

Interview Guide Autism & COVID-19

Welcome & Thank you for participating

In this interview we are curious about your experience of the Covid-19 measures. I usually use the word covid, but sometimes maybe corona. I always mean the situation that arose with the announcement of national measures due to the corona virus in March 2020.

We would like to ask you to tell us in your own words about the changes you have experienced in your situation, for example at home, at school, at work and in the care context of your child. It's about your experience, in your words and in your order. It doesn't have to be a well-developed story, you can just tell what comes to mind. There are no right and wrong answers and the interviewer is not surprised by anything.

The interviewer will continue to ask for explanations and details. If you do not understand a question or find it difficult, you can ask the interviewer for clarification. If you don't want to or can't answer a question, that's always okay. If you want to pause or finish, you can also indicate that.

Can I say you and you? (*in Dutch there is a more formal form of addressing individuals*)

Takes about an hour

Do you have any questions before we start?

Do you still agree to record this interview?

Then I start recording now.

(intro 5 min)

A. Spontaneous reporting & prioritization

(10 min)

Let's start with your experience of the corona crisis.

1. Can you tell us how you experienced the Covid situation?

Points of attention interview-intro:

- Intro at the **emotional level!**
- Invite to speak **spontaneously**
- Carefully probe for **prominence** of experiences: what weighed the most, which changes were the most disruptive?
- General **tenor**: positive, negative, double, ambivalent?
- Form an impression of **balance**: focus mainly on child? Where is parent in the story (present/absent)?

B. Perceived change - concrete & factual questioning**(10 min)**

I would like to ask a few more concrete things, so that I have a good idea of how the corona crisis has changed the situation for you and your child.

2. *Can you outline what concrete things have changed in the Covid circumstances?*

Assess actual changes

- a. home situation & family dynamics
 - b. care context child
(Pay attention to multidisciplinary → per institution and relationship between institutions)
 - c. school
 - d. work
 - e. political & social
3. *Can you explain how these things differ in concrete terms from the situation before Covid?*
 - **Ask per situation for a concrete comparison pre-post Covid**
 - **How would you characterize this change?**
 - Well-arranged to badly arranged
 - Well arranged to better arranged
 - Badly arranged to worse arranged
 - Badly arranged to better arranged
 - Not arranged to well arranged
 - Not arranged to badly arranged
 - Not settled & still not settled

C. Emotional impact child - feeling level**(5 min)**

(refer to spontaneous speaking A for transition). You already said that...

I would like to know more about the impact of the corona crisis on your child's emotional life.)

4. *How has your child reacted to the Covid measures?*

- *How has this affected your child's well-being?*

Assess specifically:

- Structure & Daily planning
- Sleeping & Eating
- Feeling Level:
 - General: emotion, emotion regulation
 - ASD-specific: symptomatic handling of emotions
 - Covid-specific: fear, (un)rest, (in)understanding?

- Comparison of brothers/sisters/nephews/neighbors? → compare

5. *Can you describe where and how your child normally feels safe/unsafe?*

Assess specifically:

- Indoor/outdoor
- Significant others

6. *Has the sense of indoor/outdoor security changed due to Covid?*

- *Is this Covid-specific.. (eg fear of the virus)*
- *...or response to Covid measures (eg response to uncertainty/grey area)*
- *...or reaction to reaction of others (eg others are more difficult to gauge)*

D. D. Emotional impact parent(s): emotional level

(5 min)

(transition from C.)

7. *How are you?*

- you as a person?
- Your emotions/fears/concerns regarding the child?
- Your emotions/fears/concerns regarding work (own/partner)?
- Your emotions/fears/concerns about society/future?

8. *What is it like for you that these questions are being asked?*

- *Who usually asks you this question?*
- *Is there sufficient attention for you as a person?*
- *Can you take care of yourself sufficiently in these circumstances?*

Assess per answer:

- *Would you specifically attribute these experiences to Covid?*
- *If no: are they comparable to pre-Covid?*
- *Or: have they become magnified/ are you more aware of it because of Covid?*

9. *How do the current circumstances affect your relationship with (important) others?*

- *Wait for spontaneous reporting FIRST; WAIT to provide examples-others. Then assess:*
 - *Partner*
 - *Siblings → do they have diagnoses?*
 - *Family*
 - *Friends*
 - *Babysitter/nanny*
- *Would you specifically attribute this to Covid?*

E. Information and care needs**(10 min)**

I would like to ask you a few more things about the provision of information during the corona crisis, and the care you or your child received or would have liked to receive during this period.

10. Did you miss care due to Covid measures?

- Were others involved besides formal care & nuclear family?
 - For example: parents, babysitter..
- What care would have been helpful to you?
 - i. For child
 - ii. For parent/family
- How would you have liked to receive this care?

11. Did you receive care via (video) calling?

- If yes: how did you experience this?
- If yes: how did your child experience this?

12. How did you experience the information provided about Covid?

Assess Specific:

- From the government
- From institutions/school/care network

13. Did you miss information?

- Has your child indicated that he/she has missed information?
- Which information provision would have been helpful to you?
 - i. For child
 - ii. For parent/family
- How would you like to receive this information provision?

F. Roleconfusion**(5 min)**

(transition from E)

14. As a parent, you were also an information provider to your child. How did you experience this?

15. How did you experience translating information provided from government/institutions to your child?

16. Did you use the COVID-19 signpost sheet on the NVA (Dutch Autism Association) website?

17. What would have been helpful to you in this dual role?

18. These questions were about Covid. Are there things we can learn from this for more regular times and/or special circumstances?

- What are the most important lessons for you to be learned from the Covid crisis with regard to ASD care and information provision?

G. Survey experience

(5 min)

19. Are there things I didn't ask, but that are important to understand your story?

20. How did you experience this interview?

21. How did you experience the questionnaires?

- Did you request support?
- Has your child requested support?

Thank you for your participation.

As agreed, you will receive a newsletter with our research findings as soon as the research has been completed.

If you still have questions after this interview, or if you want to add something, you can always send the researchers a message.

If you notice that this interview raises a new care need in you, please let the researchers know. We can always think along with you.

Thank you again for your participation

(closing 5 min)