

“All About”

**A guide to developing a respectful,
comprehensive, personal information
resource**

Janet Klees

Toronto, Ontario 2005, 2008, 2015, 2019, 2023
janet@legacies.ca

Copyright 2002, 2005, 2008, 2015, 2019, 2023 Janet Klees

ALL RIGHTS RESERVED. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the prior written permission of the publisher.

To contact the author, write or call:

Janet Klees
11 Miniot Circle
Toronto, ON M1K 2K1
CANADA
(416) 261-4536
janet@legacies.ca
www.legacies.ca

“All About...”

A guide to develop respectful, comprehensive personal information

Purpose This guide is intended for serious content and use, rather than an entertaining update or even a fairly general introduction to a person. It has been developed to hold and present, concrete, practical and respectful information of the kind that only close family members and friends can glean over the space of much time. Through trial and error, I have found that this can be a helpful way to convey important and detailed information that will help make sure that a supported person is understood within a broad, caring and valued context.

This resource book, digital document or binder of information is not meant to replace personal orientation and ongoing guidance, but rather is a source for deepening understanding, gaining information, finding answers, or turning to for reminders of vision, life experiences, and overarching goals.

This book is not for people who remain visitors and gentle friends in person's life, but for those who need (e.g., paid support persons, inner circle members) or choose to get to know person more deeply.

This guide is continually being revised and edited. For comments, edits and changes, contact Janet Klees at (416) 261-4536 or janet@legacies.ca.

Format It is intended that formats for this kind of guide can and should vary greatly from person to person. It should reflect some of the unique qualities of the person. For persons applying this information in an assisting role, it is strongly recommended that you refrain from developing cookie-cutter sets of the same resource.

I recommend some version of this guide -even if the main source is a digital document – be held in some kind of loose-leaf system where items can be easily accessed (when systems are down or people overwhelmed), and also added or changed over time (e.g., a binder). In addition, it is useful to use some system for easily finding various sections (e.g., tabs, markers) with a clear Table of Contents near the beginning of the binder. For those who have moved onto more electronic information systems, this can be easily adapted and wonderfully designed – however, a hard copy that is beautiful, up-to-date and on-hand would always be a treasured and accessible counterpart.

Photographs add dimension and context to the binder or document- especially those showing the person over time, showing the person in relationship with a variety of others, the person involved in a range of current and past activities and valued social roles.

Suggested Content

For the purposes of this template, each new section begins on new pages so that it is easy to insert information behind the page and offers a guide to how the final version might be organized. This makes this template, if printed out and put into a binder – especially in the early development - all ready to go in order to begin to create a truly unique book of information for each person. This template provides a guide to suggest the approach to the information gathered and the kinds of content that might be most useful; the creativity and the final content rests with those who know the person best.

The whole first section, **About the person**, together with the section on **Vision**, can be pulled together as a separate book or document and used for general orientation purposes for new support persons or new friends. It would probably make an attractive, enhancing coffee table kind of book (especially if it were full of photos, art, stories written by the person, etc.) that a person might want to have on hand to help describe themselves and their lives. However, it also belongs firmly within the total **All About...Guide**, because without it people will be reading about challenges, routines, priorities, and support issues without either knowing the delights of this person first, or the direction of her life as described in the vision.

Table of contents

1. About Joanna
 2. A Vision for Joanna and her future
 3. Relationships
 4. Joanna's Time
 5. Communication
 6. Supporting Joanna
 7. Health and Well Being
 8. Emergency Information
 9. Crisis Plan
 10. Funding – sources and accountability
- Appendix 1 Telling Our Stories
- Appendix 2 Emergency Planning Document
- Appendix 3 Who is the Person?

1. About Joanna...

In her family

Situate the person within her family - who are they, where they live, idea of typical kind of contact with them, closest connections, etc. This also helps people see what kind of family this is - a small comment on the family dynamics.

More detail on the family members and closest friends will come later - this is just an overview to highlight the many ways in which this person is like everyone else: a valued member with family connections. You might describe the family roles this person holds (the family historian because he reminds us about who everyone is to each other and all of our family occasions; the party planner because she lets us know the family birthday and events that are coming up, the bread baker, the dog walker, the family comedian, etc.)

How others know Joanna

Solicit written or verbal comments from a wide range of family members, friends, support persons, neighbours, etc. Get them to finish the statement *When I think of Joanna...* or *What I know about Joanna is...* This works really well as a reflection and then discussion exercise within a circle or group of people. Everybody loves it, especially the person at the centre. Be prepared to jot down the stories that no one is writing down, but everyone is enjoying hearing. Hand out extra pages and ask people to take them home and think about them. Make sure favourite support persons fill out a page or two when they leave their position. Mail out the questions for distant relatives. The whole family will love the results. P.S. This can, and does, make for a wonderful book in itself! A variation on the question is *What works for me with Joanna is* and this statement is particularly useful and powerful for people who do not use verbal language to communicate, or who need thoughtful support to maintain their well-being. The question works less well for less involved family members but works well for anyone who spends any time alone with the individual.

Joanna likes...

Joanna dislikes...

These two sections are always surprising to people. There are almost always small details about the person that they did not know and that will be helpful to their interactions with her. Again, these are great lists to compile within a circle or group of people who know the person well. The discussion should be accompanied by a reminder that this knowledge should not be used to narrow a person's world or choices, but rather to gather an awareness of who the person is. For example, one woman I know was discovered to love the colour blue. After the circle discussion, she became swamped in things blue by well-meaning members of her circle. After awhile, the circle began to understand that the woman's world had become narrower by this response, and once again began to offer a range of typical choices - of which blues of many kinds was the predominant choice. The difference is subtle but important.

What kinds of "things" might be included? Try: food (fast food, good food, favourite snack) activities (indoor stuff, spare time, anything new), types of entertainment (music - what kind?, movies, television, eating out, sports fan), best environment (low key, lots of people, noise, etc.) sports and recreation (specific sports, fan or participant), politics and civic involvement (political parties, interested causes eg., recycling, environment). Favourite people might be listed here but there will be a lot more about that later on.

Dislikes are often a shorter list, but usually a bit more specific. Over time and experience the person and the family have come to know the quirks that just don't please her.

Another helpful addition to these pages is a section that describes how you can tell if Joanna likes or dislikes something, someone or a situation. For people who do not communicate with words or a system, describing body language, facial expressions and other ways of knowing is very helpful.

Joanna's interests and passions

Here you want to outline what draws her interest, what she is passionate about, where and with what things, ideas or people she loves to spend her time. If Joanna is quite young you might indicate the kinds of interests she is exploring and note those worth looking into soon. If older, look at her bedroom to see what this says about Joanna, think about what she gravitates to, and where she is absolutely at her best self. Where does she shine?

Include some notes on how you know that this is a keen interest for Joanna – how does she show her interest and her deep satisfaction in being in this space?

Joanna's strengths and gifts

This is a more positive, more informative update than the old Strengths and Needs list, and more in keeping with the language of vision, value and worth. This includes a practical comment on limitations that the person lives within and the specific areas in which she needs support - forget the how-to's at this point.

Here is a sample, taken from Naomi's book.

Naomi is a young woman in her early thirties...

- ...who lives in her family home and loves it there*
- ...who has a great family, both immediate and extended, both nearby and far away*
- ...who has many, many real friends who meet together regularly to help support her and her parents and to help everyone figure out things in her life, and who get together with just Naomi herself on occasion*
- ...with well-defined interests - in music (plays piano, appreciation), in arts and crafts, in her cats, in written communication (post cards, e-mail) with her family and friends, etc., etc.*
- ...who has a gift for music and playing piano for others and for engaging/welcoming others into her life*
- ...who holds a number of valued and positive roles in her life (family member, correspondent, pianist, church goer, nature enthusiast and more)*
- ...with a great sense of humour*
- ...and a great capacity for love.*

BUT

- ...who is extremely fragile and vulnerable within this world to being hurt, neglected, abandoned, and left alone...*
- ...because she lives with her parents who love her and thereby offer her many hours of support and co-ordinate all of the many aspects of her life so that it flows fairly smoothly and has meaning for her...and if something happens to them, who will ensure that she lives at home where she is happiest and healthiest? Who will provide that support and co-ordinate the flow of her life?*
- ...because she has already experienced workshop day programmes and group home living and knows that these group solutions are not for her and*

cause her distress and harm...these are not options or alternatives that will make sense for her life.

...because she has dual labels of Williams Syndrome and of autism, which in essence mean that she has great difficulty in integrating sensory experiences, auditory and visual information and co-ordinating gross and fine motor skills...all of which leaves her quickly exhausted, depleting energy reserves with simple every day tasks, prone to anxiety and distress over information that is not easily understood by her, and mostly requiring sensitive, flexible people around her who know her well and are ready to adapt each situation to her requirements. She will not cope well in a group approach.

...because she has acquired a few life-defining attributes that cause people to fear her, to see her as less valued or important than other people, or to conclude that she is a burden to others...unless she is surrounded by strong images and roles that suggest she is a valued citizen with her own gifts and talents to contribute to society.

*Naomi **needs** what everyone else needs - no more, no less - a home, a place to belong, a wide range of relationships, someone to count on over the course of her life, meaningful work or chances to contribute to society, leisure pursuits that are satisfying, spiritual opportunities, and ongoing opportunities to be involved in the decisions, choices, and direction of her life.*

BUT

*Naomi **also requires** some sustained thoughtfulness in having her typical, and everyday needs met. She requires a range of thoughtful supports and resources that will allow her needs to be fulfilled, so that she, in turn, can be a real, contributing member of her community. Her parents do this best right now and they need support (co-ordination, respite, help with vision and a future plan, some idea of who might carry on after). Her support circle is a wonder of potential and they need guidance and vigilance (roles, a call to commitment, involvement with a vision and a plan for the future). Naomi needs assistance in order to fully participate in her life (1:1 support, special diet, sensory therapies, goals and dreams, choice and involvement).*

An individualized plan for Naomi will include this range of co-ordination, planning and assistive measures to ensure that Naomi stay and grow within the circle of her family, friends and neighbourhood.

Other

Anything else that would help people get to know this person in a general kind of way. This is the overview section, destined to help people to understand that this person is a very typical person in many ways, is gifted in some ways, is knowable, is interesting and unique, and someone that they will want to get to know better.

If photographs and comments from others are not a part of the above sections of About Joanna, then you might create such a section here.

In the Appendices of this document, you will find a list of questions to think more deeply about who is this person in the depth of their being? This might not be your starting place, but it is interesting to dip into these lines of thoughts along the way. **Who is the Person?**

2. A Vision for Joanna and her future

Joanna's Story

An anecdotal account, possibly written by the parents or sibling, detailing the person's life story until the present. The story should include:

- Birth
- Early Years - including the beginning of the understanding of an impairment or a difference and the impact of that on the family, on the person (eg., testing, assessment, going away, etc.), and family life generally - this person within their family in the early years.
- Elementary School Years - what kind of schooling, what was the impact on the person, her siblings, etc. Was it integrated, segregated? What was life like after school and weekends? What were friendships like? What was vacation time like?
- High School Years - where was this and what was it like? What were siblings doing at the same time? What was the relationship between the person and her siblings? Friends? Boyfriends? First jobs?
- Early adulthood - what was life like after school programming was over? Was person prepared for adulthood? What were the thoughts and expectations of what would happen next? What was available? What was planning like? Who was in the person's life? What were the most pressing needs, as seen by the family/writer of this story?
- Adulthood - same as above.

Overall Thoughts - of the author, perhaps soliciting views from others. What had life been like? What now needs to be done? What are their hopes and dreams?

A Vision for Life

It is important - even essential - to hold before us a positive, well-articulated vision of a good life for each person. This vision can provide us with direction in times of confusion when one must choose between many choices. The vision can provide us with ideas and possibilities in times of trouble, with a way of setting priorities in times of scarce resources, and with hope. A clear vision which is communicated among and shared by the people who care for the person most is our best hope for a good life for them, now and in the future.

We want this person's life to contain the same things that all of us would include to describe a good and meaningful life for ourselves:

- a place to call home
- safety and security in one's home and wherever they go in their community and wider abroad
- connections to family, friends, and a wide range of acquaintances - people who value them for their own unique combination of character, gifts, talents, and strengths
- a sense of belonging - people who value their presence and miss the person when they are not present
- a place or places to give, participate, and contribute in meaningful ways that are recognized, appreciated and welcomed
- spending their days in personally fulfilling ways
- continual opportunities to grow and expectations that they will grow and learn throughout their lifetime
- respect of those with whom they come into contact
- the opportunity to make good, well-supported choices and to be involved with governing the direction of their life
- good health as a result of living a healthy life style
- a few close and committed relationships with family members and friends, and an ever-widening circle of those committed to be with them on their life's journey
- a way to communicate with at least a small circle of people who understand them well and care to listen to the deeper messages within their actions and responses to situations
- hope for the future
- the opportunity to work on a few of life's dreams at any given time
- a satisfying spiritual life

We are committed to finding ways to achieve or sustain the vision of this life for and with this person. The vision for a good life for the person will include the following (similar to above but some elements are grouped). This section might well be developed as a stand-alone document or be used in order to develop a Vision for a good life in home and community.

A Vision for Life

Home

- issues of safety and security
- a place of peace
- welcome, and place that others want to be
- where this is – either a precise address, or a neighbourhood, or a type of dwelling
- with whom this might be shared

Where will I live and with whom? What will my home look like and feel like? What is important to have in my home? What kind of neighbourhood do I want to live in? How will I be safe in my home?

Family

- ongoing relationships, not dependent upon parents
- respect and belonging
- connections throughout time
- holding many family roles – daughter, aunt, niece and cousin

When will I see my family? When will they come to my house and when will I go to theirs? What will happen for birthdays, Christmas and other celebrations? Who will make sure that I am included?

Friends and Other Relationships

- personal committed relationships
- ongoing nature of developing new relationships and deepening others
- mutual respect, shared interests, other
- opportunities to be a friend, as well as having friends
- Intimate relationships

Who will be my friends? Where and how will I meet people and make friends? What kinds of things do I want to do with friends? Do I want a life partner or a boy/girlfriend? What are my interests that I would share with friends?

How Person Spends Their Days – Contributing to Home, Neighbourhood, Community

- typical household management routines
- holding a range of valued social roles connected to work, volunteering, pursuing interests, etc., and the importance of safeguarding these
- following the rhythms and routines that are typical and valued and followed by age and gender peers in the community
- work - part time, full time, ideal number of hours and when during the week opportunities to contribute to their community

What will I do during the week? on weekends? in the evenings? How will I earn money? How will I pay my rent or mortgage and food and more? How will I be a good neighbour and help others in my community? How will I make a difference in my lifetime? What contributions do I have to make?

Health

- healthy lifestyle choices - food, exercise, avoiding intoxicants, regular check ups
- specific follow up for any conditions or health concerns

How will I stay healthy and well? Who will help remind me to take care of myself, be a role model for healthy living, and go with me to medical appointments? Who will help me make medical decisions?



Recreation, Leisure and Hobbies

- importance of maintaining a balance in life
- as opportunity to grow and learn
- as a place to meet people and make friends
- as place and time to participate and contribute to one's community
- the arts as opportunities in some way for each person to grow at home as well as outside interests

How will I have fun and follow my interests? Who will I do things together with? How will I be able to explore and try new things? How will I discover my growing and evolving community?



Lifelong Growing and Learning

- courses, interest groups, formal pursuit of knowledge
- travel, and other ways of learning through experience
- opportunities to make real choices, be supported in more complex decision-making
- participating in the other choices which govern her life
- growing ways of effectively communicating choices
- positive interpretations of choices that have been made
- support circles as a way of offering and safeguarding choice
- engaging and understanding civic duties
- adaptive devices to make learning more possible, accessible

How will I keep learning and growing as a person? How will I remember to keep trying new things? Who will help me figure out how to afford to keep learning new things? How can I do this in a way that is exciting and not very scary?

Spiritual

- church and other formal religious
- tradition, ritual and other private and personal ways of living a life of meaning

Where will I practice important religious pursuits? What place will church or other take in my life? Who will make sure that I am a part of a spiritual community?

Cultural, Civic, Lifestyle

- belonging to a specific cultural or ethnic group – traditions, holidays, etc.
- political or civic affiliations
- lifestyle preferences

How will I be a part of my cultural community? What will I do during elections? Who will help me explore the options and possibilities?



Finances

- Annual income need
- Support requirements
- Other adaptive services
- Special funding needs for (e.g., own home in future, transportation, travel, communication tools) in \$

How will I manage my budget? How will I get the extras I need to make my life run well? Who will help me plan for the future (RDSP), or help with government agencies (ODSP, OAS)?



Voice, Rights and Responsibilities, Autonomy

- Opportunities to have a say, govern own life directions
- Shared decision making and how that might work
- Significant areas where autonomy is important

How can I make sure that my ideas and opinions are heard by the right people? How will I know what to do if I think I am being ignored? How can I stay in control of my own life, yet still get the help and guidance I need?



Dreams

- possible identification of hopes and dreams, even those that now seem remote or even impossible

What are my biggest dreams? How can I be sure that others will continue to help me work toward my dreams? How can I resist settling for whatever is offered?



Cautions, Vulnerabilities and Frailties

This is not so much a Vision life area, but rather an overall statement about the ways in which this person may be at risk of being given bad things in life. Some of the ways that people with disabilities are vulnerable is in how the rest of society perceives them when they don't know them and their deepest qualities very well. So people with disabilities are often vulnerable to:

- being seen as invisible, unimportant or of no value
- being seen as essentially a burden on others, rather than a person of value
- being seen as unable to contribute or be productive
- being surrounded by very low or no expectations
- being treated as a child for all of their lives
- being seen as sick or multiply disabled when they are robust and have only one disabling condition
- being pitied and helped when they don't need it, rendering them helpless
- being ridiculed
- being rejected and seen as not belonging, not being able to belong
- being relegated to "one of them" not one of us
- being seen as dangerous, a menace, someone to be kept away
- being seen as deserving of different treatment, and undeserving of a typical, ordinary life

Even as these vulnerabilities are painful to think about, being aware of them, naming them and safeguarding against them (making sure none of the Vision statements or future plans feed into the vulnerability, making sure there are high expectations, etc.). Therefore, include the vulnerabilities that are in the life of the person:



From Vision to Plan

Current Situation

This section provides a short statement in each life area of the current situation. This ought to be brief and factual.

- **Home**

- **Family**

- **Friends and Relationship**

- **How a Person Spends Their Days (roles and contribution)**

- **Health**

- **Recreation, Leisure and Hobbies**

- **Lifelong Learning**

- **Spiritual**

- **Cultural, Civic, Lifestyle**

- **Finances**

- **Voice, Rights and Responsibilities, Autonomy**

- **Dreams**

What needs attention?

The current situation is compared to the vision stated in the rest of the document..
Where does life meet the Vision (or seem to be well on the way) and where does it currently fall short?

This section need not be negative or solely focused on Needs. Rather, it can be an opportunity to point out dreams that are ready for the next step, typical life transitions, or a desire to expand ones relationships.

- **Home**
- **Family**
- **Friends and Relationship**
- **How a Person Spends Their Days (roles and contribution)**
- **Health**
- **Recreation, Leisure and Hobbies**
- **Lifelong Learning**
- **Spiritual**
- **Cultural, Civic, Lifestyle**
- **Finances**
- **Voice, Rights and Responsibilities, Autonomy**
- **Dreams**

Where are we now?

This is a short comparison of life right now to the vision statement. It ought to be very factual, and although this can be a bit painful to do, it needs to point out the areas where the vision is not yet attained. Especially in the area of relationships, we need to resist the

temptation to sugar-coat family relationships as deep and positive when in fact the vulnerabilities of the person and the importance of this vision (and their role in it) have never been thoroughly discussed. If this work has yet to be done - it ought to be noted. Certainly indicate the positive aspects of good sibling relations during family events, for instance, but indicate the need for the parent to begin to discuss long term future vision and responsibilities.

This comparison statement that outlines the current situation will typically allow for priorities to emerge among the various gaps outlined. Some things are more important than others. Some things will be able to be accomplished simultaneously. Often, work/contribution and where is home to be are pressing need that takes a high priority for adults. Similarly, where and what is school and exploring for interests and passions are pressing needs for young children and teens. The importance of keeping a steady focus on the encouragement and nurturing of unpaid, personal relationships is important at all life stages. The slow, steady work involved with building strong, committed relationships that will safeguard the person when you are gone should always be a priority because this work takes time, attention and vigilance.

See Appendix 4 *Still Life Planning versus Evolving Planning* to have another way to weave between the larger Vision and the day-to-day implementation of your plan.

3. Relationships

Important People in Joanna's Life

This is a section where we need to collect some precise information, but because family members know most of these people so intimately almost always the information is kept in the oral realm and not committed to paper. This is an extreme loss, should anything happen to the keeper of the memory in a sudden way. It might feel odd to itemize something as precious as a dear relationship in this way, but the alternative - of support people not being able to make contact, or not understanding the nature of the relationship and effectively "chasing" the person away - is untenable.

This section ideally should include all of the people who spend time with Joanna right now - whether on a regular or spontaneous basis.

One practical idea to make this process a little less formal is to organize this information into two parts.

The first is an anecdotal account of who this person is in connection to Joanna:

- The first and last name of the person,
- The general relationship (uncle/aunt/cousin, friend, supporter for the past 5 years, neighbour, etc.),
- How often they get together, who makes the arrangements and how (eg., mother usually calls Uncle Joe and lets him know when Joanna might be free - he then calls Joanna and sets it up),
- The nature of the relationship (what they do, do they spend time alone together, the highlights or theme - eg., this is the person she loves to walk on the beach with)
- How do you see this relationship continuing when you are not there? (will need some support to initiate get togethers, will continue entirely independently, has agreed to enter this role (eg., advisor to the Trustee), will become/remain part of the circle).

The **second** part of this section could read a little bit like an address book, listing:

Name

Address

Phone and e-mail

Best person to contact: (eg., Joanna's brother can call and give him details)

A word on paid support people - the issue of paid support people and friendship is a complex

one. For the sake of clarity for those who may have to use this section in the future, it is most clear to the word "friendship" not to use the word "friend" for those who are currently in a paid position to the person. There are some support people who reach a very special relationship with a person due to their longevity, their heart and their efforts beyond a typical paid relationship. These people ought to be included in this section, but their relationship should be delineated from that of "friend". It will be clearer to those using this book guide what this relationship is and what they might be able to expect from the relationship. We need to learn to use language that values these new support partnerships while differentiating them from what are commonly known as friendships. A final word -- not all support persons should be entered into this section automatically. This is for people who have gained some insight into a particular person, and may be helpful to come together in times of crisis or need.

Refer to Building a Context for Relationship workshop if people are interested in further exploring expanding the relationships in the person's life. A simplified version of this intentional strategy can also be found in detail in Chapter 6 and 7 in Our Presence Has Roots (2005) by Janet Klees. Please refer to author if planning excerpt major portions from this book.

Support Circle

Many of the people noted in the Important People section may meet on a regular basis in a support circle. This is a short section to note who is in the circle, when it meets, how it works, and what typically gets discussed. It is an interesting exercise to have one of the circle members attempt to look at old records if they are kept (or from memory) and write up a summary of the circle.

Bibliography on Circles

- John O'Brien - Members of each other, 1996
- Janet Klees - We Come Bearing Gifts, 1997
- Our Presence Has Roots 2005
- So You Want to Build a Circle 2005
- Bruce Kappel – Support Networks

Planning Circle or Inner Circle

Sometimes a family pulls together a smaller, more intimate group of family members and friends to address the tougher, deeper issues of future planning. This may be the group that supports the family to work out their estate and finances, that becomes the advisory group to the Trustee in the event of a Discretionary Trust, that really figures out how the support dollars are put together and figured out. One or more persons may come to take on different roles and decide that they are the person that will think about the person's health and well-being over time (going to or understanding what happens at medical appointments, ensuring diet restrictions are understood, etc.), or the person that will become involved with recruiting and interviewing new support persons as necessary, or the person who will drop in and be aware of the day-to-day "feel" of the person, her support and her home.

There are many other categories that people may choose to undertake, or even to begin to understand a bit more deeply. Often, the group as a whole gets a fair amount of detail about all of these issues so that they generally have a high degree of awareness of the planning and support issues.

At the same time it is crucial that each of these people take the time and opportunity to develop or deepen their personal relationship with the person. This is a matter that get discussed on a regular basis.

4. Joanna's Time

Purpose/Goals

This is a preamble that talks about who this person is existentially...that is, by age, gender and where they live what are the typical and valued expectations about how such a person might use their time at this point in their life?. This needs to be stated in as ordinary terms as possible, such as:

Joanna is a 25 year old woman living in Scarborough, Ontario. How do we expect 25 year old women to be using their time well? What are they doing? With whom? How often? For how long?

This should be followed by a mini-brainstorm that shows the depth and range of typical, highly valued answers to these questions.

Attending full-time or part time college, university, or business school

Working full-time or part time

Raising a family - learning, teaching,

Managing a home - cooking, cleaning, banking, shopping

Being with friends - meeting, dining, having coffee, visiting, working out, etc.

Volunteering - at school, at YMCA, on committees, with Rouge Valley

Taking an interest course - painting, writing

Being physically fit or active - running, aerobics class,

Shopping - groceries, clothes, music

Trying new things - concerts, clothing, boyfriends

Pursuing a hobby or passion - knitting, going to craft show, classes

Making time for the spiritual - church, yoga, meditation, walking

Planning for the future - travel, school, marriage, babies

This is now your standard. These are the kinds of things probably listed in the Vision that show what are the expectations, what are you trying to attain. When people start to plan for and with a person with a disability, they need to be firmly anchored to this. There may, of course, be accommodation for a person's unique set of circumstances, gifts and limitations but the outline of the week should be similar.

When people are not anchored to a strong picture of what is typical and desirable, they are open to all of society's devaluing opinions of what ought to be the life of a person with a disability - what kind of life they ought to be contented to lead: often work and recreation time spent in a "safe" program, away from the rest of the community and with their own kind (meaning

disability because those folks may have nothing else in common), doing work that is not very important and wasting time in ways that do not really matter one way or the other.

We need people to be firmly anchored to what is good and typical and desirable for us all: a week of work that we and others find important, of leisure pursuits that matter, connecting with a wide variety of people with whom we share many things in common (always shop at No Frills, a knitting enthusiast, a Scarborough resident, a fellow-artist, a church goer, etc.), a time for relaxing and reflection, a time for family and friends, a time for hobbies and passions. An unpredictable week in some ways, but one that contains enough rhythms and routines to count on, and enough surprises to be delighted by.

Aims and Goals for Joanna's Time

This is a short statement which makes specific our goals and aims for Joanna's time. A 25-year old woman has many valuing and typical choices with which to fill her week. Which of these reflect Joanna's choices.

This can be mostly drawn from the Vision plan that outlines how Joanna will spend her time. It may need to be made even more specific so that someone can clearly see how her week might unfold.

Joanna is an artist who needs to spend an important part of every week with her art - purchasing supplies, producing her art, reflecting on her art, arranging ways to display and exhibit her art, taking private or group art classes, joining an art guild, broadening her art to include photography, going to view the art of other people. She also needs to spend time managing her health - getting exercise at the YMCA twice a week, swimming once a week, shopping, cooking, preparing menus, and eating regularly. Like the rest of us, Joanna needs to spend time banking, paying bills, buying stamps, doing laundry and cleaning. Joanna is a keen correspondent and spends some time each week receiving and sending out both snail mail and e-mail. Joanna needs long and regular periods of relaxation and rest time throughout her day to manage her limited energy. This is her time to devote to her music and private reflections. Joanna spends several evening a week with friends, goes to church on Sundays and devotes her weekends to visits with her family and many family members.

Integrating medical or physical therapies

It is often a challenge for newcomers to understand how to think about a person's medical or physical condition (diabetes, tactile sensitivities) in the context of their day or week. This is particularly so when the condition is all encompassing and needs some constant thoughtfulness. In another part of the book guide you may include a whole detailed section on this condition and how to manage it, however, at this point what is needed is a much shorter paragraph or so that helps the reader begin to understand how this condition is managed within the context of a real life. It cautions people not to become over-focused on the condition so it becomes the centre-piece of that person's day. It matter-of-factly states the condition, its basic impact or consequences on the person's life, and some general helpful strategies to fit management of the condition into the swing of the person's life.

Joanna has diabetes, which means that she needs to keep a careful balance in her life between regular exercise, full and healthy meals eaten at regular times, and blood sugar levels monitored and responded to on a regular basis. Although this sounds ominous, most of it is achieved quite matter-of-factly. All people should exercise regularly, and her exercise is planned within each day, in ways that it does not conflict with other things she must do. Joanna eats typical food, but that which is fresh, healthy and in well-rounded meals. She cannot skip a meal or a snack so variety and attractiveness are key parts of the meal. Joanna must carry her glucometer with her at all times, so that blood sugars can be checked at any time anywhere. This procedure is quick and private, and responses are easy to work out. A low blood sugar can alter Joanna's energy, but other than that, with some meal and exercise planning at the beginning of each day she can carry out her day as an artist, a friend, a shopper and a banker (or whatever) as planned.

Participation

Participation in the ebb and flow of daily family and neighbourhood and community life should either be a goal or a given that needs constant attention. This section allows for you to focus on *how* a person best participates, with what kinds of supports, communication, etc. What **roles** have they taken on (intentionally designed and held, or drawn to in natural ways), where do they make welcomed contributions , what are ways that they can be involved with the least amount of support and as needed, support by a third party rather than always by the paid support person.

If you have a strategy that works well to help the person to feel comfortable (ie arrive early so she does not walk into a full and noisy room of strangers) write these ideas here.

A Typical Week

This should start out with some sort of comment that there is no such thing as a typical week. Help people to think about this as a snapshot in time, or what happens most usually on each day of the week. At some point people need to be able to see how all of the rhetoric about vision, typical weeks, and rhythms gets put into practice. Later on, even if it is outdated, it still gives people a chance to see how it all fits together.

This can be put together in various ways, depending upon the person, the types of events in her week, and the kind of support she might require throughout the week.

a) 7-day schedule - you might just write out a week's worth of events on a single sheet schedule, that shows what the person generally does with their time. Resist the impulse to write in the name of support people at this time (you can do that elsewhere if you wish), this is just what the week looks like from the person's point of view. (We usually learn something if we have not done this in awhile). Write in work, leisure, home management, personal care, time with friends (doing what?), church, etc.

(include a schedule for families to fill out)

b) Daily schedule - when a person's day is more complex, perhaps because a lot of time is spent on learning or being involved in smaller things, it may be helpful to write out the details of one or more days. This can include some time break downs, if that is helpful. This can be helpful to newcomers who are getting to know some one who requires a lot of support and wonders how the day flows with all of those details to fit in.

c) Typical chunks - describing how a typical week day morning runs, a typical summer weekend, a typical evening (perhaps/hopefully less likely), a typical work day, etc. These are the pieces of routine that are familiar to the person and give them predictability and a sense of control over their lives. In times of crisis or change (loss of a parent), caring family and friends will want to know these details in order to help them get re-established as quickly as possible.

Supports Required in A Typical Week

The following approach to thinking about “just enough” support for the person has been very helpful in order to ensure that independence and natural supports are sewn into the picture of support requirements from the beginning. This lessens our reliance on hourly waged support and ensures that larger parts of the week are supported in typical and valued ways.

Patterns of Support – ask yourself, when I look across the week...when does it make sense to have:

1. Times when he is **ALONE** (and happily and safely so; in balance)
2. Times when **FAMILY** would naturally want to be with her – regular weekend days; a Sunday meal; a week day movie, etc)
3. Times when **FRIENDS OR NEIGHBOURS** might naturally be involved (if not now; then eventually – four people times once a month each = once a week!))
4. Times when he might already be at work and supported or other places where paid or unpaid supports are already established.
5. The rest of the time would be 1:1 time, but even this happens in different ways from less to more intense:
 - a. Times when a **ROOMMATE** may provide some support to do typical things together (cooking, dishes, shopping, hanging out, inviting others over, and more)
 - b. Times when **REGULAR PAID SUPPORT** is hired and guided in order to help him keep to a typical, involved, and meaningful range of roles and ways to contribute to and be a part of his neighbourhood and community – with a keen eye to bridging to relationships with others
6. Times when it might be appropriate to use a conservative amount of **TECHNOLOGY** to know someone is safe and well, without wanting anyone around (ie a motion detector past door at night).

In the above example:

- Note the order in which to plan – first the person and family, and then the others with a priority to natural supports
- This can be quite fluid, but for planning, it shows a need for:
 - No times (yet) of complete alone time (assuming that might be built in on the Sunday at first)
 - Morning physical care support (CCAC skill specific)
 - Day time very focused support (that may become more natural supports as friends and colleagues are interested and able – usually over years)
 - A flexible roommate (or even two) to cover off typical home-based stuff
- ❖ Think about the difference between when YOU need her to have support, and when she actually needs support
- ❖ Take your time to figure out family and friend support. Let it sit for a while before you add in paid supports.

5. Communication

Understanding Joanna

There are important issues around communication for almost everyone. Some of the basic ones that you might want to write about include:

(i) communication for and with someone who does not use verbal language - is there a reliable system of communication used (American Sign Language, Bliss Symbols, own sign language) or is it a matter of gesture and interpretation. For this latter, are there some consistent ways in which the person is telling you something, or asking for something? List these as fully as possible (eg., when he goes into the kitchen and taps on the counter that means that he probably wants a drink of water).

(ii) communication for and with someone with limited verbal language - what are the strengths and limitations of her language (can answer direct, concrete questions, tells me if she has a pain, does not identify her feelings very clearly, has difficulty with abstract or complex questions)? Are there some words or concepts to avoid? Are there patterns of language used (repeating same question, answering no and meaning yes or maybe, always says yes even if she does not understand, lots of questions make her nervous) and how are these received most helpfully (distraction by moving on to another topic, framing the question in a different way, tell a story rather than ask a question, etc.)? Is the words or language an indication of discomfort, fear or anxiety that should be heeded at once? If so, how?

(iii) communication with someone with good verbal language skills - are there any concepts that are difficult for this person to grasp (eg., time means little, talking about yesterday could mean any time)? Any important hints around content or personality (eg., she is easily swayed by what other people say - she likes to please everyone and can get into trouble by agreeing to too many things or things that conflict; it is important to double check on plans she has made by giving her a note which she will then check with me; she has a hard time talking about her emotions - give lots of time to get them out; she needs reminders not to gossip about other people; she needs gentle reminders to talk about private things with her mom and her sister)

(iv) when people use behaviour as their main vehicle for communication - clearly identify the behaviour you are talking about and what the person is communicating with that behaviour. Often the behaviours in question are negative or stormy moments that are difficult to talk about in positive terms. Instead, be factual and descriptive without being judgemental about what actually occurs and then interpret the behaviour in terms of language (eg., She will start to speak loudly and then to yell, she may swear and occasionally beat the pillow on her bed. She does this when her life is moving too fast for her, and she is anxious about all of the expectations she thinks she has to meet. It seems to be her only way right now of letting us know that she needs a relaxing day. We need to let her calm down on her own, and then go up and calmly discuss how

to change her day so that she is more comfortable. We usually end by saying that she can always change her day if she wants to ask for help to do so.) This is important modelling for people who are getting to know this person better. First of all, they now know what to expect (and it is never as "bad" as they may have imagined!) Secondly, stating the facts without judgement allows the reader to see the behaviour as communication rather than something more negative (spoiled child, trying to manipulate, stubborn, out of control). Thirdly, the calm tone goes on to suggest that people who know the person realize that there are better ways to communicate, but they are currently unavailable - hope for change in the future. And fourthly, it gives them some tried and true strategies (or at least lets them know that everyone struggles to find a workable response).

Communication with family, friends, support persons

This is just a practical section that outlines the various ways in which people can communicate with each other. This might include:

- a) Joanna's Personal Daytimer - perhaps the person carries with her or keeps a daytimer in which she or other people can write their upcoming plans and appointments. This may happen through the parents or main caregiver as well, but with diligence, in time, others may come to use and rely on this more typical method of planning time together.
- b) An invitation to call the family or someone else for questions (at any time, at certain times, or the best times) or for comments, to test out ideas for future get togethers. Especially at the beginning of a new relationship it is helpful for the people who love and care for the person to have a good sense for how this new relationship is going.
- c) For support persons, there may regular support meetings, or they may be invited to request such a meeting should they feel it could be helpful. As well, they may be directed to one or more specific resource persons for information on different things (eg., our family coordinator can help you think through some good connections in the community).
- d) Daily notes or logs - some families like to keep running notes or commentary between the various people who will be spending time with the person. This is most often the case for paid support persons who cover a large portion of the day with the person and there is little direct, daily communication with the family. This can also be helpful for communication between support people who do not necessarily cross paths in the course of their support time. A useful tip to keep this kind of log respectful and focused on the person, is to encourage people to write the log in the first person ("I") - that is, from the person's point of view. Then it can be read back to the person themselves and they can add, sign it, or in another way feel a part of the log, rather than feeling it about them. In truth, it is about the support.
- e) Circle meetings - include a brief note on where, when and for what purposes the regular circle gathers, as well as information on who is included (this varies from family to family - some circles include all paid support people, others do not include any, etc.)

6. Supporting Joanna

This section is particularly difficult to generalize. However, there are some broad issues that may be covered here, followed by all of the specific supports that are unique to the person themselves.

The priorities

These are determined by the person in their own unique situation, but everyone has two or three support issues that are most important. These often include general health and well-being (especially when there is a medical condition involved maintaining optimum health is paramount to leading a good life), emotional stability and well-being (people who have to work hard at controlling their anxiety need understand and good support to help them do so before they can get on with their dreams), and a priority given to the recognition, supporting, and building of relationships. Because, in the end, good, solid personal relationships are our best safeguards all people in support roles need to understand the priority of this. This means that mundane, everyday things may get postponed or set aside to make way for an unexpected visitor, or a longer chat with a new neighbour, or a chance to join the local art guild which runs on laundry night. People need to understand this. Write it down.

a) Image

b) Skills and Competencies

c) Roles

(See *We Come Bearing Gifts*, p.127, for a detailed example of what this section might be like.)

New Supporter Orientation

Over time, you will find that you have preferred ways of introducing new support people to your family member, to the family, and to their support role. What you do, how you talk about the person and their support requirements, what order you find works the best, and what you use as guides are all well worth writing down, so that others may be able to learn from your wisdom in time. For instance, one mother insists on sitting down with family photo albums and going through a family and personal history through photographs as the very first step in orientation. Another family ensures that within the first three weeks the new supporter sits down with three or four key family and Circle members for their points of view.

a) A typical order of orientation (what do I do first?)

b) The typical length of orientation

c) Helpful articles, books, videos, podcasts and other resource materials that seem effective in getting our message across

d) When do I go on to the next step (how I know she's "got" it)

e) Who else is involved in the orientation process?

7. Health and Well Being

- a) General**
- b) Medical Information**
- c) Treatments, Therapies, etc.**
- d) Diet Plans, Menus and Information**

8. Emergency Information

A stapled-together, stand-alone information package that can and should be taken on doctor's visits, and emergency hospitalizations, etc. (One format for this section is developed and shown in *Appendix 2*).

For hospitalizations, in particular, it is good to have prepared:

- A one-page list of relevant conditions that have to be taken into account, including limits on communication
- A one-page document that outlines the rationale for why this person might need their own supports in hospital (see below)
- Access to in-depth medical information with a chronology of treatments, etc
- Information for a support person other than yourself who may accompany and support the person (their role, when and how to communicate with you, how decisions will be made, etc)
- Clarity in writing about how decisions are best made:
 - Including the presence and voice of the person and how;
 - Understanding the Power of Attorney for Health Care (Canada) and the Health Care Consent Act (Ontario) that identifies the order in which others may make decisions when the person is clearly (temporarily) unable and no PoA is signed (is not necessary most of the time)– guardian, spouse, parents/child, and so on in this order.
- A journal and pens – with a pre-written list of what to record and how; contact information for the family
- A framed photo or two to remind the medical staff of the beloved person that they are treating
- A list of what should be packed into the Go-To bag for both the person themselves and the person accompanying them

9. Crisis Plan

What plans are in place in order to assist in short-term crisis situations – who to call on, what supports may be called upon, etc.

10. Funding – sources and accountability

As possible, include the individual support plan and budget for this section. Some of you may have used or have access to J Klees' *Patterns of Support Document* that is a guide to the development of such a plan as it is expected in Canada

APPENDIX 1 – Telling our Stories

The following is an excerpt from my book, *Our Presence Has Roots (2005)*, and is offered here as a context in which to place the many stories you will tell about your family member.

How we tell our stories: Principles in action

Telling our stories is our way of inviting others in to think about community and living together in new and wonderful ways.

Early on in our coming together we decided that the best way for us to safeguard the quality of our thinking and the kind of focus that would be expected from us over time would be to limit the size of our group. Although we decided it was better, for a number of reasons, to incorporate and seek charitable status, we consider ourselves to be a family group with a deep history together. We are not a typical “organization” which seeks to grow and expand in numbers as an indication of the success of our ideas or programmes. Therefore, we do not keep a waiting list, we do not engage in membership drives to increase our general membership, and we do not seek out other like-minded people to replicate our model in other places. We are mostly about us and learning how to do things well for ourselves. That, in itself, is hard enough!

At the same time, we are all very much aware of and involved in the lives of many families or individuals without families who are similar to ourselves. So, at the same time that we decided to remain small and focused, we decided that we would take on the role of story teller for other families and individuals who might want to hear about what we had done, were doing, and were learning.

In this light, we meet with families far and wide (many of them come to us to see for themselves) to tell our story. We also tell our story to funders and potential funders, to new and old circle members, to new and old paid supporters who join us over time, and to our co-operative neighbours and other friends. We find that we need to tell our story to housing officials who make policy, to local politicians who enact by-laws, to community organizations and associations, and to other groups in our community.

Sometimes we tell our big story – the one of our history and how we came to be. Often we begin or focus on our small individual stories with their unique power to impress a clear image. Often we tell our story orally and personally, and with overheads and slides to help make our main points. Sometimes, we meet over tea and talk informally with smaller groups. Occasionally, we have had the opportunity to have our story documented by the media through written articles or television documentaries. A few times we have taken the opportunity to write parts of our story on our own. Our book, *We come bearing gifts*, is one such effort, but Linda Dawe and Helen

Dionne in particular have written with skill and grace parts of the story too. Some of the Deohaeko families have put together extensive binders that help others come to understand the story of their son or daughter. Some of the families have written vision statements about the kinds of lives their son or daughter wishes to have.

All of these formats – both formal and informal – put our story out in public in some way for others to hear and learn from. In some ways, we are leading very visible lives and we are aware of the responsibility that this holds.

Over time we have come to understand that there are some important components to keep in mind in order to do this part of our work well.

First, with families, it is important to listen to the other families as well as to tell our story. We listen to find out more about the particular path on which another family or finds itself. We listen to find out what part of our story might make the most sense to them. We listen to find out what parts of our story are similar and thus will resonate with them. We listen to allow them to find their own way along the path they are travelling. We have come to understand that we are honoured to have so many families and individuals share with us the unique and often painful story of their own journey.

Second, we have to allow our stories to come from a deep place. How we tell our story is important. Almost every word placed and every image drawn for others has the ability to uphold or to deny the truth of our whole story. Our stories need to be genuine. They need to be truthful. They need to model the very things that we believe in and stand for.

Third, we need to keep in mind that typical society has a strong stereotype in mind when people think about folks who have a developmental disability. This stereotype often includes images of slowness, unproductivity, burden, menace, pity, waste, illness, and ugliness. All of our stories need to counter this negative and false stereotype with positive imagery and stories that depict the more accurate picture of the joy and meaning that these family members bring to our lives. To do this, we try to talk in the following ways:

- focus on name, age and positive personality characteristics first (musical, good sense of humour, active, gifts);
- move on to abilities, contributions, possibilities, and dreams – you might have to work on this or enlist others’ help, but everyone has some of each of these, only we are not accustomed to thinking and talking in these terms;
- speak about impairments in every day terms that do not intimidate but give information (“she does not speak” rather than “non-verbal”). Note important limitations and the challenges that these provide “She cannot speak and so we

have to make sure that she has other ways to tell us what she needs”. Use labels only well into your story and then only when this is helpful to the story and saves a lot of related details – be sure that you have described the person as a unique individual first. Do not deny the impairment, but rather use it to describe the amount and type of support that will be required to live a good life;

- end your story with a focus on typical positive roles that the person holds and any achievements they have made within those roles “She has been park steward for 4 years and just received a volunteer award from the city”. The best way to ensure that you are doing this is to liken this person’s life, hopes, and dreams to those of a peer of the same age in your community who lives a good life and does not have a disability.

Linda Dawe is one of our most prolific speakers and in great demand among family groups across the country. One of the things that make her presentations so memorable and enjoyable is her warm introduction of her daughter, Tiffany.

Now I’m going to show you some slides about the most important person there is - in my opinion – and that is my daughter Tiffany. Tiffany is a lovely woman who lives her life with courage, dignity, and graciousness. She does many things in typical ways, but getting there is rarely easy. Tiffany is a teacher and contributes much to the lives of people around her.

Most of us end up telling our stories in less grand, but no less important ways. We are telling our story every time we put up a notice in order to find a new Supporter, every time we write a funding proposal or fill out another funding request form, and every time we show and talk about family photographs or show slides that include our family member. We tell our stories during every orientation with a new Supporter, and in every piece of paper that we use to track the various things that we think need to be tracked in writing about our family member. We tell our stories in circle meetings, in related gatherings with other members, in hallways and lobbies with friends and neighbours, and with colleagues who know little about our lives. Let’s look into these other ways a bit more closely.

When we write a job posting and we want to attract energetic, creative people who can make some kind of a commitment, we would do well to follow the pointers listed above. We need to think about writing a job posting as building an invitation. We need to begin the invitation with words that tell of at least four positive qualities of the individual. These can include characteristics or personal qualities, personal interests (especially if they are impressive, familiar, and age-appropriate), special skills or activities, and gifts. Our posting must demonstrate the basic respect and values that will characterize the rest of their experience within our family.

We need to talk about our loved ones – tell their stories and our stories, so to speak – in rich, full ways that will attract people who want to make a difference. If that rich, full life is not yet happening, we need to describe the kinds of dreams and visions that we and our family members might hold for the future. The posting of such a notice is a public event. Everyone who reads it gets a piece of the story. Even if they do not know us, or do not meet us in this process, we are contributing to their understanding of the situation of people with disabilities in their community. Let's make a positive contribution to that story. Here is one example of an effort to write a job posting that tells a small part of full story:

A woman in her thirties, who has been named as the environmental steward of a park site along Frenchman's Bay, is looking for an enthusiastic, creative assistant to help her pursue her environmental interests and duties. She attends her sites daily to perform a variety of upkeep, observation, and data collection tasks. Hands-on gardening, collecting, recording, and nature craft projects would all be of interest for this woman's time on site or back at home.

Orientation sessions with new Supporters, or just getting to know a new neighbour or circle member better are further opportunities when we cannot help but tell our story. Once again, when we use the above steps or points to give us direction, we can tell a positive story with many places for new Supporters or others to find a place to give of their own skills and talents.

Sometimes, we use photo albums or even slides to give people a visual sense of our family member in terms of their roles, activities, and relationships. These are very powerful ways to tell a story. However, we find that taking the most positively powerful photograph needs to be a conscious act of an aware person. We must be aware of the subtle messages that our photos might be showing. It is easy to show many photos of a person going about their business, but without one other person in the picture. We have found that photographs give complementary and strong, positive messages about the person when they show people in strong roles or in relationship with others. If the photos are mainly concerned with the person on their own, one may wonder about why no one else is interested in this person. If the photos typically show the other people to be paid support workers, the very same question might arise. If however, we can gather a groups of photos and slides that show a range of family, neighbours, friendly bankers and shopkeepers, a very different message is sent.

In the same way, we can make sure that photos and slides reflect the person actively holding strong, positive roles in their life. When people are seen as working at familiar jobs, partaking in typical leisure pursuits, and joining in well-known sports events a powerful message is sent about the common ground that this person shares with the listener. Even when the challenge for the new Supporter is to help create a week and a life that looks more like that in the future (but does not now), it is possible to make sure that photographs include a smaller, but still positive

range of family relations. Also there are low key roles that can be picked up on film. A sports fan can be photographed in his room decorated with all of the paraphernalia. A family member can be seen helping with chores, setting the table, hanging out with siblings, and so on.

We also use all kinds of written material that help us to tell the story of the person. We try to make sure that written documentation happens only for things that need to be tracked, rather than for idle curiosity or less important reasons. These are then tracked in as unobtrusive formats as possible. We also use written forms that can give good information about a person and their life experiences. Several of the people connected with Deohaeko Support Network have a binder of information. Sometimes these are titled, *All about Jon* for example, and they are a respectful compilation of good information about Jon, his likes and dislikes, what others say about him and how they know him, a written vision for a path into the future, and lots of other details. These books can contain health information, family stories to fill out the story of the person's whole life, and emergency information as well. We have developed an extensive list of a possible table of contents for such books. The collection of information is based on all of the things that we think the person might want to let another person know as their relationship unfolds.

Funding proposals are another opportunity for us to decide just how we want to tell our story. Oftentimes, families feel compelled to tell their story in ways that emphasize their stress at the lack of funding, or our failures due to lack of resources. We have enjoyed very good success in refusing to speak about our family members and our families in these ways. We try, instead, to tell the stories that illustrate the efforts of a person to live as full a life as possible while experiencing some practical limitations that make some things difficult. We ask for assistance in helping the individual reach their own typical and familiar goals. We emphasize how family, friends, and others have gone out of their way to support the individual as much as possible, and point out further ways that resources are needed to help this along. In the end, our resource request may not be any different than a funding proposal where a family tells of its weakness and burdens, but we feel stronger and renewed in the joy of our family member by this way of sharing our story with potential funders.

Here are a couple of examples of excerpts, written by a mother, from past funding proposals.

Brenda is supported to live in her apartment at Rougemount Co-operative with some support dollars and large amounts of my time and support. I am not getting any younger and feel the strain of managing two homes, while at the same time needing to support my own elderly mother. I am thrilled that Brenda has found a place where she truly feels at home. I worry that Brenda's new-found sense of home is at risk because of the over-reliance on my support to make this work. If something should happen to me, she would not have enough support to continue to call Rougemount home. At the same time, due to the attention our community pays to developing and maintaining natural community supports and connections, paid support costs for Brenda will

always be lower for her in this environment than in any other setting. This proposal seeks to secure a range of residential supports to Brenda in her home, so that her future at Rougemount is more assured.

1. Goals and Results

With the additional support dollars, I hope to secure Brenda's place at Rougemount well into the future. We would be able to honour Brenda's choice of Rougemount Co-operative as her home.

Additional support dollars would provide Brenda with some much needed evening support. Especially at times when a room mate is not in place, Brenda finds the evening hours long and lonely. I expect that more evening support would help Brenda to participate more in evening events, to take a more active role in preparing her own evening meal, and to begin to host small gatherings in her home so that she begins to feel more comfortable in reaching out and inviting people in when she is lonely.

Some weekend support would allow Brenda to spend more weekend time in her apartment and in her community instead of at our family home. From our experience, we know that natural supports are strengthened when the person is present during the events in the life of the community. These dollars would increase Brenda's presence and result in stronger and more natural connections within the Rougemount community.

In summary, the extra support dollars proposed would ensure that Brenda spends time in her home, based on her inclination and desires, rather than based on when support is available or I am able to be with her in the co-operative. (February 1997 funding proposal)

We are aware that our actions and decisions in many ways tell our story and demonstrate the nature of our principles in action more clearly than any Principles document. Throughout this book, I will continue to tell many of our stories in the best ways that I can. Each will tell its own story about our principles, but also about our struggles, our transient successes, and our higher hopes for the future. The stories that I tell are always in transition. The ones that I put down on paper have already changed into something new. New stories are being lived this very moment. This represents a challenge to us in having to find renewed energy every day to work on what's new and different. But it also represents our hope in knowing that what is not yet good will certainly change, and our biggest problems today will lie behind by tomorrow.

Let me end with a fuller story to show how our principles in action help us to define and make decisions in our day-to-day lives.

Becoming an artist

Two years ago, Tiffany was dabbling with paint. Now, she is becoming an artist. What's made the difference? Thoughtfulness, clear intent, and planning.

Two years ago, Tiffany started to play around with some water colours, in part because one of her supporters was an artist and had begun to notice Tiffany's interest in colour and beauty around her, and in part because Tiffany sometimes had some spare time on her hands. We were always conscious of looking for home-based hobbies and options that would give Tiffany a further sense of well-being and contentment in her own home.

In the beginning, Tiffany painted away fairly privately and quietly. Diane, her supporter, discovered that Tiffany much preferred to approach her art in very, quiet intimate surroundings. She seemed to be most focused and attentive to work in the small bedroom, with the door closed, no one else in the apartment and only Diane by her side. In time, Tiffany produced a quantity of private work of a quality that seemed to please them both. At that point, Diane helped her design a few paintings into Christmas and greeting cards.

The reception of these cards was immediate and enthusiastic. Requests for cards, whole paintings and more came swiftly from family, circle members and neighbours.

However, there was a catch. Very early on, it became clear that Tiffany was turning out to be a temperamental painter - someone who could only work when the Muse struck her. Diane believes that this characteristic has saved Tiffany as an artist. Since her production was totally unpredictable, they began to tell people not to expect any cards or paintings for a while to come. That allowed Tiffany the time, space and emotional opportunity to further explore her talent without any pressure to move into high production.

So, Tiffany continued to paint and experiment behind closed doors, with mainly Diane to view her work and understand the importance of this period. This gave Tiffany alone the control over whether or not she wanted to paint. And as she continued to choose to paint, and obviously delight in her own work, she began to choose to be an artist.

When both Tiffany and Diane felt that Tiffany was firmly choosing this direction, they slowly began to show Tiffany's art to the people around her. She made and laser-copied some more cards. She made a few framed water colours as gifts. Tiffany framed three of her paintings to hang in her own living room and began to enjoy the comments of neighbours and guests in her home.

Over time, Diane helped Tiffany to save some of her paintings and begin to have a "body of work" – an identifiable style and approach that was hers alone. Tiffany joined a local Art Centre,

and as a member went often to view other member's art, volunteer with other member artists at lawn parties and other guild functions, and generally explore the life of an art guild member. Twice she displayed her art at the members' art show.

After discussion with her circle members, Tiffany decided to enter one of her watercolours into a juried art show put on by the Pine Ridge Art Council in Ajax. In a juried show, work is judged before it is accepted into the show. Tiffany's art was not chosen for that show, but she was not deterred from painting, since many other artists were juried out as well. Tiffany has shown her art on other occasions involving small home shows with fellow Durham Region artists. Although sales have been small, Tiffany's art has been well-received.

At one point, Tiffany's mother received a request for Tiffany to show her art at the end of a one-day conference. After much thought and discussion among those of us closest to Tiffany and her art, this offer was declined. The reasons for this were varied and important. In the first place, Tiffany had not yet had an official exhibit of her own work, and probably, as an artist, was not quite ready for one. Secondly, we wanted this occasion to take place in a truly wonderful venue, as only fitting for a first exhibit. This particular venue was fine, but not lovely or particularly focused on her art. Thirdly, the conference in question was one which would draw people together who were interested in issues of disability. We thought that Tiffany's fledgling identity as an artist would be overshadowed by her identity as a woman with a disability in such an environment. Once again, we wanted to make sure that Tiffany's opportunities in her role of artist would be separate and distinct from any deliberate focus on her disability. In order to do this, she needed to be seen mostly among typical artists, and mostly among art-loving people who would come to her event because of their love of art, not mainly to support a good cause.

Today, Tiffany continues to paint, and struggles to find the funds to frame her artwork and for show entry fees. Like many artists, she continues to search for ways to show her art to the public, beyond the loving reach of family and close friends. She also continues to keep her eye open for the right venue for her "opening" show. When the time is right, and circumstances are ready, Tiffany will exhibit her art.

© Janet Klees, 2005

This is an excerpt from my book, Our Presence Has Roots, 2005. This is offered as a discussion point only. Any copying or sharing should be discussed with me first. JK

APPENDIX 2 – Emergency Planning Document

Although some of the information in this planning document is the same as you will find in the whole of your binder or book about your family member, this emergency planning document was created so that significant people would have quick access to succinct and up-to-date information in a critical situation, (ie, the individual needs critical medical attention and the family is out of town. A good friend is with the person).

Some families may want to print this out on coloured paper and staple the pages together, before inserting it in the binder. This makes it easy to slip out (without any pages missing!) for the person to carry with them. Other families keep this document up-to-date and distribute it to the significant people so they will have it at all times.

EMERGENCY INFORMATION PACKAGE

(helpful if printed in a contrasting colour – yellow is eye-catching but still readable)

It is always enhancing and a good idea to have a full and beautiful photo (head shot) of your family member on this cover page. It does not have to be large, but it should show them full of life and delight so as to show a person that might be hard to see in a medical emergency.

Relevant History and Details

Date of Birth:

Health Card Number: *In Canada, health cards are often coloured and have a photo. Some families make a colour photocopy of the card, cut it out, and attach it here for quick access in emergency.*

Preferred Hospital:

Hospital Card Number:

Social Insurance Number:

Address:

Telephone Number:

Doctors and Specialists: see page 11

First Contact in emergency: For further contacts, and preferred order of contact, see page 12.

Present Situation

Home and Support

(details of living situation – where, what kinds of family, natural and paid support, roommates, etc.)

Roles and Work

(work, volunteering, other community roles held that help to identify person in positive ways)

Character

(especially positive aspects, humour, how she approaches life, etc.)

Daily Life

(what they do on their own, and what requires assistance, attention or monitoring)

Community

(safety and awareness comments, ability to get around, typical places in community, transportation)

Vulnerabilities and Limitations

(when support is required, situations that she finds difficult to manage, situations to avoid or provide extra support, signs that show she is in trouble)

Permission/Consent –

(if there are permission or consent issues outside of the norm, or what might be assumed, these could be described here. For instance, some people have signed a Power of Attorney for Personal Care (or equivalent) and that person might be identified here, with full documentation attached at the end. For instance, others may have a Health Care Representative or parents who are the Health Care Representative may hand over that responsibility while they are out of town – the person they name should be noted here with documentation attached at the end.)

A Vision for _____
(see information in On our own...together for this section)

Where to Find Information

Medical Records (current).....

Medication Records

Medication.....

Medication Supply.....

Daily Schedule of Typical Rhythms and Routines

Daily Schedule of Typical Support

About(a binder or book of detailed information)

Budgets and Funding Information.....

Household Money.....

Wills and Family Information.....

Other information about and for the person.....

Relevant Diagnostic Information

(information that would be helpful in medical emergencies, or in situations where people may have to quickly determine a course of action, e.g. this person has some developmental impairment and a close family or friend should be called in.)

_____ has been diagnosed by a variety of specialists who have determined the following conditions:

Medical Alerts The following document or some version of it could be very help in quickly articulating to hospital personnel the reasons that this person requires known, familiar essential supports (family, paid known

MEDICAL ALERTS: (Joanna Klees)

We Are Here to Help You Help Joanna

Personal Support Required Constantly to ensure she does not wander, and remains calm in order to eat, drink, sleep, receive treatment

Communication: she does not speak and has very limited understanding of verbal language -

Sedation Risk: her medications include sedatives, therefore caution against further sedation

Choking Risk: she needs someone familiar to assist her eating and drinking

Seizure Assessment: she experiences a various types of seizures; needs a familiar person to recognize, report and document her seizures

- This is a sample; each person will need their own pertinent information.
- Bring several copies to hospital with you to share with medical personnel and to post close to the patient, such as above the head of the bed.
- Do not list more than five items on this page because medical staff will only have time to read concise information that they will find immediately helpful to the task at hand.
- Do list only the most vitally important information.
- Do have more detailed medical information available for doctors or for other information sharing opportunities.
- You may want to put up an attractive photo of the patient engaged in a favourite activity or role next to this medical alert sign.
- Print on a 5x8/letter-sized page using the whole page, adjust size of font, and in colour
- Additional Reasons Given for Support:
 - **Personal Assistance:** required to be able to accept necessary procedures, in order to be safe and decrease anxiety.
 - **Communication:** ***** does not speak and requires a person who knows her very well to interpret her needs and preferences.
 - **Type 1 Diabetes:** ***** requires somebody to interpret atypical S/S of hypoglycemia and hyperglycemia.
 - **Choking Risk:** ***** has tendency to choke and requires full attention and assistance with eating.
 - **Personal Care and Mobility:** ***** requires assistance with all personal care and to keep her safe due to compromised mobility.

Alternately, you can also include the kinds of assistance the essential care partner or supporter will provide

Recent Medical Information (important details of various conditions, etc. In some ways, this is just more information on the previous page. This should include the *impact* of the stated conditions on the person's life. For example, they should not eat chocolate because, or epileptic seizures occur about once a week. This means that the following precautions must be taken.)

Medications

- Include current medications, vitamins, etc.
- Note any medications that should *not be taken*
- Any special requirements when increasing or decreasing medications.
- Note if this is a person who is particularly sensitive and usually requires a lower dose of medication
- Note when medications should be given with foods or drink.
- Note how independently the person takes their medication.
- Note who orders medication, picks it up from the pharmacy, etc.
- Note where the medications are kept.
- Note which medications are monitored by which medical practitioners.

Diagnosis and Treatments

(This section provides a brief history of relevant diagnoses, hospitalizations, of all types of treatments received in the past, past doctors and hospitals). If this is kept brief and in chronological order, annual updates will be simpler to add in.

Communication

Making choices and being involved in decisions - (Include information on how the person indicates their choices best, how they are best involved in the larger decisions in their lives, who might help them with difficult decisions, the role of Circle members or particular friends, etc.)

Communication styles (Include information on how well the person receives information as well as how they communicate themselves. Relevant comments on literacy skills might also be useful, such as reading ability, can the person use the telephone on their own, etc.)

Communication and stress (How does this person communicate under stress, in difficult situations? How do you know when they are upset?)

Safety

(Other relevant comments about safety for this person – kinds of attention needed, least intrusive interventions as necessary, planning and strategies to avoid unsafe situations)

(at home – kitchen, bathroom, strangers to the door)

(in the community – street safety and awareness, personal safety and awareness)

Relevant Doctors, Pharmacies, and Medical Contacts

(include name, address, phone number, and date of typical appointments, e.g., every April and November)

Family Doctor:

Specialists,(including Psychiatrist, Ophthalmologist, Cardiologist, Endocrinologist, Dermatologist, Urologist, Neurologist, etc.)

Dentist:

Optometrist:

Naturopath:

Physiotherapist, (or other therapies)

Walk – In Clinic:

Pharmacy:

In Case of Emergency...

(a step-by-step, “who to call” list. Include parents, siblings, other family members, family group members, friends, Supporters, coordinator, Circle members, etc.)

More People to Contact if Needed

Family Members

Planning Circle Members

Neighbours

Other Friends

Church Friends

An Overview of Decision-Making and Future Plans

What you think the future might look like for your son or daughter. Where do you think they might be living – alone or with others? What kind of work, friends, etc. This is a bit like the Vision, but this is from your view point.

A brief outline about who will make what kinds of decisions concerning your son or daughter. E.g., who will help manage her household money, ODSP, etc.?

Who will decide on support funding and planning?

Who will assist to buy clothing?

Who will help plan holiday and family celebration times?

Who will take my seat on the board?

Who will help to hire and orient and guide Supporters?

Who will help guide her in most decisions?

Please refer to _____'s Vision when doing any planning. This is a written document outlining a vision for her future.

Paid Support People – (date this)

(include names, addresses, phone numbers, and typical schedule of their support)

Monday	Tuesday	Wed'day	Thursday	Friday	Saturday	Sunday

A Few Thoughts

(A few words or thoughts to the people who will use this document in the future – perhaps some advice, or a quote to guide them or a thank you in advance)

Who is the person?

C 2011 Janet Klees

- ❖ Each person is a very complex being and there will be parts of the person that are essentially unknowable – or at the very least will not now be known. Expect this. Be humble about this.
- ❖ It is right and good to ask a range of others this question. Many aspects of a person are only illuminated through their relationship with other people. Even a seemingly small relationship may show some aspect of the person's character that is new and different. This may well be an aspect which the person would like to show more often, leading into a whole new part of their life.

Exercise: There are many ways to find out who this person is. How do we get to know anyone? Let's brainstorm the questions we ask them, or the questions we carry around in our heads. How else would we find out some of this information?

- ❖ Ask the person
- ❖ Ask others -as with most of us, gifts and contributions are usually identified in a number of ways by a number of people, Others may see things that you are not able to see in yourself or in your family member. Consider their perspectives thoughtfully.
- ❖ Ask over time – many gifts, contribution, and character traits only become obvious in discussion and over time.
- ❖ Find out as much as possible about their history and life experiences – what interests are woven throughout

- ❖ Notice what draws their attention, attracts them, makes them laugh
- ❖ Pay attention to preferred environments, social settings, atmospheres that they create may help to identify potential areas of interests or gifts of hospitality, stillness, welcome, etc.
- ❖ Ask lots of questions of likely ideas
- ❖ Look at the spaces around them – how have they chosen to decorate – what interests come from their home, bedroom, personal possessions, photo albums
- ❖ Build up the relationship so that you can go out and try things
- ❖ Ask others to try a few new ideas and things to give more information (especially for places where people say “I don’t know if...”
- ❖ Ask people to identify “when is he the very happiest?”
- ❖ Identify and ask about related ideas
- ❖ Note or ask what motivates or energizes the person?
- ❖ What satisfies them?
- ❖ What bores them and does not bore them?
- ❖ Search in all realms of life: home, work, vacation, weekend time, spiritual, leisure, hobbies, civic life, passions, interests,
- ❖ Take negatively characterized traits and state them positively or neutrally as a way to identify new ways at looking at a person. Imagine a highly valued child or community leader with the same traits and imagine how they might be described in that person by others. I.e., hyper child might be an energetic child or a child with boundless energy; a distracted or attention-deficit child might be a child attracted to many things or with many interests; an unmotivated woman might be a woman who is very careful about where she puts her energy and her trust, a homebody.

- ❖ We also want to think about this person at a very fundamental level (also called existential). Who is this person in the deepest part of their being?

Who is this person?

❖ Who is this person...

- ❖ **...in the fullness of his life's journey** –on what stage or phase or horizon does he appear due to age, life milestones (marriage, coming of age, birth of a child, etc.) – what crises has he encountered and overcome and what are the scars and wounds that he now carries with him?
- ❖ **...in carefully listening to family and friends and those who have known her for so long?** – what words do they spontaneously choose or images do they describe to recount the story of their relationship and her presence and contributions? What is not said, left lingering, or uttered with pain and disappointment?
- ❖ **...in the possibilities of his longing, his deepest potential, and his desire for fulfillment?** What dreams can he still articulate and which ones need to be awakened again? What is secretly waiting to be seen and understood? What have others missed? Which dreams fulfilled are now stuck in time and need to move on?
- ❖ **...in relationship with all the others she has known, for this is not someone who has travelled alone?** What have others contributed in some small way to her story and how has she – known or unknown – contributed to theirs? What can you see that might not yet have been said? Are there similarities among the people in her life? What generalizations can you make about range, number, personality, purpose, commitment, etc.?
- ❖ **...from many, many perspectives for it is not just one side, however fully told, that will tell his story?** Who else might have a phrase to add, a thought to bring to the big story? How might this conversation flow so that the story is natural and true rather than contrived and artificial? Your deep belief that the story is worth telling is the beginning.
- ❖ **...told from the story as it feels standing in her shoes?** Can you remove yourself from your words and your emotions and how you might think of things if it were you standing in her place? Can you imagine her life, her beginnings, her wounds and her rejection, her capacity to love and live and adore those around her, and her experiences of the life she has lived?

- ❖ ...in terms of the things he has done and the roles he has held? In terms of the things we might do and the roles he might hold if you start with him and what truly interests and motivates him? Think of roles big and small, but most of all think of typical and valued roles for a man of his age in our culture – a man who holds similar interests and passions. What might such men be doing around our community?
- ❖ ...in terms of her dreams, her longings, her bucket lists and her potential? How long a list do you have for each of these? You need to know this person well enough until their lists are also long and full.
- ❖in terms of your own daring to articulate a dream, describe a longing, paint a picture of possibility, put words in the mouth of one who does not use words, and thereby taking the enormous risk of being wrong..
- ❖ How often have we erred on the side of impossibility, of underachievement, of no dreaming? We can try and we can be wrong. The biggest mistakes of all would be not to ask and not to articulate and then, certainly, not to listen. If we listen with heart, a detail may be wrong but it will be a grand starting place!

Appendix 4

Current thoughts on the planning process: The Still Life Plan and Evolving Planning

Janet Klees c 2012 janet@legacies.ca

There is much talk these days and much hope placed on planning and having a “plan done” for and with people with a disability and their families. I find it helpful to recognize two distinct ways to approach planning when one is in the position of planning together with families.

The first thing to recognize is that many families have always been involved in making plans, evaluating plans, and planning for and with each of its family members. Planning is how we get through days, weeks and life as a family. During various times, more or less effort is spent planning with one person in the family, but in the end, everyone has their turn and most of it happens all at one time. Some aspects of this are what I call *Evolving Planning* and this is rooted in the natural tendency of busy families.

Then there is the planning that ends in a product, often a written plan. I call this *Still Life Planning* and often busy families have little time and energy to put their ideas in writing. This approach to planning is rooted in outside planners trying to be articulate and helpful to busy families.

People who have a role in helping families with planning can often be a bit stuck on the *Still Life Plan*, and families can be almost totally focused on *Evolving Planning*. However, both parties would do well to learn from the tendencies of the other in order to enrich their own planning selves and potentials.

A *Still Life Plan* is an individual written plan that can emerge every now and then from the ongoing planning process. Within families on their own, these are rarely written out, but they are talked about all the time. For instance, the ongoing conversation in families might sound like, “with her eye for colour, she might be an artist, a graphic designer, or a

decorator”. Or “I could never see him in an apartment – he needs a yard and a place to put his hands in the dirt”. These can be goals, suggestions or life slots that people are put into long after the noted trait has changed or disappeared!

For planners in helping roles, the written plan, however, can be the culmination of a long series of conversations and understandings. A *Still Life Plan* has certain identifiable features. Ideally, it is beautiful and unique to the person for whom it is written. Its elements are arranged in ways to emphasize its character and balance, and it is detailed in ways that light up priorities and next steps. It captures all the important elements of life in this moment in time, and so it tells a story about a moment in time. It is helpful for funding for it lays things out in ways that can be looked at and thought about. On the other hand, of course it is outdated soon after it is written.

I liken this written plan to a still life painting – momentarily balanced, rich and complete, where the elements are arranged beautifully and the lights and shadows in which they are bathed are different five minutes after the last brush stroke was applied. Such a still life painting inspires us to remember a moment in time when all came together in good ways. At the same time, the very stillness of the painting reminds us that it is stuck in the time it was written and unable, on its own, to shift and be relevant to the present.

Therefore, *Still Life Plans* show beauty, balance and potential. They can model, remind and inspire. However, they do not capture the elements as they change and always need further work and understanding in order to adapt them to the real life moments in which they may be applied.

Evolving Planning is more of a process than a product. It is that which we do every day for ourselves and for and with the people we care about in life. This involves a common vision between at least two people (and often more) in communication and with some good idea of where things are at right now. It understands that plans are often verbally held and communicated in story and over time between many individuals.

Evolving planning processes includes next steps, evaluating distance covered, talking to others to get their ideas, input, permission, etc., and trying the next step. Families have been doing this forever. It is a pragmatic approach to planning and decision-making that works in busy family and community life – flexible, portable, rooted in fairly common vision, easily implemented, and often easily abandoned if not working out.

This form of planning also has its drawbacks. Planners, funders, and important allies may

find it hard to see the whole picture with everything in motion. *Evolving planning* can run into serious hitches when the people involved do not have a common value base, are not strong decision-makers, or do not have reliable communication skills. A lot is based on the relationship between the people, and if the relationships are poor the planning may also be poor. Finally, there is often no fixed point that people can refer back to for guidance or earlier visions in order to find a common base.

The fact is that most of us lead, plan and take steps in our lives that use both planning methodologies. In a world of paper-heavy plans that seem impossible to put into action, the small, practical steps of evolving planning (still coherent with the still life plan) is a helpful strategy.