Supplementary File 1A - Study Flyer

SURVIVING AND THRIVING IN PARENTING NEURODIVERSE CHILDREN

The survey aims to understand:

- Rewards and challenges in parenting neurodiverse children
- Parental health
- Access to support

- ✓ For all parents and caregivers of neurodiverse children (regardless of age)
- ✓ Takes 30 min
- ✓ Confidential
- ✓ Chance to win $100 gift card

PARTICIPATE:

https://redcap.ualberta.ca/surveys/?s=FRTCNX7FTR

or contact us at:
SurviveThrive@iwk.nshealth.ca or phone: 1-877-341-8309, Ext. 7

Centre for Research in Family Health | IWK Health Centre | CHILD-BRIGHT Network | SPOR | CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

Supplementary File 1B – Online Consent

Welcome to our survey "Surviving and Thriving in Parenting Neurodiverse Children"

The aim of this survey is to help us better understand both the challenging and the rewarding experiences of **parents (or other primary caregivers) of neurodiverse children living in Canada**. We are particularly interested in how these experiences are related to parent health. Findings from the study will help to develop future programs to promote parent well-being. Please read the information about this study below. By clicking the 'OK' button at the bottom of this introductory section, you agree to the conditions of this study and agree to participate in this study.

The term "neurodiverse child" refers to children diagnosed with a neurodevelopmental disorder (for example, Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder (ADHD), Cerebral Palsy, Epilepsy, Global Developmental Delay, Down Syndrome, Fetal Alcohol Spectrum Disorder (FASD), severe learning disability or any other diagnosis that influences how a child gets around, communicates his/her/their ideas, processes what he/she/they hear, or remembers things).

Your participation is voluntary: taking part in this survey is entirely voluntary. You are under no obligation to complete the survey and can stop at any time.

All information you give is confidential: information gathered about you through this survey will be strictly confidential. No identifying information about individuals will be included in any of the publications that derive from this survey.
In case you are interested in further studies or you wish to receive information about the results of the survey, we will ask for your name and contact information at the end of the survey. Giving your name and contact information is voluntary; if you decide not to give this information, your answers will be processed anonymously.
In the rare event that we learn anything during your participation in this study that would cause us to believe that you are in danger of harming yourself or others, you will be encouraged to seek professional help.
The IWK Research Ethics Board, the Canadian Institutes of Health Research, the Data Coordinating Centre (University of Alberta), and other funders of this study could review study information (audit the study) to make sure that the research is being done properly. In the case of an audit, your file, which *may* include your name and information that you have provided during the study, could be reviewed.

No cost: there is no cost in completing this survey. However, you will be using the Internet to complete the survey.

Chance to win a $100 gift card: by participating, you have the chance to win one of three $100 gift cards.

Time: approximately 30 minutes.

Potential harms and benefits: Some questions may be sensitive and remind you of challenging experiences in the past, but **you do NOT have to answer any questions that make you feel uncomfortable**. You may contact our study team any time if you have concerns or would like to talk about your experience (see contact information at the end of this section).
You could benefit from this survey if you consent to be contacted for future studies and programs that may provide you with helpful resources, skills, or support. For example, depending on how you answer some questions, you may be eligible to participate in a study of a pilot program for parents of neurodiverse children dealing with challenging experiences.

Storage of online information:
All personal information you provide in the survey will be treated as private and confidential. Information entered into the online survey platform called REDCap will be stored on a secure server. The data obtained from REDCap will be stored on secure servers at the University of Alberta, our contracted Data Coordinating Centre, for the duration of the study. At the end of the study, the data will be archived, so that it is only accessible by system programmers, unless required by an audit. It will be archived after study results are published (i.e. they will not be visible or accessible to system users). All identifying information, such as name and contact information, will be replaced with study ID numbers; identifiers will be excluded from databases and reports. All identifying information will be permanently deleted five years after results of the study are published.

The IWK Research Ethics Board, the Canadian Institutes of Health Research, the Data Coordinating Centre (University of Alberta), or other funders of this study could review study information (audit the study) to make sure that the research is being done properly. In the case of an audit, your file, which may include your name and information that you have provided during the study, could be reviewed.

Research rights:
Clicking the 'OK' button at the bottom of this introductory section indicates you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the investigator(s), sponsors, or involved institution(s) from their legal and professional responsibilities. Choosing not to take part will in no way affect the care you and/or your child currently receives or will receive in the future. If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. You are free to withdraw from the study at any time without jeopardizing the health care you are entitled to receive.
If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health at 902-470-8717, Monday to Friday between 8:00a.m. and 4:00p.m.

If at any point throughout the survey you are feeling that you may be in immediate danger of seriously harming yourself or someone else, you should seek help right away by going to your nearest emergency room or calling 911. You may also call Crisis Services Canada, at 1-833-456-4566.

Our research team:

Principal investigators:
Dr. Patrick J. McGrath and Dr. Elisa Kaltenbach (IWK Health)
Co-investigators:
Dr. Lucyna Lach (McGill University), Dr. Janine Olthuis (University of New Brunswick), and Dr. Anselm Crombach (University of Konstanz, Germany)
Research Assistants:
Ting Xiong (Master's Program in Psychiatry Research, Dalhousie University), and Michelle Chisholm (IWK Health)

Conflicts of interest: There are no actual, perceived, or potential conflicts of interest in relation to this study. Our research team will NOT benefit financially from commercialization of the study results.

Granting agencies: Canadian Institutes for Health Research (CIHR), Strategy for Patient Oriented Research (SPOR)
IWK Health

Contact us:

Contact the research coordinator Toll Free at 1-877-341-8309, then press 7 or by email at SurviveThrive@iwk.nshealth.ca.

In person: Dr. Patrick McGrath / Dr. Elisa Kaltenbach / Ting Xiong / Michelle Chisholm
Centre for Research in Family Health, IWK Health
5850/5980 University Avenue, Halifax, NS, B3K 6R8

Contact principal investigators: Patrick.McGrath@iwk.nshealth.ca

Elisa.Kaltenbach@iwk.nshealth.ca

Pressing this button means that you agree to the study conditions listed above and you wish to participate in this survey.

OK

Supplementary File 1C – Parenting Trauma Checklist

Below you will find some difficult experiences parents sometimes experience while caring for their child or children. Please indicate which of these events you experienced.

	Yes	No
(1) Witnessing a life-threatening situation of your child (e.g. severe bleeding, stop breathing, passing out, severe seizures)	☐	☐
(2) Witnessing a severe accident or injury of your child (e.g. car accident, falling, drowning)	☐	☐
(3) Experiencing a medical emergency of your child (ambulance rides, rushing to hospital, calling 911)	☐	☐
(4) Seeing your child undergoing a medical procedure (e.g. breathing treatments, child hooked up to machines, forced treatments, CPR)	☐	☐
(5) Your child undergoing a life-threating surgery (e.g. heart surgery, organ transplant, routine surgery that is life-threatening because of pre-existing conditions)	☐	☐
(6) Hearing of a life-threatening event of your child (e.g. that may have happened at school, in your absence)	☐	☐
(7) Fearing that your child would die while waiting for care (e.g. waiting for ambulance, waiting for transplant)	☐	☐
(8) Receiving diagnosis of life-threatening disability of your child	☐	☐
(9) Being in the ICU/NICU/PICU with your child	☐	☐
(10) Witnessing a child not in your care die or being critically ill	☐	☐
(11) Applying life-saving procedures to your child during crisis (e.g. performing CPR, give / inject rescue medication)	☐	☐
(12) Witnessing serious self-harming behavior of your child (e.g. injuring themselves, suicide attempt)	☐	☐
(13) Birth was life-threatening for mother or child	☐	☐
(14) Miscarriage	☐	☐
(15) Death of your child	☐	☐
(16) A situation in which your child threatened the health or life of you or someone else	☐	☐
(17) Other situations that were extremely frightening when caring for your child. Please explain:_____	☐	☐

Supplementary File 1D – Barriers for Help-seeking Scale

When looking or receiving support for mental health challenges related to caregiving, several obstacles can get in your way. Please indicate to what extent the following statements affected your access to care?

(1) I don't have enough time

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(2) Support is too far away

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(3) The expense and added costs (e.g. time off work, transportation) are too high

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(4) I don’t have access to support that is based on the latest research.

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(5) I don’t know how to get access to support.

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(6) The waiting lists are too long

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(7) I am not emotionally ready for receiving support

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(8) It might not be confidential

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(9) Support would not be helpful for me

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(10) Support involves loss of control/autonomy

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(11) I don't want to be labelled as having a mental illness

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(12) I feel guilty for having mental health challenges from caring for my child

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(13) My child and my family are my priority; I have to focus on caregiving

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(14) The people around me discourage me from seeking help for mental health challenges

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(15) I want to avoid talking about stressful experiences in my life

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

(16) Other: please state: _____

☐ Not at all

☐ A little bit

☐ Moderately

☐ Quite a bit

☐ Extremely

☐ Prefer not to answer

Supplementary File 1E – Demographics

Thank you for taking part in this survey. In the first section we will ask you some general questions about you and your child/ren.

[1] Are you a parent/ caregiver of a neurodiverse child or children?
☐ Yes
☐ No

[2] Do you live in Canada?
☐ Yes
☐ No

[3] Your date of birth (YYYY-MM-DD)
_____
☐ Prefer not to answer

[4] The gender you identify with
☐ Female
☐ Male
☐ Other, please specify: _____
☐ Prefer not to answer

[5] Which best describes your relationship with your child? I am the...
☐ Mother (biological)
☐ Father (biological)
☐ Mother (adoptive)
☐ Father (adoptive)
☐ Mother (adoptive)
☐ Stepmother
☐ Stepfather
☐ Legal guardian
☐ Foster parent
☐ Other, please specify:_____
☐ Prefer not to answer

[6] Your marital status
☐ Never married

☐ Married
☐ Domestic partnership (you are unmarried, but have a relationship with your partner and you live together)
☐ Divorced
☐ Separated
☐ Widowed
☐ Prefer not to answer

[7] Your highest level of education
☐ Primary school
☐ High school
☐ Occupational/ technical/ vocational training
☐ University degree (Bachelor or higher)
☐ Other: _____
☐ Prefer not to answer

[8] Your current employment status
☐ Full-time employment
☐ Part-time employment
☐ Looking for work/ unemployed
☐ Stay-at-home parent/ caregiver (unpaid)
☐ Other: _____
☐ Prefer not to answer

[9] Where are you located?
☐ Urban setting
☐ Suburban setting
☐ Rural setting
☐ Remote setting
☐ Prefer not to answer

[10] What are the first 3 letters of your postal code?

_____
☐ Prefer not to answer

[11] How many children do you have?

_____
☐ Prefer not to answer

[12] How many neurodiverse children do you have?

_____

☐ Prefer not to answer

If you have more than 1 neurodiverse child, please answer the following 3 questions based on the one with the most severe challenges. If this is not possible, please answer for the oldest neurodiverse child.

[13] Your child's date of birth (YYYY-MM-DD)

_____

☐ Prefer not to answer

[14] Please select your child's developmental disability/diagnosis (Please check all that apply)

☐ Attention Deficit Hyperactivity Disorder
☐ Autism Spectrum Disorder
☐ Down syndrome
☐ Epilepsy
☐ Fetal Alcohol Spectrum Disorder
☐ Global Developmental Delay
☐ Intellectual Disability (difficulties in intellectual functioning and adaptive behavior)
☐ Learning Disability (e.g. dyslexia, dyscalculia)
☐ Spina bifida
☐ Cerebral Palsy
☐ Other

If other, please specify: _____

☐ Prefer not to answer

[15] In which year did your child get the first diagnosis?

_____

☐ Prefer not to answer

[16] How many hours do you spend on caregiving of your child per week (0 – 168 hours)?

_____

☐ Prefer not to answer

[17] How is the daily life of you and your child(ren) affected by COVID - 19? Please only mark if this changed due to the COVID-19 pandemic. (Check all that apply)

☐ My child doesn't receive necessary treatment

☐ I am not allowed to see my child(ren) (e.g. because child(ren) lives in care facility)

☐ I have to work and take care of my child(ren) at the same time

☐ I have a profession that puts me and my child(ren) at a higher risk

☐ I am the primary caregiver for my child(ren) and am fearful of who will care for my child(ren) if I contract COVID-19

☐ The hired/volunteer support I receive to assist in caring for my child(ren) decreased substantially / is not available anymore

☐ The support I receive from family/friends to assist in caring for my child(ren) has decreased substantially / is not available anymore

☐ My family is under considerable emotional stress because of COVID-19

☐ My family is under considerable financial stress because of COVID-19

☐ Other difficulties: _____

☐ Not affected

☐ Prefer not to answer

Supplementary File 1F - PTSD Checklist for DSM-5

Below is a list of difficulties that people sometimes have in response to a very stressful experience. Please read each problem carefully and then click the option most appropriate for you to indicate how much you have been bothered by the stressful experience you just identified **in the past month**.

In the past month, how much were you bothered by	Not at all	A little bit	Moderately	Quite a bit	Extremely
(1) Repeated, disturbing, and unwanted memories of the stressful experience?	☐	☐	☐	☐	☐
(2) Repeated, disturbing dreams of the stressful experience?	☐	☐	☐	☐	☐
(3) Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?	☐	☐	☐	☐	☐
(4) Feeling very upset when something reminded you of the stressful experience?	☐	☐	☐	☐	☐
(5) Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?	☐	☐	☐	☐	☐
(6) Avoiding memories, thoughts, or feelings related to the stressful experience?	☐	☐	☐	☐	☐
(7) Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?	☐	☐	☐	☐	☐
(8) Trouble remembering important parts of the stressful experience?	☐	☐	☐	☐	☐
(9) Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	☐	☐	☐	☐	☐

(10) Blaming yourself or someone else for the stressful experience or what happened after it?	☐	☐	☐	☐	☐
(11) Having strong negative feelings such as fear, horror, anger, guilt, or shame?	☐	☐	☐	☐	☐
(12) Loss of interest in activities that you used to enjoy?	☐	☐	☐	☐	☐
(13) Feeling distant or cut off from other people?	☐	☐	☐	☐	☐
(14) Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?	☐	☐	☐	☐	☐
(15) Irritable behavior, angry outbursts, or acting aggressively?	☐	☐	☐	☐	☐
(16) Taking too many risks or doing things that could cause you harm?	☐	☐	☐	☐	☐
(17) Being “superalert” or watchful or on guard?	☐	☐	☐	☐	☐
(18) Feeling jumpy or easily startled?	☐	☐	☐	☐	☐
(19) Having difficulty concentrating?	☐	☐	☐	☐	☐
(20) Trouble falling or staying asleep?	☐	☐	☐	☐	☐

Supplementary File 1G - Life Events Checklist for DSM -5

Listed below are a number of difficult or stressful things that sometimes happen to people. These events can happen to yourself, you can witness how they happen to others, or you can learn that they happened to people you love.
Be sure to **consider your entire life** (growing up as well as adulthood) whether you have experienced these events.

	Yes	No
(1) Natural disaster (for example, flood, hurricane, tornado, earthquake)	☐	☐
(2) Fire or explosion	☐	☐
(3) Transportation accident (for example, car accident, boat accident, train wreck, plane crash)	☐	☐
(4) Serious accident at work, home, or during recreational activity	☐	☐
(5) Exposure to toxic substance (for example, dangerous chemicals, radiation)	☐	☐
(6) Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)	☐	☐
(7) Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb)	☐	☐
(8) Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)	☐	☐
(9) Other unwanted or uncomfortable sexual experience	☐	☐
(10) Combat or exposure to a war-zone (in the military or as a civilian)	☐	☐
(11) Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war)	☐	☐
(12) Life-threatening illness or injury	☐	☐
(13) Severe human suffering	☐	☐
(14) Sudden violent death (for example, homicide, suicide)	☐	☐
(15) Sudden accidental death	☐	☐
(16) Serious injury, harm, or death you caused to someone else	☐	☐
(17) Any other very stressful event or experience	☐	☐

Supplementary File 1H – Posttraumatic Growth Inventory-Short Form

We have talked about the difficulties people can face after stressful experiences, but there are also areas of growth and positive change that can be a result of such experiences. Each of the statements below indicate the degree to which change occurred in your life as a result of the stressful experience you just reported.

	No	A very small degree	A small degree	A moderate degree	A great degree	A very great degree
(1) I changed my priorities about what is important in life.	☐	☐	☐	☐	☐	☐
(2) I have a greater appreciation for the value of my own life.	☐	☐	☐	☐	☐	☐
(3) I am able to do better things with my life.	☐	☐	☐	☐	☐	☐
(4) I have a better understanding of spiritual matters.	☐	☐	☐	☐	☐	☐
(5) I have a greater sense of closeness with others.	☐	☐	☐	☐	☐	☐
(6) I established a new path for my life.	☐	☐	☐	☐	☐	☐
(7) I know better that I can handle difficulties.	☐	☐	☐	☐	☐	☐

(8) I have a stronger religious faith.	☐	☐	☐	☐	☐	☐
(9) I discovered that I am stronger than I thought I was.	☐	☐	☐	☐	☐	☐
(10) I learned a great deal about how wonderful people are.	☐	☐	☐	☐	☐	☐

Supplementary File 1I – PROMIS Global Mental Health and Global Physical Health

Thank you very much for completing the first section of this survey! In the next part, you will be asked about your well-being.

[1] In general, how would you rate your physical health?

☐ Excellent

☐ Very Good

☐ Good

☐ Fair

☐ Poor

[2] To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

☐ Completely

☐ Mostly

☐ Moderately

☐ A little

☐ Not at all

[3] In the past 7 days, how would you rate your physical pain on average?

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

0 = no pain 10 = worst pain imaginable
(Higher score means higher degree of pain)

[4] In the past 7 days, how would you rate your fatigue on average?

☐ None

☐ Mild

☐ Moderate

☐ Severe

☐ Very severe

[5] In general, would you say your quality of life is:

☐ Excellent

☐ Very Good

☐ Good
☐ Fair
☐ Poor

[6] In general, how would you rate your mental health, including your mood and your ability to think?

☐ Excellent
☐ Very Good
☐ Good
☐ Fair
☐ Poor

[7] In general, how would you rate your satisfaction with social activities and relationships?

☐ Excellent
☐ Very Good
☐ Good, Fair
☐ Poor

[8] How often have you been bothered by negative emotions such as feeling anxious, depressed or irritable?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always

Supplementary File 1J – The Multidimensional Scale of Perceived Social Support

Please indicate how you feel about each statement.

	Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree
(1) There is a special person who is around when I am in need.	☐	☐	☐	☐	☐	☐	☐
(2) There is a special person with whom I can share my joys and sorrows.	☐	☐	☐	☐	☐	☐	☐
(3) My family really tries to help me.	☐	☐	☐	☐	☐	☐	☐
(4) I get the emotional help and support I need from my family.	☐	☐	☐	☐	☐	☐	☐
(5) I have a special person who is a real source of comfort to me.	☐	☐	☐	☐	☐	☐	☐
(6) My friends really try to help me.	☐	☐	☐	☐	☐	☐	☐
(7) I can count on my friends when things go wrong.	☐	☐	☐	☐	☐	☐	☐
(8) I can talk about my problems with my family.	☐	☐	☐	☐	☐	☐	☐
(9) I have friends with whom I can share my joys and sorrows.	☐	☐	☐	☐	☐	☐	☐
(10) There is a special person in my life who cares about my feelings.	☐	☐	☐	☐	☐	☐	☐
(11) My family is willing to help me make decisions.	☐	☐	☐	☐	☐	☐	☐
(12) I can talk about my problems with my friends.	☐	☐	☐	☐	☐	☐	☐

Supplementary File 1K – The Konstanz INDEX-Adjusted questions

Caregiving can be rewarding, but it can sometimes also be difficult. In such difficult times, one might look for professional support.

(1) During such a time, have you ever sought help from a doctor, a therapist or a clinic for mental health difficulties?

☐ Yes

☐ No

(2) Has a medical doctor or a psychologist ever diagnosed that you are suffering from a mental health disorder, such as depression, anxiety disorder, posttraumatic stress disorder or another mental health disorder?

☐ Yes

☐ No

If yes, which?

a) Depression: ☐ Yes ☐ No

b) Anxiety disorder: ☐ Yes ☐ No

c) Posttraumatic stress disorder: ☐ Yes ☐ No

d) Other diagnosis: ☐ Yes ☐ No

If yes, which one: _____

(3) Have you ever thought that you might suffer from a mental health challenge– even though it was not diagnosed by a professional?

☐ Yes

☐ No

If yes, which challenges were present: _____

Supplementary File 1L – Sheehan Disability Scale

The following questions ask you to which extent you are affected by the difficulties you reported above.

(1) The difficulties have disrupted your work/ school work in the past month.

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Not at all moderately extremely

(2) I have not worked/studied at all during the past month for reasons unrelated to the above difficulties.

☐ Yes

☐ No

(3) The difficulties have disrupted your social life / leisure activities in the past month.

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Not at all moderately extremely

(4) The difficulties have disrupted your family life / home responsibilities in the past month.

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Not at all moderately extremely

(5) How many days **in the last week** did your difficulties cause you to miss school/work or leave you unable to carry out your normal daily responsibilities (0 – 7 days)?

_____

(6) How many days **in the last week** did you feel so impaired by your difficulties, that even though you went to school or work, your productivity was reduced (0 – 7 days)?

_____

Supplementary File 1M– The Parent and Family Adjustment Scales-Parenting Subscale

Sometimes the interaction with your child might be easy-going and relaxed, other times you or your child might be stressed and the interaction changes. Every parent has their own way of communicating and interacting with their child – adapted to the situation and the needs of the child. In the following, we ask a variety of questions about your interaction with your child/ren. Some might apply to you and others don't. Please indicate for each of the following statements how true or not true they are for you and your child/ren.
Depending on the abilities of your child (e.g. when your child is non-verbal or has difficulties in understanding), some of the questions might not apply to you. In this case, answer with "not applicable".

	Not true of me		True of me		
	Not at all	A little	Quite a lot	Very much	Not Applicable
1. I chat / talk with my child	☐	☐	☐	☐	☐
2. I enjoy giving my child hugs, kisses and cuddles	☐	☐	☐	☐	☐
3. I am proud of my child	☐	☐	☐	☐	☐
4. I enjoy spending time with my child	☐	☐	☐	☐	☐
5. I have a good relationship with my child	☐	☐	☐	☐	☐
6. I get annoyed with my child	☐	☐	☐	☐	☐
7. If my child doesn't do what he/she/they is/are told to do, I do it myself	☐	☐	☐	☐	☐
8. I give my child a treat, reward or fun activity for behaving well	☐	☐	☐	☐	☐
9. I follow through with a consequence (e.g. take away a toy) when my child misbehaves	☐	☐	☐	☐	☐
10. I threaten something (e.g. to turn off TV) when my child misbehaves but I don't follow through (e.g. I don't turn off the TV)	☐	☐	☐	☐	☐
11. I shout or get angry with my child when he/she/they misbehave	☐	☐	☐	☐	☐
12. I try to make my child feel bad (e.g. guilt or shame) for misbehaving to teach him/her/them a lesson	☐	☐	☐	☐	☐
13. I give my child attention (e.g. a hug, wink, smile or kiss) when he/she/they behave well	☐	☐	☐	☐	☐

14. I argue with my child about his/her/their behaviour/attitude	☐	☐	☐	☐	☐
15. I deal with my child's misbehaviour the same way all the time	☐	☐	☐	☐	☐
16. I give my child what he/she/they want when he/she/they get angry or upset	☐	☐	☐	☐	☐
17. I praise my child when he/she/they behave well	☐	☐	☐	☐	☐