



# The Nature of Family Support

**within**

Durham Association for  
Family Respite Services



A DRAFT VERSION  
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## A Foundational Document

*Please note that this version of the Draft document is fulsome edit on some re-alignments that Peg Jenner has suggested on the 2014 version document that was written by Janet Klees and Judith McGill in collaboration with Peter Dill and the DAFRS Family Support Team in 2014 and which subsequently gained good family, staff and board support.*

**This draft version of the Nature of Family Support has been published in order to provide a format for last edits and discussion before the finalization of this foundational document within the next year.**

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# The Nature of Family Support within Durham Association for Family Respite Services

*We are living in a world where our communities struggle to remain intact, in a society exemplified by impersonal, fast-paced, service-oriented and highly professionalized lives, where families are led to believe that their family members with disabilities will not live or lead or contribute to ordinary, typical lives and need to get fixed.*

***We remind ourselves that we can choose a different way - one that is natural and familiar to families and worthwhile to the whole community.***

*It is based on the value of each person, the importance of natural, genuine, authentic relationships to do the things that services cannot and it is based on the capacity of each family, and their chosen allies, to affect positive change which reawakens the capacity for the whole community to care for each other and live life more fully together.*

*From Assumptions (Family Support Discussions 2009)*





## Family Support within Durham Association for Family Respite Services

Family Support involves bringing about opportunities with individuals with disabilities and their families to build their capacity within themselves and along with others to bring about a good life in -- where relationship is key and where there is clarity that we all stand to gain when all members of our communities contribute and belong to each other.

Family Support is where the energy and vision of the family leads to lives that are sustaining and fulfilling. Families are actively engaged in many ways and will be supported and connected with others who believe in and work toward the same kind of community life.

Family Support is anchored in Social Role Valorization (SRV). This theory is a useful framework to guide the daily decisions through the work of thinking about the kind of change that is possible and how to bring that about.

SRV is a framework that acknowledges that it matters who people are in their community and their lives (their roles), it matters where and how and with whom they spend their time. If we want a community where diverse members find good things in common with each other and make room for and welcome each other, then we need to ensure that people with disabilities are present in good, valued and typical places in our families, neighbourhoods and communities where they hold valued roles, and offer contributions to other valued citizens such that their presence becomes of importance to the fabric of the community. These are the actions that will change the perceptions and stereotypes of people with disabilities among us.



## Our Commitment to Families and Family Support

Family Support involves a range of opportunities that invite families and individuals to work with others to bring about awareness, relationships, valued roles, experiences, connections and circumstances that make for a good, ordinary life with their family and community.

Families come to DAFRS in order to find the kind of relevant resources and supports that they need and desire in order to bring about a good life in community in typical ways for their family. They want supports and resources that are flexible and tailored to their family's opportunities and needs. Family support is where the energy and vision of the family leads to ways of life that can be sustaining, valued and fulfilling. Family supports works with families instead of doing for them. Families are welcome to partner with us in many ways and will be supported and connected with others who believe in and work toward the same kind of good life in community.

Our commitment to families and Family Support as outlined in this foundation document is based on our willingness and ability to listen to families deeply, to offer resources and support in genuine and respectful ways, and to continually question, evolve, and evaluate the ways in which we support families. Family Support itself evolves over time to offer new support and resources that families have identified as helpful and practical.

### A definition of a good life in community

The aim is to belong to a community where all people **are** valued, our differences are respected, our contributions drawn forth, and our needs are met in typical and valued ways so we can live in dignity among and in valued relationship with all others, and in typical life circumstances as enjoyed by all of us, as citizens.

A socially inclusive society is thereby evidenced by people –

- being present regularly and frequently in ordinary places in their communities,
- in typical and normative ways,
- in demographically representative groupings,
- holding valued social roles based on their interests and passions and choosing
- wherein they make relevant and welcomed contributions
- in and through their relationships with a range of valued and typical citizens

A focus on this definition and tracking the impact on people's lives through the evidence noted will keep Family Support in focus.



# The Importance of Family

## Families are Whole and Inclusive

DAFRS regards families as whole. Within that wholeness family members carry the hopes, vision and needs of the entire family as well as those of the individual members, fully aware that the lives of each member impacts on the other. DAFRS sets out to provide support to individuals with a disability *within the context of their* family to imagine, build, sustain and live a good life as a part of their community. Family is defined broadly to mean those who are steadfast and committed to ensuring a good life for and together with the individual with a disability. Whenever the word “family” is used, this includes the voice and dreams of the family member with a disability fully, as well as referring to committed, unrelated allies who are in long term relationship with the person.

## The Natural Authority of Families

Family Support at DAFRS acknowledges the natural authority of families and understands the family as the primary unit of a healthy community. Families consist of members who form freely given, committed, long-term relationships with each other. At a foundational level families have the potential to be a deep source of strength to their members and to offer their members such things as a home, stability, safety, belonging, life-long relationships, guidance and support. Family members deeply know each other, have shared roots, grow and develop together. Families evolve and change but stay committed to one another and stand by one another. Family Support means understanding and promoting the integrity of family relationships at a foundational level.

## Interdependence and Resilience

At DAFRS, it is our experience and belief that when a family becomes more consciously aware of how interdependent they are and learns how important it is to welcome friends, neighbours and community people into their lives, they can benefit immensely. Resilience comes from knowing that they are not alone and that there are ways to move forward with the support and engagement of others. Family Support looks to families exploring, recognizing and articulating their own sources of strength, relationship, and resilience on their own and among others.



## When Family is not Available

At times of change and transition, it is sometimes possible that family is unavailable to the person with a disability. Often we are able to continue our support and relationship with other committed members of the person's network, although from time to time we will need to assist in the re-building of unpaid, supportive and committed relationships with people who will support the voice and life path of the person into the future.

It is important for families, staff and the membership of Durham Association for Family Respite Services to point out the basic assumptions which are the starting part of our common thinking and our work. From these assumptions grow our principles which guide our work, and through these assumptions the paths to a good life in community with good family support are grounded.





## Underlying Assumptions of Family Support

An ideal community is a place where all members contribute and belong.

All people have common needs for the good things of life: belonging, family, friends, good health, safety and security, home, opportunities to contribute, opportunities for growth, sufficient money, respect, a voice in important matters of their life and community, a belief system, fairness, and to be known and treated as an individual.

Community members have the capacity to respond positively to people with disabilities although, as a whole, society does not naturally value the differences they perceive and does not readily see the common interests that members hold – without intervention and influence of their perceptions

All family members, including the member with a disability, have the capacity to envision, encourage and/or create, and/or support opportunities for them to be a contributing member of their community.

People with disabilities have the capacity to fill valued social roles and contribute to their communities; communities are less when they do not take part, and are enriched when they do.

Valued social roles, well-held over time, tend to lead to the good things of life (i.e., relationships with others, security, belonging, opportunities to contribute, financial stability, respect, and more). This is true for all family members.

Families are the most stable, reliable, deeply committed and influential support system for most people. Investing time and energy to strengthen families is time and energy well spent.

Personal, committed relationships with valued citizens are the greatest safeguard in the face of persistent vulnerabilities of people with disabilities.



# The Common Challenges and Experiences of Families

It is a paradox of human society that our places of community are both places where people with disabilities and their families experience painful and harmful devaluation (although much of it unintentional) and at the same time, the places of the richest, most accessible sources of hope and opportunity to counter these life experiences. It is essential within Family Support that we understand and learn to hold and work within this tension inherent in our world.

- ❖ **We all want and need the same things in life, however society generally has a profound misunderstanding of the human needs and aspirations of people with disabilities and their families**

We regularly see that the life of a person with a disability becomes defined by a unique (or “special”) need and all of their universal needs and aspirations (those common to all people) get ignored. This is particularly obvious at (but certainly not limited to) times of transitions (i.e, entering school, leaving school, family illness, moving out of the family home, starting a new job, losing a job, getting married, finishing college, death of loved ones, moving (whether by choice or not) , hospital stays and times of relationship absence, change or breakdown etc.)

- ❖ **Society tends to devalue those who are seen to embody certain characteristics**

When people with disabilities are afforded life experiences defined by their disability, they tend to get left out of typical schooling, work, relationships, recreation, homes etc. and instead get poor education, congregated living arrangements, much idleness, no opportunities to develop relationships with valued citizens, resulting in the filling of negative social roles. This happens repeatedly, not because ordinary people wish them harm, but because ordinary people see their difference and make conclusions about the person based on this difference. They then (frequently unintentionally) reject the person as unlike and less worthy than most valued people. This is the essence of social devaluation. This state of devaluation of people with disabilities can have a devastating impact on how they form and maintain relationships and the kinds of life experiences they have access to and support to participate in.



❖ **People with disabilities live in a state of heightened vulnerability - leading lives where they are at greater risk than others**

Social devaluation throughout society results in people with disabilities living in a state of vulnerability. They are regularly at risk for such things as their very health and safety, but also regularly at risk of poor treatment and atypical opportunities. Additionally, the impact of such experience is often greater for devalued people than it is for a valued person.

❖ **We need to use this information to work well within our community for the common good of all.**

Family members with disabilities experience harm even within our communities. In fact, they often go to programs and services that they believe to be safe, which almost always diminish their ability to be seen in valued roles as contributing members of their community sharing in interests common to others. As a result the natural development of friends and allies will not happen. In part, what we have to offer families is clarity on what real and typical community is and what is really set apart from community. Often, people with disabilities get cast into devalued roles, and then community members see them as not belonging in community life. Instead places away from community life are set up, and then even fewer valued roles are made available to devalued people. This happens even when people have the best of intentions. The result is that unless this is understood and action is taken, people with disabilities get embedded in devalued roles and the life experiences that these roles tend to offer.

Communities however, are also where the good things of life can be found and provide many opportunities to safeguard and strengthen other roles and messages about the person. Some of the richest opportunities offered in community cannot and will not be replicated anywhere else. It is possible to change a person or community's negative perception of a person with a disability in exciting, respectful, and genuine ways where both parties benefit. It is these kinds of ideas and strategies that DAFRS strives to bring to families and communities to the benefit of us all.



## The Role of Family Support at Durham Association for Family Respite Services

Building a good life in community is more easily achieved when families understand the role and impact of societal devaluation in the life of the individual with a disability and their family. This leads people to not expect the person to be present, to contribute and take part in community life in typical ways. This then reduces typical life experiences and increasing the likelihood of being further excluded from ordinary community life. Family Support helps families to understand social devaluation, its impact, what it looks like and how to prevent, minimize and compensate for it. Family Support also helps families to see where the good things of life can be found in communities and how to help their member with a disability get access to those things and thereby change the community and the understanding of its members.

Persistent work is needed to move toward and sustain communities where all people belong; communities where people with disabilities have a home, enough money, safety, security, opportunities to contribute, opportunities to grow, relationships, respect, a voice in important matters and more. When such elements are present in a community there are positive social dynamics in place that sustain the community and increase belonging in this way.

In the meantime, positive change can be made one person at a time when these dynamics are understood and powerful role-based strategies are skillfully applied.

Family support helps families to recognize, understand and counter the process of devaluation and to build, strengthen and/or safeguard positive roles so that their family member is more likely to experience more of the good things of life, including valued contribution, relationships and belonging.

When people with disabilities contribute and are known in a community, the other members of the community will be more likely to welcome and support their membership. Also, when people with disabilities fill valued social roles, other community members are more likely to see them as a fellow member and when seen as a fellow community member, more valued roles are likely to be available to people with disabilities.





## Family Support in a Time of Limited Resources

We are living in a world of limited financial and material resources. Even as families and others continually strive to ensure that people with disabilities gain their fair share of what is available, within DAFRS there will be natural limits to financial resources, availability of paid staff time and supports, and access to all training events, services and more. Families and staff will continually encourage each other to find ways to share scarce material resources while keeping within the mission and values of DAFRS.

At the same time, we know that between ourselves we have an abundance of ideas, supports, skills, opportunities, creative options, energy, time, ability to innovate, faith in each other, potential for growth, and love for our family members and each other.

It will be with a positive attitude to finding and celebrating this abundance and ever growing our own capacity that we will greet new families and believe that among ourselves we will always have enough. In addition, we also believe and see that we live in communities of potential and abundance and we will focus on finding, using and contributing to the abundance of our communities as much as to our own.



## Family Support Principles of Practice

Principles are essentially guideposts that allow us to keep to pathways that are more likely to lead to a good life in community. They help keep us in line by helping answer "if we want a good life in community...then..."

### **Family Support understands that relationship is of the utmost importance**

It is freely-given, committed relationships with people that will best safeguard the lives and lifestyles of family members with disabilities throughout their lives. People need a range of relationship in their lives – not all relationships are significant, but all are important. Everyone needs significant and lasting relationships to help them through life's transitions and challenges. These relationships act as safeguards against vulnerability because it means that there are people who quite simply "have their back" and are willing to stand by them as they take on change. It means that there are people who understand what it takes to help them to feel safe and respected and who will work with them to get their needs met even when it means taking on an advocacy stance. Families in their many forms have much to offer in terms of safeguarding and affording a good life for their members.

Family Support aims toward building, nurturing and sustaining the existing freely given relationships in a person's life - within the family, among families, within networks and neighbourhoods, and beyond. Significant time, attention, care and learning amongst each other, is asked for in order for this to happen over time. Equally important, is time spent on nurturing and developing new freely-given relationships in order to expand and deepen the individuals' and families' social networks.

### **Family Support role models positive interpretations of vulnerable people**

In order to change public attitudes, all aspects of Family Support at Durham Association for Family Respite Services sends the message that people with disabilities and their families are valued members of their communities. This means that the activities/decisions of the board of directors, the administration, the staff; the location; the language used about the people within it; all work together to convey the message that people with disabilities and their families are valued community members. Family Support shares the stories of people with disabilities and their families contributing to their communities. Family Support conveys the message that families who have members with disabilities enrich their communities.



## **Family Support points families to valued social roles for all family members**

Family Support recognizes that social roles influence our relationships, skills, opportunities, the places we spend in time in, our finances, the respect we are afforded and more. Family Support conveys this to families and encourages and supports the filling of valued social roles especially for the vulnerable family member.

## **Family Support is embedded in typical community life**

At the forefront of Family Support is the understanding that we are all members of our community, that everyone has a contribution to make, and that our communities are stronger when each member is able to participate and contribute. We are intensely interested in helping to build communities that welcome, recognize, and appreciate the contributions of all members.

Valued social roles are those found in typical, valued community life, therefore within DAFRS, Family Support sets out to support and encourage individuals and families to engage with their communities in typical and ordinary ways, and in so doing affect meaningful change within their own neighbourhoods and communities. The promotion and support of valued social roles and engagement in community life are intrinsically linked. Social roles give people their place and community life is where valued social roles unfold.

## **Family Support focuses on the interests, passions and contributions as a starting point**

All family members have important contributions to make to the lives of their own family, to other families, to their neighbourhoods and communities. Many of these contributions are essential to the common good. Family Support starts with a focus on the passions and contributions of family members, rather than on their disabilities or perceived problems. Supporting people to identify their interests and what they can uniquely contribute to their communities is critical in helping them connect with and engage with other community members who share those interests. Such community connections expand a person's knowledge of what is possible and desirable, set the foundations for valued roles, relationship and belonging.



## **Family Support Recognizes the family as the primary decision-maker and natural safeguard of the emerging voice of the person**

Family Support seeks to influence, support, encourage, teach, mentor, coach and connect families but it does not take over the decision-making role. The natural authority of families is recognized and the family is understood as the primary unit of a healthy community. As such, parents are the natural decision-makers for their children, and families and their networks are the natural supports to young adults and adults with disabilities in their decision-making processes, even as they strive to direct their own lives with their own emerging voice. The natural authority of families is upheld in order to best support the growing voice and autonomy of family members with disabilities with an understanding of shared decision-making over time.

## **Family Support recognizes the family as the implementer of decisions**

Family Support might walk along side of families as they implement the decisions that they have made, but Family Support does not take on the role of implementing. During times of crisis and need for immediate support or intervention, Family Support might invite other families and community members to help. It is acknowledged that in rare instances, a Family Support might provide time-limited direct support to a family in crisis.

## **Family Support is flexible and responsive to Families**

Family Support seeks to develop partnerships of trust and respect with families and in doing so, come to understand their circumstances and the impacts that change will have in their lives. Family Support helps families to envision approaches and changes that will work for them. Family Support itself evolves over time to offer new support and resources that families have identified as helpful and practical.

Additionally, Family Support offers many different ways and opportunities for families to understand, learn about, engage with, and connect to the work at hand; it is recognized that each family will carve their own path and at their own pace.

## **Family Support recognizes and seeks to work through tensions within families**

All families have times where they hold conflicting views on what is best and how to proceed. Family Support strives to hold the tension between divergent needs and goals while at the same time working towards dialogue and consensus so that the vital and fundamental family relationships remain intact. During times when such conflict arises, Family Support offers support to all parties with an eye to compromise, slowing the pace, and sorting through alternative solutions.





## **Family Support helps families prepare in advance for crisis**

Family Support helps families prepare in advance for crisis. Rather than crisis being episodic, out-of-the-blue, and requiring reactive responses, there is a deep understanding of the ways in which complex situations may become critical. In place, is support to plan for destabilizing events so that individuals and families can become more aware of the factors which can tip the scales and create further chaos. Families are invited into the process of taking stock, understanding the situation, taking preventive measures, and working with others (paid and unpaid) to take the best steps for the health and wellbeing of their whole family.

At the same time, Family Supports endeavours to be playful and aware of patterns, and shifts in the experiences of families over time so that it can develop timely, practical supports that work proactively and preventatively.

## **Family Support recognizes that families are a unique and valuable resource to one another.**

Family Support develops and supports opportunities for families to connect, support one another, and build capacity for change. This includes encouraging the development of principles to guide the work, role modelling gracious hospitality, identifying commonalities, building constructive group dynamics and the sharing of ideas. Family Support might seek to mobilize families to address emerging issues in their communities or respond to such requests from a number of families.

It is evident that strong family leaders emerge when families are support to come together in relevant and principled ways. Family Support has a role in creating a context for nurturing such family leadership by offering families further learning and leadership opportunities.

## **Family Support is ongoing**

Family members typically stay involved with each other throughout their lives. As members mature, the dynamics and the relationships change, but the commitment to each other stays present. As people with disabilities mature Family Support helps families to think about and plan for transitions and changing roles. Family Support is responsive to families through many of life transitions and stages.



## **Family Support builds the capacity of families**

Family Support focuses on capacity building which is about supporting, encouraging and developing vision-holding, leadership, critical analysis, decision-making, management, and safeguarding abilities within families and community.

Family Support offers training, connections, resources, coaching, mentoring, role models, information and encouragement to family members in order to enhance their skills and knowledge and their belief in themselves, to promote valued social roles for all members of their family.

Family Support recognizes that families are the most effective change agents for their sons and daughters. Family Support builds the capacity of the family as a whole and each of its members.

## **Family Support safeguards its practice through internal and external evaluation**

Family Support engages in regular internal and external program evaluation in order to keep its work focused and aligned with its principles. There are many family issues, community issues and program issues that could change the work of Family Support. Evaluation serves to keep the focus on family support and inform the program of slippage. Evaluation also serves to encourage consciousness of where principles are contravened. Continued consciousness enables correction should the opportunity arise. Evaluation teams include others who then learn about families and the work of family support and thereby increases networks.



# The Day-to-Day Strategies of Family Support with Durham Association for Family Respite Services

DAFRS sets out to strengthen or sustain a family's ability to enable the good things of life for their family member with a disability in ways that strengthen the whole family and indirectly their community.

The goal is always that family members with disabilities are able to be deeply engaged in meaningful lives in their community with relationship, roles and places of belonging in genuine and safeguarding ways.

## What Families are Helped to Do

Family Support centers around the belief that everyone is in a constant state of learning and growing. Eventually, the family is offered support to articulate a broad vision and plan for a good life.

There are needs common to all humans (i.e., for love, belonging, shelter, security, respect, etc.) These are difficult to address in ordinary ways when a person with a disability has been made vulnerable by society's negative perceptions. Learning to identify and work with the strengths and interests of the person is crucial while also remaining aware of the vulnerability of the person in eyes of much of the society.

Family Support accomplishes its goals by providing a range of information, resources, connections, guidance, role models, and relationship opportunities to individuals with disabilities and their families so that they might be supported to engage in building positive and typical lives for themselves from whatever point they may start. These supports may be offered by and with other families, community members, volunteers, and paid professional staff persons with relevant experience and areas of expertise. In joining together with others, the capacity and understanding of all people will be deepened and the whole community will benefit.

Family Support assists families to focus on the abilities and interests of the person while balancing the real vulnerabilities of the person by offering supports in the in the following ways:

### 1. Develop and hold a positive vision

Families are encouraged to develop a vision for and with the vulnerable member of their family that consists of the relevant, unique expression of the "good things of life" in their life. The vision focuses on the family member with a disability and yet encompasses the whole family. Typically, the vision will describe elements of a good life across a number of universal domains such as home, work, leisure, health and fitness, lifelong learning and more. At the centre of the plan is the idea that all individuals need access to and support to hold valued roles in family and community and that these roles change and evolve through the lifespan.



## 2. Enhance the influence the person has in life

Families are encouraged to listen to, nurture, and if needed, interpret the voice of their family member so that overtime the person develops more influence over the decisions in their life.

## 3. Use the theory of Social Role Valorization (SRV) to guide thinking and decision-making

Families are encouraged to use SRV to guide their decisions on the pathway to the good things of life, especially for their family member with disabilities. Families are guided to do such things as:

- Observe the world and think critically about the enticements to leave the familiar, typical and valued life path for one of "special" or "disability".
- Encourage the Community Presence of their family member
- Encourage Positive Societal Perceptions of their family member
- Provide, seek, support opportunities that encourage the development and use of positive skills and habits.
- Promote Valued Social Roles for their family member with a disability
  - i. Understand the skills and potential contributions of their family member and how these could be offered to and strengthen the community
  - ii. Craft valued social roles for their family member which recognize their strengths, interests, skills, relationships, habits, community membership, etc.,
  - iii. Identify and safeguard current valued roles
  - iv. Identify and deepen current positive roles
  - v. Identify and craft new valued roles with contribution at the core
  - vi. Ensure that valued roles are embedded in a context:
    - a. based on the *genuine interest* of the person
    - b. in *typical and valued community* settings
    - c. on a *frequent and regular* basis
    - d. where a *contribution* emanates from the role
    - e. and *other valued people are present* who might be open to relationship of varying degrees
- Promote a positive and relevant interpretation of the paid support as one of "bridge" to relationships

## 4. Establish and Maintain Relationships

Families are supported to develop, deepen, and/or sustain family relationships and relationships unique to their vulnerable family member. They are encouraged to acknowledge those who love, know, respect and stand by their family member.

Families are supported to notice, explore, and develop the strong connection between deepening and sustaining valued social roles and increased opportunity for relationship to develop.





## DAFRS and the Principle of Social Role Valorization (SRV)

The principle of social role valorization (SRV) is not immediately familiar to most people who come to DAFRS as board members, families, or even as new staff members. However, the depth and truth of this anchoring principle and its implementation framework is often clear and recognizable to people once they hear it described in common language, and once they understand its effectiveness as it guides the implementation of strategies that make a positive difference in the lives of people who are vulnerable. Fairly quickly, most people can appreciate this framework as a way to safeguard and build lives of value and meaning within the hearts of our communities.

Simply put, SRV explains that human beings are hard-wired to judge one another and quickly decide whether the other is "like me and mine" or "unlike me and strange and different". Those we recognize as like us and ours, we embrace and treat well. Those whom we judge to be essentially different, we push away and distance ourselves from. Much of this interaction is unconscious, however the impact on people and their lives and opportunities is very real.

Two things impact powerfully upon whether another person is seen to be "one of us" or "one of them" and these are: a) the company we keep lets others know that we (a new person) are okay if we are seen together with people, singularly or in groups, that they already know and like, understand and value; b) the roles we are perceived to hold - everyday, familiar and valued roles (sister, employee, and teacher) help others to see a person as knowable and sharing common values, while weird, unfamiliar and negative roles (adult day programme participant, special needs guy, and criminal) make others see the person as different and discomfoting, causing them to withdraw or turn away. Some roles are chosen by us in our lives (teacher, swimmer, neighbour) and others are thrust upon us by circumstances (poor person, sister, disabled person). The roles we are seen to hold are powerful ways that influence how the other will judge us. Interestingly, building relationships (i.e., the company we keep) that are rich, rewarding and safeguarding most easily arise when a person holds a range of typical and familiar roles in their lives (uncle, neighbour, drummer, volunteer, church member).

As an organization, as staff and board members, and as families and community members we can use this principle to positively influence the perception of the people with disabilities we love in our community, so that other community members are able to perceive their interests, gifts, talents and the things they have in common with that community member. When people with disabilities are included in everyday family and community life - among their non-disabled family members, peers and neighbours and holding typical, ordinary roles - the aspects of their lives and personalities that are familiar, knowable and in common with others are emphasized. The disability does not disappear, but it becomes less important. This allows community members to share common spaces and experiences and includes each other as "like me and mine". They come closer, ask questions, invite, offer opportunities and enter into relationships.



When this is not done, people with disabilities are almost always grouped together- to work, to live, to recreate - and set apart from others so that what is emphasized instead is their disability, the ways that they are different, and their strangeness from "the rest of us". Other community members who come across people in such groups and settings turn away, feel uncomfortable, address the group rather than individuals, and save their best opportunities and genuine relationships for people who are more "like themselves".

More specifically, as an organization, through board, staff and families, we can assist families to see and bring out the wonderful and positive and ordinary aspects of their family member's personality and lives; we can help families to remember the value and benefit of just being one of the family or one of the crowd in ordinary ways; we can offer strategies that assist people with disabilities to make their contributions in regular society in typical ways; we can promote ways in which people are seen and become known among their non-disabled peers so that their common interests and familiar roles shine through; and we can identify interests and build strong and new roles based on these. We can use all of this as a context for encouraging relationship – which will bring new opportunities of its own. We can gently bring awareness and teach about the impact of a life where the person is seen and treated as different, and how simple changes can more effectively bring about the Vision for a good life that almost every single family member has for their whole family.

Therefore, the resources, information, and supports offered to and with the families of DAFRS are provided within an SRV mindset. This means that from board to staff to volunteers to mentoring families SRV is a lens through which we design, develop and offer ourselves. DAFRS was started and developed many of its programmes and services in the past without a conscious thought to the principle of SRV. However, when this principle and framework became known, it was thought to be a natural fit for providing guidance to the work of the organization.

Although the work within DAFRS has long been steeped in the ideas of SRV, it is only in the past few years that this is being applied consciously and with some rigour. This work will continue into the future. This means that we continue to think about the parts of our supports and resources that seem to challenge the principle of SRV and keep on trying to figure out how to offer supports in a way more consistent with this guiding principles and therefore, likely more able to bring the people into a good life.

For the time being, where we might offer a resource that is not fully true to the principle of SRV - and therefore less effective in bringing about good life opportunities for the person - we allow our deep caring and respect for the family to come first: we identify what is a compromised situation, we do not remove beloved and appreciated supports unless we have something better to offer, we encourage families to give the new and unfamiliar a try in small steps, and meanwhile we ensure that whatever we do provide is of the highest possible calibre.

Over the course of the Board's year, we will spend more time understanding the principle of SRV and its practical implications and we will discuss the ways in which we are working in line with the principle and where we still have work to do.



## SRV One-Pager – c 2009, 2011 Janet Klees [janet@legacies.ca](mailto:janet@legacies.ca)

Human beings, by nature, are a judging and discerning species. Our minds leap to almost- instantaneous judgments about who people are, whether or not they are worthy, and then whether they are “part of “us” or “one of them”. The impact of these split-second – often unconscious - judgments are significant, strong and life defining. And they can occur just as easily to assume good things about a person who has done nothing to “deserve” it as to assume bad things about a person who has equally done nothing to deserve this judgment.

No matter what you, yourself, may think about people *personally*, society in general does not judge all people as equal or equally worthy. In fact, it has been shown that society, in general, *devalues* or automatically has poor regard for, and little protects or offers/brings the good things in life (home, work or contribution, good nutrition, friends, family, etc.) to people who are generally not valued by that society.

Our society (Western, industrialized, information-based) values newness, speed, productivity, perceived competence, a limited definition of beauty, perfection, youth, money, education, competition, and material wealth. Our society likes these things, holds them up as right and good and highly favours those people and groups who are seen to embody these things.

On the other hand, people who are not seen to fit this mold, or in fact, are seen to embody just the opposites – age, slowness, lack or low productivity, incompetence, non-classic beauty, imperfection, aged or senior, poor, uneducated or illiterate, and without material wealth – are perceived as being different from this norm in such a negative way as to not deserve the good things in life that others are afforded. Much of this process of perceiving and then judging an individual or a group of people is quick and unconscious – people are not aware of this happening and do not talk about it. In fact, many people would be horrified to see themselves as treating people who are disabled, homeless, or elderly as less valued or different in ways that impact them poorly. An objective look at the lifestyles, opportunities and situations lived by people who are seen as less worthy according to society’s values informs us that people who are devalued are constantly living much poorer quality lives than their valued counterparts – not by choice, but by societal action and design. As products of this very society, all of us learn what our society values, and unless we make a conscious effort to examine the process and do otherwise, we take on those values, and thereby, also those prejudices and devaluations.

Social Role Valorization (SRV) is a framework that helps us look at what we can do to influence society’s quick perceptions of a given individual or group. SRV is an empirical (that is, scientific, provable) theory that not only enlightens us about these powerful forces in society, but also shows us how to observe our environment, analyze its factors, and choose actions that will significantly impact how individuals and even groups are perceived by both individuals and whole sections of society. In particular, SRV asks us to pay attention to the social roles that people hold (both negative and positive; both current and potential). Many of our quick judgments about people are based on our perception of the social roles that they hold. Where people are perceived to hold roles that we see as familiar, typical and positive, we tend to feel more comfortable and positive and more inclined to welcome them into some of the good things in life. Where people are perceived to hold negative, odd, or unfamiliar roles, we tend to step back and often simply allow for mere basics of life (or even less) to be afforded them. SRV also helps us to pay attention to both the imagery and competency perceived within those roles and to invite and encourage individuals into close, personal relationships with other valued citizens so that such relationships are mutual, enriching, and safeguarding.

SRV gives us insights on how historically services, programmes and our culture have been organized in (often unconscious) ways that reflect and reinforce society’s negative views and stereotypes of people it does not value. We can positively shape society’s attitudes or, at least, to add some positive perspectives by focusing on roles and images are familiar and valued that adds balance to the initial perception of devaluation. This also allows the person’s positive characteristics, interests, gifts and contributions to come to light – a positive benefit for the whole society.



## APPENDIX 3

# Durham Association for Family Respite Services (Current Version)

## Vision

That all people enjoy a full and meaningful life within the community.

## Mission

DAFRS works in partnership with families with a member who has an intellectual disability or a child with a physical disability, providing Family Support (services, resources, and other types of assistance) that enhance the capacity of the whole family to care for one another and to sustain and/or enhance their valued social roles as family members and as members of the community.

## Values

DAFRS believes

- in the essential importance of good family life.
- that communities have a fundamental responsibility to welcome and support people with disabilities.
- that, when provided with adequate support, families provide the safest, most consistent and loving environment for family members.
- in the importance of promoting valued social roles for people with disabilities.

## We do all this by:

- respecting the primary decision-making role of families
- supporting people with disabilities to have valued and typical choices and significant and supported control over the direction of their lives
- promoting the importance of valued social roles for people with disabilities
- encouraging and supporting the capacity of the community to be responsive to people with disabilities
- seeking to provide paid support that is of excellent quality and of sufficient intensity to maintain or enhance family functioning
- engaging in ongoing reflection and evaluation to ensure that our work continues to take into account existing pressures and trends within the community and province and is true to our principles
- replacing existing services and service practices only when an equal or better alternative can be provided





### **Principles of Family Support:**

- Family support reflects the right and the responsibility of parents to make decisions regarding all their children including their child with an intellectual disability
- Family support enhances the competency of family members to make informed decisions
- Family support reflects the power of small personal responses by family, friends and members of the community.
- Family support enables the family, and individual family members, to fulfill, sustain and/or enhance relevant and valued social roles
- Family support is flexible enough to accommodate unique needs of different families.
- Family support is a role model of positive interpretations of people with intellectual disabilities and their families and thus teaches parents and the community to do so as well.
- Family support communicates to families and to involved community members that their loyalty and responsibility are to family, not to the organization.
- Family support programs provide a diverse range of supports to families with diverse characteristics and needs (including age, crisis, short/long term, etc.)

### **Family support services should:**

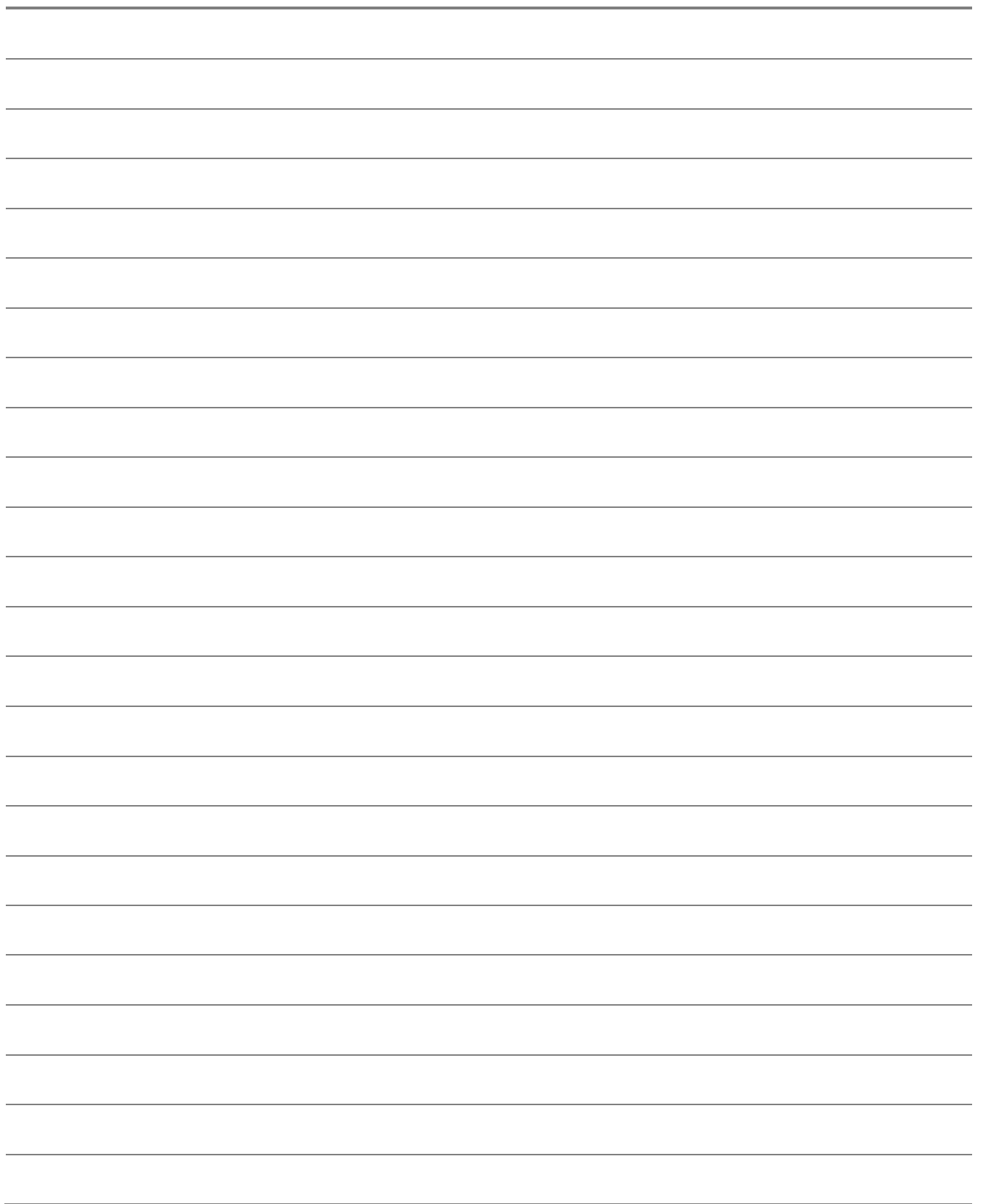
- (1) fit into normative family life as smoothly as possible,
- (2) intrude upon family life as little as possible, and
- (3) enable and support the family to carry out its normative familial processes as much and as well as possible
- (4) assist families to promote valued social roles for their disabled family member
- (5) be founded, where possible, on unpaid, community connections
- (6) where required, provide excellent paid support (trained, reliable, etc.)

























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