



***Nurturing
Assistance***

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***A Guide
to Providing Physical
Assistance for Parents
with Disabilities***

CILT... a resource centre

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Nurturing Assistance

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To the pioneering parents with disabilities who laid the groundwork for the development of nurturing assistance ... and to their children.

“Never doubt that a small group of thoughtful committed citizens can change the world - indeed, it is the only thing that ever has.”

- Margaret Mead

“We are in the centre of a great social movement...we need to celebrate who we are. We live in a world that tells us we ought to be someone else. That’s not true, we are exactly who we are supposed to be.”

- Judith Snow

“By investing in the quality of a child’s life through support for parents with disabilities to care for them, we are making an important contribution to the future. We are also demonstrating our society’s growing appreciation, acceptance and value for people with disabilities.”

- Tracy Odell

Nurturing assistance is a time-limited service that provides physical assistance to parents with disabilities who have young children. Its function is to physically assist parents to undertake the tasks involved in caring for their children, as if the parents were doing it themselves. It can also help strengthen the emotional and bonding aspects of the parent-child relationship. The service can last from birth through the first ten years of life.

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Foreword

This book is for people with disabilities who are considering whether nurturing assistance can enable them to become parents and fulfill parental responsibilities. It tells what one needs to know to put all the pieces in place. It is also for policy makers, program funders and service providers struggling with ways to respond to the new wave of parents seeking support.

“Nurturing Assistance” is the name we give to the personal support, provided by special attendants, that assists people with disabilities to be parents. We believe nurturing assistance is a positive addition to those special situations in which the person with a disability who requires attendant services is planning to raise children.

In the same way that people with disabilities need personal supports – attendant services or personal assistance services – nurturing assistance enables parents with disabilities to function in the home and community, raising healthy and loving children. Throughout this book you will learn of numerous examples of how nurturing assistance has benefited people in Toronto and parts of Ontario since at least 1988.

Whether or not you have a disability, having children is an individual choice. Getting married, settling down and having children – adopted or otherwise – is still the most common lifestyle choice in Western society. However, that doesn’t mean that having a spouse or children is necessary to “validate” your existence as a person with a disability. It’s up to you.

That being said, we also know that people with disabilities have been shut out of parenthood in the past for different reasons. For example, many adoption agencies have refused applications from parents if one or both have a disability. Also, Children’s Aid agencies have been known to declare parents with disabilities “unfit.”

Canadian agencies, in the past, have seized the children of parents with disabilities, putting them in so-called “protection.” There is documented and experiential evidence that forced sterilization has been imposed on unwitting children and youth with disabilities, both male and female. The fact that sex education for youth with disabilities has been generally ignored indicates society’s distaste of the disabled person as “parent.”

CILT is a leader in the field of parenting with a disability. We have received national and international attention. However, the real attention should go to the growing numbers of persons with a disability who have refused to listen to the experts and loved ones who say, “*You can’t be a parent with a disability.*” Let us focus on the pioneers who simply “filed away” that statement with all the other “can’ts” and just went ahead and had babies or found a way to adopt. Good for them! This book is because of them.

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Preface

CILT began working on the Nurturing Assistance Project in August 2000. The first task was to define the concept of nurturing assistance more clearly. The project went on to document the process consumers might follow in preparing for nurturing assistance, to begin working with a nurturing assistant and to make it a rewarding experience for both parent and child. As well, CILT explored ways to make nurturing assistance a workable and cost-effective arrangement for service providers. Most importantly, consumers who have direct experience with nurturing assistance were invited to tell their stories.

The project's contributors include:

- Parents with a disability who have experience with nurturing assistance or a similar type of service;
- Parents who have not used nurturing assistance, but would like to have had access to it;
- Nurturing assistants;
- Attendants;
- Service providers;
- Independent Living Resource Centres (ILRCs);
- Consumers who would like to use nurturing assistance in the future.

It is worth noting that nurturing assistance is an option – a choice – for parents to consider. It is not for everyone, and should not be assumed to be a necessity. Disability itself is not what qualifies a person to receive nurturing assistance. It is when disability results in an inability to do the physical tasks ordinarily performed by a parent that nurturing assistance becomes an option that may be helpful, even necessary.

The advice and recommendations in this book are based on information provided to us through our investigations which, of necessity, are limited by the resources available to us. They may not be

appropriate to your particular circumstances. Accordingly, the authors and publisher cannot be responsible for any injury or damage that results.

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PART I: Parenting with a Disability and Nurturing Assistance

Introduction

In 1999, CILT published *The Parenting Book for Persons with a Disability: From planning your family to raising adolescents* (see page 92). This unique resource was well received and remains in demand. *The Parenting Book* offers practical advice and information primarily to consumers, but also to health professionals and other service providers. Nurturing assistance was identified in the book as a much-needed service, but very little information on the subject was found to be available. As a result, CILT's Nurturing Assistance Project, and ultimately this book, were conceived.

CILT consulted many stakeholders – consumers, family members, service providers, nurturing assistants, and international contacts – as the Nurturing Assistance Project progressed. They shared their experiences for the benefit of those who may find themselves in similar circumstances, and contributed their ideas for improving the system for future generations of parents with a disability. Their contributions have been invaluable.

Another vital source of information were the surveys completed by 24 Independent Living Resource Centres (ILRCs) across Canada, and 92 attendant service projects in Ontario. The goal was to find out if the concept of nurturing assistance was generally understood in CILT's home province and around the country, to document who is currently providing nurturing assistance programs, and to determine what

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the demand for such services is perceived to be. More details about the surveys and their results can be found in Appendix E.

Chapter 1: Defining the Context

Guiding Principles: The Independent Living Philosophy

The basic tenet of independent living is that people with disabilities know their own needs and are capable of finding solutions to problems surrounding disability issues. The independent living philosophy recognizes that people with disabilities have the right to run their own lives, make their own decisions, and be active participants in their communities.

The principles of independent living associated with nurturing assistance assert that, with respect to parenting, consumers must have direct control over who provides their nurturing assistance, and where, when, and how the services are provided. Specifically, the principles are:

1. Parents with disabilities and their children should be integrated as fully as possible into communities;
2. Those who best know the needs of parents with disabilities and their children and how to meet those needs are parents themselves;
3. The needs of parents with disabilities and their children can be met most effectively with comprehensive programs providing a variety of services.ⁱ

What Do We Mean by “Disability”?

Disability is a broad term, referring to physical, visual, hearing, intellectual and emotional impairments, and chronic health conditions.ⁱⁱ Although nurturing assistance is by definition most applicable to those who need physical help in caring for their children, resources that may be helpful for parents with disabilities affecting vision, hearing, speech and cognitive reasoning are included in this book. The Resources section and Index at the back of the book will guide you in finding related information.

What Do We Mean by “Parents”?

When we refer to parents, included are those who have experienced biological or assisted conception, as well as step, foster and adoptive parents.

Parenting with a Disability

Statistics on parenting with a disability in Canada and the U.S. show that there are significant, and probably increasing, numbers of persons with a disability who are becoming parents.

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The 1994 *National Longitudinal Survey of Children and Youth*, conducted by Statistics Canada, estimates that “roughly nine per cent of children from birth to eleven years of age have a parent who is restricted in his or her activities because of health conditions.”ⁱⁱⁱ

At a conference of the U.S. National Academy of Social Insurance in 1999, the late Barbara Waxman Fiduccia, noted researcher and advocate for parents with disabilities, stated that 10.9 per cent of all families in the United States have one or more parents with a disability.^{iv}

CILT’s Parenting with a Disability Network (PDN), established in 1994, has enjoyed increased membership in recent years, signifying a rising interest in the subject in Canada.

An interesting statistic from the United States, cited by Barbara Waxman Fiduccia in a national report published by *Through the Looking Glass*, is that 40 to 60 per cent of parents who have physical, cognitive or sensory disabilities need child-related assistance. Yet only 10 per cent of those parents receive any financial assistance to pay for it. Furthermore, she said, “34 per cent of parents go without PAS [personal assistance services] for themselves in order to get PAS time for child care.”^v

The Canadian Context

A number of studies on disability issues in Canada have been released over the last two decades asserting the rights and responsibilities of Canadians with disabilities as full participants in Canadian society. The inclusion of persons with physical and mental disabilities in the equality rights section of Canada’s Charter of Rights and Freedoms in 1985 was a significant milestone for Canadians with disabilities. From the *Obstacles Report* in 1981, which made 130 recommendations for public policy reform, to a federal report issued in 2001 entitled, *In Unison: A Canadian Approach to Disability Issues*, the disability rights movement in this country has been pushing in the direction of independent living and empowerment for individuals with disabilities.

According to *In Unison*, the vision is that “[p]ersons with disabilities participate as full citizens in all aspects of Canadian society. The full participation of persons with disabilities requires the commitment of all segments of society. The realization of the vision will allow persons with disabilities to maximize their independence and enhance their well-being through access to required supports and the elimination of barriers that prevent their full participation.”^{vi}

The report goes on to say that governments in Canada have identified three “building blocks,” which are key to realizing this vision. They are disability supports, employment and income. Support for parents with disabilities should surely be counted among those “disability supports,” just as participation and equal opportunity would certainly mean that our society has the collective will to support parents with disabilities in their role.

Parents with disabilities are still, however, in the shadows as far as these consultations, reports and policy initiatives are concerned. One of the few recent policy statements directly relevant to parenting issues is found in a report recently published by the Canadian Council on Social Development: “Governments, employers and community groups can... ensure that disability supports and services are available to all those who need them, regardless of employment status or income... [and] recognize that accessible transportation, child care and home supports are essential employment supports to people with disabilities.”^{vii}

But even in Ontario, which supports nurturing assistance through the Ontario Ministry of Health and Long-Term Care’s provision of attendant services (see pages 29 and 94), the conditions determining eligibility are not yet set out in the Ministry’s guidelines. At the time of writing, parents with disabilities apply and qualify on a case-by-case basis.

In terms of public policy and the social context, parents with disabilities in Canada who seek personal supports to care for their children are still fighting for recognition, and legitimacy of their need and right to parent their own children, their way.

Chapter 2: Defining Nurturing Assistance

What is Nurturing Assistance?

Nurturing assistance is a time-limited service that provides physical assistance to parents with disabilities who have young children. Its function is to provide assistance to parents by undertaking physical aspects of caring for the children as if the parents were doing it themselves. It can also help strengthen the emotional and bonding aspects of the parent-child relationship. The service can last from birth through the first ten years of life.

Parents have always counted on others for help. How much help they receive can depend on their inclination to ask for and accept it, as well as the family’s particular situation. Factors like the age of the

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child or children, the age of the parents when they have their first child, as well as cultural background can have some bearing on the role played by extended family. Family and friends form a core group of potential helpers for parents with disabilities.

When help is required beyond this core group, public health resources – such as visiting nurses, community hospital programs and new mothers’ groups – are free for the asking. There are support groups for specific purposes such as providing advice on breastfeeding. Nannies, babysitters or mother’s helpers, paid and arranged privately, are also part of the wider circle of resources available to those who need and can afford them.

However, the common array of resources is unlikely to fulfil the fundamental need that parents with a disability have for attendant services dedicated to basic physical and bonding assistance. “Nurturing assistance” is the name given by Tracy Odell to this type of service. Tracy is the first person in Canada to recognize it as something different from the informal help and attendant services provided through existing channels.

Because people are used to thinking of help as “babysitting” and “giving parents a break,” nurturing assistance is easily misunderstood as something that temporarily takes the place of a parent. Nurturing assistants should be neither expected nor allowed to assume this type of role because they are neither babysitters, mother’s helpers, advisors nor nannies. Neither are they volunteers or family members.

Comment [AMC1]: Is a comma necessary here?

Nurturing assistants are paid employees who work under the direction and in the presence of the parent with a disability. Their role is to assist the parent with bathing and changing the child, preparing meals, lifting and carrying, nursing and cuddling the child, playing and parent-child interacting, etc., according to the day-to-day needs of the parent and child. A simple example of what a nurturing assistant would do would be getting a baby’s attention with a rattle, then handing the rattle to the parent to facilitate parent-child interaction. The parent is responsible for that child’s care and safety. Therefore, a parent may also have the nurturing assistant hold the child’s hand for safety while crossing a busy street.

While some parents arrange to have nurturing assistants who are different from their personal assistants in order to distinguish the two roles, there is usually a great deal of overlap. The amount of overlap can depend on the parent’s living situation. For instance, when a consumer hires attendants through the Direct Funding program, there might be an opportunity to foster more common ground between the two roles than there would be in a supported living arrangement, where the individual has no control over who comes in for a particular shift. Also, when attendant services are centrally managed and provided, certain services may be distinguished from others by someone other than the parent (e.g., personal care versus non-personal care, or housekeeping versus attendant care).

Even when the job is clearly understood as being under the direction of and in the presence of a parent with a physical disability, concerns of parents, family members, or service providers can arise about the

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child bonding with the nurturing assistant rather than the parent. The nurturing assistance model addresses this by providing tips for training nurturing assistants (see page 38).

Are Nurturing Assistance Services Available in Ontario?

Nurturing assistance is currently available through three programs to some parents with physical disabilities who are already receiving attendant services in Ontario. The first two ways – Support Services Living Units (SSLU) and Attendant Outreach programs (see Glossary) – both come from the services that are provided and managed by an attendant service provider. SSLUs are designated apartments or clustered settings in which attendants are available to provide services to adult tenants with disabilities around the clock; Outreach programs provide attendant services to adults with disabilities who do not live in these units, but in ordinary residential areas. In both cases, parents may be living in either a social housing unit or a private residence. A third way that parents with physical disabilities have obtained nurturing assistance is through the Direct Funding (DF) program (see page 92). Through DF, consumers receive funding to hire, train and manage their own attendants. Consumers with young children have been able to allocate some of this funding to hire nurturing assistants.

People who do not use attendant services for personal care are not usually eligible to receive nurturing assistance from a service provider. Nurturing assistance may or may not be appropriate for individuals with disabilities solely affecting, for example, vision, hearing, speech and cognitive reasoning. However, some areas need to be explored further. For instance, a woman with a mild disability may find that it is exacerbated by pregnancy, or someone with a temporary illness or injury might suddenly require attendant services. Support for parents in this type of situation needs to be considered. Nurturing assistance may be appropriate when individuals require personal attendant services in time-limited circumstances.

Relationships and Communication

“Some clear direction was required from me, initially, to help the nurturing assistant understand that the focus of the job was to strengthen the development of my relationship with my daughter.” – Tracy Odell

Many aspects of the parent’s relationship with a nurturing assistant parallel those with attendants. Among the important elements both have in common are that

- there is some level of compatibility between you,
- you follow a written agreement/understanding,
- duties are clearly defined by you,
- you have open, honest communication with the nurturing assistant,

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- you are both permitted to learn from mistakes, and
- you work in an environment of mutual respect.^{viii}

In emphasizing the focus of the nurturing assistant's job as strengthening the bond between parent and child, Tracy Odell identifies the key difference between a nurturing assistant and an attendant. Other factors come into play, such as the nurturing assistant's relationship with the whole family as well as to the parent with a disability.

Nurturing assistance affects not only the parent with a disability in his or her relationship with the child, but more broadly the family as a whole. For instance, consumers often find that their child can be comforted, disciplined, etc., only by the parent with primary child care responsibilities – too often the parent without a disability. Ideally, nurturing assistance can help in forging a stronger, more equal bond between parents and children, so that both parents can participate more fully in daily events and activities.

Also, the nurturing assistant can enable the parent with a disability to be solely responsible for the child, leaving the other parent with more free (and guilt-free) time. The family is healthier and stronger as a result. The parent with a disability has the opportunity to feel “loved and useful as a parent and a partner.”^{ix}

Given time and appropriate support, children can learn to respond to verbal requests from the parent who cannot physically intervene. As Tracy Odell, a mother with a disability reports, the early development of a child's language skills can be the result of having to rely heavily on verbal interaction. She says that her daughter, at 18 months, would “stop trying to climb furniture on request. When David is around, she will go for it. I find this amazing – and also reassuring.”^x

The issue of discipline is critical to integrating a nurturing assistant into family life. As many people have strong and instinctive feelings about appropriate strategies for disciplining children, it is particularly important in this area to be clear about the strategy you want the nurturing assistant to follow.

Rationale for Nurturing Assistance

By Tracy Odell

As a life-long disability advocate, I was overwhelmed by how “disabled” I felt when I had my first baby. Although my baby was fairly small (5 pounds, 6 ounces), I did not have the power to lift her. At the best of times, I can lift only a few ounces of weight. My baby was fussy and squirmy. I could not hold her in place for nursing, without being afraid she would wriggle and fall off my lap. My husband had to attend every nursing session (and I nursed baby on demand), just to make sure I could hold the baby safely. It was some time before we figured out a way to prop pillows and wedge them between me and a table, so there was literally, no “wobble room” to endanger our baby.

It was also overwhelming to be so much at the mercy of other people's energy levels. As a new parent, my sleep was shortened, interrupted and disrupted – even when baby slept through the night. I feared she had stopped breathing! My husband was similarly sleep-deprived, as he had to get up to bring the baby to me to nurse, get us into position, and do the constant, compulsive, new-parent checking for both of us. He had little energy or patience left to help me do things for the baby my way during waking hours. One of our first “big” fights was over whether or not to make the baby wear socks. I felt frustrated that, even though I was my baby's mother, I did not have the final say about what she would wear and how she would be cared for. I was heartbroken if my daughter cried and could only be comforted by someone else, as I looked on. My role as my baby's mother was being eroded, as I had to give that right over to the people who were “helping” me, because they were doing the best they could, within their own energy limits, and because they could ensure my child's needs were met.

I felt I needed someone who could help me care for my baby, my way, on my own terms. Just because I did not have the strength to lift her, did not mean I had no interest in holding her, comforting her, dressing her or playing with her. Yet to do all these things meant getting someone to help. Even family and well-meaning friends aren't really helping if they just take over. I was feeling disenfranchised. I was feeling like a stranger who did not know the likes and dislikes of my own child. I wanted to be, and needed to be, a parent to my child in my own right.

Infants need to be held by someone who loves them. A mother's love is not diminished by the fact that she happens to have a physical disability, even if that disability prevents her from holding her own infant. Gradually, I began to come up with the idea of having assistance to care for my child, similar to attendant support that helps me care for myself. If there was someone available, for some time each day, where I would be totally responsible for my child's care, I believed we would both benefit. My baby would benefit from having more intimate contact with a loving mother, and I would benefit from having a stronger relationship with my own child. There would be some time in every day where I could be the person to pick out what my child would wear. I could be the person to make my child laugh and giggle while I played with her, and learn about her ever-changing likes and dislikes.

Nurturing assistance, the phrase I used to describe this type of help, would do all this. Nurturing assistance would help me to interact and bond with my child, and be a mother in every real sense of the word. It would liberate my husband from my insistence on doing things my way (although he was the one doing them); it would liberate me from feelings of uselessness; and most importantly, it would strengthen the mother-child bonds by having real interaction and involvement between my baby and me.

Children have needs on both physical and emotional levels; so do parents. The nurturing assistant helped me not only to meet my child's physical needs without an unhealthy dependence on other family members, but also helped us both to meet some emotional needs at a very emotional time. I needed to feel involved in my baby's upbringing. I needed to feel I was having an influence in her little world. I

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didn't need a contest of wills with other adults in our lives over every little decision – like whether or not to wear socks.

Now I have two girls, ages 11 and 13. As we enter these turbulent and stressful teen years, I trust that the time I spent in direct interaction with my children as infants, through the nurturing assistance I had, will see us through, and with loving bonds stronger than ever.

[CALL OUTS; to be interspersed throughout text]

“Just because you don't need attendant services, it doesn't mean you don't need nurturing assistance when you have a child.”

- Nancy Barry, prospective parent

“The job of a nurturing assistant is to put the parent in the position to engage the baby. Putting the baby into a position where ‘the mother can do the essential work of nurturing’ accomplishes this. It is not the assistant who is doing the nurturing, then, but the parent who is assisted in doing what is necessary for the emotional and physical bond to evolve.”

- Jay MacGillivray, midwife

“From the baby's perspective, it's mandatory to have proper nurturing and bonding to have a ‘right life’. Nurturing assistance could have helped me tremendously with that process.”

- Susan Hoogveld, mother with a disability

“You've got to know what you want, communicate it well, and be aggressive when necessary.”

- Bill Meyerman, father with a disability

“The relationship between parent and nurturing assistant ... [is] directed by the parent, but it's also shared and it's always evolving.”

- Lisa Jones, single mother with a disability

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“Every once in a while an attendant will express an opinion, such as, ‘You’ll spoil her!’ When this happens, my response is, ‘That’s my decision.’”

- Theresa Cornell, single mother with a disability

“Raising a child isn’t always easy. Having a family member with a disability isn’t always easy. But the joy experienced in sharing life with loved ones far outweighs any stressful times. Nurturing assistance is one way to further minimize that stress – the key, for us, has been finding out how to best make it work.”

- Lisa Bendall, spouse of parent with a disability

“I did not feel that my relevance was diminished [by the presence of nurturing assistants], nor did I feel that my role as a parent was any less important. Everything that these caregivers did for my children was requested and supervised by my wife or me.”

- Stephen Little, father of twins

“I’m a single dad, and have been since my son was born. Our time together is limited to one eight-hour period each week, and that is possible only because I have the help of an attendant. Nurturing assistance has been essential to my forming a relationship with my son.”

- Single father with a disability

“It’s the nature of the relationship: no matter how well everyone gets along, a third person is still in the middle of a family situation.”

- Steve Fraser, adult child of a mother with a disability

“Parents need to be concrete about establishing their expectations of nurturing assistants.”

- Nurturing assistant

“I believe the attitude of professionals, service providers and nurturing assistants going into the home should always reflect a desire to assist and support the parents, and to strengthen them in their role as parents. In other words, we don’t go in to judge whether or not parents are doing a good job, but rather

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to ensure that they have all the supports in place so that they are on an equivalent playing field with able-bodied parents.”

- Heather Sloman, Occupational Therapist

“Mothers with disabilities need a real sense of entitlement – they need to feel at liberty to give directions and have them carried out in the way they want.”

- Judy Panko Reis, mother with a disability

Part II: DEVELOPING WORKING MODELS

Introduction

The first chapter in this section is for policy makers, funders, or service providers who want to develop a nurturing assistance program for individuals already receiving their services. Its focus is on information that would be useful to service providers who assist individuals with physical disabilities through Support Services Living Unit (SSLU) programs (Supportive Housing) or Attendant Outreach programs. The majority of service providers receiving Ontario government funding for nurturing assistance services are under the Central Region Office of the Long-Term Care Division of the Ontario Ministry of Health and Long-Term Care (see page 94). This chapter is relevant to today's Ontario, where growing numbers of "self managers" on Direct Funding are their own "service providers."

The experiences of service providers who have already developed and implemented nurturing assistance programs in the Toronto area have been invaluable in compiling this information.

Please note that the following information is meant to assist service providers and funders with the provision of nurturing assistance, and in no way represents all aspects of nurturing assistance program development and provision.

Chapter 1: Developing a Working Model for Service Providers and Funders

By Diane Duncan , Personal Support Services Manager, Tobias House, and Michael Mathieson, Executive Director, Access Apartments for Physically Disabled Adults in Toronto.

In partnership with the parent(s), the first step for the service provider is to develop a model of how nurturing assistance will function within the context of the organization.

There are two initial options to consider and there are advantages to both, depending on how the arrangement is structured:

Nurturing assistance is provided by attendants as an extension of their jobs. In this case, nurturing assistance can build on relationships that are already established between the attendant and consumer. Consistency exists because the children regard the attendant – whether he or she is helping with personal care or with the children – as “mommy’s (or daddy’s) helper.”

Individuals providing nurturing assistance fulfil only that function. Attendants providing nurturing assistance focus their energies solely on the parent’s needs to help the child. As well, their job description is very clear. The down-side of this option is that the nurturing assistant’s focus is narrow, which may lead to service limitations if the parent needs personal assistance during a nurturing assistance time slot.

The choice of which option to develop will affect a number of subsequent decisions, such as hiring, union considerations, ongoing supervision and how to phase out the position when nurturing assistance is needed less or not at all.

Hiring

The organization and the consumer should discuss whether to hire internally or externally for the position. Internal policies and collective agreements could well influence this decision. Hiring externally is likely to be a viable option only if a distinct position is created for the purpose of nurturing assistance.

The consumer will have the final say in who is selected as well as full control of the whole process: wording of the ad; the interview; determining selection criteria; hiring; evaluation; and, if necessary, termination. The service provider will decide on pay scales and working conditions depending on existing collective agreements.

Developing a nurturing assistance position may create a new class of employees. The organization must determine how the collective agreement allows for this.

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Ongoing Supervision

The consumer will be doing more ongoing supervision simply because the parent is directing services to enable him or her to do parenting tasks. The parent and the organization should develop clear channels for communicating concerns about and to staff members. The service provider should give consumers a working knowledge of organizational policies and practices around supervision in order to make informed decisions.

Phasing Out

As the child gets older, nurturing assistance should be needed less and less until it is no longer necessary. Depending on the parent's disability, this may happen over months or years. It will be important to estimate how long nurturing assistance will be needed, and to plan for its phasing out. "Phasing out" may mean that eventually individuals hired exclusively for nurturing assistance will have to be laid off or move into other positions within the organization.

If the service provider decides to combine personal attendant services and nurturing assistance services with one individual, then the phasing out stage would involve just a decrease in nurturing assistance tasks or hours worked, but not a lay-off.

Negotiations with Consumers

During the preparatory phase, it is important to assess with the parent which tasks he or she can do independently with the child and which tasks require assistance. The service provider and consumer should discuss roles and responsibilities, and establish clear expectations about day-to-day operations – such as who is responsible for scheduling staff, who will receive requests for sick time, vacation, etc., and who is responsible for covering shifts that a nurturing assistant cannot work. The consumer and the service provider must understand that often the job skills necessary for nurturing assistance are quite different from general attendant service skills. Parents must also be comfortable with the individual who is helping them with providing care for their child and expectations placed on a nurturing assistant may be higher than those placed on an attendant. The parent will perhaps want to have more autonomy with supervision of the person employed as a nurturing assistant than with other attendants. It is therefore important to negotiate supervisory responsibilities at the outset.

Hiring is a key area to consider in ensuring that things run smoothly. The parent must be comfortable working with nurturing assistants and must be able to trust them completely. The parent should therefore be involved in all aspects of hiring. This includes the decision to hire internally or externally, how and where to advertise, involvement in interviewing and decisions on hiring.

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Negotiating with Funders

The following is a sample of a brief proposal that can be used to request approval and funding from the Ontario Ministry of Health and Long-Term Care for the provision of nurturing assistance. Everything between the triangular brackets should be personalized to the consumer and the service provider.

Sample Proposal

<organization's name>

NURTURING ASSISTANCE PROPOSAL

FOR <consumer's name>

<date>

Submitted to the Ontario Ministry of Health and Long-Term Care

by <consumer's name> and <agency contact name>

Historical Overview or Background

<Outline an objective view of need and past experience for nurturing assistance services. Proposals often include this type of information. The following is an example of how it might be presented:

Over the last eleven years, the Ontario Ministry of Community and Social Services and, subsequently, the Ontario Ministry of Health and Long-Term Care have funded agencies providing community-based attendant services to provide nurturing assistance to consumers who have young children. It has always been understood that nurturing services are provided to assist the parent with a disability with their child and is not a "babysitting service" or "child care" in the absence of the parent with a disability. The role of nurturing assistance is to assist the parent with a disability to assume his/her full parental responsibilities, thus creating a bond with their child(ren) like most non-disabled parents enjoy.

Historically, nurturing assistance has been provided for mothers with a physical disability. However, both mothers and fathers of young children can benefit equally from the assistance that a nurturing assistant can provide.

Typically, nurturing assistance is provided at the highest level during the child's infancy. Gradually, as the child matures, the level of nurturing assistance will reduce as parenting tasks become less physical. Some individuals have also received additional housekeeping services as part of their nurturing assistance program.>

Current Situation

<Work with consumer to outline consumer's current situation, circumstances and family makeup>

Comment [AMC2]: Is this indicative of a different style of text or layout?

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Rationale for Services

<Work with consumer to outline rationale for services; include personal comments from consumers>

Requirements for timing and hours

Example: As <consumer's name> works full time, she/he is requesting nurturing assistance for the following:

- a) Monday to Friday, 5 p.m. - 10 p.m.
- b) Saturday and Sunday, 12 p.m. - 8 p.m.

This is a total of 41 hours per week.

Cost

<The approximate annual cost (Canadian dollars) for nurturing assistance as outlined above would be:

Salaries	\$27,950.00
Benefits	\$4,200.00
Total	\$32,150.00

Provide an estimated hourly wage (as of 2001: \$13.33 + 15% benefits). State current salaries. A three- or five-year budget plan may be helpful or an age target to phase out assistance (e.g., age 7).>

Implementation and Length of Service

<consumer's name> would like to implement nurturing assistance services as soon as possible. The duration and amount of services that will be required is difficult to predict. Once the children are toilet trained, there may be a minimal decrease in the weekly hours used for nurturing assistance. As was mentioned in the historical section of this proposal, nurturing assistance will no longer be required once <consumer's name> has full verbal control of the children and physical intervention is no longer required. This should occur when the children reach the age of <this must be negotiated with the consumer as nurturing assistance can be phased out as early as four or five, yet has continued until the child reached the age of 10 in some situations>. Thank you for your consideration.

Insurance

Appropriate insurance for staff is always necessary for service providers, including those providing consumers with nurturing assistance. Service providers must inform their insurance carriers of the types of programs and services they provide and to whom they provide these services. Most types of

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“malpractice” insurance coverage for staff will cover incidents with consumers and their property as long as neither the service provider nor the staff are negligent. This insurance should be extended to include not only consumers and their properties, but to their child(ren) as well. The rationale is that the consumer retains control over these services, which continue to be considered as “activities of daily living.” The insurance carrier may levy an additional charge, however the increase should be minimal.

Recruiting/Interviewing

Refer to page 33 for tips on recruiting and interviewing nurturing assistants.

Disciplinary Issues and Ongoing Supervision

There will be instances when an employee will need to be corrected. As stated above, the parent should have a good understanding of organizational practices in this area. For example, when and how should the parent discuss undesirable behaviour with the employee? When does it become a matter of discipline? When should the service provider become involved? What are grounds for dismissal? Is the consumer clear in his/her mind about the distinction between the nurturing assistance role from a babysitter or an attendant? Is the nurturing assistant clear about this? Reference to the *Employment Standards Act* may be helpful.

[CALL OUT]

Success Story

A woman in New Brunswick with a severe form of muscular dystrophy successfully got full support for her nurturing assistance through the Ministry of Health in New Brunswick. The Muscular Dystrophy Association was instrumental in helping this to come about, believing in her capacity to be a successful single parent, even though her parents and other professionals in her life would only recommend terminating her pregnancy. The mother felt that 24-hours, 7 days per week would be needed, at least initially. The provincial government granted her request. After the baby was born, the mother arranged for neighbours in her apartment building to be “on call” and reduced her service hours considerably. The mother wanted this, as it was less intrusive than people being around them 24/7. Mom and baby did just great.

Chapter 2: Developing a Working Model for Parents

This chapter is essentially a workbook for parents who qualify for nurturing assistance through the Ontario Ministry of Health and Long-Term Care (i.e., those who are already receiving attendant services as self-managers through Direct Funding (DF) or through services providers via the Attendant Services Outreach program or a Support Services Living Unit (SSLU)). It includes guidelines to follow as you plan, prepare and organize nurturing assistance services for your family.

The term “nurturing assistance” encompasses a wide range of duties, performed strictly in the presence and under the direction of the parent – from personal care for children, to assistance in preparing family meals, to household assistance.^{xi} Each family situation demands a different combination of services. Tracy Odell, who was the first parent to arrange nurturing assistance services through the Ontario Ministry of Health in 1988, offers this rule of thumb:

“Services should be limited to those areas that enhance the consumer’s independence and are compatible with his or her values in managing the home and loving his or her child.”^{xii}

Planning and Preparation

“Remember, there is no such thing as perfect parenting. Anticipating, planning and seeking information are ways of minimizing stress and avoiding dangerous situations.”^{xiii}

It is essential for persons with disabilities and those around them (family, friends, health care providers, attendants) to recognize that a lack of independence need not diminish a person’s value and competence as a parent. What it does is shift the focus to facilitating self-determination instead of self-sufficiency in the role of parent.^{xiv}

You may need to prepare yourself (and those around you) mentally for parenthood by reinforcing your role as primary decision-maker in the care of your children. You should let it be known that you want to personally carry out as many parenting tasks as you can. You also need to plan for nurturing assistance to do the things you cannot do safely or independently. Give yourself as much time as possible to go through a process of identifying what your needs will be and how much extra physical support may be necessary in caring for your child.

Inadequate planning for the birth or adoption of a child can have devastating results, as in cases where child protection agencies, such as the Children’s Aid Society, are called in by health professionals, neighbours, etc. Once such agencies become involved, there is a possibility that the child will ultimately be removed from the home. Parents with disabilities should be prepared to make changes to their lifestyle and to be creative in anticipating and solving potential problems.

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When a parent with a disability applies for attendant services, nurturing assistance needs should be included in the application. If the consumer has already been accepted into a government-sponsored attendant services program, the services provider can make a one-time application to the Ontario Ministry of Health and Long-Term Care to cover nurturing assistance needs. “Self-managers” – those who are receiving Direct Funding – can request nurturing assistance themselves. When approved, a negotiated amount would be included in their budgets.

If you anticipate needing nurturing assistance, make sure you consult with services providers or the DF program as early as possible. Make inquiries as soon as you know you are pregnant. According to *The Parenting Book for Persons with a Disability: From planning your family to raising adolescents*: “Keep in mind that there is no standard, easy process to follow when you are trying to arrange subsidized assistance. It is best to prepare your case ahead of time and present it in an assertive manner.”^{xv}

Even those who qualify for nurturing assistance find that the limited hours available make it essential to have back-up plans for the time you are not formally covered. You may have to rely on others, for example your spouse, family and friends, to help out on a regular basis. Personal assistance can always be purchased privately if you have the resources to do so. A few organizations may be able to offer limited support under certain circumstances (see Appendix C). Careful planning before your child’s arrival will be required to create the patchwork of support you’ll need, and constant review of your family’s changing needs will be required thereafter.

Recruiting and Interviewing

Before you begin the process of recruiting, interviewing and hiring a nurturing assistant, think carefully about what you will need assistance with, and when. Then you can begin to design a program to meet these needs.

The first step is to write a job description, or job descriptions, that will meet your needs. Secondly, put together reasonable shifts to meet your scheduling needs.

[BOX] Tip: Create a schedule in chart form, blocking out your needs and preferences by day and time.

Example: Parent needs assistance with dressing her child and with breakfast; bathing and bedtime routine, and laundry. Proposed solution: Establish a three-hour morning shift and four-hour evening shift, which could include bathing and laundry.

[BOX] Tip: Having assistance in large blocks of time provides more flexibility than having one hour here and there throughout the day.

Once you have decided on a shift schedule, you can determine how many nurturing assistants are needed. Keep in mind that people get ill and need to take days off. Also, factor in vacation time for nurturing assistants. You should plan ahead for how you will cover their shifts when they are away.

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[BOX] Tip: You may want to hire an extra nurturing assistant for the purpose of providing relief to your regular nurturing assistant.

Finally, decide on a start date and deadline to receive applications. Include all of this information in the advertisement.

The next step is to prepare the job ad. Even if someone with experience in doing this is helping you, or if you choose to follow the example given below, you should make sure it reflects your values and the decisions you have made, as outlined above. Remember, the job ad is your starting point in the interviewing process.

Advertisements

The following are sample advertisements for nurturing assistants. Internal ads, which are posted or distributed within an SSLU where the job description is generally understood, should contain less detail than external ads.

In cases where the parent has a strong preference for either a male or female nurturing assistant, it may or may not be acceptable to include this information in the ad. The *Ontario Human Rights Code* specifies that “the right . . . to equal treatment with respect to services and facilities without discrimination because of sex is not infringed where the use of the services or facilities is restricted to persons of the same sex on the ground of public decency.”^{xvi}

In addition, the Code stipulates that “the right . . . to equal treatment with respect to employment is not infringed where . . . an individual person refuses to employ another for reasons of any prohibited ground of discrimination in section 5, where the primary duty of the employment is attending to the medical or personal needs of the person.”^{xvii}

In a situation where a mother is breastfeeding, for instance, and would be uncomfortable with a male nurturing assistant, it would probably be acceptable to state gender preference explicitly in the ad. However, if you are considering running an ad that states your preference for one gender or the other, be clear about your reasons so that your choices cannot be interpreted as discriminatory.

Following, are sample ads for nurturing assistants. You may choose to hire one person who can fulfil both nurturing assistant and personal care attendant roles. In this case you should add tasks of personal care attendants to your ad.

Sample Internal Ads (i.e., within an SSLU)

Sample Job Description:

Nurturing Assistance

Assisting parents with a disability with the physical aspects of caring for an infant under the direction of the parents. Duties will include but are not limited to:

changing diapers

bathing

keeping baby's area clean and tidy

baby's laundry

Location: (fill in)

Shift Schedule:

Position #1: Monday & Tuesday 2300 – 0900

OR just generalize it: e.g. Position #1 <day of week>, <shift start and end time>

Position #2: Wednesday 2100 – 0900

 Thursday 2300 – 0900

Approximate Start Date: <fill in>

To apply, please forward a resume and cover letter to: <fill in>

Closing Date: <fill in>

Sample External Ads

“Are you energetic and looking for progressive work?

Do you want to put your excellent people skills to use? Seeking a challenge? A parent with a physical disability requires assistance with daily activities and interactions with his/her children (including help with lifting and carrying, bathing, meal preparation, feeding, etc.). This kind of assistance makes independence of lifestyle and parenting choices possible. We are seeking men and women to work on a part time basis. Send resume and cover letter (including reference to this ad) by fax to _____ (or to address). No phone calls please. Only those selected for interviews will be contacted.”

“Want to try something new . . .

in a casual work environment, with flexible hours and good starting wage? We train you to provide attendant services to parents with physical disabilities under their direction, assisting them with the physical aspects of caring for their children in order to strengthen parent-child relationships. Please send

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resume & cover letter (including reference to this ad) by fax to _____ (or to address). No phone calls please. Only those selected for interviews will be contacted.”

[BOX] Tip: Parents generally suggest not using the term “nurturing assistant” in external ads, as it is not widely recognized.

External ads could be placed in community newspapers, posted at community centres or at colleges with nursing or Early Childhood Education programs.

When the closing date for applications has passed, select candidates for interviews from the applications you have received. Determine how many interviews you will conduct and when you want to do them.

Interviewing and Selecting

You will find a series of sample interview questions in Appendix A. An interview does not need to be longer than 45 minutes. If you are interviewing one after the other, allow at least 15 minutes between to take a break and prepare for the next candidate. As a measure of courtesy, try to time interviews to ensure that one applicant does not encounter another.

The interview should have eight to twelve questions to keep it within this time frame, depending on the length of the questions. You could use some of the questions outlined in Appendix A, or use them as a guide to write your own. You can also ask additional questions that occur to you during the interview, particularly if you want to gain more information on a particular issue.

[BOX] Tip: Don’t forget to write down the applicants’ answers!

[BOX] Tip: For safety, you may want to consider having the interview outside of your home or with a second person present. Involving a family member, such as your spouse, in the interview may be useful as he or she will also be interacting with the nurturing assistant.

Once you have completed all of the interviews, compare candidates and choose whom you will hire based on their answers. It can be tempting to go with a “gut feeling,” but liking somebody does not necessarily mean he or she will be a good employee. However, intuition can be valuable because some people do not interview well but make excellent employees. Try to balance out well-answered questions with your intuition. Don’t forget to contact the references given by any candidate to whom you plan to offer the job.

[BOX] Tip: Once you have made a final decision, always check the prospective employee’s references and have a criminal reference check done by the police department.

When you have decided whom you will hire, call and offer the position. If they verbally accept, arrange an appointment to sign a contract and do some orientation. You should also call or write to the unsuccessful candidates and tell them you are not offering them the position.

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On the appointed day, have a contract ready to give to your potential employee. Offer them the choice to take the contract and read it over for a few days and think about it. This way they don't feel compelled to sign it if there are some things they don't like about your offer. (If this is the case, you may need to negotiate changes.)

[BOX] Tip: Prepare a job description to attach to the employment contract.

Sample Employment Agreement

Employment agreements are important to protect all parties involved, in case of a dispute and to establish working standards and the termination process.

Note: All information between the triangular brackets must be personalized.

<Date>

<Name>

<Street>

<City, Province>

<Postal Code>

Dear <Name>:

<Employer> is pleased to offer you a position as a part-time nurturing assistant for <consumer's name> at <address>. Your shift configuration will be <days of the week> <hours>. This shift configuration is subject to change based on the needs of the parent and child and sufficient funding for the position from the Ontario Ministry of Health and Long-Term Care. The position will encompass duties as listed in the attached job description and other related duties as assigned by the parent. This position will commence on <date>. Your hourly wage will be \$ < wage hourly >.

In the event of termination of employment you will receive notice of severance and any other payments as prescribed by the *Employment Standards Act* and this shall be your full and final entitlement.

I would like to offer you congratulations on your new position as nurturing assistant.

Sincerely,

<Employer's name>,

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<Title, if appropriate>,

<Employer's address>.

I, <Employee's name> have read the above conditions. I fully understand their meaning and I agree to all the conditions of employment.

Signature

Sample Job Description

Under the direction of the parent, the nurturing assistant will attend to the physical needs of the child. These needs may include, but are not limited to:

- Dressing and undressing
- Bathing
- Changing diapers
- Lifting and carrying the child to the parent
- Feeding and assisting with feeding
- Laundry
- Organizing and tidying child's bedroom and belongings, clothes, etc.
- Maintaining a safe and healthy environment

[BOX] Tip: Include all the basics you feel are important in meeting your child's physical needs, but do not try to include every detail of what the nurturing assistant may be required to do. You cannot foresee everything, so a more general job description gives you room for flexibility, as needs change.

Orientation and Training

The first step in providing effective orientation and training for a newly hired nurturing assistant is to define and communicate your needs clearly.^{xviii}

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An initial orientation session will set the stage for the nurturing assistant. It gives the nurturing assistant important information about your general approach to parenting, your expectations and your objectives for nurturing assistance. You will have the opportunity to explain your disability in language the nurturing assistant will understand, and to express what you feel is relevant to the nurturing assistant's responsibilities (what you can and cannot do for your child, your priorities, and so on). You should explain what you hope to achieve through nurturing assistance and what the nurturing assistant's role is. Follow up by doing this again in a week, in a month and in six months.

A training checklist can be a valuable tool to use to give a new nurturing assistant a picture of what needs to be done, when, and in what order. See Appendix B for a sample training checklist, which you may use or adapt to your own circumstances.

Supply your nurturing assistant with information about employment and rights. (Note: this will not apply if you are living in an SSLU.) You can provide booklets on employment standards, human rights, health and safety, employers' health tax and workers' compensation. Check with your local government departments for such resources. Understanding the legal requirements and restrictions related to the job will help to foster mutual respect and confidence.

Introduce the nurturing assistant to your other staff, if you have any, as part of his or her orientation. This will help create a team approach. Since staff may have different shifts, you may want to arrange for a brief meeting do this. You might also want to introduce the nurturing assistant to other family members – spouse, parents, siblings – and perhaps even close friends, and anyone with whom he or she might interact.

In familiarizing the nurturing assistant with your lifestyle and household situation, you must have him or her understand the importance of the job to your well-being and role as a parent. It is critical that the nurturing assistant be both reliable and punctual. You should state clearly your ground rules, such as any smoking and alcohol restrictions. Emphasize that the nurturing assistant should be prepared to take direction only from you in caring for your child or performing other tasks. Having the assistant form a personal bond by taking the initiative in providing care for your child is not the objective of nurturing assistance.

At the same time, it is important for you to understand the perspective of the nurturing assistant, as the role may be difficult and finely balanced. For instance, during play the nurturing assistant must get your child interested in an activity and just as his or her interest picks up, switch the focus to you by giving you the toy or putting the child on your knee to continue the activity. At this point, the nurturing assistant can even put him/herself in the background or even disappear altogether for a few moments. It takes a person capable of warmth in dealing with children, but also able to separate so as not to be the centre of a child's delight and attention. Effective orientation will reduce misunderstandings and general anxiety levels for both you and your nurturing assistant. It will also help establish what will ideally be a long-term relationship.

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[SIDEBAR]

Guidelines for Establishing Good Relationships

The Gateshead Personal Assistance Pilot Project in the U.K. offers the following guidelines for establishing a healthy relationship between family members and nurturing assistants:

- Explain the role carefully to your nurturing assistant(s). They must be clear that they are working to your instructions, not on their own initiative.
- If they have their own suggestions, listen to them but make it clear that the final decision is yours.
- As always, make it clear that they must not criticize or undermine your decisions in front of your family.
- Try never to leave them alone with a younger child. When you do, you are crossing the line between personal assistance and babysitting.
- Explain the role of nurturing assistance to your children as soon as you feel they are old enough to understand it. Most children quite quickly understand that nurturing assistants are in the family home as mommy or daddy's "helpers" or "attendants."
- Sometimes your child may directly ask your nurturing assistant for assistance. This is inevitable as the relationship develops. Some parents with a disability insist that their children always say "please" and "thank you" in these instances so that they understand the assistant is not there to do their bidding.
- If you have older children, think carefully about what is reasonable to ask your child to do and what the nurturing assistant should be doing for them on your behalf. At what age should your child be washing dishes, helping with the shopping, tidying their room and so on? All parents with a disability worry about overloading their children with responsibilities that they would not otherwise have to assume. But remember, it is healthy for children to take on age-appropriate responsibilities. Nurturing assistants are not 'maids' and should not supplant a child's natural and healthy growth toward independence.

(Source: "Parenting," at www.disabilitygateshead.org.uk/boss/parent.htm, Web site of Gateshead Council on Disability in the U.K.)

Scheduling

Your nurturing assistant's working times should be scheduled to maximize your time for interacting with your child. For instance, try to avoid scheduling nurturing assistance during nap times. If this is not possible, nap times are good times to organize and wash toys, sort out outgrown clothes, etc. As the baby's patterns will change over time, consider renegotiating the schedule monthly. This will allow you

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to work around your baby's changing needs, but will still allow you to set up a schedule that both you and your nurturing assistant can rely on. As the baby grows, he or she will likely settle into a more predictable routine, and you can adjust the schedule for nurturing assistance accordingly.

Think through how much flexibility you will require, and convey this at the interview stage. If you need a great deal of flexibility and do not communicate your expectations clearly, your nurturing assistant could become unhappy with too many last-minute changes to the schedule. This could well affect your nurturing assistant's commitment to the job. In other words, strive to be professional; keep in mind that the nurturing assistant is doing a job at your home.

Consider establishing a system whereby the nurturing assistant helps you keep track of the hours he or she has worked. You can have a sign in/sign out system, which will provide ready documentation at all times, which is helpful in cases where the nurturing assistant works unscheduled, shorter or extended shifts.

Sick or Emergency Shift Cancellations

Attendants who wake up ill should be instructed to try to give you at least four hours notice. If they are early morning staff, they should call as soon as possible. Nurturing assistants should be told that if they have a contagious illness, they should stay home so as not to compromise the parent or child.

Vacation or Extended Leave

Ask your nurturing assistants to let you know with as much notice as possible if they are planning a vacation or will need extended leave, so that a replacement can be found.

Safety

Discuss safety precautions and explain the use of your equipment. Inform the nurturing assistant of the consequences of not following your directions. If you are the employer, under the terms of the Direct Funding program, you are responsible for the health and safety training of your workers under the *Health and Safety Act*.

Stress the importance of general cleanliness, such as in food preparation. Also for health and safety, universal precautions should be understood and followed. For example, ask the nurturing assistant to wear gloves when handling food if that is your preference, or make sure that your nurturing assistant has completed training in infant CPR and other first aid procedures as you decide.

Have the nurturing assistant take safety precautions seriously, such as making sure locks are fastened and stove burners are turned off. As for personal safety, if you need to be lifted or transferred during the time your nurturing assistant is on duty, clarify who will do this – the nurturing assistant, if he or she

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happens to be one of your regular attendants – or someone else. If possible, establish a routine whereby lifting and transferring is done before the nurturing assistant's visit.

Other safety issues will be unique to your situation. For instance, an older child can learn how to safely climb up on the footrests of a power wheelchair, so that you and your child can have close contact to play, make faces, brush hair, and so on. The nurturing assistant will take direction from you on how to teach the child to climb up safely, and should remain immediately beside you in case the child slips.

Most importantly, the parent is the one primarily responsible for the safety of the child, not the nurturing assistant. It is up to the parent to decide what information and special training a nurturing assistant might need to have in order to perform his or her job responsibilities effectively, and what tasks/activities are appropriate for the child's age and stage. It is very common for two adults to disagree on child rearing. The nurturing assistant's views should not be one more set of opinions to deal with.

Chapter 3: Adoption and Nurturing Assistance

To ensure that infants and children available for adoption are placed in stable, loving homes, the province of Ontario requires a home study to be completed. Home studies involve a series of interviews with a social worker, approved specifically in adoption, who will get to know you and educate you about adoption. Among other things, you will be asked to provide references and to have home visits from the social worker. A home study results in a government reviewed and approved document. A list of adoption social workers is available from the Ontario Ministry of Community and Social Services (see page 94).

A complete knowledge of nurturing assistance, whether or not you qualify for government support and how much assistance you would be likely to receive should you adopt a child, is critical information to offer your social worker as part of your home study. Prepare a back-up strategy as well, should the support you anticipate not work out exactly as planned. Look at all your options for the future. What would you do if your disability were to change – if your mobility decreased, for example?

According to *The Parenting Book for Persons with a Disability*, “Persons with a disability who decide to pursue adoption hope they will be judged as prospective parents solely on their ability to give a child a caring home. The reality is that disability is a factor which requires you to show that you have taken measures to ensure you have the necessary supports in place to provide a safe, suitable environment for a child. This must be recognized and documented as part of your home study.”^{xix}

According to another recent publication, “Stereotypes depicting women with disabilities as having to be ‘cared for’ rather than as caregivers present ongoing challenges to those women wishing to adopt children.” Fathers do not fare any better; the article gives an example of a man using a wheelchair, who was told that his problems “playing baseball” reflected poorly on his capacity to be a fit father for an adoptive son.^{xx}

When considering adoption, be open to the understanding that adoptive parents face some different parenting issues from biological parents. You will be confronted with questions and assumptions from family, friends and strangers about both adoption and disability, which you would not otherwise have had to deal with. These areas of sensitivity may take some thought and preparation on your part to handle well, both before and after the adoption. A key element in your planning and preparation can be your knowledge of nurturing assistance, and whether or not you are eligible for government supported assistance.

Denise Jacobson and her husband both live with physical and speech disabilities due to cerebral palsy. They adopted a son, David, a number of years ago and Denise has written a book, *The Question of David*, about their experiences. The following are a few suggestions from Denise Jacobson:^{xxi}

For prospective adoptive parents

Nurturing Assistance

- Be upfront with social workers and physicians – ask them if they have any concerns about whether or not you would make a good parent.
- If they are unable to assist you, don't give up – use disability and adoption networking to identify professionals who will give you the time and support you deserve.

For medical professionals

Jacobson emphasizes that social workers and physicians interested in strengthening parenting and adoption options for disabled parents-to-be ought to:

- Read the literature on adoption for people with disabilities available via the Through the Looking Glass Web site: www.lookingglass.org
 - Remember that the same screening standards should be applied in adoption screening of all potential parents, regardless of whether they have a disability.
- Learn about the disabled parent's support system – what resources are available to them, i.e., family, friends, neighbours, and any other assistance.
- Examine your own concerns and be honest if you have any feelings of discomfort – you may not be the best person to handle this issue.

Part III: Viewpoints

Introduction

Please note that the views expressed here do not necessarily reflect CILT policy. They are individual perspectives, and are not necessarily shared by or similar to others.

This section explores the diversity of experience that various individuals have had with nurturing assistance. Mothers and fathers with a disability, an able-bodied spouse, a nurturing assistant and an occupational therapist are among those who tell their stories. By sharing their experiences, both positive and negative, they also introduce ideas and issues for further discussion. In the section on Planning and Preparation (see page 32), the point is made that anticipating needs and potential problems is essential. The experiences of others may well help prospective parents to envision their own nurturing assistance preferences. For those who are already parents, the voices of others with similar goals and circumstances can offer peer support.

A Delicate Balance

Four-year-old Margaret Cornell lives in a lively Scarborough neighbourhood with her mom, Theresa. Theresa has arthrogryposis, a congenital disability affecting the joints and muscles, and she uses a motorized stretcher for mobility. Margaret loves to play on the roof garden located on the second floor of their apartment complex, while Theresa and her attendant take care of household chores in the adjacent laundryroom.

The grocery store and bank are both close to home, making errands enjoyable and manageable for mother and daughter now that Margaret is old enough to safely follow her mother's instructions. "You should see the looks we get, when Margaret hops up on my stretcher to go with me for short trips!" says Theresa.

Theresa works full-time fielding inquiries at the College of Physicians and Surgeons of Ontario. She and Margaret's father separated when the baby was a year old. Since then, Theresa and Margaret have organized their lives with the help of attendant services provided by Ontario's Attendant Outreach program, in an SSLU staffed around the clock with attendants, through Access Apartments. "Since we have to have an attendant with us during Margaret's every waking moment, I do sometimes go over the allowable monthly limit for service hours. For instance, if Margaret is sick and I have to stay home from work with her, I'll need extra time. On the other hand, she's with her father every other weekend, so I can 'borrow' from the weeks where I don't need quite as many hours. Outreach is flexible enough to accommodate this," says Theresa.

Theresa doesn't differentiate between attendants and nurturing assistants, finding that it works better for her to have one person doing both types of activity at any one time. Otherwise, she says, she'd feel that she was imposing by asking the personal attendant to do something child-related when she wasn't hired for that purpose. Also, she points out, there would be too many different people running through the apartment if she had separate attendants and nurturing assistants, with the ensuing confusion about who was supposed to be doing what. Theresa doesn't want to factor that confusion into Margaret's life.

For Theresa and Margaret, a typical weekday begins at about 5:45 a.m. when Theresa gets up. An attendant/nurturing assistant arrives at 5:45 a.m. She helps get Margaret organized for school and Theresa ready for work. They leave the apartment at about 7:00 a.m. to meet their bus.

Margaret attends junior kindergarten in the morning and, because the school has a day care centre on-site, there are no additional transfers to worry about during the day. Her mother picks her up at 5:00 p.m. and they head for home. Margaret carries a communication book back and forth to school, so that Theresa and the teacher can keep in daily contact by writing notes to each other.

An attendant is with them to assist in the evening until 10:00. "We have two different attendants in one day," says Theresa. "From Monday to Friday we have a total of four attendants. And three that we have during the week also work on weekends. So right now we have a fair bit of consistency."

On the weekends that Margaret and Theresa spend together there is another routine, consisting of two back-to-back shifts in one day: 8:00 a.m. till 12 noon, and 12:00 till 10:00 p.m. On weekends, wake-up is at about 8:00 a.m. Mornings are generally reserved for chores, like laundry, cleaning and baths. In the afternoon Theresa usually books WheelTrans for an excursion, accompanied by an attendant. After returning home and having dinner they may go out for a walk.

"If it's a rainy day, Margaret will probably have a nap in the afternoon. That's when I get involved in rearranging my living room furniture, or some other project that Margaret's better off sleeping through."

Margaret is a typical four-year-old, with an inquiring mind, a love of consistency, and a willingness to test her boundaries from time to time. "She has temper tantrums, like any normal four-year-old," says Theresa. "I don't believe in violence as a form of discipline. I believe that if you wait, the tantrum will play itself out. If it does continue, I ask my attendant to put Margaret in her room, and I let her know that she'll be in there until she's calmed down. She knows I mean business! Usually five to ten minutes is all it takes." For the most part, Margaret knows the rules and abides by them. "But she has to know that my word is the final one." The one thing Theresa expects is that attendants always send Margaret to her mom for permission, on any issue.

Every once in a while an attendant will express an opinion, such as, "You'll spoil her!" "When this happens, my response is, 'That's my decision.'" When interviewing and training attendants, Theresa

tries to be clear about the rules of her home and the way she is raising her child. But, day-to-day, “I’m open to other people’s suggestions. If there are different ways of doing things that might make life easier, I’m happy to listen.” She finds that interpersonal problems tend to surface on weekends when attendants are present non-stop.

It’s inevitable that children will bond with those caring for them. Margaret has lately become more attached to one attendant over the others, and Theresa has had to tell that attendant that Margaret needs to have the same respect for all attendants who care for her. “It’s not her fault,” says Theresa. “She’s done nothing to encourage a closer relationship. It’s just that sometimes an attendant will get comfortable with a child, almost as if she’s her own. It’s up to the parent to tug on the attendant, and ask her to pull back a bit. For an attendant, the most important things to learn are how to take direction and when to pull back.”

Attachments form in more than one direction, says Theresa. “I’ve developed close bonds myself with certain attendants. But you have to look at the long run. When your child is 15, you don’t want her turning to someone else other than yourself. Children need to take you as seriously at the age of 15 as they do at age one. Attendants need to know that for them, it’s a job. They go home at the end of the day. We’re the ones continuing on.”

“Margaret knows I have limitations and she’s been very good at adapting to them,” says Theresa. “She’s at the point where she prefers to be alone with me, now that we can do that for short periods.” The latest news from her teacher is that Margaret has learned to write her name – another sure sign that things are moving along just as they should.

- *Based on material from an interview*

Everything to Gain

Bill Meyerman was in a car accident when he was five years old, and since then has used a wheelchair for mobility. He has lived with spinal cord injury for more than 30 years. Bill and his wife, Kim, live in Kingston, Ontario, with 20-month-old Maya. Kim works full-time, while Bill stays home with Maya. They also care for two foster children, between the ages of 5 and 18, for short stays of about three to six months.

When Maya was eight months, her parents took her with them to Washington, D.C. While there, a stranger who saw her with Bill remarked, “Oh, your baby is so cute!” It was the first time a casual observer had voiced the assumption that Bill was Maya’s father, rather than an uncle or friend who was “giving mom a break.”

Nurturing Assistance

How you and your child are perceived by strangers may seem inconsequential in the scheme of things – but the feeling of pride prompted by an admiring stranger’s off-the-cuff remark is one cherished reward of new parenthood that rarely comes Bill’s way. Bill feels that publicly funded nurturing assistance similarly acknowledges and supports his role as Maya’s father. “It says that she is mine, and that I’m pulling my weight in this marriage. Being able to make decisions on your child’s behalf and carry them out even for a few hours a week, without your disability determining what you can and cannot do, gives you back your dignity.”

Bill was already receiving attendant services through the Attendant Outreach program when Bill and Kim found out they were expecting a baby. He discussed his need for additional assistance after the baby’s birth with Outreach staff. It was agreed that he would receive extra hours in the morning, as he anticipated having difficulty getting ready for the day and caring for the baby at the same time.

When Bill had his initial discussions with Outreach, he asked if the same two attendants he was then working with could also be made available for nurturing assistance. He also requested that the attendants visit with Maya, Bill and Kim together before Kim’s return to work. This was Bill’s idea – not program policy – and Bill feels that it did contribute to what turned out to be a smooth transition. As anticipated, his attendants were wonderful with the baby. Bill’s respect for and confidence in the attendants who became his first nurturing assistants certainly played a part in the development of a rewarding relationship.

“There’s no one personality type to look for. What’s most important is how you get along and communicate,” says Bill. He also believes that consistency is important. This can be a challenge, as most people in the Outreach program have a number of different attendants coming in and out of their homes.

Both the willingness to be one’s own advocate and “the awareness of what it takes to get what you want” play an important part in getting services such as nurturing assistance in the first place, according to Bill. “You’ve got to know what you want, communicate it well, and be aggressive when necessary. Growing up in an institution taught me to work within the confines of the system. I learned to go for it. I always have the feeling that there’s not much to lose, and everything to gain.”

At first Bill was receiving 7.5 hours a week and sometimes more if he needed assistance with doctor’s appointments. When Maya started day care three mornings each week, Bill’s nurturing assistance was reduced to a total of three hours. On the days she goes to day care, someone from Outreach comes and helps him to get her out of the car.

Someone with a spinal cord injury typically expects his or her service needs to increase with age, and Bill feels that he will need some form of nurturing assistance until his daughter is eight or nine. “I believe this may not be available to me because of inflexibility and underfunding within the system,” says Bill.

Nurturing Assistance

Bill views his experience with nurturing assistance as successful, in the sense that his daughter is well cared for. He believes that the program needs to be expanded, however, because it does not allow for anything beyond the basic needs. "There are lots of things I could do with my daughter during the day if I had more hours of assistance," says Bill. "We could go to the park, or I could take her to pick out a birthday gift for my wife. Right now I'm restricted in the amount of quality time I can spend with Maya."

Bill believes that there should be a standard number of hours for which parents with a disability are eligible and, he adds, "Perhaps the program should be run by a separate agency, or ILRCs (Independent Living Resource Centres), so that nurturing assistance can finally get the attention it deserves."

- Based on material from an interview

The Pitter-Patter of Larger Feet

Probably the biggest adjustment I had to make at home when I married a man with a disability was to get used to attendants. I found this much more difficult than learning to share a household with another person – that part, which other couples often find challenging, seemed easy! But the daily intrusion of non-family members into the home was trying for me at first. They were there at times when I least wanted to be "on" for visitors: at 6:30 in the morning, when I answered the door in my bathrobe, and last thing at night, while I wearily waited for them to leave so that I could crawl into bed.

Ian, my husband, tried to convince me that attendants are a positive thing – that they provide help. That was easy for him to say: the alternative to attendants, for him, was lack of independence. The alternative to attendants, for me, was privacy and quiet!

We've lived together for six years now, though, and I'm much more at ease with attendants in our home than I used to be. Two years ago, the dynamics of our household shifted yet again: my husband and I had a beautiful, bright and active baby girl.

At the start, the role of attendants as nurturing assistants was probably not as significant in our family as we had expected it to be. I think that it would have been different if I, as the mother, was the parent with the disability, or if Emily had been an easier baby. Right from birth, Emily clearly preferred the company of her mom, and because she is a spirited child, she made no bones about it! It was often easier for me to step in and take over the parenting from Ian than listen from the next room to Emily crying for me.

Another factor was my inability to drive. I can't think of a single occasion when I went out to do errands while my husband looked after Emily at home with an attendant. It was simpler for us to all go out together, with my husband as driver and me as diaper-changer and sustenance-provider. Even now we tend to do errands as a family rather than go through the rigmarole of arranging help for Ian.

Nurturing Assistance

And, of course, there's the time squeeze that any family with two full-time jobs and full-time day care is forced to contend with. Add to that having a disability in the family – a disability is incredibly time-consuming. In the early days of having Emily, as we rushed to get washed, dressed and ready for work on weekday mornings, Ian simply did not have the time to devote to parenting. A few fleeting tickles and exchanges with his daughter when they happened to find themselves in the same room at the same moment were about as much as he could muster. If he had taken the time to direct an attendant to get Emily dressed or feed her breakfast, we would have been late for work. It was easier for me to do it myself.

We also learned along the way that a good personal attendant for Ian is not necessarily an ideal nurturing assistant for Emily. The morning attendant we had when Emily was born (they met when Emily was less than 24 hours old) was very good with her. Consequently, she needed very little direction from Ian when, for instance, he asked her to distract Emily while I was outside shovelling the snow from our car. She seemed to know instinctively how to hold her and talk to her so that she would calm down. Our next morning attendant did not take the same initiative. If an attendant needs too much instruction from Ian to assist with Emily, it becomes less of a help and more of a hindrance. Again, it was easier for me to do it myself.

However, not long ago we started to think about other ways we could be using nurturing assistance to ease our lives. We realized that we could recruit and hire someone specifically for her qualifications to assist with Emily, instead of trying to marry the nurturing assistant tasks with the attendant services for Ian. We followed this strategy, and it worked: it enabled us to get a better fit for Emily's own needs. We also realized that if we used nurturing assistance during the times that Ian doesn't require personal attendant services, the two would not conflict (and make us late for work). So we schedule Ian's new nurturing assistant for Saturday afternoons or Sunday mornings.

So far, so good! Ian is now able to take Emily to the park or the store, and give me some much-needed time at home to mow the lawn or pay bills. And Emily looks forward to seeing the nurturing assistant, whom she likes, and going somewhere special. The first time the nurturing assistant arrived to help, Emily turned around and said, "Bye, Mommy!" about every two minutes until they were out the door.

Probably the best thing about nurturing assistance is that it allows Ian to be the primary caregiver for a while. It strengthens his bond with Emily. It is noticeable in our daughter's behaviour when he has spent time with her, away from me. She is more affectionate with him, and is more likely to approach him when she needs a parent's help.

Raising a child isn't always easy. Having a family member with a disability isn't always easy. But the joy experienced in sharing life with loved ones far outweighs any stressful times. Nurturing assistance is one way to further minimize that stress – the key, for us, has been finding out how to best make it work.

- *By Lisa Bendall*

Change – You Can Count On It!

Lisa Jones, a health policy planner with the Halton Peel District Health Council [in Ontario], is a single mom. In a bright, two-bedroom apartment, filled with sunshine and laughter on a recent Sunday morning, she is raising her two daughters, Laural, 8, and Emily, almost 3, along with Laural's pet rabbit, Midnight.

Grinning at the kids' antics as a photographer captures them with their mother is Janet Rondeau, a first-year nursing student at George Brown College and Lisa's nurturing assistant. You might better call Rondeau Lisa's "weekend executive assistant on the home front".

The relationship between parent and nurturing assistant is "very special," says Lisa. "It's directed by the parent but it's also shared and it's always evolving."

Lisa found her own ideas evolved as time went by. After Laural was born, she had a live-in nanny. But having an extra person permanently within the confines of the apartment proved stressful. So when she was expecting Emily, she went another route. "As your needs change, you change what you need," she says.

Although she has the use of her arms, she couldn't lift the baby in and out of her crib. So she needed someone overnight initially. Later, as Emily grew, Lisa needed help only during the day. When her maternity leave ended and she returned to work a different pattern evolved.

Mornings are the most hectic time. During the week, Lisa has an assistant come in from 6:45 a.m. to 9:15 a.m. Her mother also helps out from about 7:30 a.m. on, eventually taking Emily to the babysitter as Laural leaves for school and Lisa herself sets off to work. "For a short time, we really need two extra people," she says.

In the afternoon, Laural goes to her grandmother's after school, but through the evening and overnight, Lisa has the kids to herself.

Assessing needs and scheduling time within the funding allotted to families is one of the biggest issues in successful nurturing assistance, says Diane Duncan, manager of support services at Tobias House, which specializes in attendant services and assisted living projects. "Parents can't have assistance around the clock, so it's important to calculate the time when needs are most important."

Finding help from someone compatible, someone the children feel comfortable with and who has the right attitude toward disabilities, can also be a challenge, says Lisa. "You need someone who understands that when the kids ask, 'Can I wear this tank top?' or 'Can I have a cookie?' the answer is: 'Ask your mom.'"

Nurturing Assistance

Even at the best of times, the parent may feel jealous, Lisa says. "It's hard when you see someone swinging your kids around, doing things that you want to do but can't. You feel resentful. You have to deal with that."

Lisa is uncomfortable with the term "nurturing" assistance. "Nurturing is really something spiritual; it's about love, and that's my role," she says.

But support and assistance for new mothers is crucial, she believes. "Everyone needs help. The need is just more visible when it comes to people with disabilities."

- By Helen Henderson

Excerpt reprinted courtesy The Toronto Star Syndicate, from an article originally appearing in The Toronto Star, April 2001.

A Father's Perspective

As a teenager, I had never contemplated the prospect of being a parent except for perhaps the most elemental and initial step of that journey. When I acquired a spinal cord injury in my teenage years, the thought of becoming a parent, including that initial step, seemed so far out of reach that I never gave it much consideration.

Time has a funny way of working its magic. Relationships and getting married proved to be my reality, but it was not until my second marriage that I seriously considered having children. Adoption was always a possibility and technology was beginning to open up even more possibilities for persons like me. Throughout it all, I never doubted my capacity to raise children. Not having any brothers or sisters, though, I was never exposed to the real world of raising children. If I had been, I would have had much more to think about. As the saying goes, "Ignorance is bliss."

So my wife and I embarked on the journey of having children. Fortunately, she was acquainted with the reality of raising children. However, as "our" pregnancy progressed I found myself speaking with other wheelchair users to get their thoughts on how to handle babies. I asked about "tricks" that they found useful. And then the big moment came – we had twins! All of a sudden two parents were not enough. It somehow seemed that our twins had us outnumbered.

This is when I found myself becoming involved with the concept known as nurturing assistance. In my case I did not use an attendant to help raise my children or provide opportunities to develop meaningful relationships with them. I paid for and used the services of people who were able to do the purely physical things that would prove difficult or impossible for me, like bathing the children in a tub. Other aspects of their involvement included providing infant care for one baby while I was busy with the other. They also helped to keep the house liveable by doing the children's laundry, doing the dishes, helping to

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Nurturing Assistance

load the infant carriers into the car or playing with the children on the ground. By adding these additional household responsibilities we weren't strictly adhering to the definition of nurturing assistance. However, it was the most practical solution for our family at the time.

I did not feel that my relevance was diminished, nor did I feel that my role as a parent was any less important. Everything that these caregivers did for my children was requested and supervised by my wife or me. As parents we are fortunate to have many abilities and resources to care for our children. We are grateful that we can get assistance for those aspects, which over time, would prove to be more of a challenge to us as parents. Our children are about to turn three, so many of the physical challenges are behind us – they are walking, talking and feeding themselves. I know the future challenges are there in terms of helping them to learn to ride a bike, learn to skate or swim, or grow psychologically. I may need help from other people in some of these endeavours. I'll ask for it when necessary and receive it gratefully.

Nurturing assistance doesn't replace me as a parent – it makes me a better parent!

- *By Stephen Little*

Nurturing Assistance through Direct Funding

Mike (names have been changed) has a congenital disability affecting his joints and muscles. The Toronto-area wheelchair user is a business student at York University, as well as a small-business owner. He is also a single father of two-year old Gregory, with whom he spends eight hours each Saturday. (The balance of Gregory's time is spent with Mike's ex-wife.) Because of the nature of Mike's disability, a nurturing assistant is always present when he is with his son.

Mike receives attendant services through the Direct Funding program. From the time Gregory was three months, Mike has qualified for an additional eight hours of nurturing assistance, which he feels complements his role as a parent without replacing him. The way Direct Funding works is that whenever a consumer's needs change (for instance, when a person with a disability becomes a parent and needs extra assistance to care for a child) his/her attendant services budget is revised accordingly. The consumer may then hire a person specifically for nurturing assistance or perhaps extend the hours of an attendant already employed, who might be ideally suited to the additional responsibilities.

"I'm a single dad, and have been since my son was born. Our time together is limited to one eight-hour period each week, and that is possible only because I have the help of an attendant. Nurturing assistance has been essential to my forming a relationship with my son," says Mike.

Nurturing Assistance

In Mike's view, the fact that he has never been a full-time father explains why it took him longer to adapt to parenthood. Because of the external circumstances that essentially kept them apart until Gregory was three months, he feels that it was harder for him to bond with his son. He is confident that, with the help of nurturing assistance, they have now managed to overcome the obstacles to bonding that they initially encountered.

As Gregory has grown from baby to toddler, the nurturing assistant's duties have evolved. In addition to bathing, changing, lifting, cuddling and other baby-specific tasks, she now helps with lunch, runs after the child when necessary, and accompanies Mike and Gregory when they use public transportation.

For Mike, keeping the same nurturing assistant with them is not a big factor in the success of the relationship. In fact, he feels that having different nurturing assistants tends to foster a stronger attachment with the parent rather than the attendant.

Because Gregory is at such an active stage, Mike has recently hired a younger nurturing assistant who is able to keep up better. The new person will alternate Saturdays with the current nurturing assistant, and Mike will plan different activities depending on which "nanny" will be there.

Mike is aware that the limitations built into the system are in some ways defining his role as a father. At eight hours of nurturing assistance every week, he has hit the maximum allowable under Direct Funding. "I would like to have a full weekend with Gregory, every other weekend," says Mike. "This would give me the same rights as any other single parent, and would open up new opportunities for us. Right now, it's not possible."

Mike believes that the system needs improvement to make it work effectively for both parent and child. Creating nurturing assistance as a totally separate service would help: "I'd like to see nurturing assistance managed through a central database and funded with a view to the specific needs of parents, rather than under limits that were established for attendant care in general."

- *Based on material from an interview*

Attachment Issues

The term "attachment" means the process of building an emotional bond between parent and child. Research has shown that parent-child bonding is essential to a well-adjusted life.

According to midwife Jay MacGillivray, the physical component of nurturing a baby is as important as the essentials of feeding, clothing and changing diapers. "Even in the first hour of life, you can see a baby working to engage a woman," says Jay. "When you hold babies in the crook of your arm, they are at the perfect distance from your face, a distance appropriate to their vision." For someone without the

physical ability to hold her baby independently in this position, daily assistance in doing so is critical to the bonding process. “Also, they need to hear the mother’s heartbeat, which is the predominant sound in utero. Most women instinctively hold their babies on their left side, near the heart. The sound of the heartbeat and the face of the mother are double reassurance for a newborn. You don’t want to lose that moment of connection,” says Jay.

Jay’s practice is called Access Midwives of Toronto, for good reason. Many of her clients have physical disabilities. Jay’s fluency in sign language and sensitivity to the capabilities as well as the needs of women with disabilities are qualities that draw many to her practice.

Physical responses are essential to nurturing a baby, according to Jay. When babies cry, for instance, so many believe you are spoiling them if you pick them up. Not true, says Jay. “Babies want to interact with you. They try to draw you to them to make that physical connection. As you hold them, their eyes follow your face and they start to utter sounds, to reward you for your efforts. It’s sad that in our culture we seem to have lost the ability to respond to babies instinctively.”

In Jay’s view, the job of a nurturing assistant is to put the parent in the position to engage the baby. Putting the baby into a position where “the mother can do the essential work of nurturing” accomplishes this. It is not the assistant who is doing the nurturing, then, but the parent who is assisted in doing what is necessary for the emotional and physical bond to evolve.

Nurturing can be such a simple thing, according to Jay. Just lying quietly with a baby is nurturing. Breastfeeding is an excellent way to nurture, with the baby experiencing the touch, sight, smell and taste that all together represent comfort and safety. Many women with disabilities have been told that they should not consider breastfeeding because of the medications they may be taking, but “The truth is, there are far fewer drugs that will prohibit breastfeeding than we used to think. From a nurturing perspective, it’s well worth considering breastfeeding once you have been reassured that any medications you are taking will not in fact harm your baby,” says Jay. A nurturing assistant can facilitate breastfeeding by helping to position the baby and by being there to make physical adjustments as needed.

Many other simple interactions can be part of nurturing. There is a tone most people pick up around babies, a sing-song voice that babies respond to. And the fastest way to calm a baby is to whisper in its ear; it seems that the sound, the rush of air on the baby’s face and face-to-face touch is a healing combination. “The more time a baby spends against a woman, to feel her, smell her and hear her voice, the better,” says Jay. Activities like these are most important for nurturing assistants to attend to, particularly where newborns are concerned. The nurturing assistant can bring the baby up to the mother’s face, where it can hear her voice and feel the air on its face. “It’s not just the baby who needs the mother,” Jay points out. “A woman needs to smell her baby, too. There’s an importance to this, it’s part of her imprinting her baby.”

Nurturing Assistance

As much as nurturing assistance can foster bonding, it might also interfere with it if the nurturing assistant is not working strictly under the parent's supervision. There are many creative ways to foster the nurturing assistant's role within the family. At the ILRC in Winnipeg (see page 88), which is the only Canadian ILRC with a formal nurturing assistance program, nurturing assistants are trained to adapt methods of caring for the child so that these techniques replicate as closely as possible the mother's style. Although some parents would prefer that the nurturing assistant do the tasks without imitating the parent's style, the main point is that nurturing assistants are encouraged to develop a sense of "third person invisibility," in order to maintain the family.

- *Based on material from an interview*

Nurturing and Bonding

Coulson Hoogveld is 12 and has cerebral palsy, due to a stroke he experienced before he was born. He lives in Richmond, B.C., with his mother, Susan; his father, Terry; and his brother, Matthew, who is now eight years old.

Susan, like Coulson, lives with a disability. Hers is lupus, a chronic disease with a variety of symptoms caused by inflammation in one or more parts of the body. It is estimated that lupus affects more than 50,000 Canadians.^{xxii}

"Lupus is a hit and miss condition," explains Susan. "You can be very sick or feeling fine, even for a couple of years." Unfortunately, when Coulson was born Susan was going through a bad stretch. In fact, her lupus was adversely affected by both of her pregnancies.

During Susan's first pregnancy, she was in hospital for four months before giving birth because her doctor was concerned about pre-eclampsia. Hospital staff kept asking her if she would have enough "family support" after the baby was born. She told them again and again that she had little she could count on beyond her exceptionally supportive husband, who nevertheless had a busy and erratic schedule as a real estate broker. The staff had no alternatives to suggest.

The medical team who assessed Coulson after birth predicted he would be a needy baby. As a young man, he is outperforming all expectations. But at the time, his future looked uncertain.

The province of B.C. has an "at home" program (now extremely difficult to access) which helped Susan by providing a couple of hours a week in home care. This was for her, however, and not to help her with her son. She budgeted about \$200.00 each month for respite care, to ensure that she would have some breaks.

The fact was that Susan was sick for most of Coulson's babyhood. When he was an infant she could barely get out of bed, let alone care for a baby – and a baby with cerebral palsy, at that. She had sores at

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the ends of her fingers, which made it excruciating to bathe and change Coulson. She would cry through every diaper change.

Now Susan wonders how she did it all herself, especially when Coulson was a newborn. "Having someone there to help me, while still being in charge, would have been the answer," she says. "From the baby's perspective, it's mandatory to have proper nurturing and bonding to have a 'right life'. Nurturing assistance could have helped me tremendously with that process."

Susan Hoogveld works part-time in Information and Referral at the Independent Living Resource Centre in Richmond, B.C. (see page 86). The ILRC, which is less than a year old, has had a number of calls from parents with disabilities wanting to obtain "Continuing Care," which is the provincial government's social service umbrella providing in-home assistance for individuals with disabilities.

"At the ILRC we're growing quickly. I hope we'll soon be in a position where we will be able to start new programs. To my knowledge, nurturing assistance as a government-funded program does not exist in B.C. We want to see it happen."

- Based on material from an interview

Through the Eyes of a Child

For parents with a disability who use nurturing assistance, the service ultimately has one purpose: the well-being and healthy adjustment of their child or children. In this narrative, Steve Fraser speaks as an adult now able to look back at what it was like to share a parent with ever-present attendant services. Steve's mother, Louise Fraser, died in February 2001.

When Louise Fraser was 34, she was involved in a car accident and became paraplegic. Her son Steve lived with his dad until his mother was able to take care of him again. Steve was eight when he moved back in with his mother. After a brief stint in an apartment on Bloor Street, Louise moved them into Access Apartments in the west end of Toronto. The residential complex has one wheelchair-accessible apartment on each floor, and attendant services are arranged according to daily needs. Staff are on-site 24 hours a day, every day.

Although not formally designated as nurturing assistants, Louise's attendants helped her to do things with Steve as well as providing her with personal assistance. They came in during the early morning to help her out of bed, have a shower, and get ready for the day. They were there at lunch and dinner to prepare meals, and at the end of the day to assist her with her evening routine.

As far as Steve was concerned, at eight years of age he could pretty much take care of himself. The attendants prepared their dinner, and sometimes he got involved. If he and his mom were going out for dinner or to the movies, an attendant would help Louise get ready. On overnight trips, an attendant

would travel with them. Without an attendant, Steve and his mom could not have enjoyed this type of activity together.

Attendants were part of the daily routine. But they were not a neutral factor in Steve's life by any means. In fact, their presence was felt both positively and negatively during his youth.

"It was a great system all round," says Steve. "You knew there was someone available in case of need or emergency. I never felt like my mom had to depend on me to take care of her, or that I was expected to take on too much, too soon." For the most part, the attendants liked Steve and he liked them.

Whenever Louise had issues with attendants, she'd talk it over with them and work it out.

Steve felt protective of his mom and would settle her down and calm her when she was upset, but he added that "she told me that any problems that came up between her and an attendant were the adults' concern, not mine. If I heard any arguing going on, I was to stay out of it, go to my room. I could make the situation worse, she said, by getting into it."

Steve remembers flare-ups from time to time. "My mother had a short temper, she was not one to let things roll off her back – and attendants can easily be rubbed the wrong way." It's the nature of the relationship: no matter how well everyone gets along, a third person is still in the middle of a family situation. What Louise hated most of all was having to depend on others for private matters. "She had a hard time with that side of things after the accident," says Steve. For Steve and Louise, there was sometimes a feeling of having very little personal space of their own.

One time Louise had a problem with an attendant who had a "not my job" type of attitude. The situation came to a head when the attendant yelled at Steve one day for no apparent reason. Louise asked the office to handle the situation, but it got worse instead of better. Finally, there was a confrontation in Steve's presence. His natural instinct: to stand up for his mom. It was hard to hold back, but his mother's preparation paid off. He knew she would not want him to interfere, and he respected her wishes. Looking back, he realizes that he had to learn to get along with everyone and hope for the best.

Mostly Steve remembers the good relationships his mom had with her attendants. One such memory is of their first Christmas in the new apartment. As the day approached, Louise spoke with one attendant about her dream of cooking a turkey for Steve and herself. But the apartment had just a stovetop – no oven – so it was impossible. The attendant ended up cooking a turkey for them downstairs in the staff kitchen, helping to make a perfect Christmas memory for Steve and Louise.

- *Based on material from an interview*

Why Not Me?

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Nancy and Gordon Barry have been married for three years. Like many young couples, Nancy and Gordon are thinking about having a baby. They have to do more than the average amount of planning before that can happen because Nancy has cerebral palsy, a disability she has lived with since birth. Now 34, she has never required attendant services for herself. Her needs would change, however, to meet the demands of caring for a child. Nancy and Gordon have come to the conclusion that whether or not she can qualify to receive nurturing assistance will be a major factor in making their decision.

Nancy works full-time as the Peer Support/Volunteer Coordinator at the Centre for Independent Living in Toronto (CILT). Her husband, who is able-bodied, also works full-time. Both plan to continue working should they have a child.

Nancy is in the process of answering the many questions that arise when she considers becoming a mother. While she can look after herself independently, she worries that she does not have the strength in her arms to lift or change a baby on her own. A toddler would present further problems. If the child ran off, she would not be able to chase after him or her. Some of the situations she envisions can be managed with the help of devices such as harnesses, which can be used to rein in an active two-year-old. Safety is a huge concern, however, and she knows that even the right equipment would not be enough to enable her to handle safely all the physical aspects of looking after a child.

Nancy sees herself as being fully in control as a parent only if she can use nurturing assistance. Just as attendants are often described as one's "arms and legs" for personal needs, she sees a nurturing assistant as being her arms and legs in looking after her baby. This includes activities both in and out of the house, as she anticipates needing help with such tasks as grocery shopping.

Nancy and Gordon have considered the possibility of family pitching in to help. Gordon's family is out of town, however, and Nancy is an only child. "I have great parents," she says, "but I don't want to depend on them to help me take care of my baby. I need the independence to be able to interact with my child on my own. And they need to be free to just enjoy being grandparents." She feels that having her parents provide the daily help she'd need would negatively affect the family dynamics. For instance, parents with disabilities often end up calling in favours from family and friends. The need for these favours may become so great that it can become an unhealthy emotional situation. The parent might feel distanced from the raising of the child or the family member or friend may presume to have more rights over the care of the child than what the parent would want. A nurturing assistant would provide the professional, non-personal support Nancy requires, without the emotional involvement of a family member.

Nancy's concern about upsetting the balance within the family extends to Gordon as well. "I want him to be able to experience parenthood like every other father, without being overwhelmed with responsibilities related to the child's needs just because there are things I can't do." While acknowledging that some responsibilities will necessarily be divided along physical lines – for instance,

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Gordon will have to drop off and pick up their child from school and other activities – she wants to be able to do her fair share.

While most prospective parents do not have to think much past pregnancy, delivery and accommodating their lifestyle to an infant, Nancy is well on the way toward developing a parenting plan that reaches beyond the toddler years. “Parenting is stressful, and physical barriers make it all the more difficult,” she says. Nancy and Gordon believes they would need some nurturing assistance at least until their child is in school full-time.

Nancy has found it helpful to talk to other parents about how they’re handling things. “I’m not the only person with a disability in this situation,” she points out. She’s met people who have decided to go ahead with parenting in spite of the obstacles, as well as those who have held back. Because of her job at CILT, she’s familiar with the Parenting with a Disability Network (PDN), which is a rich source of information and experience on parenting with a disability.

As the eligibility criteria for attendant services now stand, Nancy cannot receive nurturing assistance if she and Gordon decide to have a child. But she is not likely to take no for an answer. “I’ve been a good advocate on my own behalf in other areas, and I would certainly push for expanded nurturing assistance through the government-funded attendant services program,” she says.

That’s where she feels the responsibility lies. She believes that whoever funds attendant services should be funding nurturing assistance – without the requirement that you have to qualify for the first to get the second. Nurturing assistance is not an added bonus but should be on the list of “essential service needs” that attendant services are designed to fulfil.

“What it all comes down to,” says Nancy, “is that people with disabilities have the right to have children just like everyone else, and should be eligible for the assistance that makes it possible.”

- *Based on material from an interview*

A Nurturing Assistant’s Point of View

Jillian (names have been changed) is a part-time nurturing assistant. She works two 12-hour shifts per week, from nine in the morning until nine at night. She is employed by a Support Services Living Unit (SSLU) in Toronto. At the SSLU, nurturing assistance is arranged according to the residents’ needs. The distribution of hours allotted per month by the Ontario Ministry of Health and Long-Term Care for nurturing assistance is determined by the parents together with the staff, and can be reassessed, as the child’s needs change.

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Jillian was hired to work as an attendant providing personal assistance to adults with physical disabilities living at the SSLU. Her current job is her first assignment as a nurturing assistant. She had been working as an attendant for a couple with a new baby, and offered to help them out with the baby if they needed her. They all got along so well together that Cindy and Josef, baby Natalie's parents, took Jillian up on her offer. Although Jillian had not had specific training as a nurturing assistant, her rapport with the family and personal experience with children were the qualifications that mattered to these new parents, both of whom have disabilities.

Jillian emphasizes that it is important to go through an agency wherever possible when hiring a nurturing assistant, as this will help to ensure adequate screening of potential candidates. Checking references is essential, as is a thorough interview process. She also feels there should be a trial or probation period in order to find out how the nurturing assistant interacts within the family. She believes that parents need to be concrete about establishing their expectations of nurturing assistants, going so far as to write them down as part of the employment contract, along with the job description.

Some may prefer to hire a nurturing assistant who has worked for a time as an attendant to the parent with a disability, says Jillian, as they might feel more comfortable with that person. However, this is a matter of personal choice and people find they have good experiences both with nurturing assistants they've used before as attendants and those hired specifically for nurturing assistance.

Jillian loves her job. Her own experiences and those of other nurturing assistants have taught her that the relationship of the nurturing assistance within the family requires diligence and sensitivity on all sides to make it work well. "Nurturing assistants are sometimes put in a difficult position," says Jillian. "Of course, you have to go by what the parents want. But sometimes they'll give directions and won't include themselves as much as they could. There are many activities that parents and I can do together with the baby, but I think that maybe their fears or lack of experience can get in the way. For example, if I'm playing with the baby, I have to remind myself to say, 'Let's go and see mom.' Nurturing assistants appreciate it when the parent takes that type of initiative as well."

Another way parents can be involved is to be at Jillian's side as she performs such tasks as bathing or changing the baby. "Just the sound of mom or dad's voice helps the baby to relax. Without this, my job starts to become closer to a nanny than a nurturing assistant."

A common fear is that the baby will bond more with the nurturing assistant than the parents, particularly if there is one nurturing assistant spending large blocks of time with the family, rather than several shorter periods. "You can't help but get attached to babies," observes Jillian. She thinks that if a nurturing assistant feels this is happening it's best to reduce her hours or space them out if possible, just to get the comfort level back to normal.

Jillian also appreciates working with staff from other agencies, where appropriate. Cindy, Josef and Natalie, for example, have had visits from an occupational therapist who does some exercises with the

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baby to help strengthen her neck. This additional support means that Jillian can be part of the child's interaction with others, and so doesn't feel as immersed in her own relationship with the baby. Even this scenario has a down side, however. "Babies can become confused about who's who with so many people around them," says Jillian.

All of these concerns aside, there is no doubt in Jillian's mind that being a nurturing assistant has great rewards for parents with disabilities, their children and the nurturing assistants who work with them. Like any other relationship, it just takes lots of time and effort.

- Based on material from an interview

Points in Question: An OT's View of Issues in Nurturing Assistance

This article is based on an interview with Heather Sloman, an occupational therapist (OT) working with COTS (Community Occupational Therapy Services) in Toronto. Some of her clients are parents with a disability.

In general, occupational therapy focuses on developing skills; restoring function and independence; maintaining ability; and promoting health and safety. Occupational therapy can include, among other services, assessment, consultation, direct treatment and advocacy. Once an assessment is complete, the individual and the OT work together to determine what services are needed, with the goal being increased independence and improved quality of life^{xxiii}.

"I believe the attitude of professionals, service providers and nurturing assistants going into the home should always reflect a desire to assist and support the parents, and to strengthen them in their role as parents," says Heather Sloman. "In other words, we don't go in to judge whether or not parents are doing a good job, but rather to ensure that they have all the supports in place so that they are on an equivalent playing field with able-bodied parents." Heather has identified and discussed some key issues she feels need to be addressed by the attendant services system that currently governs the provision of nurturing assistance

Nurturing assistants are generally hired through the attendant care system. In an SSLU, for instance, nurturing assistants are booked into the required timeslots. This leads to inconsistency, as there are different people going into the home all the time. The extent of the inconsistency depends on the total number of hours of nurturing assistance, i.e., more hours of nurturing assistance that are required, the greater number of different people there will be working with the baby. "The theory is that the parent provides the consistency in that type of situation," says Heather. "But if the parent has a severe disability, there is so much more interaction between the baby and the nurturing assistant. Having different people all the time must take its toll on the baby." Perhaps one answer is that nurturing

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assistance should not be tied to the attendant services system but should be developed as a separate program, and funded accordingly.

Another problem is that when someone is in the home to help with parenting, it's too easy to let him or her do everything. It's natural to respond to babies, to pick them up and play with them when they're crying. When a relationship develops with a family it becomes easier to just go ahead and do things instead of waiting to be asked. And it's easier for parents to stop asking. "It can be hard to tell when you've crossed the line. The service can become in time more like child care or babysitting, with the parent busy elsewhere," says Heather. The ideal situation is to have a nurturing assistant who takes the initiative in keeping the parent involved. However, according to Heather, "[b]oth parent and nurturing assistant should constantly be coming up with creative strategies for working together with the baby."

In some ways, the nurturing assistant's relationship within the family is not natural. Most people tend to bond with babies in spite of their best intentions to remain detached. Parents with disabilities have to be aware that this can happen and react appropriately if they suspect the nurturing assistant has become too involved or attached in an unhealthy way to their child. This is also an argument for setting up a separate program to administer nurturing assistance, says Heather. "If nurturing assistance was a separate service, there could be a different kind of training provided to nurturing assistants than there is for attendants, which may well lead to a different attitude on an ongoing basis."

Funding is another major issue, even for parents who qualify for nurturing assistance through government programs. The maximum number of hours of attendant services available under Ontario Attendant Outreach program or Direct Funding is 180 hours per month. This includes whatever portion is allocated to nurturing assistance. In reality, the requirements of a parent with severe disabilities caring for a new baby can far exceed that limit. Parents with disabilities may need to purchase additional services each month, especially if they have no family support to bridge the gap. "The financial implications are far-reaching," Heather points out. "Babies are demanding and the situation improves in some ways as they get older in terms of increased independence, but the increased mobility of toddlers introduces new safety concerns and responsibilities. Most parents with disabilities can't anticipate needing less nurturing assistance even when they are beyond the infant stage. That means it's difficult to predict the long-term costs of nurturing assistance, and other financial decisions can hang in the balance."

If parents have a problem in the relationship it's not always clear whom they can call for help. As an OT working in the community, Heather helps parents and nurturing assistants to come up with solutions to problems that emerge as the child grows. For instance, as babies start to move around more, a parent with a disability might find it impossible to hold or rock the baby on his or her lap any longer. An OT can help by suggesting adaptations to clothing or equipment that might improve the parent's ability to grasp the child. She can make suggestions for play with the baby, for example.

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Michele Wates of the Disabled Parents Network and Lisa Nichols, with DPPi Information Services, both in the U.K., advocate a continual review of needs for parents with disabilities as their babies and children move through various stages of development. They say, "Service involvement should be experienced by disabled parents as supportive rather than negative; as forward-looking rather than crisis-oriented, but the fact of needed support services should not be taken to imply parental incompetence... Provision of childcare equipment should be an integral part of the assessment. Advice on childcare strategies that is tailored to individual needs should be part of the support package... it is important to be clear that carrying out a risk assessment is not the same as regarding a child or baby as being 'at risk.' ...Services [should be able to] respond quickly to fast changing and fluctuating needs... Parents with disabilities should be involved in evaluating and developing services."^{xxiv}

All services need a process for review and input, which in turn feeds into education and training. The system as it now stands lacks such a process.

Awareness of Diversity

In this book, we have read about the experiences of parents with different disabilities, those within traditional families or single-parent families, and those from different cultural backgrounds. There are parents with disabilities within same sex couples. Diversity is part of the richness of life, and disability is just part of the blend of characteristics that makes parenting a unique experience for every family. Yet for all our differences, as parents we have a vast common ground, in both our joys and our challenges.

Cultural diversity can have an impact on parenting with a disability. Through the Looking Glass (TLG), a U.S.-based parenting and disability organization, serves ethnically diverse families from many cultures. More than half of its clients are people of colour. Since the agency's services usually occur in the families' homes, they have found that respect for cultural context is critical. For instance, factors such as wariness of outsiders and a strong preference for extended family support may come into play.

TLG has found that, "[I]ike all families, families of colour vary in the degree of their identification with or integration into the disability community. They may exist almost completely in the non-disabled realm. But the most worrisome families may be isolated from both disabled and able-bodied communities, as well as their ethnic communities."^{xxv}

In Canada, particularly in our urban centres, we pride ourselves on our ethno-cultural diversity. Bilkis Vissandjee, academic co-director of the Centre of Excellence for Women's Health in Montreal, says that, nevertheless, most Canadian programs and services make too many assumptions about the needs of immigrant and aboriginal women in Canada. Part of her job is to make sure researchers talk directly to these women in making recommendations related to health policy matters. For instance, when an association of community-based clinics consulted her on a proposed health information telephone service, she pointed out that phone delivery is not ideal for those who face language barriers.^{xxvi}

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In line with TLG's experience, Vissandjee's doctoral research in India taught her that women in that culture usually turned to each other for advice rather than to outside sources of information, such as a doctor, on issues related to family health. Naturally, people who move to North America from other countries bring their cultural context along with them.

Anne Warrick, a Canadian speech language pathologist and expert in community-based rehabilitation in developing countries, has also spent time in India and makes similar observations to those of Vissandjee. She points out that people tend to look for solutions to their problems in a "family to family" way, rather than looking to organizations or government-run programs for help.

In Canada, where parents with disabilities report that the sharing of information and "networking" with others offers vital support, those from a different linguistic and cultural background can find themselves at a distinct disadvantage. One of the challenges in finding out what the needs are for services such as nurturing assistance, and designing programs to meet these needs, is to ensure that parents with disabilities from any cultural backgrounds will have equal access to information, programs and services.

International Impressions

In response to a call for information on nurturing assistance sent out by CILT, through the Internet, via news releases and in a series of articles published in CILT's Parenting with a Disability Bulletin, voices from around the globe contributed their perspectives on issues related to nurturing assistance. By sharing their information and insights, consumers in other countries have contributed to the body of knowledge on this important subject. Most importantly, they are now part of a network of stakeholders who will continue to receive information about what is taking place in Canada.

Please note that the term "nurturing assistance" is found only within Canada, and mostly in Ontario. In other countries terms such as personal assistance, attendant services and parent support encompass the concept of nurturing assistance, and are commonly used when describing the type of physical assistance required by parents with disabilities who have young children.

Through the Looking Glass (U.S.A.)

Through the Looking Glass (TLG) is a community, non-profit organization, which was established in Berkeley, California in 1982. TLG "has pioneered clinical and supportive services, and training and research serving families in which one or more members – whether parent or child – has a disability or medical issue. TLG's mission has been to create, demonstrate and encourage resources and model early intervention services that are non-pathological and empowering, and which integrate expertise derived from personal disability experience and disability culture."^{xxvii}

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TLG's founder and executive director, Megan Kirshbaum, Ph.D., has been a clinician in the disability community for more than 27 years, and believes strongly in the value of making "a place for the family experience and for family and relationship-focused issues within the independent living movement."^{xxviii}

As related in a 1999 Washington Post article,

"With a \$5,000 March of Dimes grant [Megan Kirshbaum] turned a garage behind her house into an office and research facility. With another \$25,000 from the National Easter Seal Research Foundation, she bought a video camera and recorder and began to gather data from the wisest sources she knew: parents with disabilities.

Her husband, Hal, was her partner in this venture until the progression of his multiple sclerosis made it too difficult for him to help.

She had named her new non-profit agency 'Through the Looking Glass,' a playful tribute to Lewis Carroll and the notion that disabilities ought to be seen from a new angle.... Kirshbaum's research has put her squarely at the centre of a community of psychologists, infant specialists, occupational therapists and social workers who want to help Americans with disabilities raise their children. With a \$2.5 million, five-year grant from the U.S. Education Department's National Institute on Disability and Rehabilitation Research (NIDRR), she has established the National Resource Center for Parents with Disabilities, with co-director and medical anthropologist Paul Preston, the son of deaf parents."^{xxix}

A significant milestone in the history of TLG was the completion in 1997 of the first national survey of parents with disabilities in the United States. The survey revealed that "emotional aspects of parenting" and "physically caring for children" presented problems to a majority of respondents. Four out of five reported that they needed some kind of personal assistance services to assist with tasks related to parenting. In fact, over 50% reported that they used personal assistance for help with parenting. "Yet those who rely on government sponsored personal assistance are typically not allowed to use that help for parenting instead of personal care," stated the report.^{xxx}

Problems with using personal assistance services were that it often was not available when needed (54%), was unreliable (46%), interfered with the parent's role (38%) and assistants were inexperienced in knowing how to care for children (35%).^{xxxi}

Personal challenges are ubiquitous for families living with disability. According to Kirshbaum, parents with disabilities report numerous problems with public reactions to appearance or behavioural differences. "They frequently need to learn to strategize about how to handle cruel and stigmatizing comments or actions, as well as social awkwardness... The cumulative effect of pervasive and repetitive negative social messages is that we construct a personal framework of meaning regarding disability. This frame can, in turn, have a profound effect on individual family members' self-esteem, sense of defeat, and depletion. It can narrow our families' sense of the range of what we can do together, of who we can be together."

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Parents with disabilities “can experience profound shifts in meaning, however, from contacts with individuals with long-term disability experience and disability community involvement. This shift can occur through a variety of means: (a) networking, whether formalized or through support groups and programs; (b) joint social change efforts; (c) informal socializing in the community; (d) interaction among colleagues in the workplace.”^{xxxii}

“At [TLG] we have chosen to pursue a conscious ‘depathologizing’ process where we bring the perspectives of the disability culture(s) to clinical intervention with families with disability issues in parent or child,” says Kirshbaum. “An attempt is made to focus on aspects of the infant mental health and family therapy modalities that are consistent with the depathologizing process. Staff ‘peer clinicians’ (psychotherapists with personal disability experience) frequently function as cultural intermediaries and reframing agents.”^{xxxiii}

“But we are much more like than unlike other families. We need to be able to safely share the total spectrum of this experience without wariness. The depths of its despair and the degree of its trauma cannot be understood without an awareness of its wisdom, resilient beauty, and playfulness.” In the end, says Kirshbaum, “Our families are profoundly ordinary.”^{xxxiv}

Growing into the Role (U.S.A.)

Judy Panko Reis is co-executive director of the Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago (RIC). Her perspective is both professional and personal: Judy cannot use the left side of her body because of a brain injury, and uses a wheelchair or scooter for mobility due to rheumatoid arthritis.

When her son, now 13 years old, was a baby, she was still ambulatory with the aid of a brace and cane. Still, there was virtually no assistance available for someone in her position. “I found that, in 1987, doctors were completely without resources to guide a disabled woman through a pregnancy,” she said. So she began working with doctors at RIC to help others in her situation. Now, having lived through various stages of childhood development, she is well tuned to the challenges and changes involved in parenting with a disability.

“I think that it’s important for mothers with disabilities to make the distinction between independence and self-determination,” says Judy. “There are so many devaluing messages directed toward parents with disabilities, but self-determination means you can accept and direct the care provided by an attendant without compromising your feelings of competence. Just because there are things you cannot do physically, it doesn’t mean you can’t feel pride in self-determination.”

When Judy was a new mother she was not capable of performing without assistance all the tasks involved in caring for a baby. There were no government-funded programs offering any level of support, so she hired attendants privately to help out.

She feels that attendants who are mothers themselves understand more naturally the mother's need for independence. "There is something magnetic about 'being there for the baby.' It's easy to get absorbed with the baby's needs, to see that as the primary role. This means the attendant does not feel that she is there to assist the mother, who can feel left out as a result. If she is not assertive, she might not know how to reverse the situation. Mothers with disabilities need a real sense of entitlement – they need to feel at liberty to give directions and have them carried out in the way they want. And, like all new mothers, mothers with disabilities need time to grow into their role."

As Judy points out, "Caring for a child is a dynamic situation. My son's needs and my ability to meet them changed as he grew older. For instance, when he was a baby, dressing was a challenge, which became easier once he could push his hand through his sleeve without struggling. However, at that stage he was able to run around and I was not able to chase after him. So, things changed but did not necessarily get easier."

In the United States, government assistance for parents with disabilities is a point of contention. Programs vary from state to state. "Personal assistance" as a concept is dedicated to persons with disabilities, says Judy. "Oddly, parenting has not traditionally been regarded as an 'activity of daily living.' In many states, if the children are able-bodied the family is not considered eligible for child-related assistance." This assumption has been challenged in the state of California, says Judy, in cases where parents have actually lost custody of their children because they have not been able to obtain assistance with parenting.

"I think it's important for all women with disabilities to link up with networks that are friendly and compatible with their concerns. Social isolation is a major problem for people with disabilities, especially women. Parents need to be reminded that they are not alone, and that there are many like themselves around the world. There are lots of places to turn to for emotional support, and a sense of inclusion and connectedness. For those without the time or inclination to join a support group, there are [Internet-based] parenting listserves and mailing lists to hook up with, including the RIC's newsletter, Resourceful Woman, which regularly carries a column called 'Resourceful Parenting' by Carol Gill and Christine Jasch. It's in everybody's interest to get connected," concludes Judy.

To subscribe to The Resourceful Woman, a newsletter produced by the Rehabilitation Institute of Chicago, refer to the contact information on page 99.

- Based on material from an interview

Parenting with a Disability: The U.K. Model

The failure of service providers to address the issue of support to adults with disabilities in their parenting role is causing serious difficulties for parents with disabilities and their families in the U.K. Under the *Community Care Act* (1990), social service departments and health authorities have a duty to

assess and address the support needs of adults with disabilities. Although this includes the need to fulfil typical adult roles and should therefore include parenting, this has tended to be overlooked.

In 1999, however, the Social Service Inspectorate (SSI) began a review process to find out the state of the country's services for parents with disabilities. The review was prompted by a consortium called Parents Too!, which brought to SSI's attention a list of concerns about the difficulties experienced by parents with disabilities in their attempts to obtain appropriate services and support. Over the course of nine months, inspectors visited eight social services departments around England and produced individual inspection reports on the services provided to parents with disabilities.

As the inspection progressed, Department of Health officials told Parents Too! that findings on the ground bore out what they had said. The final report, "A Jigsaw of Services," was published in April 2000. The findings came as no surprise, but the report is a landmark in the sense that the problems facing parents with disabilities in accessing services have for the first time been identified in a government document, with the intention of improving practice in social services departments.

The same week the report was released, another significant event took place. Two consumer groups in the U.K., Parents Too! and ParentAbility, came together to form the Disabled Parents Network. This new group had as its first task to build on the work that had been done by SSI, and to push for improvements in services to parents with disabilities.

"A Jigsaw of Services" – Summary

The findings detailed in "A Jigsaw of Services" can be briefly summarized under three main headings:

1. Parents with disabilities need to be recognized as an identifiable group of service users. Current practice is variable, with little evidence of conscious service planning for this group. The failure at management and policy-making levels to recognize and plan for their service needs may be partially explained by this lack of context.
2. A more holistic, co-ordinated response to the whole family situation is needed. A lack of flexibility within the system makes it very difficult for parents with disabilities to get hold of services that support family life.
3. A greater understanding of the practice implication of the Social Model of Disability (also known as the Independent Living Model) needs to be fostered. Service providers have a tendency to focus on the effect of an individual's medical conditions upon their child or children rather than on the support needs of the parent.

Another aspect of the situation revealed by the report was that the assumption underpinning much current practice is that the interests of parents with disabilities are in conflict with those of their children. Services frequently start out from the perspective that children of parents with disabilities should be seen as "in need" or "at risk." Services that have the effect of separating children from their

parents (whether in the short or long term) or that propel children into inappropriate family roles (i.e., that of so-called “young carers,” without addressing the support needs of adults with disabilities in their parenting role, undermine the family lives of people with disabilities.

In reality, the rights of adults with disabilities to found families and live as other families, and the rights of children to live in families that provide for their needs as children, are entirely compatible. The needs of children are best met when the support needs of parents with disabilities are acknowledged, assessed, facilitated and regularly reviewed.

There are no easy formulas for responding to disabled parents’ support needs. “A Jigsaw of Services” acknowledges that parents with disabilities sometimes do not approach social services for fear that their children will be removed from home. Although the report says that Inspectors did not find evidence to bear out these fears, the Department of Health’s own figures show that the disability of a parent is the third commonest reason for a child being received into care. Disabled parent organizations constantly hear instances of social services departments offering solutions that do not support the parenting of a person with a disability, including the use of full time nursery facilities, fostering and overnight child-minding where parents have requested support in the home.

Sometimes parents with disabilities and those supporting them feel that they have been set up to fail. A mother with learning difficulties had a supporter who visited her daily. She was informed that the assistance was going to be withdrawn because “[w]e need to find out if you can manage on your own.” It was not surprising, given that this support had been set up in consultation with the mother and with due consideration of her needs, that the mother was not able to cope without the support, and within weeks her baby had been taken into care.

This case raises larger questions about whether the fact of needing assistance (physical, emotional or social) should be taken as evidence of parental incompetence. Official thinking is inconsistent on this point. On the one hand, family support, funded by governments and the voluntary sector, is based on the assumption that all parents have support needs and that this is both acceptable and socially expedient – since raising children is not an activity that either could or should be undertaken by a child’s parents in isolation. On the other hand, doubts are readily expressed if it is thought that parents with disabilities will not be able to cope alone.

Providing Supportive Services for Parenting

Parenting support needs should be speedily and clearly identified, supportively assessed and effectively addressed in ways that neither stigmatize parents with disabilities nor disadvantage their children.

Good services to parents with disabilities have the following characteristics:

- Parent support is seen as key to children’s welfare;
- Drive is to support, not separate or substitute;

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- Services aim to reinforce the parenting role;
- Judgements about parenting capacity are made within the context of support;
- Coordination takes place between different service providers;
- Consultation takes place with parents with disabilities themselves;
- Services are compatible with individual family lifestyles;
- They are flexible enough to support family lifestyles;
- They are available when needed and not when things have reached crisis point;
- They do not depend on a partner giving up paid work;
- They do not depend on young people taking on inappropriate care roles;
- Every parent qualifies for support, even in the event of a child being accommodated;
- Parents with disabilities are involved in designing and evaluating services.

Services need to address both specific and generic support needs of adults with disabilities in their parenting. These include:

- Access to information;
- How pregnancy, childbirth and parenting impact on specific disabilities;
- How a particular disability will impact on pregnancy, childbirth and parenting;
- Specialist equipment, assistance with parenting tasks;
- Accessible transport;
- Emotional or cognitive support;
- Access to peer support networks.

Excluding adults with disabilities from access to support in their parental role, whether this happens deliberately or by default, consciously or not, cannot be justified. The right to non-discriminatory services in the U.K. is upheld by the *Disability Discrimination Act (1995)* and the right to family life is upheld by the *Human Rights Act (2000)*. Those who argue that support to parents with disabilities is too costly need to take into account that the breakdown of family life will inevitably be more costly in economic and social terms than even the most expensive support package.

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We are currently working on research based on a survey of social services departments in the U.K., which asked if they had written policies in relation to providing services to parents with disabilities. As well as being an awareness raising exercise in itself, this provided very useful information about what is happening currently. We got an 80 per cent response rate (with a bit of prompting), which gives us a good basis to report back on where people are getting stuck and to gather examples of best practice that might be developed more widely. This is one of the most rewarding pieces of work I have been involved in to date. We now have contacts in 80% of English social service departments, and that in itself is extremely useful!

This article was compiled from published sources, including: Michele Wates, "Providing Supportive Services to Disabled Parents"; Michele Wates and Lisa Nichols, "Supporting Disabled Adults in their Parenting Role"; Michele Wates, "A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role," Disability, Pregnancy and Parenthood International, No. 31, July 2000, p. 13 – 15. Reprinted by permission.

Nurturing Assistance for Parents with Disabilities in Denmark

The Danish Council of Organisations of Disabled People, with the support of Denmark's Ministry of Social Affairs, recently concluded a project exploring the possibility of granting physical help to parents with disabilities for tasks related to their role as parents. Copies of the project's final report have been sent to all 275 councils in Denmark.

The purpose of the project was to examine whether parents with disabilities receive the support necessary to enable them to undertake their role as parents on equal terms with others. The participants were fully competent parents, and their children had no extraordinary needs for specific support.

The project concluded that the rules of the social legislation do not prevent Danish councils from granting the assistance that parents with disabilities need, but that nevertheless it is not always forthcoming. Assistance varies greatly from council to council. One of the reasons is that specific needs arising from or connected to parenting are not mentioned separately in the legislation as a basis for compensation. The adult's needs or the children's needs for specific support are taken into account, but the combination of disability and parenting has not been considered. The whole picture needs to be seen, but this does not always happen. Consequently, there is a great need to clarify the underlying rules.

One of the most important principles in the Danish "handicap policy" is the compensation principle. This means that people with reduced functional ability must be compensated to the widest possible extent for the consequences of that loss. "Compensation" may mean material, financial or personal assistance. In many cases, assistance is granted regardless of income or assets. Denmark's social legislation, for

example, allows for the possibility of granting aid, as well as housing and personal assistance. However, the family's capabilities and resources must be taken into consideration.

For further information, contact The Ministry of Social Affairs, Holmens Kanal 22, 1060 Copenhagen K, tel. +45 33 92 93 26, e-mail: sm@sm.dk

- By Kirsten Plambech, Consultant, Socio-politics, Danish Council of Organisations of Disabled People

Japanese Parents with Physical Disabilities

When I talk about the parents with disabilities and their lives, few people understand what I mean. Most say, "Excuse me, but you made a mistake. You want to talk about parents with a disabled child, not parents with disabilities, don't you?" Even specialists, such as social workers, have the same reaction. It is a pity, but parents with disabilities are almost unknown in Japan. We sometimes find related accounts in the newspaper, on TV programs or dramas, but they are always introduced as touching stories where there is a great deal of community support – which is not the norm.

However, it does not mean that parents with disabilities live quiet, solitary lives. They form small self-help groups and share information. They have been finding their own way, and gradually they have become empowered and have started to introduce their nurturing style to the community.

The group to which I belong, Lovely Parents, was born from Ms. Yuko Konta's experiences. When she and her husband had their first child, they had little information on how parents with disabilities care for their children. They lived with their anxiety and emotional conflicts. They wanted to find out how other parents with disabilities managed with parenting, so they sent questionnaires to friends. News of their interest spread over all of Japan and eventually Lovely Parents was established.

This article focuses on our group of parents with physical disabilities and its supporters. However, first of all I will describe some features of Japanese family life, the social welfare system and recent government reforms to provide a clear understanding of the cultural context around parents with disabilities. I will also introduce the activities of Japan's CILs (Centres for Independent Living), because we cannot discuss nurturing assistance without mentioning the support provided by CILs. Finally, I will introduce the activities of our group and some issues that matter to parents with disabilities.

Japanese Family Life

The elderly population in Japan has continued to increase in recent years, while the birth rate has been on the decline. Double-income families have become common, and the environment of children and families has changed. Values related to child rearing within families and communities have become weaker. Furthermore, the number of reported cases of child abuse is rapidly increasing. As a result, the demand for social welfare has increased, and is likely to increase even more in the future. In the midst of all this change, the social welfare system is expected to play the role of a safety net for all.

In 1988, the government of Japan began to reform the social welfare system. But it was not until 1994 that the Japanese government enacted a plan called “Basic Direction for Future Child Rearing Support Measures (Angel Plan),” based on the needs of working parents and as one of the measures to stop the declining birth rate. The Angel Plan was intended to make society as a whole take responsibility for supporting child rearing, comprehensively and systematically. The government has been promoting measures in various sectors including welfare, employment, education, and housing. For example, there have been attempts to diversify nursery care services. Also, community support centres for nurturing (kosodate-shien senta) have been established, not for day care but to provide a place for children to interact with others twice each week. Also, a new program provides community volunteers to support mothers (bosi-hoken-suishinin). The government has also enacted the Child Care and Family Care Leave Law to promote the harmonization of working lives with family lives. It is now easier to continue working after maternity leave, for instance.

A new version of the Angel Plan was launched in April 2000, which further enhanced the program.

Lack of Awareness of Parents with Disabilities

These reforms were drawn up mainly to support working married mothers, or double-income families. The focus was on improving working conditions, developing various types of nursery services, providing economic support, and maintaining parents and children’s health. However, they do not make any provision for nurturing assistance. Though the Japanese government has been working to create a friendlier environment for parents to bear and raise children, parents with disabilities and their families remain significantly underserved.

We find the same tendency when we look into disability-related programs and services. Most are for individuals, not parents with disabilities.

Because of this, parents with physical disabilities are taking care of their children by using their own home-help services (public), attendant services (private, CILs, etc.), economic support, and public apartments for persons with disabilities.

From the perspective of parents with disabilities, there are many problems with these services. First of all, some home-helpers don’t help with bathing, feeding, and diapering, etc. They say they provide services only for the people with disabilities, not for their children. Some cities discontinue home-help services when the children are eight or nine years old, because they are “old enough to help their disabled parents”! Furthermore, the gap between social services in urban and rural areas in Japan means that parents who live in rural areas use home-help service for a few hours, twice a week, whereas in Tokyo some families receive 24-hour support.

Japan’s CILs provide 24-hour attendant services. Because such services were generated from the experiences of consumers, they take into account the diversity within independent living situations,

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including parenting. However, many CILs are located in big cities, so most rural areas do not have consumer-oriented attendant services.

Community welfare volunteers help with “friendly visiting” or providing information in all communities. They visit and talk with parents with disabilities.

Parents with disabilities have to struggle to set up a support system in a society where they encounter a lack of understanding and recognition, social services, and limited information.

As for parents with cognitive or psychiatric disabilities, they cannot even use attendant services because attendant services are intended for people with physical disabilities. However, recently some mothers with cognitive disabilities have started using social welfare institutions such as group homes and community centres to bring up their children. They are lucky if they gain access to the social welfare system with the help of social workers, and are able to remain with their children and their husbands. But most people with cognitive disabilities live in communities without any help. Many of them do not have impairments severe enough to qualify for a Certificate of Disability (service ID), or they are not aware of their disabilities, so they do not get economic support or home-help services. Parents end up being separated from their children, who are taken to children’s homes.

No social services exist specifically for Japanese parents with disabilities. In fact, they seldom use the general services available for people with disabilities, such as group homes, community centres and attendant services.

CILs: The Best Resource for Parents with Disabilities

Today there are 97 CILs in Japan providing 24-hour attendant services, independent living programs, peer counselling and advocacy services. Though it is still a new idea in Japan that people with disabilities can organize their own services, some advanced CILs have formed partnerships with municipalities.

CILs mainly promote independent living for individuals with severe disabilities. One of their goals is to create the prerequisites for the empowerment of persons with disabilities, because this opens up the possibility of independent living and full participation in society. Empowerment is indispensable to independent living. It is the same with parenting. Parents with disabilities are a minority in the community, and they often have to struggle harder than non-disabled parents to access playgrounds, schools and other public places.

When it comes to nurturing assistance, CILs tend to think of it as being almost the same as attendant services. Attendants and nurturing assistants are both paid employees who work under the direction of the person with a disability, but many parents with disabilities recognize that there is a difference between attendant services and nurturing assistance.

What Kinds of Needs Do Parents with Disabilities Have?

1) Self-help groups

Parents with disabilities are in the minority even within the independent living movement in Japan. There are no research centres or associations focussing on their needs. However, small groups of parents with disabilities exist. Self-help groups each have their own history, and many are part of a network of consumer associations. For example, Karugamo-no-kai is a self-help group of mothers with visual disabilities. Karugamo-no-kai publishes journals and has meetings several times a year, and published a book about parenting with visual disabilities three years ago. Kangaroo-no-kai is a self-help group of mothers with hearing disabilities.

2) Lovely Parents

Lovely Parents is a group of 56 mothers with physical disabilities (no fathers) and some supporters from all over Japan. As I have already noted, our group does not provide nurturing assistance services but shares information, questions and thoughts about parenting; publishes a journal three times a year; and has social events a few times a year. As members are unable to meet frequently, five or six groups have formed, with five or six members each, to exchange information and concerns by circulating notebooks. These notebooks are reviewed and edited for a journal, published three times yearly. The first journal was published in 1992.

Over the years, many of questions come up again and again, particularly in letters to editor. Here are some samples:

Home-helper

- I have some trouble with my home-helper. She doesn't do any childcare. She can't understand the needs that parents with disabilities have. Do others have the same problem?
- I worry about the relationship between my child and home-helper

Volunteers

- Is it easy for you to find volunteers (not attendants), who understand the needs of parents with disabilities?
- Do you think volunteers are good resources for parents?

Taking care of children

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- Is there anyone outside your family who can take care of your children?
- How do you deal effectively with emergencies, for example, if your child burns his/her hand?
- I can't take my child to the hospital in an emergency. How can I deal with this?
- Do you have any good ideas about talking with your children in a more relaxed way?
- What do you say to help your children understand your disability?
- What do you do or say to your children when they ask you to carry them or hold them in your arms?

Going outside

- I use a wheelchair, and often face trouble when I go out with my children. For example, inaccessible buildings or transportation, or a lack of personal assistance throws off our schedule. The inaccessible environment frustrates me. Do you have similar experiences? Do you have any solutions?
- I can't go out with my little child without a non-disabled person. When did you start going outside alone with your child?

Bullying

- Do you intervene when there is bullying between your child and his or her classmates?
- Do your children communicate regularly with you about bullying?
- What do you expect of teachers when you think your child is being bullied?

Conclusion

Japanese parents with physical disabilities may have similar social needs to those in Canada. Though it would be impossible to list all social needs, anxieties or worries, each Lovely Parents journal covers many topics, including the joys experienced by parents.

Because Japan does not have associations providing nurturing assistance to parents with disabilities in Japan, association of parents with disabilities or research centres, it will take a great deal of time for these issues to be understood as part of family services. It will also take a long time before parents and CILs are able to create a Japanese nurturing assistance system.

What should we do, then, to facilitate parenting for individuals with disabilities? Simply put, Japanese families need social support, and the government needs to reform its basic structure, programs and

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services in order to provide it. Now is the best time for parents with disabilities to advocate for change, and to make government aware that they exist and have needs that must be taken into account.

- By Naoko Iwata, *Supporter, Lovely Parents*

Assistant Professor, Okinawa International University

ⁱ Adapted from Ian Parker, Hazel Self, Vic Willi (with Judith O’Leary), *Power Shift*, Toronto: CILT, 2000, pp. 6 –7.

ⁱⁱ *Serving Mothers with Disabilities in Your Child Care Program*, Oakland, California: Berkeley Planning Associates, 1997, p. 45.

ⁱⁱⁱ “Parenting with Disabilities,” in *The Progress of Canada’s Children ’97*, Ottawa: Canadian Council on Social Development, 1997, p. 15.

^{iv} Barbara Waxman Fiduccia, “Child Care and PAS,” *National Academy of Social Insurance Meeting*, July 30, 1999.

^v Ibid.

^{vi} *In Unison: A Canadian Approach to Disability Issues*, 2001, at http://socialunion.gc.ca/pwd/unison/values_e.html

^{vii} Gail Fawcett, *Bringing Down the Barriers: The labour market and women with disabilities in Ontario*, Ottawa: Canadian Council on Social Development, 2000, at www.ccsd.ca/pubs/2000/wd

^{viii} *Self-Manager’s Handbook: Self-Managed Attendant Services in Ontario*, Direct Funding Pilot Project, Toronto: CILT, 1995, p. 48.

^{ix} Tracy Odell, “Nurturing Assistance,” Unpublished Report, March 1990, p. 4.

^x Ibid., p. 3.

^{xi} Ibid., March 1999, p. 1.

^{xii} Tracy Odell, “Supplemental Attendant Care: Homemaking assistance to a parent with a physical disability,” Unpublished Report, circa 1988, p. 2.

^{xiii} Elaine Carty, Tali Conine, Leah Dobell, Angela Holbrook and Chris Seminuck, “Parenting with a Disability: Assistive Devices and Adaptations for Child Care,” *Abilities*, Winter 1997, Issue 33.

^{xiv} “Health Issues for Women with Disabilities,” in *Rehabilitation Medicine: Principles and Practices*, by Joel A. DeLisa (Editor) et al, 3rd Edition, Philadelphia: Lippincott Williams & Wilkins, 1998, Chapter 67, p. 1706.

^{xv} *The Parenting Book for Persons with a Disability: From planning your family to raising adolescents*, Toronto: CILT, 1999, p. 47.

^{xvi} Human Rights Code; Revised Statutes of Ontario, 1990; Section 20(1).

^{xvii} *Ibid.*, Section 24(1) (c).

^{xviii} This section is adapted, with permission, from *Self-Manager’s Handbook: Self-Managed Attendant Services in Ontario*, Direct Funding Pilot Project, Toronto: CILT, 1995, pp. 43 – 46.

^{xix} *The Parenting Book for Persons with a Disability: From planning your family to raising adolescents*, Toronto: CILT, 1999, pp. 25 – 26.

^{xx} “Health Issues for Women with Disabilities,” in *Rehabilitation Medicine: Principles and Practices*, by Joel A. DeLisa (Editor) et al, 3rd Edition, Philadelphia: Lippincott Williams & Wilkins, 1998, Chapter 67, p. 1707.

^{xxi} Judy Panko Reis, “Author Provides Answers to the Adoption with Disability Question,” in *Resourceful Woman*, The Health Resource Center for Women with Disabilities, Rehabilitation Institute of Chicago, Winter 2000, Vol. 9, Issue 1, page 5.

^{xxii} Source: Lupus Canada Web site at www.lupuscanada.org

^{xxiii} “What is Occupational Therapy?” at www.cots.on.ca, website of Community Occupational Therapy Services (COTS).

^{xxiv} Michele Wates and Lisa Nichols, “Supporting Disabled Adults in their Parenting Role,” NSPCC Training Pack, at www.rethinkingcare.org/papers/paper41

^{xxv} Megan Kirshbaum, Ph.D., “Babycare Assistive Technology for Parents with Physical Disabilities: Relational, Systems, and Cultural Perspectives,” *AFTA Newsletter*, Spring 1997, p. 25.

^{xxvi} Sathya Achia, “Multicultural Monitor: Bilkis Vissandjee,” *Chatelaine*, July 2000, p. 72.

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^{xxx} L. Toms Barker and V. Maralani, *Challenges and Strategies of Disabled Parents: Findings from a national survey of parents with disabilities* [NIDRR, Rehabilitation Research and Training Center on Families of Adults with Disabilities, Grant No. H133B30076]. Berkeley, California: Through the Looking Glass, 1997, p. iv.

^{xxxi} Paul Preston, and Margaret Jakobson, "Keeping Our Families Together: A Report of the National Task Force on Parents with Disabilities and their Families," *Through the Looking Glass*, 1997.

^{xxxii} Megan Kirshbaum, "Family Context and Disability Culture Reframing: Through the Looking Glass," *The Family Psychologist*, Fall 1994, p. 10.

^{xxxiii} *Ibid.*, p. 11.

^{xxxiv} *Ibid.*, p. 12.

APPENDIX A: Interview Questions

The following are possible interview questions that were adapted from a list provided by Tobias House in Toronto, and are used by permission. The bracketed questions indicate what the interviewer should be looking for in the applicant's answer. Please note that these are suggestions only, which you can use, modify or eliminate as you choose.

Q. Please tell me why you have applied for this position and specifically, what about this position interests you?

Q. Have you ever cared for children in a previous job, or personally?

[Does the applicant have a genuine interest in this work?]

Q. From what you now know about the nurturing assistant position, what skills and personal qualities do you have that would be valuable on the job?

[Does the applicant understand the scope of the job and how it will engage his or her own abilities? This will also bring out details of skills that you can't learn from the resume.]

Q. Please give an example of a circumstance in which you were expected to do a certain task and you went beyond the call of duty.

Q. Things will come up that we both did not anticipate as being part of the job. What would your reaction be to that? Give an example of how you reacted in the past when asked to handle unexpected tasks.

[Will the applicant limit him or herself to a basic job description or do more when necessary?]

Q. How does this job fit into your personal and career plans for the next three years?

[Will the applicant have some commitment to the job and does he/she have life goals that can be somehow achieved through this position?]

Q. What do you think are some of the concerns a parent might have with regard to their support services?

OR

Q. What do you think a parent would consider important about the services they receive from a nurturing assistant?

Q. Please describe the type of staff member you would like to work with if you were parent with a disability.

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[Is the applicant able to take the consumer's perspective?]

Q. Assume that you are currently employed with me/service provider and a friend or family member asks you what your job is. How would you reply?

[Does the applicant understand confidentiality, i.e., to not give too much information, but also to understand the job well enough to give a basic description?]

Q. You receive directions from a parent in a manner that you perceive as being abrupt or rude. How do you handle the situation?

[How will the applicant resolve conflict? Is he or she willing to recognize and overlook a "bad day"?)

Q. What is one of the most difficult or challenging decisions you have made recently?

Q. How would you describe the decision-making approach you used in this situation, e.g., were you decisive and quick, or were you slow and thorough? Were you too slow or too quick?

Q. Did you involve other people in making this decision, or did you prefer to decide alone? Why?

Q. Have you ever made a decision that your employer disagreed with? What was your reaction to being told you were wrong?

[How will the applicant go about making decisions when necessary? How does the applicant handle constructive criticism?]

Q. You receive direction from a parent to discipline his or her child in a certain way and you disagree with this method of discipline. How would you proceed?

Q. Tell me your thoughts on disciplining children.

Q. What does "consistency" mean to you in this context?

Q. What are the most important things to remember when you're involved in a situation that requires discipline?

[How willingly will the applicant take directions when he/she disagrees with them? Are the applicant's views on discipline compatible with your own?]

Q. Do you have any first aid training specifically geared to infants and/or children?

[Does the applicant have relevant training?]

Q. What are the most important lessons you have learned in your career?

[Does the applicant learn from mistakes? What are the applicant's fundamental values?]

Q. Describe a time when you had to take action in an urgent or an emergency situation.

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Q. How did you cope with the stress and pressure of that situation?

Q. When you have had a very stressful week, how do you relieve the stress you have been feeling?

[How clearly does the applicant think and take appropriate action in urgent situations? Does the applicant know how to cope with and relieve stress?]

Q. How would a past supervisor describe you as an employee?

[Does the applicant understand him or herself and his or her work practices?]

Q. Tell us about a specific experience you have had in talking to clients or customers when you had to communicate under difficult circumstances. How did your communication skills come into play to resolve the situation?

[Does the applicant understand basic communication skills?]

Q. Describe a situation in which your job required you to say, professionally, how you really felt about a situation. What did you say and how did you say it in order to achieve a positive outcome?

[How does the applicant approach conflict resolution?]

Q. Building rapport is sometimes a very challenging thing to do. Give an example of a time when you were able to build rapport with a child in your care, even though the situation was a difficult one and the odds were against you.

[Is the applicant able to get along with people he/she disagrees with or dislikes?]

Q. Do you have any allergies or sensitivities to dogs/cats/pets in general, perfumes, cigarette smoke, etc.? You will be exposed to some or all of these things on any shift. Will this create a problem for you?

[Are there factors within your home environment that are incompatible with this applicant?]

APPENDIX B: TRAINING CHECKLIST

The following training checklist can be used to give a new nurturing assistant a picture of what needs to be done, when and in what order. A new nurturing assistant can use a checklist at first to follow along while a trained person performs each activity, checking off each item as it is completed. The sample provided here is appropriate for a parent with an infant, to be adapted according to individual requirements, as well as the child's age and stage.

Daily Routine: Nurturing Assistant: _____ Date: _____

1. Assistance in Personal Care for Baby, i.e., helping parent with these activities		
	Done:	Comments:
Bathing		
Grooming		
Dressing		
Holding		
Cuddling		
Changing		

2. Assistance in Preparing Meals/Feeding		
	Done:	Comments:
If mother is breastfeeding, assist with positioning. If formula is used, prepare formula and bottles according to manufacturer's specifications.		
Assist with parent's hand washing, position receiving blanket(s)		
Assist with positioning of baby		
Assist with burping		

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3. Household Assistance, i.e., helping a parent with these activities		
	Done:	Comments:
Washing/drying family dishes		
Baby's laundry		
Keeping baby's furniture (crib, changetable, etc.) clean		
Dusting baby's room		
Caring for baby's belongings		
Assistance in tidying other rooms as needed		

4. Assistance with Play		
	Done:	Comments:
Organize child's play area to facilitate parent-child interaction		
Position baby with parent for play; assist in activities involving music, songs, clapping, dancing		
General Activities: Going for walks, pushing stroller Going shopping, e.g., for toys, trying on clothing, helping child in and out of car seat		

(Adapted, with permission, from Self-Manager's Handbook: Self-Managed Attendant Services in Ontario, Direct Funding Pilot Project, Toronto: CILT, 1995, p. 46; and Tracy Odell, "Supplemental Attendant Care: Homemaking assistance to a parent with a physical disability, Unpublished Report, circa 1988, p. 1.)

APPENDIX C: DIRECTORY OF USEFUL CONTACTS

Independent Living Resource Centres (ILRCs)

Canadian Association of Independent Living

Centres (CAILC)

350 Sparks Street, Suite 1004

Ottawa, Ontario K1R 7S8

Phone: (613) 563-2581

Fax: (613) 235-4497

E-mail: cailc@magma.ca

Web site: <http://www.cailc.ca>

Alberta

Independent Living Resource Centre of Calgary

#7-11th Street, N.E.,

Calgary, Alberta T2E 4Z2

Phone: (403) 263-6880

TTY: (403) 263-6874

Fax: (403) 263-6811

E-mail: info@ilrcc.ab.ca

British Columbia

Cowichan Valley ILRC

#207-225 Canada Ave,

Duncan, British Columbia V9L 1T6

Phone: (250) 746-3930

Fax: (250) 746-3662

Nurturing Assistance

E-mail: cvilrc@cvilrc.bc.ca

Nanaimo and Region ILRC Association

2122 Northfield Road,

Nanaimo, British Columbia V9S 3B9

Phone: (250) 758-5547

Fax: (250) 758-5504

E-mail: nanil@direct.ca

Disability Resource Centre

160-5726 Minoru Blvd.,

Richmond, British Columbia V6X 2A9

Phone: (604) 232-2404

TTY: (604) 232-2479

Fax: (604) 232-2415

E-mail: graphic@direct.ca

Vernon Disability Resource Centre

3402 27th Avenue, Suite 107

Vernon, British Columbia V1T 1S1

Phone: (250) 545-9292

Toll-free: 1-877-288-1088

TTY: (250) 542-2193

Fax: (250) 545-9226

E-mail: bcilrc@home.com

Disability Resource Centre

1519 Pandora Avenue,

Victoria, British Columbia V8R 6P9

Phone: (250) 595-0044

Fax: (250) 595-1512

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Nurturing Assistance

E-mail: drc@islandnet.com

Manitoba

Independent Living Resource Centre - Winnipeg

393 Portage Avenue, Suite 311 A

Winnipeg, Manitoba R3B 3H6

Phone: (204) 947-0194

Fax: (204) 943-6625

E-mail: thecentre@ilrc.mb.ca

The ILRC in Winnipeg has pioneered a nurturing assistance program which is unique to the province of Manitoba. The focus is on networking to create personalized solutions to parenting problems (e.g., through adaptive equipment) and skill-building for the consumer. Staff orientation materials have been developed. Funded by the Ministry of Health and the Ministry of Family Services with Health and Social Assistance, the nurturing assistance program is open to persons with a disability who require assistance in caring for their children. Consumers access the service through self-referral, setting up an appointment for a program orientation. The ILRC can assist at all stages of the process, including proposal writing, funding negotiations, staffing and providing additional resources for consumers.

New Brunswick

CRVA-PA INC.

132A, 16e rue,

Shippagan, New Brunswick E8T 2K2

Phone: (506) 336-1304

TTY: (506) 336-1322

E-mail: crvapa@nbnet.nb.ca

Newfoundland

Independent Living Resource Centre

4 Escasoni Place,

St. John's, Newfoundland A1A 3R6

Phone: (709) 722-4031

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Nurturing Assistance

TTY: (709) 722-7998

Fax: (709) 722-0147

E-mail: info@ilrc.nf.ca

Nova Scotia

Metro Resource Centre for Independent Living

2786 Agricola Street, Suite 212

Halifax, Nova Scotia B3K 4E1

Phone: (902) 453-0004

Fax: (902) 455-5287

E-mail: mrcil@dbis.ns.ca

Ontario

Breaking Down Barriers

An Independent Living Centre

18 Schoolhouse Lane

Collingwood, Ontario L9Y 4H5

Phone: (705) 445-1543

TTY: (705) 445-1658

Fax: (705) 445-1656

E-mail: bdb@georgian.net

Kapuskasing Regional Resource Centre for Independent Living

29 Byng Avenue, Suite 5

Kapuskasing, Ontario P5N 1W6

Phone: (705) 335-8778 or (705) 335-8552

Fax: (705) 335-5666

E-mail: krrcil@nt.net

Kingston Independent Living Resource Centre

Nurturing Assistance

859 Princess Street,
Kingston, Ontario K7L 1G7

Phone: (613) 542-8353

Toll-free: 1-800-553-4572

TTY: (613) 542-8371

Fax: (613) 542-4783

E-mail: info@kilrc.com

Web site: www.kilrc.com

Independent Living Centre of Waterloo Region

3400 King Street East,
Kitchener, Ontario N2A 4B2

Phone: (519) 894-8350

TTY: (519) 894-8377

Fax: (519) 893-2213

E-mail: info@ilcwr.org

Independent Living Centre - London

433 King Street, Suite 101

London, Ontario N6B 3P3

Phone: (519) 660-4667

Fax: (519) 660-6818

E-mail: pquesnel@odyssey.on.ca

Ottawa Carleton Independent Living Centre

75 Albert Street, Suite 207

Ottawa, Ontario K1P 5E7

Phone: (613) 236-2558

Fax: (613) 236-4562

E-mail: ocilc@magma.ca

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Nurturing Assistance

RISE - Parry Sound Independent Living Centre

17 Bay Street, Unit D

Parry Sound, Ontario P2A 1S4

Toll-free: 1-800-634-6828

TTY: (705) 746-6996

Fax: (705) 746-1448

E-mail: rise@vianet.on.ca

Niagara Centre for Independent Living

111-A Church Street,

St. Catharines, Ontario L2R 3C9

Phone: (905) 684-7111

Fax: (905) 684-1199

E-mail: ncil@vaxxine.com

Independent Living Resource Centre

1201 Jasper Drive, Suite B

Thunder Bay, Ontario P7B 6R2

Phone: (807) 345-6157

TTY: same as phone

Fax: (807) 345-0266

E-mail: ilrctbay@baynet.net

Independent Living Resource Centre - Thunder Bay

1201 Jasper Drive, Suite B

Thunder Bay, Ontario P7B 6R2

Phone: (807) 345-6157

TTY: (807) 345-6157

Fax: (807) 345-0266

E-mail: ilrctbay@baynet.net

Nurturing Assistance

Centre for Independent Living in Toronto (CILT) Inc.

205 Richmond Street West, Suite 605

Toronto, Ontario M5V 1V3

Phone: (416) 599-2458

Toll-free: 1-800-354-9950

TTY: (416) 599-5077

Fax: (416) 599-3555

E-mail: cilt@cilt.cnd.com

CILT is home to the Parenting with a Disability Network (PDN), a peer support and information-sharing network for parents and prospective parents with a disability. The aim of PDN is to help families develop unique solutions to parenting challenges. PDN publishes the bi-monthly Parenting with a Disability Bulletin. It is available as a benefit of PDN membership, which is free of charge. PDN has also published The Parenting Book for Persons with a Disability: From planning your family to raising adolescents (1999) ISBN 1-89555676-32-0, 140 pages, \$20. Contact PDN for more information and to order publications.

The Project Information Centre (PIC) is a centralized database clearinghouse for applications made to SSLUs and Attendant Services Outreach programs in Toronto. Located at and operated by CILT, PIC processes applications and assists consumers by providing information about eligibility criteria for attendant services and the application process. Individual service providers carry out assessments to determine eligibility and then make the decision to offer services. Outside Toronto, consumers may apply directly to attendant service providers in their immediate geographic area.

Consumers who want to take full responsibility for recruiting, managing and administering funding for their own attendants can apply to the Self-Managed Attendant Services – Direct Funding Program, which is available province-wide. The Direct Funding Program (DF) is located at CILT.

Québec

Centre de ressource à la vie autonome du

Montréal Métropolitain

5255, ave Decelles, bureau 4042

Montréal, Québec H3T 1V6

Phone: (514) 340-3590

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Nurturing Assistance

TTY: (514) 340-7135

E-mail: crva-mtl@moncourrier.com

Centre-Ressources pour la vie Autonome

Région du Bas St-Laurent, 589, rue

Richard, CP 1810

Trois-Pistoles, Québec GOL 4K0

Phone: (418) 851-2211

Fax: (418) 851-9904

E-mail: crvabsl@globetrotter.qc.ca

Centre de ressources pour la vie autonome d'

Abitibi-Témiscamingue

240, 4 ième avenue,

Val D'Or, Québec J9P 1G6

Phone: (819) 824-5434

Toll Free: 1-800-594-5434

Fax: (819) 824-4749

E-mail: crva-at@sympatico.ca

Saskatchewan

South Saskatchewan ILC

2240 Albert Street,

Regina, Saskatchewan S4S 2V2

Phone: (306) 757-7452

Fax: (306) 757-5892

E-mail: ssilc@sk.sympatico.ca

North Saskatchewan ILRC

#112-514 23rd St. E.,

Saskatoon, Saskatchewan S7K 0J8

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Nurturing Assistance

Phone: (306) 665-5508

Fax: (306) 244-2453

E-mail: nsilc@dlcwest.com

Provincial Government

Note: For information on attendant services and government contacts in provinces other than Ontario, contact your local ILRC (see listings commencing on page 86).

Ontario Ministry of Health and Long-Term Care

Long-term Care Division – Toronto Area Office

2145 Yonge Street, 10th Floor

Toronto, Ontario M7A 1G2

Phone: (416) 327-8952

Fax: (416) 327-4486

For other area offices contact:

Health and Long-term Care – Main Branch

Hepburn Block, 10th Floor

80 Grosvenor Street

Toronto, Ontario M7A 2C4

General Inquiry: (416) 327-4327

TTY: 800-387-5559

Toll Free: 800-268-1153

Web site: www.gov.on.ca/health

Ontario Ministry of Community and Social Services

Adoption Unit

Central Services Provincial Services Branch

2 Bloor Street West, 24th Floor

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Nurturing Assistance

Toronto, Ontario M7A 1E9
Phone: (416) 327-4733
Fax: (416) 327-0573
E-mail: adoption.unit@css.gov.on.ca

Community Care Access Centres (CCACs)

CCACs are government-funded health care organizations, operating under the Ontario Ministry of Health and Long-Term Care. CCACs provide one-stop access for people who need in-home health services and support, as well as information and referral on health-related issues. One of the CCACs' primary functions is to manage the transition from hospital to in-home health care. Furthermore, they are specifically mandated to serve persons with physical disabilities. There are 43 CCACs in Ontario, each of which is governed by its own board of directors, drawn from the local community and elected by the CCAC's membership.

The bad news is that, although it is part of CCACs' mandate to arrange for the provision of visiting health and personal support services in peoples' homes, CCACs are not generally in a position to offer nurturing assistance. Due to funding limitations, CCACs have been reducing their services and focusing strictly on medically necessary services.

The criteria for admission to receive services from CCAC are: 1) the need for professional service and, 2) sufficient impairment to require personal support with daily living. Nurturing assistance cannot be provided by CCAC as a stand-alone program because it does not fulfil these criteria. In the past CCACs have been known to "top up" services such as homemaking on a short-term basis, in cases where either professional service or personal support are already being supplied by another service provider. Still, the above two criteria must be met before this can be done. For example, in one case a mother with a disability was discharged from the hospital after having an episode with cancer. She was receiving professional services already, so they provided short-term personal assistance that involved her child. But that was only until they set up babysitting/child care services. With the current tightening up of their mandate, the CCACs will experience less flexibility with service provision than ever.

Although many CCACs are experiencing these difficulties, check with your local branch about the possibility of getting nurturing assistance under personal support, respite or homemaking. At the very least, knowledgeable and helpful CCAC personnel may know of other resources with which to put you in touch.

CCAC has office locations all around Ontario. To find out the one closest to you, or for more information about CCAC, contact: Ontario Ministry of Health and Long-Term Care INFOline at 1 (800) 268-1154 (Toll-free in Ontario only). In Toronto, call (416) 314-5518; TTY: 1 (800) 387-5559. Visit the CCACs' Web site at <http://gov.on.ca/health/english/contact/ccac>

Nurturing Assistance

Healthy Babies, Healthy Children (HBHC)

(416) 338-7600

The Ontario government established the Healthy Babies, Healthy Children (HBHC) program in 1998 to ensure that new parents have advice and support to help children get the best start in life.

When you have a new baby you will be told about the program in hospital. If you have questions or concerns at any other time, you can call for more information. One of the options an HBHC nurse may recommend is a visit from a family home visitor. "Family Home Visitors" are not nurses, but are trained HBHC staff who answer questions about child development and teach practical skills such as how to bathe the baby, breastfeed or buy nutritious food, and generally how to recognize what your child needs and wants.

Home visitors provide parental support in terms of "learning needs," rather than the type of physical support provided by nurturing assistants. If more assistance is needed, the home visitor will make an appropriate referral.

Government: Toronto

Homemakers and Nurses Services Program

Intake (416) 392-8545

HMNS can in some cases provide limited homemaking assistance, when all other resources have been exhausted. HMNS is a means-tested program, which requires you to prove financial need in order to qualify. If eligible, you can receive help with light housekeeping, laundry, meal preparation, etc. This service is akin to nurturing assistance in that the primary caregiver must be present. Home support workers are not trained to provide personal care. The average amount of service is a few hours a month, depending on need. Call the number listed above for more information on this municipal government-funded service.

Non-profit organizations: Ontario

DisAbled Women's Network (DAWN) Ontario

162 - 975 McKeown Ave, Suite 5A

North Bay, Ontario P1B 9P2

Phone: (705) 494-9078

TTY: (705) 494-8566

Fax: (705) 840-1656

E-mail: dawn@thot.net

Web site: <http://dawn.thot.net>

Nurturing Assistance

DAWN Ontario is a province-wide organization that supports women with all types of disabilities. DAWN provides information, speakers, and resources to its members, women's groups, disability groups, the general public, and the public and private sectors.

The Anne Johnston Health Station

2398 Yonge Street

Toronto, Ontario M4P 2H4

Phone: 416-486-8666

Fax: 416-486-8660

The Anne Johnston Health Station is a community health care centre with a complete medical staff of doctors, nurses, chiropodists, occupational therapists, pharmacists and counsellors. The centre also provides a range of programs and services that promote the health and well-being of individuals and their communities. The "Barrier Free Health Zone" offers family medicine and related services to Toronto residents, focusing on disabilities involving the spine such as multiple sclerosis, spina bifida, cerebral palsy, paraplegia, quadriplegia, and others.

Victorian Order of Nurses (VON), Toronto-York Region

Parent & Infant Support Volunteer Program

3190 Steeles Avenue East, Suite 300

Markham, Ontario L3R 1G9

In Toronto: (416) 499-2009 ext. 2143

In York Region: (905) 477-2143

Fax: (416) 499-8460

VON's program provides "an extra pair of hands" for parents who have arrived home with a healthy newborn. A volunteer provides practical assistance in the home up to a maximum of three hours per week, under the direction of the parent. The program is available from birth until the baby reaches the age of six months. Volunteers are not trained to deal with health issues, but have received basic instruction on safety and care of infants, and have had experience with babies. All volunteers are over the age of 18, and many are mothers themselves. Each has been interviewed and screened (including a police record check and three references).

The Volunteer Visitor can

Nurturing Assistance

- provide emotional support to the parents
- hold the baby
- play with siblings
- help the parent with changing diapers
- help the parent with formula preparation
- assist with feeding the baby, with parent supervision
- watch the baby while the parent takes a nap or shower, or has a break, as long as the parent does not leave the home
- help the parent give the baby or other children a bath, as long as the parent is directing and participating
- accompany the parent and baby to appointments and outings (note: the volunteer cannot drive the car)
- Help with light household chores
- Prepare food, drinks, etc., for the parent and other children.

Every effort is made to accommodate language and culture, however, this depends upon whether there is a suitable, available volunteer who lives or works close to the parent's residence.

Visually Impaired Parents (VIP)

c/o Canadian National Institute for the Blind (CNIB)

Diana Bissett, Phone: (416) 288-1225; E-mail: bissett@sympatico.ca

Lynn Qiggaittuq, Phone: (416) 498-9717

VIP, which began in 1992, is a consumer-run support group for parents who are visually impaired. VIP meets once a month to share experiences and explore common interests. Guest speakers – such as a child psychiatrist, a behavioural therapist, a police officer talking about safety – are booked from time to time. Workshops on parenting issues, as well as picnics, parties and day trips, create a lively and varied program. Babysitting is available free of charge.

Private Agencies

Maternal Infant & Child Ltd.

Nurturing Assistance

Phone: (905) 896-9666

Maternal Infant & Child Ltd. is an in-home nursing and support service. The service provides nursing students as mother's assistants, to help new mothers with laundry, breastfeeding, emotional support, information, community referral, etc. Often these services are enlisted for families bringing home infants requiring special assistance. The timeframe varies from one-time to ongoing, depending on need. The service is paid for through private insurance coverage.

International

Disabled Parents Network (DPN)

P.O. Box 5876

Towcester, England

NN12 7ZN

Telephone help line: 011-44-870 241 0450

E-mail: information@DisabledParentsNetwork.org.uk

Web site: www.disabledparentsnetwork.org.uk

DPN is run by parents with disabilities, their allies and family members, people with disabilities who would like to be parents in future, and others who are already grandparents. DPN works with people who plan and provide services and support to make them more aware of the needs of parents with disabilities and how these needs can best be met. DPN provides advice, gives back-up support and points parents towards additional sources of help.

Disability, Pregnancy & Parenthood International (DPPi)

National Centre for Disabled Parents

Unit F9

89-93 Fonthill Road

London, England

N4 3JH

Phone: 011-44-800 018 4730

TTY: 011-44-800 018 9949

Fax: 011-44-207 263 6399

E-mail: info@dppi.org.uk

Nurturing Assistance

DPPi provides an information service on practical everyday parenting for persons with disabilities, including a quarterly journal.

The Health Resource Center for Women with Disabilities

Rehabilitation Institute of Chicago

345 East Superior Street

Room 106

Chicago, Illinois 60611

U.S.A.

Phone: (312) 238-8003

Fax: (312) 238-1205

E-mail: HRCWD@rehabchicago.org

The Health Resource Center for Women with Disabilities in Chicago is a comprehensive health facility run by women with disabilities, offering information, referral, workshops and seminars. The Center publishes a newsletter, Resourceful Woman, which includes a regular column called "Resourceful Parenting."

Through the Looking Glass (TLG)

National Resource Center for Parents with Disabilities (NRC)

2198 Sixth Street, Suite 100

Berkeley, California 94710-2204

U.S.A.

Phone: (510) 848-1112

U.S. Only: (800) 644-2666

TTY: U.S. Only: (800) 804-1616

Fax: (510) 848-4445

E-mail: tlg@lookingglass.org

Web site: www.lookingglass.org

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Nurturing Assistance

The NRC provides information, referral, training and consultations regarding parenting with a disability. Particular focus is on custody, adoption, adaptive baby care equipment, pregnancy and birthing, and intervention with parents with cognitive disabilities. Programs include:

- Information & Referral
- Technical Assistance & Consultations
- Professional Training & Workshops
- Publications and Training Modules
- National Library and Resources Clearinghouse
- Parent-to-Parent Network
- International Newsletter
- Web site and Bulletin Boards

San Francisco Bay Area Services

Comprehensive services to parenting families with diverse disabilities and medical issues include:

- Home-based parent/child intervention, family support, and parenting education for families with disabilities in parent or infant/child
- Home-based infant mental health services when parent or infant has a disability
- Infant/Toddler developmental evaluation and early intervention
- Adaptive baby care equipment evaluation and provision for parents, expectant parents or parenting grandparents with physical disabilities
- Home-based early intervention and family support services for Deaf parents and their hearing babies
- Childbirth and parenting education for expectant parents with cognitive disability
- Support group for parents with cognitive disabilities
- Support group for parents with physical or visual disabilities
- Support groups for parents of disabled babies or children
- Play therapy for children with disabilities and children of parents with disabilities
- Family therapy for parents with disabilities and their adolescent children
- Parenting evaluations for child protective services-involved parents with disabilities

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Nurturing Assistance

Research

TLG has conducted numerous significant projects concerning families with disabilities since 1982, and all research is conducted from a non-pathological and disability community perspective. Current US-wide research projects are:

- Parents with Disabilities and their Teenage Children
- An Analysis of Evaluations of Child Protection System-Involved Parents with Cognitive Disabilities

Other

Childbearing and Parenting Program for Women with Disabilities

c/o School of Nursing

University of British Columbia

T201 - 2211 Westbrook Mall

Vancouver, British Columbia V6T 2B5

Phone: (604) 822-7444

Fax: (604) 822-7466

E-mail: carty@nursing.ubc.ca

APPENDIX D: RESOURCES

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Web sites:

www.cailc.ca

The Canadian Association of Independent Living Centres (CAILC) is a national umbrella organization that consists of local autonomous Independent Living Resource Centres (ILRCs). Each ILRC is community-based and controlled by and for persons with disabilities. CAILC is controlled by the individual ILRCs and its responsibilities mainly consist of providing support, training, networking with government and non-government organizations, and information dissemination. CAILC's mission is to promote and enable the progressive process of citizens with disabilities taking the responsibility for the development and management of personal and community resources. See page x for a list of Canadian ILRCs.

www.cilt.ca

The Centre for Independent Living in Toronto (CILT) Inc. is a non-profit, community-based resource organization that is controlled by and for people with disabilities. CILT helps people with disabilities to learn independent living skills and integrate into the community, and encourages them to take control of their own lives by exercising their right to examine options, make choices, take risks and even make mistakes. Programs include Information and Referral, Peer Support, Volunteer, Independent Living Skills Training, Project Information Centre, Parenting with a Disability Network and Direct Funding – Self-Managed Attendant Services.

www.disabledparentsnetwork.org.uk

Disabled Parents Network is a new organization that was formed when two existing groups joined forces: ParentAbility - a parent support network that had been growing steadily bigger since it started in 1982 – and Parents Too! a group that had been working since 1995 for improvements in the services available to parents with disabilities. Along with information, peer support and a help line, Disabled Parents Network has created a collection of photographs and drawings showing images of people with disabilities as parents. This is designed to be used for workshops, exhibitions and other public events. Disabled Parents Network also produces a quarterly newsletter for members.

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www.disabilitygateshead.org.uk

Gateshead Personal Assistance Pilot Project has published on its Web site a series of short guides providing information and advice to persons with a disability who wish to live independently by using personal assistance. Some information applies directly to nurturing assistance.

www.lookingglass.org

Through the Looking Glass (TLG) is an organization providing information on a variety of parenting issues. Included on TLG's Web site is a report of the National Task Force on Parents with Disabilities and their Families, Keeping our Families Together, which provides a rare statistical perspective and touches on personal assistance issues. See page 64 for further information on TLG.

www.disabledparents.net

Parents with Disabilities Online is an Internet "one-stop resource for parents with disabilities" that includes information on adaptive parenting aids, medical information, personal stories and other resources. It also is the home of the Parent Empowerment Network, which is an e-mail community of parents with disabilities, people with disabilities who hope someday to become parents, and (where applicable) non-disabled partners of parents with disabilities. It is a means of connecting with other parents, through an electronic mail listserver. All you need is access to an e-mail system that allows you to send and receive e-mail from the Internet. The Parent Empowerment Network list is a "closed" e-mail listserver, which means that before you can participate you must first "subscribe" to the list. There is no charge to subscribe.

APPENDIX E: NURTURING ASSISTANCE PROJECT SURVEY RESULTS

Note: For a full report of survey results, please contact CILT.

As part of the Nurturing Assistance Project, CILT surveyed 24 Independent Living Resource Centres (ILRCs) in Canada, and 92 Attendant Service projects in Ontario. The goal was to find out if the concept of nurturing assistance was generally understood across the province and around the country, who is currently providing this type of service and what the demand is perceived to be for nurturing assistance. We gathered some interesting results, but it is important to note that the numbers cited below are not necessarily statistically significant given the small numbers of respondents. We are not seeking major patterns and trends, but rather a sense of any developing interest in nurturing assistance around the country. Much of the value derived from the surveys is in the respondents' comments and observations.

ILRC Survey

A total of 16 out of 24 organizations (66 per cent) responded to the Nurturing Assistance Survey for Independent Living Resource Centres (ILRCs). Only one of these organizations, the ILRC in Winnipeg, is actually involved in providing nurturing assistance to clients under its Brokerage Program. Three of the ILRCs (St. John's, Thunder Bay, Vernon) provide assistance to clients by means of advocacy and liaison with service providers on an as-needed basis.

Of all respondents, 63 per cent indicated that they receive inquiries about parenting with a disability in general, which may or may not include nurturing assistance as a specific point of inquiry. A respondent in B.C. pointed out that unless people are aware that services like nurturing assistance exist, they generally will not think to ask for or about it. The survey results back this up, as 60 per cent of those who receive inquiries about parenting with a disability felt that their callers would benefit from nurturing assistance if it were available. It was noted by one respondent that nurturing assistance tends to be done informally, through family and friends, simply because in most areas of Canada, it is not available from any other source: "People usually piece together the services they need."

More than half of the respondents (56 per cent) said that nurturing assistance is a needed service. Their comments include

"Young people with disabilities are getting married and are looking forward to having children, and they might benefit from practical assistance. We think this sounds like an excellent idea – good luck!"

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“We hear parents speak of their need for some assistance, and when they ask for help we have no resources either to refer them to or offer [them].”

“There are a number of existing and potential parents with a disability in the community who would benefit from the program [but] there is a definite fear [of expressing their need for assistance] due to the belief that they will be negatively judged.”

“We don’t get many inquiries about it, but I know there is a huge need.”

“It would take a lot of stress off couples.”

Most of those who responded to the survey (87 per cent) said they would find a resource on nurturing assistance useful for reference and educational purposes.

The ILRCs that responded to the survey are:

Disability Resource Centre, Richmond, British Columbia

Cowichan Valley Independent Living Resource Centre, Duncan, British Columbia

Vernon Disability Resource Centre, Vernon, British Columbia

Independent Living Resource Centre of Calgary, Alberta

South Saskatchewan Independent Living Centre, Regina, Saskatchewan

Independent Living Resource Centre, Winnipeg, Manitoba

Independent Living Resource Centre, Thunder Bay, Ontario

Kapuskasing Regional Resource Centre for Independent Living, Kapuskasing, Ontario

RISE – Parry Sound Independent Living Centre, Parry Sound, Ontario

Breaking Down Barriers – An Independent Living Centre, Collingwood, Ontario

Independent Living Centre, London, Ontario

Independent Living Centre of Waterloo Region, Kitchener, Ontario

Niagara Centre for Independent Living, St. Catharines, Ontario

Ottawa Carleton Independent Living Centre, Ottawa, Ontario

Independent Living Resource Centre, St. John’s, Newfoundland

Metro Resource Centre for Independent Living, Halifax, Nova Scotia

Attendant Service Providers in Ontario Survey

Nurturing Assistance

A total of 40 out of 92 organizations (44 per cent) responded to the survey. Of those, all were fully aware of the concept of nurturing assistance, and more than half have had requests for nurturing assistance or similar type of service. Almost half of the survey respondents (19 out of 44) provide the service themselves. The Ontario Ministry of Health and Long-Term Care funds the service for all but one of these organizations.

It is interesting that most of the respondents do not use the term “nurturing assistance” within their organizations. Instead they refer to “assistance with child care or parenting,” “attendant services,” and “personal support.” As one respondent put it, “The term is new – the need is not.”

In all cases, application must be made to the service provider as a first step. Nurturing assistance is considered part of the overall individualized plan for the consumer.

While not all respondents gave specific details about their application process, the procedure generally depends on the organization’s policies. Self-referral is usually the start of the process, although outside referrals were mentioned as another way to initiate the application process (for 16 per cent of respondents).

Since the Ontario Ministry of Health and Long-Term Care provides funding for the organizations’ nurturing assistance services in all but one case, the Ministry’s general eligibility criteria for attendant services must be met by an individual in order to qualify for nurturing assistance. The person must be

- insured under the *Health Insurance Act*,
- 16 years of age or older,
- permanently physically disabled and requiring physical assistance with activities of daily living,
- able to direct his or her own care,
- able to have any medical/professional needs met by the existing community health networks (e.g., CCAC),
- able to have their attendant services provided in their own home, workplace, school,
- Unable to have their needs met through other existing programs or services.

A last eligibility criteria is that they must be a consumer already receiving attendant services for personal care from the organization to which they are applying.

The selection process involves home visits in some cases, and a selection committee in others.

As with the ILRCs, the majority of Attendant Service Providers who responded to the survey felt that a resource book on nurturing assistance would be useful for reference and education, for both clients and

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staff in service training. One respondent summarizes by saying, “This is an important initiative – there have been limited resources available to date.”

The Attendant Service Providers in Ontario Survey respondents are as follows:

Access Apartments, Toronto

Canadian Paraplegic Association, Toronto

Canadian Red Cross, Toronto

Cheshire Homes, Belleville

Cheshire Homes London Inc., London

[North York] Community Care Access Centre, Toronto

[York] Community Care Access Centre, Toronto

Disabled Persons Community Resources, Ottawa

The Friends, Parry Sound

Goldcrest Co-ops, Toronto

Guelph Services for Persons with Disabilities, Guelph

Halton Cheshire Homes, Burlington

Handicapped Action Group Inc.’s Independent Living Services, Thunder Bay

Joyce Scott Non-Profit Homes Inc., Milton

Nucleus Housing Inc., Toronto

Ontario March of Dimes - Halton Outreach, Milton

Ontario March of Dimes, Fergus

Ontario March of Dimes, Nepean

Ontario March of Dimes, Richmond Hill

Ontario March of Dimes, Sault Ste. Marie

Ontario March of Dimes, Simcoe

Ontario March of Dimes, Thorold

Ontario March of Dimes, Toronto

Participation Apartments - Metro Toronto, Toronto

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Participation House, Brantford

Participation House, Mississauga

Participation House Project, Kitchener

Participation House Project, Oshawa

Participation Lodge - Grey Bruce, Holland Centre

Participation Projects, Sudbury

Participation Projects - Supportive Housing, Sudbury

Peel Cheshire Homes, Brampton

Peel Cheshire Homes, Mississauga

Personal Choice Independent Living, Ottawa

Physically Handicapped Adults Rehabilitation Association, North Bay

Providence Continuing Care Centre - Attendant Outreach Services, Kingston

Residential Services Association for Persons with Physical Disabilities, Windsor

Tobias House Attendant Care, Toronto

Three Trilliums Community Place, Toronto

Visiting Homemakers Association - Health and Home Support Program, Attendant Care Outreach, Ottawa

APPENDIX F: GLOSSARY

Attendant

A person who works with, and under the direction of, a consumer to provide physical assistance with routine activities of living, described as attendant services. Examples include eating, dressing, bathing, toileting, housekeeping, meal preparation and, in some cases, maintenance of tracheotomy or respiratory equipment.

Attendant Outreach

Program operating in Ontario through which consumer-directed attendant services are provided on a visitation basis.

Attendant Services (see also Self-directed Attendant Services)

Consumer-directed physical assistance with routine activities of living, which the person with a disability would do for him or herself were it not for physical limitations. This assistance is provided by another person and involves positive human interaction. The consumer, in self-directing, exercises responsibility for decisions and training involved in his or her own immediate physical assistance.

Centre for Independent Living in Toronto (CILT)

Incorporated in 1984, CILT is an Independent Living Resource Centre, and member of the Canadian Association of Independent Living Centres (CAILC). CILT co-ordinates a number of programs related to attendant services and parenting issues: Project Information Centre (PIC), Self-Managed Attendant Services – Direct Funding Program (DF), and the Parenting with a Disability Network (PDN).

Community Care Access Centres (CCACs)

Government-funded health care organizations that co-ordinate services for people who are eligible for home care assistance using contracted services such as Visiting Homemakers or Red Cross Homemaking Services.

Consumer

A person with a disability who uses or requires self-directed attendant services.

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Consumer Choice. Self-directed means that the consumer him/herself chooses the way in which health, attendant services and related supports are delivered.

Developmental Disability (see Intellectual Disability)

Direct Funding (see also Self-Managed Attendant Services – Direct Funding Program)

A self-management option through which the consumer receives funds and undertakes all responsibilities associated with being an employer. Funds are sent directly to the consumer to pay for and manage self-directed attendant services. The amount of a consumer's funding is determined according to individual service needs.

Disability

A broad term referring to physical, visual, hearing, intellectual and emotional impairments and chronic health conditions.

Employment Agreement

A contract outlining job conditions and responsibilities, which is filled out when an attendant is hired and signed by both employer and employee.

Independent Living

An approach to life that recognizes the right of citizens with disabilities to self-determination, which includes examining choices, making decisions, and taking responsibility and risks just as any individual, with or without a disability, has the right to do.

Independent Living Movement

An international trend, born in the 1960s, promoting consumer control, choices, individual responsibility and full participation in community life. The Independent Living Movement's goal is an independence that allows individuals to take responsibility for their lives, to make choices and to take risks. The term is used in contrast to the traditional institutional or medical model of disability.

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Independent Living Resource Centres (ILRCs)

ILRCs are consumer-controlled, cross-disability, community-based, non-for-profit organizations, which promote independence and full participation of persons with different disabilities in community life. Their purpose is to ensure that services and opportunities are available to people who have a disability. Currently there are 23 ILRCs across Canada, who belong to the Canadian Association of Independent Living Centres (CAILC).

Intellectual Disability

An impaired ability to learn, which sometimes causes difficulty in coping with the demands of daily life. Usually present from birth, intellectual disability is not the same as mental or psychiatric illness. The term “mental retardation,” is no longer acceptable, with the preferred terminology being person with an intellectual disability, person with a mental handicap, or person with a developmental disability. (Source: Canadian Association for Community Living, www.cacl.ca)

Nurturing Assistance

A service that provides physical assistance to parents with disabilities who have young children. Helping to strengthen the parent-child relationship, its function is to physically assist parents to undertake the tasks involved in caring for their children, from birth through the first ten years of life.

Nurturing Assistant

Paid employee who works under the direction of and in the presence of the parent with a disability. A nurturing assistant’s role is to assist the parent with bathing and changing the child, preparing meals, lifting and carrying, nursing and cuddling the child, playing and parent-child interacting, etc., according to the daily needs of the parent and child. Nurturing assistants are not babysitters or nannies, neither are they volunteers or family members.

Parenting with a Disability Network (PDN)

The Parenting with a Disability Network (PDN), formed in 1994 and hosted by CILT, is a peer support and information-sharing network for parents and prospective parents with a disability. The aim of PDN is to help families develop unique solutions to parenting challenges. PDN publishes the Parenting with a Disability Bulletin bi-monthly.

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Project Information Centre (PIC)

The Project Information Centre (PIC) is a centralized database clearinghouse for applications made to SSLUs and Attendant Outreach programs in Toronto. Located at and operated by CILT, PIC processes applications and assists consumers by providing information about eligibility criteria for attendant services and the application process. Individual service providers carry out assessments to determine eligibility and then make the decision to offer services. Outside Toronto, consumers may apply directly to attendant service providers in their immediate geographic area.

Self-Determination

The four principles of self-determination are:

Freedom: the ability to exercise the same rights as all citizens. People with disabilities, with assistance when necessary, can establish where they want to live, with whom they want to live and how their time will be occupied;

Authority: the control over whatever sums of money are needed for one's own support, including the re-prioritizing of these dollars when necessary;

Support: the organization of these resources as determined by the person with a disability, without "supervision" or "staffing";

Responsibility: the wise use of public dollars.

(Source: Web site of U.S. National Program on Self Determination, www.self-determination.org)

Self-Direction

Refers to the greater choice, flexibility and control available to self-managers.

Self-Managed Attendant Services – Direct Funding Program

An initiative which, by making each participant the employer of his or her own attendants, responds to the participant's need for more choice, control and flexibility in relation to government-funded attendant services. Consumers who want to take full responsibility for recruiting, managing and administering funding for their own attendants can apply to the Self-Managed Attendant Services – Direct Funding Program (DF), which is available province-wide in Ontario. DF is located at CILT.

Self-Manager

The consumer as the legal employer of his or her attendants.

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Support Services Living Unit (SSLU)

Designated apartments and clustered settings providing attendant services on a 24-hour basis. Attendants are employed and managed by the SSLU.

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