

Family Quality of Life Survey

Main caregivers of people with intellectual or developmental disabilities

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Availability of the Survey Package

The *Family Quality of Life Survey Package* (instructions, an administrator's manual, a codebook for variables, and data files in SPSS and delimited text formats) is currently available in English and may be downloaded free of charge from:
<http://www.surreyplace.on.ca/Education-and-Research/research-and-evaluation/Pages/International-Family-Quality-of-LifeProject.aspx>

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Family Quality of Life Survey

Main Caregivers of People with an Intellectual or Developmental Disability

What is the Family Quality of Life Survey?

The *Family Quality of Life Survey* (FQOL Survey) is a method of focusing on the quality of life of families who have one or more members with an intellectual or developmental disability. It is a way to address the degree to which family quality of life is enjoyable, meaningful, and supported by the types of resources that are important to family members, as well as the struggles faced by families.

How should the FQOL Survey be used?

The FQOL Survey is intended for two uses. First, it may be useful for service practitioners and family members as part of an overall assessment of support needs and program design. Second, it may be used as an instrument to describe and measure family quality of life, within the limitations of its conceptualization, for research or evaluation purposes.

Structure of the FQOL Survey

There are many ways to look at family quality of life. The FQOL Survey looks at aspects of family life that we consider critical based on previous research and practice.

The FQOL Survey has several parts:

- The first part, *About Your Family*, introduces your family members.
- The following 9 parts address specific areas of family life: health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation, and community integration. Each of these 9 parts has 2 sections. Section A contains questions that gather some general information and provide context. Section B contains questions related to 6 key concepts: importance, opportunities, initiative, attainment, stability, and satisfaction. These questions may seem somewhat repetitive. They are meant to be that way, because they ask the same question about each of the 9 different areas of life.
- The final short part of the FQOL Survey asks for overall impressions of family quality of life.

How Should the FQOL Survey be Administered?

The FQOL Survey may be completed by the main caregiver (self-administration), or completed by a researcher or practitioner with the main caregiver (face-to-face administration). When self-administered, a way should be provided for the main caregivers who have questions to contact someone with knowledge of the survey.

Informed consent should always be obtained in writing from the person responding to the survey.

In some cases, researchers find it useful to augment the information gathered from the survey with a personal interview.

Confidentiality and Ethical Considerations

The completed FQOL Survey contains confidential information. When it is used by service organizations for assessment of support needs and program design, established policies and guidelines followed for all confidential information should be used.

When the FQOL Survey is used for research or evaluation purposes, all personal information of families and individuals with intellectual or developmental disabilities should be concealed, and only aggregate data or anonymous case examples should be reported. Those using this survey should comply with the ethical requirements of their universities, organizations, or relevant governing bodies.

Use of the terms “Intellectual Disability” and “Developmental Disability”

We use the term “Intellectual Disability” in this international survey to denote difficulties with cognitive development or cognitive impairment from a variety of causes because it is the term that is accepted and used internationally. Many countries use other terms that refer to the same condition (e.g., mental retardation in the United States, learning disabilities in the United Kingdom, and developmental disabilities in Canada).

We use the term “Developmental Disability” to denote conditions associated with a wide variety of disabilities that emerge prior to birth or during the developmental (childhood) years. People with developmental disabilities, as the term is used here, may or may not have an intellectual disability.

This survey may be used with people who have either an intellectual disability or developmental disability.

Translation

The *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities* was developed in English. It is our wish to translate the survey to other languages, and to make the translated versions available on our website. If you would like to translate the Survey to your language for use in your country, we would be pleased to have you contact us so that we can work together to make it available.

Difficulty downloading the FQOL Survey?

If you encounter difficulty downloading the survey, or obtaining a properly formatted copy, please contact Barry Isaacs: barry.isaacs@surreyplace.on.ca.

Instructions for Completing the FQOL Survey

Who answers the questions in the survey?

The Family Quality of Life Survey is to be completed by the main caregiver of the family member with an intellectual or developmental disability. The main caregiver may be a parent, a sibling, a spouse or life partner, or other family member as defined in the “About Your Family” section (page 1). It is not to be completed by the family member with an intellectual or developmental disability or a family member who may assist in the care, but is not the main caregiver.

When completing this survey

1. Please answer every question as fully as possible.
2. Write in any additional information or comments that might help us to better understand your family's situation in the spaces beside the questions.
3. If a question is not applicable, please say so and explain why.
4. The survey takes about one hour to complete.

For office use only

Participant ID:		
Survey site:		
Date:		
Country:		
Method of Completion:		
<input type="checkbox"/>	Self administered by main caregiver	
<input type="checkbox"/>	Face to face / Telephone administration	
	Interviewer:	
	Occupation:	
	Place of study/work:	
<input type="checkbox"/>	Was there a follow up interview? (check ✓ if yes)	

About Your Family

Around the world people think of families differently. When completing this survey, we ask you to think of your *immediate family* — those people who are closely involved in the day-to-day affairs of your household. Family members may be related by blood or by close personal relationship.

1. **What is your relationship to your family member(s) with an intellectual or developmental disability?**
 (For example: mother, brother, sister, spouse/partner.)

PERSON(S) WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY

2. **Please indicate the gender and age for all family members with an intellectual or developmental disability:**
 (Use the space to the right of the table to add others if needed.)

		Gender	Age	Live at home with you? (check ✓ if yes)
<i>Person 1</i>	1	Male		
	2	Female		
<i>Person 2</i>	1	Male		
	2	Female		
<i>Person 3</i>	1	Male		
	2	Female		

- 3a. **Below are some of the specific diagnoses or reasons that may be associated with an intellectual or developmental disability. Please check (✓) any that apply to your family member(s) with an intellectual or developmental disability.**

Person 1 Person 2 Person 3

1	1	1	Intellectual or developmental disability (cause unknown)
2	2	2	Autism Spectrum Disorder
3	3	3	PDD (Pervasive Developmental Disability)
4	4	4	Down syndrome
5	5	5	Prader-Willi syndrome
6	6	6	Fragile X syndrome
7	7	7	Williams syndrome
8	8	8	Rett syndrome
9	9	9	PKU (Phenylketonuria)
10	10	10	Dual diagnosis (intellectual/developmental disability & psychiatric disorder)
11	11	11	Cerebral Palsy
12	12	12	Fetal Alcohol Spectrum Disorder
13	13	13	Other (please specify) _____
14	14	14	Other (please specify) _____

3b. Often people with an intellectual or developmental disability have other conditions. Please check (✓) any that apply to your family member(s) with an intellectual or developmental disability.

Person 1 Person 2 Person 3

1	1	1	Behavioural problems
2	2	2	Mood/expression/anxiety problems
3	3	3	Severe psychiatric disturbances (schizophrenia or other psychoses)
4	4	4	General problems with motor control/coordination
5	5	5	Seizures
6	6	6	Alzheimer disease or other types of dementia
7	7	7	Major vision impairment
8	8	8	Major hearing impairment
9	9	9	Sensory integration impairment
10	10	10	Speech and or language difficulties
11	11	11	Feeding or eating difficulties (feed tubes, major allergies, sensitivities, etc.)
12	12	12	Heart problems
13	13	13	Asthma or other respiratory disease
14	14	14	Gastro-intestinal/digestive/stomach problems
15	15	15	Other (please specify) _____
16	16	16	Other (please specify) _____

3c. Please describe condition(s) checked in 3b above.

4. What level of disability-related support is needed for your family member(s) with an intellectual or developmental disability?

(Check ✓one for each family member with an intellectual or developmental disability. Add others if needed.)

Person 1 Person 2 Person 3

5	5	5	Does not require disability-related support
4	4	4	Requires disability-related support for only a few aspects of life
3	3	3	Requires disability-related support for some aspects of life
2	2	2	Requires disability-related support for most, but not all, aspects of life
1	1	1	Requires disability-related support for almost all aspects of life

5. What level of communication best describes your family member(s) with an intellectual or developmental disability?

(Check ✓one for each family member with an intellectual or developmental disability. Add others if needed.)

Person 1 Person 2 Person 3

5	5	5	Able to communicate about a wide variety of topics in a meaningful way
4	4	4	Able to communicate within a limited range of topics in a meaningful way
3	3	3	Able to communicate needs, wants, and some ideas in a meaningful way
2	2	2	Able to communicate basic needs and wants
1	1	1	Very little meaningful communication

6. Is there anything else you would like to tell us about your family member(s) with an intellectual or developmental disability?

IMMEDIATE FAMILY

7. Is your immediate family...?

- 1 a one-parent family
- 2 a two-parent family
- 3 other (please specify) _____

8. List all of the adults in your immediate family who take a parental role. Please also indicate their ages, whether they live at home with you, and whether they act as caregivers?

<i>Relationship to family member(s) with an intellectual or developmental disability</i>	<i>Age</i>	<i>Live at home with you? (check ✓ if yes)</i>	<i>Act as caregiver? (check ✓ if yes)</i>
Biological Mother			
Step Mother			
Foster Mother			
Biological Father			
Step Father			
Foster Father			
Sibling (specify)			
Other (specify)			
Other (specify)			

9. List the siblings of the person(s) with an intellectual or developmental disability by their relationship. Please specify if adopted, foster, or step-sibling, etc.

<i>Relationship to family member(s) with an intellectual or developmental disability (for example: brother, foster sister, step-brother, adopted sister)</i>	<i>Age</i>	<i>Live at home with you? (check ✓ if yes)</i>	<i>Act as caregiver? (check ✓ if yes)</i>

10. Please list any other people you consider to be members of your immediate family who are not listed above.

<i>Relationship to family member(s) with an intellectual or developmental disability (grandmother, live-in caregiver, etc.)</i>	<i>Age</i>	<i>Live at home with you? (check ✓ if yes)</i>	<i>Act as caregiver? (check ✓ if yes)</i>

11. Which family member(s) is most involved in the day to day life of your family member(s) with an intellectual or developmental disability? (check ✓one)

- 1 Mother
- 2 Father
- 3 Mother and father
- 4 Siblings
- 5 Parents and siblings
- 6 Parents and other family members
- 7 Parents, siblings, and other members
- 8 Other family members (for example: grandparent, aunt, cousin)

12. How much responsibility do you personally have in the day to day affairs of your family? (check ✓one)

- 1 Much more responsibility than I would like
- 2 More responsibility than I would like
- 3 About the amount of responsibility I like
- 4 Less responsibility than I would like
- 5 Much less responsibility than I would like

13a. How much responsibility related to your family member(s) with an intellectual or developmental disability do you personally have? (check ✓one)

- 1 Much more responsibility than I would like
- 2 More responsibility than I would like
- 3 About the amount of responsibility I like
- 4 Less responsibility than I would like
- 5 Much less responsibility than I would like

13b. Comments:

1. Health of the Family

In this section, you are asked to consider the overall health of your family. Sometimes one or more members of a family have health problems and these problems affect the other members of the family. In responding to the questions below, think of your family as a whole.

Section A

1a. Are there major physical and/or mental health concerns for your family member(s) with an intellectual or developmental disability?

- 1 Yes
- 2 No

1b. If yes, please describe:

2a. Are there any major physical and/or mental health concerns for other members of your family?

- 1 Yes
- 2 No

2b. If yes, please describe:

<i>Who? (Relationship to family member(s) with an intellectual or developmental disability)</i>	<i>Health concern</i>

3. What barriers are there to your family accessing health care? (check ✓ as many as apply)

- 1 Long wait for service
- 2 No known treatment for health concern
- 3 Services not available in my area
- 4 Transportation is a problem
- 5 We cannot get to appointments easily, we have trouble getting around
- 6 We do not know where to go for health care services
- 7 We do not understand easily what health care professionals say
- 8 Poor treatment by health care professionals
- 9 We have different beliefs about health care
- 10 Other (specify) _____
- 11 Other (specify) _____

Section B

1. **How important is your family's health to your family's quality of life?** (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all

2. **Are there opportunities in your area for your family's health needs to be met?** (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any

3. **Do members of your family make efforts to maintain or improve their health, such as engaging in regular exercise, paying attention to diet?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4. **To what degree do members of your family enjoy good health?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

5a. **In the near future, is it likely that your family's current level of health will ...?** (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. **If improve or decline, why?**

6. All things considered, how satisfied are you with the health of your family?
(check ✓ one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

2. Financial Well-Being

In this section, you are asked to think about how your family is managing financially. Individual members of your family earn different amounts of money and have different financial needs, but in responding to the questions below, think of the financial situation of your family as whole.

Section A

1. **In your country, how would your total family income, including all pensions, be described?**
(check ✓one)

- 5 Well above average
- 4 Above average
- 3 Average
- 2 Below average
- 1 Well below average

2. **When you think of the total family income, including all pensions, do you consider your family to be** (check ✓one):

- 5 Well off
- 4 Managing well with some extra
- 3 Doing okay
- 2 Just getting by
- 1 Struggling

3. **Does your family receive any financial support from sources other than employment (such as gifts, pensions, investment income)?** (Please list)

4. **What percentage of your total family income, including all pensions, does your family spend each month, on average, for special care, medication, support, or equipment for the family member(s) with an intellectual or developmental disability?**

- 5 None
- 4 Less than 10%
- 3 10% to 25%
- 2 26% to 50%
- 1 51% or more

5. **How many of your family's basic needs (for example, food, clothing, adequate housing) are met by your family income? (check ✓one)**

- 5 All
- 4 Most
- 3 Some
- 2 A few
- 1 None

6a. **After all the necessary expenses are paid at the end of each month, does your household have money left to do with as you wish? (check ✓one)**

- 1 Yes
- 2 No

6b. **If no, does this present a hardship for your family financially? (check ✓one)**

- 1 Yes
- 2 Somewhat
- 3 No

Section B

1. **How important is financial well-being to your family's quality of life?** (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all

2. **Are there opportunities for members of your family to earn enough money to do the things your family wants?** (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any

3. **Do members of your family make efforts to maintain or improve the financial situation of your family?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4. **To what degree does your family's financial situation meet your family's expectations?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

5a. **In the near future, is it likely that your family's financial situation will ...?** (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. **If improve or decline, why?**

6. All things considered, how satisfied are you with the financial well-being of your family?
(check ✓one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

3. Family Relationships

In this section, think about the general tone or feeling that is usually present in your family. An individual in a family might get along better with some family members than with others, but here we are interested in the atmosphere that emerges from all of the relationships within your family as a whole.

Section A

1. Who takes responsibility for keeping the day-to-day things going in your family?

(check ✓ one)

- 1 Everyone pitches in to the best of their ability
- 2 Some do more than others
Please specify who does more _____
- 3 Most responsibility is on one or two people
Please specify who does most _____
- 4 Things just take care of themselves

2. Who takes the MOST responsibility for each of these nine aspects of running your family home? If responsibilities are shared, list all those involved. (check ✓ any that apply)

	<i>Mother</i>	<i>Father</i>	<i>Siblings</i>	<i>Other</i>
a. Grocery shopping	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
b. Cooking	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
c. Care of person with disability	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
d. Other child care	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
e. Yard work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
f. House cleaning	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
g. Laundry	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
h. Earning money	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
i. Maintenance and repairs	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
j. Other (specify) _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
k. Other (specify) _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

3. To what extent does your family...? (check ✓ one answer for each item)

	<i>A lot</i>	<i>Quite a bit</i>	<i>Some</i>	<i>Not much</i>
a. Help each other do things	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
b. Go places together	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
c. Enjoy each other's company	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
d. Support each other in times of trouble	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
e. Help solve family problems	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
f. Trust each other	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
g. Work together toward family goals	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
h. Have a sense of belonging together	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
i. Generally have similar values	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
j. Do things as a family	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Section B

1. **How important are your family relationships to your family's quality of life?** (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all

2. **Are there opportunities for members of your family to maintain and enhance good relationships with each other?** (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any

3. **Do members of your family make efforts to keep good relationships within your family?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4. **To what degree do members of your family enjoy good relationships with each other?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

5a. **In the near future, is it likely that your family relationships will ...?** (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. **If improve or decline, why?**

6. **All things considered, how satisfied are you with the relationships within your family?**
(check ✓ one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. **Please provide any additional information or explanations that you would like.**

4. Support from Other People

Families sometimes get practical and emotional support from a variety of other people, such as relatives, friends, neighbours and others. In this section, you are asked to think about the support to your family as a whole from other people.

Section A

- 1a. How much do relatives (other than those you identified as your immediate family) help your family do *practical* things, such as look after family members, shop, or look after the house? (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

- 1b. How many hours a week, in total, do these relatives do these things?

_____ hours

- 2a. How much do relatives (other than those you identified as your immediate family) give your family *emotional* support, such as talk with you, listen to you, or offer encouragement? (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

- 2b. How many hours a week, in total, do these relatives do these things?

_____ hours

- 3a. How much do friends and neighbours help your family do *practical* things, such as look after family members, shop, or look after the house? (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

- 3b. How many hours a week, in total, do these friends and neighbours do these things?

_____ hours

4a. How much do friends and neighbours give your family *emotional* support, such as talk with you, listen to you, or offer encouragement? (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4b. How many hours a week, in total, do these friends and neighbours do these things?

_____ hours

5a. How would you describe your own *personal* social life outside your family?
(check ✓one)

- 1 About what I would like it to be
- 2 Somewhat less than I would like it to be
- 3 Much less than I would like it to be

5b. Please explain:

Section B

1. **How important to your family's quality of life is the practical and emotional support you get from other people, excluding service providers?** (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all

2. **Are there opportunities to receive practical and emotional support from other people, excluding service providers, should your family need it?** (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any

3. **Do members of your family make efforts to get practical and emotional support from other people, excluding service providers?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4. **To what degree does your family receive practical and emotional support from other people, excluding service providers?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

5a. **In the near future, is it likely the practical and emotional support you receive from other people, excluding service providers, will ...?** (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. If improve or decline, why?

6. All things considered, how satisfied are you with the practical and emotional support your family gets from other people, excluding service providers? (check ✓ one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

5. Support from Disability Related Services

In this section you are asked to think about the support received from disability related services. Although these services are often directed toward the person with the intellectual or developmental disability, they often affect the family as a whole.

Section A

1. Indicate which of these services, if any, are available in your area. (check ✓ as many as apply)

- 1 Special disability benefits / funding
- 2 Service coordination / social work
- 3 Individual / family support worker
- 4 Paid attendant or caregiver
- 5 Respite care
- 6 In-home health care
- 7 Advocacy services

- 8 Special education
- 9 Supported community employment
- 10 Sheltered employment workshop
- 11 Day Programs / Activities

- 12 Supported group living / group home
- 13 Supported independent living
- 14 Institution, residential hospital, or other large care facility

- 15 Family doctor
- 16 Pediatrician
- 17 Medical specialist(s) (please specify) _____
- 18 Psychiatrist
- 19 Psychologist

- 20 Vision services (beyond routine)
- 21 Hearing services (beyond routine)

- 22 Nutritional services
- 23 Speech and language therapy
- 24 Behavioural support
- 25 Occupational therapy
- 26 Physiotherapy
- 27 Counselling / psychotherapy

- 28 Other (please specify): _____
- 29 Other (please specify): _____

2. Which of these services have you or any of your family members used?
(check ✓ as many as apply)

- 1 Special disability benefits / funding
- 2 Service coordination / social work
- 3 Individual / family support worker
- 4 Paid attendant or caregiver
- 5 Respite care
- 6 In-home health care
- 7 Advocacy services

- 8 Special education
- 9 Supported community employment
- 10 Sheltered employment workshop
- 11 Day Programs / Activities

- 12 Supported group living / group home
- 13 Supported independent living
- 14 Institution, residential hospital, or other large care facility

- 15 Family doctor
- 16 Pediatrician
- 17 Medical specialist(s) (please specify) _____
- 18 Psychiatrist
- 19 Psychologist

- 20 Vision services (beyond routine)
- 21 Hearing services (beyond routine)

- 22 Nutritional services
- 23 Speech and language therapy
- 24 Behavioural support
- 25 Occupational therapy
- 26 Physiotherapy
- 27 Counselling / psychotherapy

- 28 Other (please specify): _____
- 29 Other (please specify): _____

3a. Are there disability related services you need that you are not currently getting?
(check ✓ one)

- 1 Yes
- 2 No

If you answered “No”, please move on to Section B on page 22.

If you answered “Yes”, continue with questions 3b and 3c on the next page.

3b. If there are disability related services you need that you are not currently getting, please list them.

3c. Why are you not receiving the disability related services you need?

(check ✓ as many as apply)

- 1 Long wait for service
- 2 The services we use just don't help enough
- 3 Services not available in my area (please specify) _____
- 4 Transportation is a problem
- 5 We cannot get to appointments easily, we have trouble getting around
- 6 We do not know where to go for services
- 7 We do not understand easily what service people say
- 8 Poor treatment by staff
- 9 We have different beliefs about support services
- 10 Other (specify) _____
- 11 Other (specify) _____

Section B

1. How important to your family's quality of life is support from intellectual or developmental disability related services? (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all

2. Are there opportunities in your area to receive the intellectual or developmental disability related services your family needs? (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any

3. Do members of your family make efforts to obtain the disability related services they need? (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4. To what degree are your family's needs, related to the family member(s) with an intellectual or developmental disability, being met by the services in your area? (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

5a. In the near future, is it likely that the support your family receives from disability related services will ...? (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. If improve or decline, why?

6. All things considered, how satisfied are you with the disability related services your family receives? (check ✓ one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

6. Influence of Values

Many people derive fulfilment and guidance from the values they hold. Such values may emerge from personal standards of conduct, beliefs based on spirituality, formal religion, or cultural background. For most people, values emerge from a combination of these sources. In this section, you are asked to think about the degree to which your family is influenced by personal, spiritual, religious and cultural values, and to consider their impact on your family as a whole.

Section A

1a. **Are your family's values...?** (check ✓all that apply)

- 1 Personal
- 2 Spiritual
- 3 Religious
- 4 Cultural

1b. **Please explain:** _____

2. **To what degree do people in your religious, spiritual/cultural community accept the disability of your family member(s)?** (check ✓one)

- 5 Very much
- 4 Quite a bit
- 3 Somewhat
- 2 A little
- 1 Hardly at all
- 0 Not strongly involved in a spiritual/cultural community

3. **To what degree do people in your religious, spiritual/cultural community help your family practically with your disability-related needs?** (check ✓one)

- 5 Very much
- 4 Quite a bit
- 3 Somewhat
- 2 A little
- 1 Hardly at all
- 0 Not strongly involved in a spiritual/cultural community

4. **To what degree do people in your religious, spiritual/cultural community help your family emotionally with your disability-related needs?** (check ✓one)

- 5 Very much
- 4 Quite a bit
- 3 Somewhat
- 2 A little
- 1 Hardly at all
- 0 Not strongly involved in a spiritual/cultural community

5. **To what degree do your personal, spiritual, religious and/or cultural values help your family members accept and cope with disability?** (check ✓one)

- 5 Very much
- 4 Quite a bit
- 3 Somewhat
- 2 A little
- 1 Hardly at all
- 0 Do not have strong personal, spiritual, or cultural values

Section B

1. **How important to your family's quality of life are personal, spiritual, religious and/or cultural values?** (check ✓one)
- 5 Very important
 - 4 Quite important
 - 3 Somewhat important
 - 2 A little important
 - 1 Hardly important at all
2. **Are there opportunities for members of your family to develop and hold personal, spiritual, religious and/or cultural values that can contribute to your family's quality of life?** (check ✓one)
- 5 A great many
 - 4 Many
 - 3 Some
 - 2 A few
 - 1 Hardly any
3. **Do members of your family make efforts to maintain or strengthen personal, spiritual, religious and/or cultural values that contribute to your family's quality of life?** (check ✓one)
- 5 A great deal
 - 4 Quite a bit
 - 3 Some
 - 2 A little
 - 1 Hardly at all
4. **To what degree do members of your family hold personal, spiritual, religious and/or cultural values that contribute to your family's quality of life?** (check ✓one)
- 5 A great deal
 - 4 Quite a bit
 - 3 Some
 - 2 A little
 - 1 Hardly at all

5a. In the near future, is it likely that the personal, spiritual, religious and/or cultural values that contribute to your family's quality of life will...? (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. If improve or decline, why?

6. All things considered, how satisfied are you with the degree to which personal, spiritual, religious and/or cultural values contribute to your family's quality of life? (check ✓one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

7. Careers and Preparing for Careers

Part of an adult's life is engaging in work. Similarly, part of a child's life is learning for the future. In this section, think of your family as a whole.

Section A

1. List each member of your immediate family by role (for example, mother, step-brother), including the family member(s) with intellectual disabilities, and check (✓) the appropriate occupational activity. Briefly describe the work or school attended.

<i>Family member</i>	<i>Retired</i>	<i>Not employed</i>	<i>Employed Full time</i>	<i>Employed Part time</i>	<i>Student Full time</i>	<i>Student Part time</i>	<i>Describe work or school or why not employed</i>

- 2a. Does your family member(s) with an intellectual or developmental disability engage in the daily activities he/she/they wants?

<i>Person 1</i>	<i>Person 2</i>	<i>Person 3</i>	
<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 1	Yes
<input type="checkbox"/> 2	<input type="checkbox"/> 2	<input type="checkbox"/> 2	Somewhat
<input type="checkbox"/> 3	<input type="checkbox"/> 3	<input type="checkbox"/> 3	No
<input type="checkbox"/> 4	<input type="checkbox"/> 4	<input type="checkbox"/> 4	Does not apply

- 2b. If no, why not?

2c. What daily activities does your family member(s) with an intellectual or developmental disability engage in? (check ✓all that apply for each family member with an intellectual or developmental disability.)

Person 1 Person 2 Person 3

1	1	1	Community based paid employment
2	2	2	Community based supported employment (paid or unpaid)
3	3	3	Self-employment
4	4	4	Volunteer work
5	5	5	Sheltered workshop
6	6	6	Vocational training
7	7	7	School
8	8	8	Day programs
9	9	9	Other
10	10	10	Does not engage in vocational or educational activities

3. Have any members in your family given up their careers or education to care for the family member(s) with a disability?

- 1 Yes
- 2 No

If you answered “No”, please move on to Section B on page 30.
 If you answered “Yes”, continue with question 4.

4a. Who in your family has given up their career or education to care for the family member(s) with a disability?

4b. Please tell us about it:

5a. Will they resume in the near future?

- 1 Yes
- 2 Maybe
- 3 No

5b. Please explain:

6. What impact has this had on your family?

Section B

1. **How important is it to your family's quality of life, for family members to pursue or prepare for the careers they want?** (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all
- 0 Does not apply to my family

2. **Are there opportunities for members of your family to pursue the careers they want and attend the schools they want?** (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any
- 0 Does not apply to my family

3. **Do members of your family make efforts to develop their education and/or careers?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all
- 0 Does not apply to my family

4. **To what degree have your family members been able to prepare for and have the education and careers they want?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all
- 0 Does not apply to my family

5a. In the near future, is it likely that your family's ability to pursue and prepare for the careers they want will ...? (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline
- 0 Does not apply to my family

5b. If improve or decline, why?

6. All things considered how satisfied are you with your family's careers and ability to prepare for those careers? (check ✓one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied
- 0 Does not apply to my family

7. Please provide any additional information or explanations that you would like.

8. Leisure and Recreation

In this section, consider the leisure and recreation activities of your family as a whole.

Section A

1. What things do members of your family do together in groups of 2 or more people for leisure and recreation?

<i>What 2 or more family members? (for example: mother, father, siblings, person with disability)</i>	<i>Activities they do together</i>

2. What things do members of your family do individually for leisure and recreation?

<i>What family member? (for example: mother, father, siblings, person with disability)</i>	<i>Activities he or she does individually</i>

3. To what degree is your family member(s) with an intellectual or developmental disability involved in your family leisure and recreation activities?

- 5 Always or almost always
- 4 Frequently
- 3 Occasionally
- 2 Rarely
- 1 Not at all

Section B

1. **How important are leisure and recreation to your family's quality of life?** (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all

2. **Are there opportunities for your family members to engage in leisure and recreation activities?** (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any

3. **Do members of your family make efforts to take part in leisure and recreation activities?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4. **To what degree do your family members engage in leisure and recreation activities?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

5a. **In the near future, is it likely that your family's leisure and recreation will ...?** (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. **If improve or decline, why?**

6. All things considered, how satisfied are you with your family's leisure and recreation?

(check ✓ one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Please provide any additional information or explanation that you would like. In particular, please explain if your family members are not able to participate in leisure and recreation activities to the degree they would like.

9. Community Interaction

Community is a sense of connection with people and places in your area. In this section, consider the community interaction of your family as a whole.

Section A

1. What community groups, clubs, or organizations, are members of your family, including the family member(s) with an intellectual or developmental disability, involved in?

<i>Family member</i>	<i>Group, club, or organization</i>

- 2a. Has your family experienced any form of discrimination in your community?

- 1 Yes
 2 No

- 2b. If yes, please explain

3. What type of community does your family live in? (check ✓one)

- 1 Large urban centre
 2 Small city
 3 Small town
 4 Rural
 5 Other (please specify) _____

4. Do you like living in this community?

- 1 Yes
 2 Somewhat
 3 No

Section B

1. **How important to your family's quality of life is it for members of your family to interact with people and places in your community?** (check ✓one)

- 5 Very important
- 4 Quite important
- 3 Somewhat important
- 2 A little important
- 1 Hardly important at all

2. **Are there opportunities for members of your family to interact with people and places in your community?** (check ✓one)

- 5 A great many
- 4 Many
- 3 Some
- 2 A few
- 1 Hardly any

3. **Do members of your family make efforts to interact with people and places in your community?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

4. **To what degree does your family interact with people and places in your community?** (check ✓one)

- 5 A great deal
- 4 Quite a bit
- 3 Some
- 2 A little
- 1 Hardly at all

5a. **In the near future, is it likely that your family's interaction with people and places in your community will ... ?** (check ✓one)

- 5 Greatly improve
- 4 Improve
- 3 Stay about the same
- 2 Decline
- 1 Greatly decline

5b. **If improve or decline, why?**

6. All things considered, how satisfied are you with your family's interaction with people and places in your community? (check ✓ one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Please provide any additional information or explanations that you would like.

10. Overall Family Quality of Life

1. Are there everyday experiences that *add to* your family quality of life that we have not covered in this survey?

2. Are there everyday experiences that *take away from* your family quality of life that we have not covered in this survey?

3. Is there anything else about your family's structure and/or organization that is important to your family quality of life that we have not asked about in this survey?

4. Is there anything else that is important to your family quality of life that we have not asked about in this survey?

5. Overall, how would you describe your family's quality of life? (check ✓one)

- 5 Excellent
- 4 Very good
- 3 Good
- 2 Fair
- 1 Poor

6. Overall, how satisfied are you with your family's quality of life? (check ✓one)

- 5 Very satisfied
- 4 Satisfied
- 3 Neither satisfied or dissatisfied
- 2 Dissatisfied
- 1 Very dissatisfied

7. Finally, what things do you think could improve your family quality of life?

Thank you for completing the Family Quality of Life Survey.