

# family life

## survey



FAMILY AND DISABILITY STUDIES INITIATIVE  
UNIVERSITY OF ALBERTA



UNIVERSITY OF  
ALBERTA



Alberta Association for  
Community Living



0910 EXR CRS 10889

**Thank you for taking the time to complete this survey.** The information you share will help us better understand the challenges that families with children with disabilities face, and the resources that parent-carers need to juggle multiple roles and responsibilities.

The survey includes questions about you and your family's health and wellbeing, and the strategies and resources you need to keep your family life running. You can complete this questionnaire yourself or, if you prefer, we could complete it together over the phone.

If you would prefer to complete this survey over the phone, please call Amber Savage at 780 492 8568.

Most of the questions in this survey ask you to choose from a list of possible answers, such as "I agree", or "I disagree". You select your answer by filling in the corresponding circle. For example

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**Question: Do you live in Canada?**

Yes

No

Once you have completed the survey, please return it to us together with the signed consent form in the postage paid envelope provided. Thank you.

The first section of this questionnaire asks about your participation in paid work and other activities.

**1 In a typical week, approximately how much time do you spend**

- > in **paid work** (including any unpaid overtime) \_\_\_\_\_ hours
- > doing **unpaid volunteer work** or service for any organisation/group \_\_\_\_\_ hours
- > doing **unpaid housework** activities including cooking, cleaning, shopping, home budgeting, yard work or home maintenance \_\_\_\_\_ hours
- > **actively / physically looking after your children** (bathing, dressing, transporting, etc) \_\_\_\_\_ hours
- > **caring for an elderly family member** \_\_\_\_\_ hours
- > **implementing home** (therapy) **programs** for your child/ren with disabilities \_\_\_\_\_ hours
- > **attending appointments** with health, education or other professionals \_\_\_\_\_ hours

**2 Given the choice, would you like less, the same number, or more hours of paid work?**

- Less
  Same number of hours
  More

If you do not spend any time in paid work, please go to question 19 on page 4.

**3 Which of the following best describes the hours you usually work?**

- Regular daytime schedule or shift
- Regular evening shift
- Regular night shift
- Rotating shift (for example, change from days to evenings to nights)
- Split shift (for example, some hours in the day and the remainder in the evening or night)
- On call
- Irregular schedule

**4 Do you work mainly...**

- for others, that is for wages, salary or commission
- in your own business, farm or professional practice
- other (please specify)

The next questions are about how much control you have over your work:

		Never	Rarely	Sometimes	Often
5	<b>"I have a say in what I do at work."</b>	①	②	③	④
6	<b>"I can work from home if I wish."</b>	①	②	③	④
7	<b>"I have a say in how I do my job."</b>	①	②	③	④
8	<b>"I have a say in my own work speed."</b>	①	②	③	④
9	<b>"My scheduled work hours are flexible."</b>	①	②	③	④
10	<b>"I can decide when to take a break."</b>	①	②	③	④
11	<b>"My work demands a high level of skill or expertise."</b>	①	②	③	④
12	<b>"My job requires me to take the initiative."</b>	①	②	③	④
		Definitely not	No, I don't think so	Yes, I think so	Definitely yes
13	<b>"I can take leave, paid or unpaid, to care for my children (to see a doctor, or meet with a teacher etc) if I need to."</b>	①	②	③	④
14	<b>"I can take extended leave without pay if I need to."</b> (for example, to be home for the children, care for a family member etc)	①	②	③	④

The next questions ask about the balance between work and family activities:

	All the time	Most of the time	Sometimes	Never
15 How often do you come home from work too tired to do the chores that need to be done?	①	②	③	④
16 How often is it difficult to fulfill family responsibilities because of the amount of time you spent on your job?	①	②	③	④
17 How often do you arrive at work too tired to function well because of the household or child care work you had done?	①	②	③	④
18 How often is it difficult to concentrate or fulfill your work responsibilities because of your family responsibilities?	①	②	③	④

19 What is your marital status?

- currently married and living together, or living with someone in a marital-like relationship
- never married and never lived with someone in a marital-like relationship
- Separated
- Divorced or formerly lived with someone in a marital-like relationship
- Widowed

If you are **not currently married or living with someone** in a marital-like relationship, please go to question 38 on page 6.

20 In a typical week, approximately how much time does your partner spend...

- > in **paid work** (including any unpaid overtime) \_\_\_\_\_ hours
- > doing **unpaid volunteer work** or service for any organisation/group \_\_\_\_\_ hours
- > doing **unpaid housework** activities including cooking, cleaning, shopping, home budgeting, yard work or home maintenance \_\_\_\_\_ hours
- > **looking after your children** (bathing, dressing, transporting, etc) \_\_\_\_\_ hours
- > **caring for an elderly family member** \_\_\_\_\_ hours
- > **implementing home** (therapy) **programs** for your child/ren with disabilities \_\_\_\_\_ hours
- > **attending appointments** with health, education or other professionals \_\_\_\_\_ hours

21 Given the choice, do you think your partner would like less, the same, or more hours of paid work?

- Less
- Same number of hours
- More

If your **partner does not spend any time in paid work**, please go to question 38 on page 6.

**22 Which of the following best describes the hours your partner usually works?**

- Regular daytime schedule or shift
- Regular evening shift
- Regular night shift
- Rotating shift (for example, change from days to evenings to nights)
- Split shift (for example, some hours in the day and the remainder in the evening or night)
- On call
- Irregular schedule

**23 Does your partner work mainly...**

- for others, that is for wages, salary or commission
- in his/her own business, farm or professional practice

other (please specify)

The next questions are about how much control your partner has over his/her work.

	Never	Rarely	Don't know	Sometimes	Often
<b>24 My partner has a say in what he/she does at work.</b>	①	②	③	④	⑤
<b>25 My partner can work from home if he/she wishes.</b>	①	②	③	④	⑤
<b>26 My partner has a say in how he/she does their job.</b>	①	②	③	④	⑤
<b>27 My partner has a say in his/her own work speed.</b>	①	②	③	④	⑤
<b>28 My partner has flexible work hours.</b>	①	②	③	④	⑤
<b>29 My partner can decide when to take a break from work.</b>	①	②	③	④	⑤
<b>30 My partner needs to have a high level of skill or expertise to do his/her job.</b>	①	②	③	④	⑤
<b>31 My partner is required to take the initiative at work.</b>	①	②	③	④	⑤

	Definitely not	No, I don't think so	I don't know	Yes, I think so	Definitely yes
<b>32 My partner can take leave, paid or unpaid, to care for the children</b> (to see a doctor, meet with a teacher etc)	①	②	③	④	⑤
<b>33 My partner can take extended leave without pay if need be</b> (to be home for the children, care for a family member etc)	①	②	③	④	⑤

The next questions ask about the balance between your partner's work and family activities.

	Never	Sometimes	I don't know	Most of the time	All of the time
<b>34 How often does your partner come home from work too tired to do the chores that need to be done?</b>	①	②	③	④	⑤
<b>35 How often is it difficult for your partner to fulfill family responsibilities because of the amount of time he/she spent on their job?</b>	①	②	③	④	⑤
<b>36 How often does your partner arrive at work too tired to function well because of the household or child care work he/she had done?</b>	①	②	③	④	⑤
<b>37 How often is it difficult for your partner to concentrate or fulfill his/her work responsibilities because of their family responsibilities?</b>	①	②	③	④	⑤

The next section of the questionnaire asks about your family life and resources.

**38 How many people are so close to you that you can count on them if you have a serious personal or family problem?**

- None
- 1 or 2
- 3 to 5
- 6 to 9
- 10 or more

**39 How much concern or interest do people show in how you and your family are doing?**

- No concern or interest
- Little concern or interest
- Uncertain
- Some concern or interest
- A lot of concern or interest

**40 How easy is it to get practical help from neighbours if you or your family should need it?**

- Very difficult
- Difficult
- Possible
- Easy
- Very easy

**41 In general, professionals/services respond to our family's needs and priorities**

- Strongly disagree
- Disagree
- Uncertain
- Agree
- Strongly agree

Please use this space if you would like to explain further

The next four questions are about financial strain.

**42 Thinking back over the past three months, how much difficulty have you had paying your bills?**

- No difficulty at all
- A little difficulty
- Some difficulty
- Quite a bit of difficulty
- A great deal of difficulty

**44 In the next three months, how often do you think that you and your family will experience bad times such as poor housing or not having enough food?**

- Almost never
- Once in a while
- Sometimes
- A lot of the time
- Almost always

**43 Thinking again over the past three months, generally, at the end of each month did you end up with**

- More than enough money left
- Some money left
- Just enough money left
- Somewhat short of money
- Very short of money

**45 In the next three months, how often do you expect that you will have to do without the basic things that your family needs?**

- Almost never
- Once in a while
- Sometimes
- A lot of the time
- Almost always

The next four questions are about your personal sense of control over things in your life.

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**46** In the last month, how often have you felt that you were unable to control the important things in your life?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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**48** In the last month, how often have you felt that things were going your way?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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**47** In the last month, how often have you felt confident about your ability to handle your personal problems?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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**49** In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often



The next questions ask about the meaningfulness of your family life.

		Strongly disagree	Disagree	Agree	Strongly agree
50	I am creating the life I want for my children.	①	②	③	④
51	We are a close-knit family.	①	②	③	④
52	As a family we feel a strong sense of belonging in our community.	①	②	③	④
53	All we seem to be doing is reacting to one crisis after another.	①	②	③	④
54	We are able to do things together that are important to us.	①	②	③	④
55	I worry that we do not spend enough quality time together as a family.	①	②	③	④
56	We are always on edge wondering “what next?”	①	②	③	④
57	It is difficult for us to get into any kind of routine because our circumstances keep on changing.	①	②	③	④
58	Overall, having a child with a disability has been positive for our family.	①	②	③	④
59	As a result of having a child with a disability, our family unit has emerged stronger.	①	②	③	④
60	As a result of having a child with a disability, some wonderful people have come into our lives.	①	②	③	④
61	As a result of having a child with a disability, we have learned what is really important in life.	①	②	③	④
62	As a result of having a child with a disability, we laugh more and are less bothered by trivial things.	①	②	③	④
63	Generally, I think all members of our family feel valued and appreciated.	①	②	③	④

		Strongly disagree	Disagree	Agree	Strongly agree
64	We are trapped by our daily routine.	①	②	③	④
65	I often feel that our family stays together only out of necessity.	①	②	③	④
66	We exist: any hopes or dreams we had now seem out of our reach.	①	②	③	④
67	Planning family activities is difficult because we misunderstand each other.	①	②	③	④
68	In times of crisis we can turn to each other for support.	①	②	③	④
69	We cannot talk to each other about the sadness we feel.	①	②	③	④
70	Individuals (in the family) are accepted for what they are.	①	②	③	④
71	We avoid discussing our fears or concerns.	①	②	③	④
72	We express feelings to each other.	①	②	③	④
73	There are lots of bad feelings in our family.	①	②	③	④
74	Making decisions is a problem for our family.	①	②	③	④
75	We are able to make decisions about how to solve problems.	①	②	③	④
76	We don't get along well together.	①	②	③	④
77	We confide in each other.	①	②	③	④

The next questions explore the extent to which your family life balances the needs of your child with disabilities with the needs of all other family members.

	Does not apply	Strongly disagree	Disagree	Agree	Strongly agree
78 Overall, we are able to balance the needs and wants of each family member.		①	②	③	④
79 Our family life routine revolves around our child with disabilities.		①	②	③	④
80 Generally, every person in our family does their fair share of the chores.		①	②	③	④
81 Responsibility for keeping our family life running is shared.		①	②	③	④
82 I often worry that my other children are missing out.	<input type="radio"/>	①	②	③	④
83 My other children are usually able to do the things they like to do.	<input type="radio"/>	①	②	③	④
84 I often worry that I do not spend enough quality time with my other children.	<input type="radio"/>	①	②	③	④
85 I often worry about how the lives of my other children are affected by having a brother/sister with disabilities.	<input type="radio"/>	①	②	③	④
86 I am generally satisfied with how my life has turned out.		①	②	③	④
87 I have had to give up more of my life to meet my child/ren's needs than I ever expected.		①	②	③	④
88 I have as much time for myself as any other parent with children this age.		①	②	③	④
89 I feel trapped by my duties as a parent and caregiver.		①	②	③	④
90 I think my partner is generally satisfied with how his/her life has turned out.	<input type="radio"/>	①	②	③	④

		Does not apply	Strongly disagree	Disagree	Agree	Strongly agree
91	I think my partner feels trapped by his/her duties as a parent and caregiver.	<input type="radio"/>	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
92	I think my partner has as much time for him/herself as any other parent with children this age.	<input type="radio"/>	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
93	I think my partner has had to give up more of his/her life for the children than he/she ever expected.	<input type="radio"/>	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④

The next section of the questionnaire asks about the people in your household, and your child or children with disabilities.

- 94 How many people live in your household?
- 95 How many of them are under the age of 6?
- 96 How many are 6 to 12 years of age?
- 97 How many are 13 to 17 years of age?
- 98 Including yourself, how many of them are 18 years of age or older?
- 99 How many children in your household have a long-term physical condition, mental condition, learning or health problem that reduces the amount or kind of activities they can do?

Please tell us a little about your child with a long-term physical condition, mental condition, learning or health problem. If you have more than one child with a condition or health problem, **please tell us about the same child you described in the 2009 survey.**

100 **What is this child's gender?**

- Male  Female

101 **What is this child's age?**  
(years and months)

**What is this child's name?**

**What is this child's birthdate?**

102 **To what extent does a long-term physical condition, mental condition, learning or health problem reduce the amount or the kind of (age-appropriate) activities this child can do?**

- Not at all  
 A little  
 Fair amount  
 Quite a lot  
 Great deal

Compared with other children his/her age, does this child have any difficulty with...

103 **... speaking?**

- no difficulty  
 some difficulty  
 a lot of difficulty

104 **... walking?**

- no difficulty  
 some difficulty  
 a lot of difficulty

105 **... learning?**

- no difficulty  
 some difficulty  
 a lot of difficulty

106 **... personal care activities like bathing, dressing and eating?**

- no difficulty  
 some difficulty  
 a lot of difficulty

The next questions are about this child's social inclusion and participation.

**107** Is this child integrated into a regular early childhood service (such as daycare or preschool) or school?

- Yes  No

**108** Does this child participate in any integrated (with non-disabled children) organised playgroups, sports or other recreational activities?

- Never  
 Occasionally  
 Regularly

**109** Does this child participate in any playgroups, sports or other recreational activities that are organised especially for children with disabilities?

- Never  
 Occasionally  
 Regularly

**110** Does this child belong to any mainstream community groups/clubs (such as 4H, Girl Guides, Scouts etc)?

- Yes  No

**111** Does this child belong to any community groups/clubs that are just for children with disabilities?

- Yes  No

**112** Does this child have any friends or playmates, about his/her own age, that do not have disabilities?

- Yes  No

If yes, about how many would you say?

- 1 or 2  
 3 to 5  
 6 to 9  
 10 or more

**113** Does this child have any friends/playmates, about his/her own age, that have disabilities?

- Yes  No

If yes, about how many would you say?

- 1 or 2  
 3 to 5  
 6 to 9  
 10 or more

**114** If this child is 12 years of age or older, does he/she do any paid work (e.g. works at McDonalds)?

- Yes  No  Does not apply

The next set of questions ask about early intervention and home programs for this child. That is, any strategies or therapeutic activities that have been prescribed by a health professional, such as an occupational or physical therapist, to promote this child's learning and development.

**115** Are you expected to carry out any prescribed activities/exercises (or home program) to promote this child's learning and development?

- Yes
- No

If "no" to the previous question please go to question 124 on page 16.

**116** How much difficulty have you had finding a slot in your daily routine to carry out the prescribed activities/exercises for this child?

- No difficulty at all
- A little difficulty
- Some difficulty
- Quite a bit of difficulty
- A great deal of difficulty

**117** To what extent do you carry out the activities/exercises prescribed by a health professional for this child?

- We do not carry out any at all
- We carry out some, but not as often as we should
- We routinely carry out some
- We carry out all of them, but not as often as we should
- We routinely carry out all

How often are the activities/exercises prescribed for this child integrated into (that is, just a routine part of) the following activities?

	Never	Rarely	Sometimes	Often
<b>118</b> Meal times	①	②	③	④
<b>119</b> Bath times, including dressing and undressing	①	②	③	④
<b>120</b> Play/leisure time at home	①	②	③	④
<b>121</b> Bed times	①	②	③	④
<b>122</b> Play/leisure time at a local park, playground or recreation centre	①	②	③	④
<b>123</b> Grocery shopping and other routine community outings	①	②	③	④

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**124 Does this child have any of the following long-term conditions which have been diagnosed by a health professional?** Please fill all that apply

- Vision impairment
- Hearing impairment
- Intellectual disability (mental handicap)
- Asthma or severe allergies
- Heart condition or disease
- Kidney condition or disease
- Diabetes
- Epilepsy
- Cystic Fibrosis
- Autism Spectrum Disorder
- Fetal Alcohol Spectrum Disorder
- Cerebral palsy
- Spina Bifida
- Muscular Dystrophy
- Down syndrome
- Missing or malformed arms, legs, fingers or toes
- Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD)
- Emotional, psychological or nervous difficulties
- Complex medical care needs
- Other condition/s (please specify)

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**125 How would you describe this child's general health?**

- Poor
- Fair
- Good
- Very good
- Excellent

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**126 What is your relationship to this child?**

- Mother (biological or adoptive)
- Step mother
- Foster mother
- Father (biological or adoptive)
- Step father
- Foster father
- Other (please specify)

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If this child is **less than 4 years of age**, please go to question 151 on page 19.



The next questions ask about this child's behaviours.

		Not true	Somewhat or sometimes true	Very true or often true
127	<b>This child becomes overexcited.</b>	①	②	③
128	<b>This child chews or mouths objects or body parts.</b>	①	②	③
129	<b>This child confuses the use of pronouns.</b> (e.g. uses you instead of I)	①	②	③
130	<b>This child doesn't show affection.</b>	①	②	③
131	<b>This child grinds his/her teeth.</b>	①	②	③
132	<b>This child has nightmares, night terrors, or walks in his/her sleep.</b>	①	②	③
133	<b>This child is impatient.</b>	①	②	③
134	<b>This child has inappropriate sexual activity with another.</b>	①	②	③
135	<b>This child is jealous.</b>	①	②	③
136	<b>This child kicks, hits others.</b>	①	②	③
137	<b>This child laughs or giggles for no obvious reason.</b>	①	②	③
138	<b>This child is preoccupied with only one or two particular interests.</b>	①	②	③
139	<b>This child refuses to go to school, activity center, or workplace.</b>	①	②	③

		Not true	Somewhat or sometimes true	Very true or often true
140	This child repeats the same word or phrase over and over.	①	②	③
141	This child smells, tastes, or licks objects.	①	②	③
142	This child switches lights on and off, pours water over and over, or similar repetitive behaviour.	①	②	③
143	This child is stubborn, disobedient, or uncooperative.	①	②	③
144	This child says he/she can do things that he/she is not capable of.	①	②	③
145	This child sees, hears, something that isn't there, has hallucinations.	①	②	③
146	This child tells lies.	①	②	③
147	This child is tense, anxious, worried.	①	②	③
148	This child under-reacts to pain.	①	②	③
149	This child gets upset or distressed over small changes in routine or environment.	①	②	③
150	This child wanders aimlessly.	①	②	③

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**151 Have you ever considered placing this child out-of-home?**  
(for example, in foster care or residential care)

- ① No, we have never considered placement as an option for our child.
- ② Occasionally the subject of placement comes up, but we do not seriously consider it.
- ③ Yes, we have thought about it a lot, but have done nothing.
- ④ We have inquired about placement, but done nothing else.
- ⑤ We have taken steps to place our child, paper work is in progress.
- ⑥ We have placed our child out-of-home.

If you have seriously considered or taken steps to place this child ③ ④ ⑤ ⑥ please tell us, in your own words, what was your main reason for doing so?

The next questions ask about child care arrangements for this child.

**152** Is there anyone living in your household, apart from you or your partner/spouse, who takes care of this child on a regular basis?

- Yes
- No

**153** If you answered “yes” to question 152, who is this person/these people living in your household who take care of this child on a regular basis?

- grandparent/s
- the child’s brother and/or sister
- other relative
- non-relative, including a live-in nanny

**154** Do you currently use any other child care arrangement/s for this child?

- Yes
- No

If Yes to question 154, please go to question 158 on page 21

**155** If you answered “no” to question 154, would you like to use child care (for example, day care or before and after school programs) for this child?

- Yes
- No

**156** What kind of care would you prefer to use?

- Care in someone else’s home by a non-relative
- Care in someone else’s home by a relative
- Care in child’s home by a non-relative
- Care in child’s home by a relative other than child’s brother or sister
- Care in child’s home by child’s brother or sister
- Daycare centre (this does not include a home based daycare)
- Before and after school program
- Nursery school/ Preschool

Other child care arrangement (please specify)

**157** Why are you not using child care?

- Cost for preferred arrangement is too high
- Preferred arrangement is not available in my community
- Hours of preferred arrangement does not fit my schedule
- On a waiting list
- Preferred arrangement did not have places for children with special needs
- Transportation to/from preferred arrangement is a problem

Other (please specify)

If you do not use any child care arrangement, please go to question 163 on page 22.

**158 About how many hours per week do you use each of the following child care arrangements?**

- > Care in someone else's home by a non-relative \_\_\_\_\_ hours
- > Care in someone else's home by a relative \_\_\_\_\_ hours
- > Care in child's home by a non-relative \_\_\_\_\_ hours
- > Care in child's home by a relative other than child's brother or sister \_\_\_\_\_ hours
- > Care in child's home by child's brother or sister \_\_\_\_\_ hours
- > Daycare centre (this does not include a home based daycare) \_\_\_\_\_ hours
- > Before and after school program \_\_\_\_\_ hours
- > Nursery school/ Preschool \_\_\_\_\_ hours
- > Other child care arrangement \_\_\_\_\_ hours  
(please specify)

**159 Does your main child care provider understand the needs of this child?**

- Yes       No

**160 Given the choice, would you like to use less, the same number, or more hours of child care?**

- Less
- Same number of hours
- More

**161 If you answered "more" to question 161, why are you not using *more* child care?**

- Cost for preferred arrangement is too high
- Preferred arrangement is not available in my community
- Hours of preferred arrangement does not fit my schedule
- On a waiting list
- Preferred arrangement did not have places for children with special needs
- Transportation to/from preferred arrangement is a problem
- Other (please specify)

**162 What is the main reason why you chose your current childcare arrangements?**

- Close to home
- Affordable
- Hours fit my schedule
- Was recommended by friend/relative
- Only option available
- Recommended by a health care professional

Other (please specify)

**163** Has a child care program or service ever refused to take care of this child because of his/her condition or health problem?

- Yes       No

The next section asks about you and your health and wellbeing

**164** How would you describe your general health?

- Poor  
 Fair  
 Good  
 Very good  
 Excellent

**165** Over the past two weeks, have you felt down, depressed, or hopeless?

- Yes       No

**166** Over the past two weeks, have you felt little interest or pleasure in doing things?

- Yes       No

**167** Do you have a long-term physical condition, mental condition, learning or health problem that reduces the amount or the kind of activity you can do?

- Yes       No

**168** If “yes” to question 167, to what extent does a long-term physical condition, mental condition, learning or health problem reduce the amount or the kind of activity you can do?

- Not at all  
 A little  
 Fair amount  
 Quite a lot  
 Great deal

**169** Do you have any of the following long-term conditions which have been diagnosed by a health professional? (please fill any that apply)

- Asthma  
 Heart condition or disease  
 Kidney condition or disease  
 Diabetes  
 Epilepsy  
 Intellectual disability (mental handicap)  
 Depression and/or anxiety disorder  
 Other (please specify)

In the last year, have any of the following happened to you?

170 You suffered a serious illness, injury or assault  
 Yes  No

179 You were seeking work unsuccessfully for more than one month  
 Yes  No

171 A serious illness, injury or assault happened to a close relative  
 Yes  No

180 You had a major financial crisis  
 Yes  No

172 Your parent, partner or child died  
 Yes  No

181 You had problems with the police and a court appearance  
 Yes  No

173 A close family friend or another relative (aunt, cousin, grandparent) died  
 Yes  No

182 Something you valued was lost or stolen  
 Yes  No

174 You broke off a steady romantic relationship  
 Yes  No

183 Someone in your household had an alcohol problem  
 Yes  No

175 You had a serious problem with a close friend, neighbour or relative  
 Yes  No

184 Someone in your household had a drug-use problem  
 Yes  No

176 You had a crisis or serious disappointment in your work or career  
 Yes  No

185 Your partner lost his / her job, but not by choice (fired / redundant, contract ended)  
 N/A  Yes  No

177 You thought you would soon lose your job  
 Yes  No

186 Your partner was seeking work unsuccessfully for more than one month  
 N/A  Yes  No

178 You lost your job, but not by choice (fired / redundant, contract ended)  
 Yes  No

187 You had a separation due to relationship or marital difficulties  
 N/A  Yes  No

**188** Over the last 12 months, what was your total household income?

- Less than \$20,000
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$69,999
- \$70,000 to \$79,999
- \$80,000 to \$89,999
- \$90,000 to \$99,999
- \$100,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 to \$249,999
- More than \$250,000

The next and final section of this questionnaire asks about decisions you have made, and actions you have taken in order to keep your family life running (that is, to free-up time, increase family resources, or reduce demands).

**To keep your family life running in the last 12 months, have you and/or your partner**

	Yes	No
<b>189</b> not taken a job?	①	②
<b>190</b> quit working altogether?	①	②
<b>191</b> turned down a promotion or a better job?	①	②
<b>192</b> taken a less demanding job?	①	②
<b>193</b> worked fewer hours?	①	②
<b>194</b> reduced your participation in community organisations/groups?	①	②
<b>195</b> reduced your level of contact with professionals and other services?	①	②
<b>196</b> made a deliberate decision to have fewer children?	①	②



To keep your family life running in the last 12 months, have you and/or your partner

		Yes	No			Yes	No
197	cut-back on family activities and time together?	①	②	207	increased your use of childcare?	①	②
198	reduced your own participation in leisure or sports?	①	②	208	called on friends or neighbours for assistance?	①	②
199	cut-back on time spent implementing home programs for your disabled child?	①	②	209	turned to other families with disabled children for support?	①	②
200	changed work hours to different times of day or night?	①	②	210	increased your use of respite care?	①	②
201	decided to do more of your paid work from home?	①	②	211	employed a nanny or housekeeper?	①	②
202	become self-employed?	①	②	212	enlisted as much help as you can from professionals and other services?	①	②
203	asked any of your children to take-on some extra responsibility?	①	②	213	called on members of your extended family for support?	①	②
204	renegotiated the division of household labour ? (i.e. taken on a greater/lesser share)	①	②	214	taken a job or worked more hours?	①	②
205	made modifications to your home or vehicle?	①	②	215	increased your involvement with a community organisation or group?	①	②
206	moved to a different place (city, neighbourhood etc) to be closer to support?	①	②	216	gathered as much information as you can about a problem or challenge?	①	②

To keep your family life running in the last 12 months, have you and/or your partner

		Yes	No			Yes	No
217	purposely avoided negative or needy friends/family?	①	②	224	called on child's peer group for assistance?	①	②
218	reduced time spent with non-family members?	①	②	225	purchased items to increase your child's home based activities (gaming systems, computer)?	①	②
219	chosen jobs based on better benefits?	①	②	226	enrolled child in day camp or summer camp?	①	②
220	became an advocate, took political action?	①	②	227	cut down on spending on non-necessities?	①	②
221	furthered education in hopes of better employment (more money, fewer hours)?	①	②	228	made an effort to have 'dates' with your partner?	①	②
222	became less rigid about household chores?	①	②	229	made your family life more structured and stronger in routine?	①	②
223	independently fundraised for devices, supports your child needed?	①	②				

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230 **Please describe any other decisions you have made or actions you have taken in order to keep your family life running** (that is, to free-up time, increase family resources or reduce demands)?

A large, empty rectangular box with a thin black border, intended for the respondent to provide their answer to the question above. The box occupies most of the page's vertical space below the question.

**Thank you so much for assisting us with this important project.**

To acknowledge the time you put into this project, we would like to send you a cheque in the amount of \$30.00. We will also be interviewing a small number of parent-carers to explore, in more depth, strategies for juggling work and family and caregiving. A member of the research team may contact you to see if you would be willing to be one of the interview participants. Please note, the information you have given us will remain strictly confidential.

Address:

Telephone:

Cell number:

**Code no. F**