some, this limited imagination of what is possible is reinforced in the school transition planning processes. Is it any wonder that many families and youth find the prospect of even beginning to think about transition planning overwhelming and anxiety producing?

4. Preparing for and Building a Meaningful Adult Life

4.1 Acknowledgement That We Grow and Change with the Support of Others

For youth to take on and fully embrace change, their families would also need to embrace and take part in that change. The wellbeing of the youth and that of their families/loved ones were intricately and intimately linked. When it comes to making changes in ones’ life, families usually bear the consequences of those changes and need to be part of the process from the beginning.

We need to recognize that personal change requires us to consider and engage others. My change always necessitates that those around me change, adapt, reorder their pictures of what is possible, and ultimately stretch their imagination of who I am. I need people to be there for me when I stumble, or if I fall. For me to sustain change I need to know that people are behind me and that they have my back. Each of us asks the same questions when we take on change. Who will be there for me? Where is the safe place for me to fall back into? Who believes in me?

When Independent Facilitators are invited to support adolescents as they prepare to build a meaningful adult life, they and their family must be confident that there will be an opportunity to build a relationship of trust with the Facilitator over time. This commitment assures youth that they can build their vision slowly and that the changes that they are planning will not have to be rushed into recklessly or unnecessarily. It encourages everyone involved to envision the transition from secondary school to adulthood in the context of the youth's whole life. This helps in creating a solid bridge from adolescence to adulthood, knowing that changes will unfold in the immediate, midterm, and long-term time frames.

Where there are no existing family connections, the Independent Facilitator must make every effort to recognize those who love and care for the youth we and who are prepared to stand by them over time. Independent Facilitation aims at fostering these kinds of relationships. The foundation of transition work is relational.

“There are days where the worries about the future are so great, they can be crushing. Fear of the unknown is powerful, immobilizing. Having a creative problem solver who has an unshakable belief in inclusive communities and has the skill and ability to navigate opportunities and find connectors is invaluable. We were so worried as we tried to sort out what is next – after secondary school. By meeting with our Independent Facilitator and our son to map out the possibilities, the people in our lives, the places and roles we can explore puts us more at ease. Just knowing someone is there to help us scout out opportunities and walk alongside my son, gives us strength and renewed focus. It gives us permission to continue to believe in that vision, to believe in those dreams and most of all believe in our son.” (Parent supported by FSF)

4.2 Contemplating the Transition to Adulthood

We have found that families vary considerably as to when they begin to contemplate and prepare their adolescent for adult life. Some families, who are committed to social inclusion from the start, set out to prepare their child for adulthood when they first start school in kindergarten, by ensuring that they have as many typical peer models and friendships as possible. These efforts are undertaken to help the child to develop strong social and language skills and an expectation for learning and contributing all they can. These same parents advocate within the school for an appropriate individual education plan that consists of legally mandated requirements such as annual goals, learning expectations, teaching strategies, accommodations and most importantly a transition plan. This makes for a coherent set of learning goals that progressively challenge the

child's abilities, so that they might learn and understand age appropriate expectations. They intentionally set out to find ways to help their child engage with their typical age peers in personally satisfying leisure and/or volunteer roles in the community. These parents acknowledge and celebrate when their child is directing their own life and are keenly aware of how each of these experiences prepares their child to better envision a future for themselves that involves taking up adult roles related to post-secondary education, paid work or volunteering.

Not all families, however, have the confidence and support from others to imagine and then set out to achieve an inclusive life for their child, from the start. Many parents have never been exposed to the philosophy and potential benefits of school inclusion, and so follow along with any placements recommendations that are made for their children. When all they have known for their child is self-contained classrooms, they come to believe that segregated settings are the safest and most secure and preferred option.

For many families to contemplate the future and what it means for their young adult to be leaving secondary school at the age of twenty-one, the first obstacle for them to face is the long-held belief that their son or daughter will remain a 'forever child' and will be wholly dependent on them throughout their adulthood. It is truly difficult for some families – to begin holding adult expectations for their sons and daughters when they have been told from the very beginning that their child will never be able to speak on their own behalf or make decisions in any way due to their inability to function above their so called 'Mental Age' (MA). We have found over and over that the concept of Mental Age is not helpful when it comes to supporting an adolescent to begin their adult life.

Everyone has a rich inner life. It is our task, as an Independent Facilitator to connect with who the person is in a way that makes that visible to ourselves and others. All of us have a unique way in which to direct our lives and make decisions alongside others. We each have found a way to make our will apparent to others that is, what we are willing and not willing to do. Using speech is only one way of making oneself understood and making decisions. Our role as Independent Facilitators is to listen carefully and observe keenly how each person expresses their will and desires as they (age and) begin taking up their adulthood. From practice, we have learned that adolescents who have developmental disabilities hunger to be taken seriously alongside their age peers. This need to belong invariably makes them eager to be challenged by adult expectations to the greatest extent possible.

As Independent Facilitators, a large part of our role is to encourage and support adolescents to become interested in their own story, in what has happened in their lives and in who they have become. We support them to begin telling their own story and defining what they want and need, in order to be happy and satisfied with their lives. For this to happen, they need to have concrete experiences of being in adult settings where they are supported to assume adult roles to the extent they can. We are very conscious of the need to scaffold learning experiences in such a way that

adolescents slowly grow into the adult role as they come to appreciate what is expected of them. In this way, the adolescent and others become aware of how they need to be accommodated so that they can move closer to the adult expectations that are part of the role.

“When I started volunteering at the community garden I didn’t believe that anyone cared whether I showed up when I said I would. When the Volunteer Coordinator asked me where I had been, I realized she meant it and that there were people who were counting on me. I make sure now I am there before my shift and I have my volunteer shirt nice and clean and my nametag on. My parents can’t believe that it is my job to help make pizzas for the outdoor pizza oven.” (Adolescent served by FSF)

This belief in Mental Age and the expectation of little potential growth is clearly one of the most fundamental reasons that transition planning is postponed and/or ignored entirely by some families and school staff.

4.3 Strengthening the Adolescent’s Voice

Independent Facilitation is focussed on taking direction from the adolescent and helping them to develop a stronger sense of self and a vision for the future. This involves being present and listening in such a way that the youth strengthens their voice and their capacity to speak up for themselves in whatever way possible. Helping to strengthen an adolescent’s voice also leads them to being more able and willing to enter into dialogue with those who matter in their lives, both about things that are troubling them, and what they envision for themselves. It helps them to understand who they are and what their own story is. When adolescents are carefully listened to over time they begin to be eager to tell their own story and listen to others’ stories

Independent Facilitation acknowledges that each person has the capacity to express their will and their preferences in some way and can be involved in directing and taking charge of the key decisions in their life to the extent possible.

Independent Facilitators are committed to ensuring that the pacing and nature of change is dictated by the adolescent with the help of their family/loved ones and that we take our direction from them and their families. We realize how essential it is for each adolescent to learn how to evaluate and negotiate the risks that are necessary for taking on and embracing change.

4.4 Supporting the School-based Transition Planning Process

In Ontario, a transition plan is described as the school’s written plan to assist the student in making a successful transition from school to work, further education, and community living (see ONTARIO MINISTRY OF EDUCATION 2002). According to the ONTARIO MINISTRY OF EDUCATION’s (2000) every transition plan must include the following elements:

- “specific goals for the student’s transition to postsecondary activities. The goals must be realistic and must reflect the strengths, needs, and interests of the student;
- the actions required, now and in the future, to achieve the stated goals. The actions identified must build on the student’s identified strengths, needs, and interests;
- the person or agency (the student, parents, educators, providers of specialized support and services, community agencies) responsible for or involved in completing or providing assistance in completing of each of the identified actions;
- timelines for the implementation of each of the identified actions.” (ibid., 17)

We have observed that most families begin transition planning in earnest only once the necessity is upon them. The necessity for planning becomes most apparent when the school first approaches the student and the family to consider taking a career planning course and/or begin enrolling and preparing for cooperative work experiences. It also becomes abundantly evident when suddenly the student refuses to return to school and the family has to confront the reality that adulthood has begun, whether they have prepared for it or not.

While most families try to hold a positive outlook about their young adult’s transition to adulthood they are nevertheless often consumed by various questions regarding their own future and the future of their loved one.

These are common questions parents held about their young adult’s future:

- What is he capable of in terms of volunteer and work roles?
- What concrete skills and talents does she have that she can utilize in the workplace or volunteer settings?
- How will he manage the drastic change in his routine and everyday environments?
- How will she manage to maintain the friendships and connections she has made in secondary school?
- Will he be lonely and begin to withdraw into his room and isolate himself?
- How do we engage her in setting the pace and direction of the change?
- How will we know what he would like to do with the rest of his life when he can’t figure it out and doesn’t speak about it?
- What is she truly passionate about and what motivates her?
- How anxious will he be in taking on change and how will we help him manage the anxiety?
- Will he receive any individualized funding from government so that he can hire support people to accompany him as he establishes adult work, volunteer and leisure roles?
- How will we know if she truly wants something to change or whether she is just making us happy or trying to stop us from asking again?

Here are some common questions about the future of the parents and siblings:

- What will this mean for us as parents and siblings to have him suddenly home full time?
- What will this mean for us financially? What is the economic impact on the family?
- Other than we, (as) his parents, who will be in her life? What new relationships will she develop and which will she maintain?
- How can we have the courage to invite others in to help us with all of this?

In fact, one of the greatest and most pressing concerns for a lot of parents during transition planning is the economic impact and reality of their young adult returning home. Since most youth with developmental disabilities leaving school do not have individualized funding or a solid commitment of a full-time day program option to replace full time schooling, they are at a real loss. Some parents find themselves at graduation forced to leave the workforce well before retirement age, so that they can take up the care and supervision of their young adult and thereby losing a significant source of financial security.

For secondary school transition planning to be successful it needs to start as soon as the student enters secondary school, at around fourteen years of age. This means that families need to communicate this in the initial Identification, Placement, and Review Process (IPRC) meeting. Their expectation that a meaningful transition plan will be put in place that will outline goals and solid actions for building the son or daughters work experience and resume must be clearly stated. Additionally, each Individual Education Plan (IEP) meeting throughout secondary school needs to pay careful attention and place particular focus on the transition from school to work. This will ensure that the plan can emerge over time, as the student begins considering his hopes and dreams for the future and identifying where his gifts and talents lie and what he is truly passionate about are essential and must be ongoing. Students cannot do this alone. The plan needs to evolve collaboratively within a broader team context involving a range of other people.

“I think for my daughter to have the courage to try so many new experiences, she needed to know that our Independent Facilitator was willing to take the time to come to know how she communicates and explore her fears and hopes. She also makes it clear to our daughter that she is not alone and that there are plenty of people around her that believe in her and will help her step by step.” (Parent supported by FSF)

When Independent Facilitators begin supporting a person and their family at the start of secondary school, it is much less pressured. Time is available to assist them to contemplate the future, clarify their vision and expectations from the school, and set the stage for a meaningful transition to work experiences and adult life. For families who are determined to make the most of their son or daughters secondary school experience, we support them to make it clear from the initial meetings with school staff, what their expectations and needs are regarding:

- Extent and regularity of meetings with teachers and resource staff
- Kinds of communication exchange that will occur on a daily basis
- Nature of in-class accommodations and educational programming
- Extent of educational resources and supports dedicated to their son or daughters educational programming and curriculum
- Means and mechanisms for taking up concerns with school staff
- Extent of cooperative work placements desired
- Extent of regular classroom engagement and secondary school course credits anticipated and desired

Independent Facilitators partner with families to build a school transition team that is made up of ‘Champions’ of people that share a positive and hopeful vision of the students’ future. This

collaboration within the school and with other partners ensures better decision-making and more deliberate plans.

“When we had school meetings to plan for a co-op work placement, our Independent Facilitator was there to support us in bringing forward the gifts of our son. She had a keen understanding of the manner in which he communicates and was able to identify the many areas of talents and interests which bring him joy. She was able to bring forward this information in a non-threatening way to the school staff so we could all begin to think creatively about the possibilities.” (Parent supported by FSF)

Unfortunately, it is our experience that adolescents with developmental disabilities typically have no standing at transition planning meetings, and so have no formal input into the decisions that are made. Even though students and their allies have a right to be involved in all meetings related to transition, we find that it only happens if and when parents advocate loudly and clearly that they want their son or daughter and other allies to participate actively in these meetings.

“Since our Independent Facilitator has experience in supporting others through transition she has brought credibility to our family as we navigate our daughter’s adult life. This is mostly because others can see that she appreciates what accommodations and support would need to be put in place to make it work and is willing to partner with them to explore what works and what does not.” (Parent supported by FSF)

Some of the families we support receive very little support from the school in transition planning. Their sons or daughters typically have more complex needs. The family has been told that there is little urgency on the part of the school to discuss transition planning because the staff consider it unnecessary or inappropriate to even consider cooperative work experience. These youth, having gained no real volunteer or work experience, most often reach the end of secondary school having no prospects or any hope for taking up work or other adult roles.

Families tell us that just knowing that there is an Independent Facilitation Organization that is willing and able to support the entire family as they begin contemplating and imagining the future together and taking concrete steps as they go boldly into the next phase of their life, can make a huge difference in the entire families’ sense of well-being, and their preparedness to act in a hopeful manner.

5. Supporting Families to Go Beyond and Build on School Transition Planning Efforts: Informal and Formal Planning

It is essential to build the adolescent’s social network throughout secondary school so that once they begin launching their adult life there are people who can offer them meaningful support and ideas. Informally, this involves the adolescent and the family consciously including others in the conversation about what will happen after graduation and what is possible. Relationships of trust emerge over time and are strengthened by concerted action and demonstrated commitment.

Intentional formal planning processes are helpful in laying a solid foundation for taking action. They shape vision and concerted action. They clarify indecision and help people to confront potential obstacles in a methodical way, and produce documentation that can help guide action and ensure accountability. However, formal planning does not guarantee outcomes, only people in committed relationships can do that. Without using planning as a way to solidify and deepen relationships, a written plan is meaningless. Without ongoing facilitation and dialogue and having people to stand by the individual, the plan is sure to fail.

Formal planning is not a quick fix because it happens over time through many conversations, and culminates in a planning day. A planning day is meant to act as a catalyst for change and it signals the beginning of a new conversation between a broad group of people about what may be possible.

There are several tools which Independent Facilitators employ in the formal planning process one of which is LifePath Planning.³ In developing this tool, I relied largely on the work of Wolf WOLFENSBERGER (2013) and his concept of social role valorization. In the early seventies, WOLFENSBERGER offered profound insight into the wounding and devaluing experiences common to those who live with a developmental disability. LifePath Planning is a one day planning process I developed which draws upon his deep understanding of the need for establishing and maintaining valued social roles as a safeguard from furthering the process of devaluation.

“A key aim of LifePath planning, is for people who have a developmental disability to gain a tangible sense of co-creating their life with the help of others. When people occupy a devalued social status and have experienced exclusion, co-creation is all the more vital because they are vulnerable to a diminished, negative and hardened story about who they are and who they might become. They begin to act from a rich and coherent story of themselves as resourceful and capable of building their life out of both their vulnerabilities and their unique capacities. It focuses on creating a safe dialogue where others are able to build more abiding ties and identification with the person and a deeper appreciation for his lived experiences and aspirations.” (Judith McGill in O’BRIEN 2014)

6. Marking a Rite of Passage to Adulthood

One of the formative intentions behind the development of LifePath Planning was to help adolescents move consciously and intentionally from childhood to adulthood in a symbolic way. The planning day is designed to celebrate this coming of age as a rite of passage into adulthood. It involves all those who love and care for them and all those who have acted as champions and advocates throughout the persons’ life. It gathers all those who have steadfastly believed in them and want them to have a productive and meaningful future.

LifePath planning aims at bringing people together to create a ‘turnaround event’ where there is a felt sense that things will proceed differently from this day forth. The day marks an extraordinary new beginning where new intentions are formed and new understandings are reached about the

³ LifePath Planning is copyrighted by Judith McGill and is a formal planning process.

adolescent's purpose in the world and where he belongs. The day supports the adolescent to begin 'storying' their own life by sharing pictures and stories from their life as well as their hopes and dreams for themselves. It signals to the adolescent that those who are closest are committed to helping them take up adult roles and responsibilities, and manage all the changes that are about to come, one step at a time. This sense of having a team of people who are willing and prepared to assist them to successfully and fully enter into adulthood, is immeasurably helpful to adolescents as they navigate the unsure waters of adulthood.

7. Deepening Connection with Others

The LifePath formal planning day helps those present to better grasp, who is in the adolescents' social network, and the role they have played and continue to play in his life. It helps everyone in the network to begin thinking about how it may be possible to consolidate these existing relationships and offers them a sense of shared purpose and solidarity. The day helps those present to strengthen their identification with the person and his family by broadening their knowledge and appreciation of the person's and family's lives. It offers the opportunity to sense both the longings and the triumphs of the person and to resonate more authentically and personally with the persons' humanity. It is a powerful way to build allies who are well informed and prepared to advocate where and when necessary. Not only by identifying past advocacy efforts and current advocacy needs, but also by learning to listen more carefully about how they can be of help. People attending planning days tell us that, most importantly, it opens up dialogue about how they can personally make relevant and timely offers to contribute to the person's life in a meaningful way.

“Doing a one day formal planning day has opened up dialogue amongst our family. We had only superficially talked with our other two children about it. The planning day was the key to this. Her siblings heard the ‘whole story’ of her past, present and future. The day spurred us to invite other people into her life who can help her plan. As a result of coming together, these friends are stepping forward to provide more constructive support. As her parents, we have begun to clarify what we want for the future and listen to what she wants. We now want something different than we previously thought. Instead of a group home we are now thinking something more individualized and with one other roommate. You have opened our eyes to the possibilities. You have also opened our eyes to what her life could look like beyond day programs. The transition process is just too daunting to tackle it alone.” (Parent supported by FSF)

8. Supporting Adolescents and Families to Focus on Identifying, Supporting and Maintaining Valued Social Roles

The Thames Valley Study (KING et al. 2005) defines roles as “socially expected behaviour patterns or clusters of meaningful activities that are expected of, and assumed by, individuals in various contexts of their lives” (WARDA 1992). It suggests that when adolescents leave school they need to be supported within the context of their families and others of their choosing, to identify, plan for and think about taking up social roles in three major life domains:

- Social relationships (friendships and sexual relationships);

- Productivity or occupational roles (employment, further education, and volunteerism);
- Leisure/Recreation Roles

One of the most critical aspects of having an Independent Facilitator's support during the school years is the focus they put on assisting adolescents to expand and strengthen their social roles and embed themselves in neighbourhood locales that give them a sense of belonging well in advance of their leaving school. Beyond planning for and envisioning their adult life, adolescents need to have concrete support in finding and having 'real-world opportunities for skill development'. They can determine for themselves and with the help of others, which adult roles feel right for them, and where they feel they can make a contribution. They benefit greatly during the school years in having support to identify places they feel good about that are nearby, accessible to their home, and that offer a range of possible roles.

There are many changes that occur naturally as adolescents leave secondary school and begin taking up their adulthood. First, their physical world is expanded immensely because, for the most part, they go from navigating and participating in two primary environments school and home, to becoming acquainted with and participating in several new environments at once. Some of these might include work, volunteer and leisure settings in the community (ROTH & BROOKS-GUNN, 2000). Within each of these new places or environments come new adult roles that they will be expected to familiarize themselves with and adapt to within a relatively short period of time.

While adolescents begin taking up their new life as an adult, Independent Facilitators assist them to take note of and pay attention to how they are shifting their perception of who they are and what is possible. We invite them to take up their life, their story, in an active sense and figure out what it is that keeps them in a 'stuck place'. Complacency and 'this is all I get' may fuel their inaction. As Independent Facilitators, we aim to help people find other possible interpretations, other story lines, alternative narratives, about their lives.

We need each other to embolden us, to give us courage to speak and explore our truth, our vulnerability and our uncertainties. We need each other to be a mirror, to reflect back on what we hear so that it can become more real, so that in our own speaking we can hear what our commitments and priorities are. We need others to inspire us to act differently and choose another story; to coax us into picking another story line and to help us get unstuck. It is what lives between us in the silent spaces of our lives that helps us to understand more about who we are. It is in seeing how we fit into other people's lives and stories that gives us a sense of belonging and meaning.

It is our shifts in self-perception and identity, that, when deeply internalized, dramatically shift the perceptions of others. When someone is truly engaged in a new role others see us differently, even those near and dear to us. These shifts in perception catalyze and motivate further action. We have

learned that for adolescents to shift their self-perception it is never enough to use the words; they must feel it because something is changing in their lives.

The Thames Valley research (KING et al. 2005) emphasizes the critical need for transition supports to “be customized (in order) to meet youths’ life goals, values, interests, and skills (i.e., flexible and responsive to changing needs and situations)” (ibid.). It also indicates that to be successful, adolescents with developmental disabilities need:

- Help to identify and express their interests, values, and strengths
- Help in formulating long-term goals (i.e., their vision of their future) and supporting them on this path
- Guidance and experiences that correspond to their goals, values, interests, and skills.
- Emotional and instrumental support (practical support and coaching)
- Information about services, opportunities, and other aspects of the local environment
- Support to enhance and develop the individual and family’s self-knowledge, strengths, and support network

9. Conclusion: Lessons Learned

In conclusion, it is evident from our experience in supporting people with developmental disabilities and their families that the practical supports we offer have contributed significantly to their efforts in preparing for and building a meaningful adult life. In those jurisdictions where there are no Independent Facilitation supports available, efforts need to be made to find innovative ways to offer these supports in the context of families both in and out of school settings.

The following is a summary of the key lessons we have learned at Families for a Secure Future about helping adolescents in making a successful transition to adulthood and building a meaningful life:

- Adolescents need support to identify and take up adult roles. People and organizations in the community welcome individuals within the context of a social role – they are especially generous as they come to learn and identify with the person’s story and are less likely or willing to accommodate groups of people with disabilities. Friendships are formed within a context of work, volunteer and leisure, settings.
- Personal transformation happens over time as courage is fueled by action and a shifting sense of self. It is essential for people to see themselves differently day-by-day so they will act differently. Changing self-definition takes more than encouragement – it takes concrete changes in circumstance. To change how you see yourself there needs to be a real change in what you are taken up with day to day in terms of investments of time and money and the kinds of contributions you are helped to make. As you experience shifts in relationships, focus and direction, your self-perception begins to shift naturally as you integrate your new reality and commitments.
- People and families need support to understand and defend their legal and legislative rights around school inclusion. They also need support to navigate and interpret school policy frameworks and protocols related to transition planning so that they can participate fully.
- Power is part of every interaction, and transition planning is ultimately about shifting/balancing power dynamics to support the adolescent to take more power and make more decisions in their life. This shift in power needs to be taken on responsibly and incrementally, and it involves most critically, helping adolescents learn to speak up for themselves and follow through with their commitments.

- It is necessary and beneficial to have formal planning conversations witnessed by others who care, so that they can help to take up the questions and challenges that emerge in partnership with the adolescent. It also assists the adolescent to own their feelings to a greater extent and take more responsibility for their life to the extent possible.
- Adolescents need to be helped to recognize and acknowledge their own gifts and unique contributions so that they can communicate it these more clearly to others and imagine more capably about their future. They also need to be carefully supported to give up the negative stereotypes that they have internalized about themselves, and what is possible. For this to happen, they need to be helped to understand how their disability has shaped their life and their story, both positively and negatively.

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