

STUDY NO. _____

PROCESSES OF CARE QUESTIONNAIRE

We would like to understand and measure the experiences of parents who have a child with a disability. In particular we wish to know about your perceptions of the care you have been receiving over the past year from the Kitimat Child Development Centre.

The questions in this section are based on what parents, like yourself, have told us about the way the care is sometimes offered. We would like you to indicate how much the event or situation happens (or doesn't happen) to you at the Kitimat Child Development Centre. You are asked to answer each question on a scale from 7 (To a Very Great Extent) to 1 (Not at All).

The care that you and your child receive from the Centre may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

1. **PEOPLE:** refers to those individuals who work directly with you or your child. These **may include** psychologists, therapists, social workers, doctors, teachers, etc.
2. **CENTRE:** refers to all staff from the Centre, whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

The following is an example of the kinds of questions you will be asked.

This example also shows what your answer could mean.

	Indicate <u>how much</u> each event or situation happens to you.							
TO WHAT EXTENT DO THE PEOPLE WHO GIVE YOU QUESTIONNAIRES...	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not At All	Not Applicable
...provide you with clear instructions on how to complete them?	7	6	5	4	3	2	1	0

If you circled #7 (To a Very Great Extent), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (To a Moderate Extent), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.

We would like you to think about your experiences over the past year at the Kitimat Child Development Centre. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

For each question, please indicate how much the event or situation happens to you by circling **one** number (from 1 to 7) that you feel best fits your experience.

PEOPLE: refers to those individuals who work directly with you or your child. These **may include** teachers, psychologists, therapists, social workers, doctors, etc.

IN THE PAST YEAR	Indicate <u>how much</u> this event or situation happens to you.							
TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
1.) ..suggest therapy plans that fit with your family's needs and lifestyle?	7	6	5	4	3	2	1	0
2.) ..fully explain treatment choices to you?	7	6	5	4	3	2	1	0
3.) ..offer you positive feedback or encouragement (e.g. in carrying out a home program)?	7	6	5	4	3	2	1	0
4.) ..explain things to your child in a way that your child understands?	7	6	5	4	3	2	1	0
5.) ..take the time to establish rapport with you or your child when changes occur in your services?	7	6	5	4	3	2	1	0
6.) ..discuss with you everyone's expectations for your child, so that all agree on what is best?	7	6	5	4	3	2	1	0
7.) ..make sure that your child's skills are known to all persons working with your child, so the skills are carried across services and service providers?	7	6	5	4	3	2	1	0

IN THE PAST YEAR	Indicate how much this event or situation happens to you.							
TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
8.) ..tell you about options treatment or services for your child (e.g., equipment, school, therapy.)	7	6	5	4	3	2	1	0
9.) ..accept you and your family in a non-judgmental way?	7	6	5	4	3	2	1	0
10.) ..provide ideas to help you work with the health care “system”?	7	6	5	4	3	2	1	0
11.) ..recognize the demands of caring for a child with special needs?	7	6	5	4	3	2	1	0
12.) ..trust you as the “expert” on your child?	7	6	5	4	3	2	1	0
13.) ..look at the needs of your “whole” child (e.g. at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
14.) ..show sensitivity to your family’s feelings about having a child with special needs (e.g. your worries about your child’s health or function)?	7	6	5	4	3	2	1	0
15.) ..anticipate your concerns by offering information even before you ask?	7	6	5	4	3	2	1	0
16.) ..make sure you have a chance during visits to the Centre to say what is important to you?	7	6	5	4	3	2	1	0

IN THE PAST YEAR	Indicate how much this event or situation happens to you.							
TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
17.) ..let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0
18.) ..remember personal details about your child or family when speaking to you?	7	6	5	4	3	2	1	0
19.) ..tell you about the reasons for treatment or equipment?	7	6	5	4	3	2	1	0
20.) ..follow up at the next appointment on any concerns you discussed at the previous one?	7	6	5	4	3	2	1	0
21.) ..make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
22.) ..provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
23.) ..answer your questions completely?	7	6	5	4	3	2	1	0
24.) ..explain what they are doing when you are watching your child in therapy?	7	6	5	4	3	2	1	0
25.) ..recognize that your family has the final say when making decisions about your child's treatment?	7	6	5	4	3	2	1	0
26.) ..tell you about the results from assessments?	7	6	5	4	3	2	1	0

IN THE PAST YEAR	Indicate how much this event or situation happens to you.							
TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
27.) ..provide you with written information about what your child is doing in <u>therapy</u> ?	7	6	5	4	3	2	1	0
28.) ..consult with you when discussing equipment or services?	7	6	5	4	3	2	1	0
29.) ..provide a caring atmosphere <u>rather</u> than just give you information?	7	6	5	4	3	2	1	0
30.) ..tell you the details about your child's services, such as the reasons for them, the type of therapies and the length of time?	7	6	5	4	3	2	1	0
31.) ..treat you as an individual rather than as a "typical" parent of a child with a disability?	7	6	5	4	3	2	1	0
32.) ..develop both short-term and long-term goals for your child?	7	6	5	4	3	2	1	0
33.) ..treat you as an equal rather than just a parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
34.) ..plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0

IN THE PAST YEAR	Indicate how much this event or situation happens to you.							
TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
35.) ..make sure you have opportunities to explain what you think are important treatment goals?	7	6	5	4	3	2	1	0
36.) ..make sure you feel like a partner in your child's care?	7	6	5	4	3	2	1	0
37.) ..make sure you are informed ahead of time about any changes in your child's care (e.g. therapists, programs, equipment)?	7	6	5	4	3	2	1	0
38.) ..help you feel competent as a parent?	7	6	5	4	3	2	1	0
39.) ..provide you with written information about your child's progress?	7	6	5	4	3	2	1	0
40.) ..seem aware of your child's changing needs as he/she grows?	7	6	5	4	3	2	1	0
41.) ..provide enough time to talk so that you do not feel rushed?	7	6	5	4	3	2	1	0
42.) ..treat you and your family as people rather than as a "case" (e.g., by not referring to you by diagnosis, such as the "spastic diplegic")?	7	6	5	4	3	2	1	0

IN THE PAST YEAR	Indicate how much this event or situation happens to you.							
TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
43.) ..listen to what you have to say about your child's needs for equipment, services, etc.?	7	6	5	4	3	2	1	0
44.) ..make themselves available to you as a resource (e.g. emotional support, advocacy, information)?	7	6	5	4	3	2	1	0
45.) ..give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0

IN THE PAST YEAR	Indicate how much this event or situation happens to you.							
TO WHAT EXTENT DOES THE CENTRE	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
46.) ..have information available to you in various forms, such as booklet, kit, video, etc.?	7	6	5	4	3	2	1	0
47.) ..have support staff that are polite and courteous to you and your family?	7	6	5	4	3	2	1	0
48.) ..give you information about the types of services offered at the Centre, or in the community?	7	6	5	4	3	2	1	0
49.) ..promote family-to-family gatherings for social, informational, or shared experiences?	7	6	5	4	3	2	1	0
50.) ..provide opportunities for special guests to speak to parents on topics of interest?	7	6	5	4	3	2	1	0
51.) ..provide support to help cope with the impact of child disability (e.g. by advocating on your behalf or informing you of assistance programs)?	7	6	5	4	3	2	1	0
52.) ..notify you about the reasons for upcoming case conferences, meetings, etc., about your child?	7	6	5	4	3	2	1	0
53.) ..have information available about your child's disability (e.g. its causes, how it progresses, future outlook)?	7	6	5	4	3	2	1	0

IN THE PAST YEAR	Indicate how much this event or situation happens to you.							
TO WHAT EXTENT DOES THE CENTRE	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
54.) ..provide advice on how to get information or to contact other parents?	7	6	5	4	3	2	1	0
55.) ..provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
56.) ..have general information available about different concerns (e.g. financial costs or assistance, genetic counseling, dating and sexuality)?	7	6	5	4	3	2	1	0

What is your relationship to your child with special needs?

- | | |
|--|--|
| <input type="checkbox"/> Birth Mother | <input type="checkbox"/> Birth Father |
| <input type="checkbox"/> Stepmother | <input type="checkbox"/> Stepfather |
| <input type="checkbox"/> Adoptive Mother | <input type="checkbox"/> Adoptive Father |
| <input type="checkbox"/> Foster Mother | <input type="checkbox"/> Foster Father |
| <input type="checkbox"/> Other Guardian, please specify: _____ | |

On what date did you complete this questionnaire? ____/____/____
Day / Month / Year

ANY COMMENTS:

PLEASE CHECK THAT BOTH SIDES OF ALL PAGES ARE COMPLETED

CONFIDENTIAL WHEN COMPLETED

THANK YOU!