

List of themes for scientific research

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www.kindvanauti.nl

In the scientific research into autism, one group is underexposed. The children of parents with autism. How do they experience their parents' autism? What consequences do the children notice of their parents' autism and what consequences are present but go unnoticed?

In the Netherlands we do not know how many people we're talking about. KindvanAuti's estimate is that there are 70,000 underage children who have a parent with autism or where both parents have autism.

We do not know of how many (underage and adult) children we speak. We also do not know the consequences of an upbringing in which autism takes center stage.

KindvanAuti Foundation has questions. We have compiled a preliminary list of questions. We hope that scientists will want to investigate these questions.

Which questions would KindvanAuti Foundation like to see answered? Below is a (non-exhaustive) list:

1.

How many underage children are there in the Netherlands of whom one or both parents have autism?

2.

In what ways does upbringing by a parent with autism differ from parenting with a parent without autism? It seems obvious to look at emotional attunement and empathy.

3.

What effects does upbringing by a parent (or parents) with autism have on the child when it is not yet an adult?

4.

What effects does upbringing by a parent (or parents) with autism have on the child once it is an adult?

5.

Research has been conducted into the obstacles that parents with autism claim to experience for themselves. In that study, these experiences were compared to obstacles that parents without autism claim to experience (Pohl et al. *Molecular Autism* (2020) 11: 3). What obstacles do the children of parents with autism say they experience? What do the children have to say when they are minors and what do the children who have grown up have to say about their experience?

6.

Beatrice Beebe examines how parents tune in to babies and what effects this has (Beebe, *Psychoanalytic Psychology*, 2014, vol. 31, number 1, 4-25). Is there a link between Beebe's research and autism in the parent?

7.

Is it possible to diagnose (adult) children of parents with autism without having to diagnose the parent (s) with (presumably) autism? Some of the parents with autism avoid care and refuse to cooperate directly or indirectly with a request for help from their child(ren).

8.

The authoritative publication *1 op de 4* of the Dutch Youth Institute (Van Gennep, 2017) describes child abuse as follows: "We understand child abuse as all forms of mental and physical abuse,

neglect and abuse, whether sexual or not, both in the family and out there.” Autism is accompanied by a lack of empathy. The parent with autism is unable, insufficiently able or less able to attune his behavior to the child, has less eye for the needs and limits of their child. This creates a risk of emotional neglect of the child, resulting in attachment problems and identity problems. The parent regularly has a reduced reflective capacity, which makes the parent consider harmful behavior such as physical violence as less harmful than it is. The question is: to what extent is child abuse more common in families where autism takes center stage?

9.

One of the common, sometimes unspoken, assumptions in mental healthcare is that of compensation. The compensation theory assumes that, for example, the diminished empathy of the parent with autism can be compensated for by the parent without autism. The questions are what this compensation theory is based on and whether this compensation theory is correct?

Does parenting by a parent (or parents) with autism have consequences for the child's financial, social, social status when it is an adult? And are there consequences in the areas of emotional development, health, mental health?

10.

How many children in the Netherlands have a parent who has autism or both parents have it?

11.

Which factors determine whether upbringing by a parent with autism is successful?

12.

What positive effects does upbringing by a parent with autism have?

13.

To what extent are parents with autism aware of the consequences of autism on upbringing and to what extent are they not aware of this?

14.

To what extent are children aware of their parent's autism and the consequences this has for upbringing and the child (in childhood and later when the child is an adult)?

15.

To what extent is a parent without autism aware of the limitations of the other parent?

16.

How effective is the treatment of children of parents with (suspected) autism? Sometimes children of parents with (presumably) autism end up in care because of other problems or symptoms. How effective is the assistance to this specific group? For example, consider the risk of 'pleasing' the therapist. Children of parents with autism grew up in an environment in which the needs of the parent with autism predominated.

17.

What percentage of parents with autism refuse diagnosis and help?

18.

How do parents with autism respond when their child needs to be comforted or soothed?

19.

How do parents with autism assist their child during puberty?

20.

How do parents with autism respond to their child in emergency situations?

21.

In children whose parents have autism, are there specific problems that are more common. Think of problems such as: skin picking (dermatillomania), eating disorders, depression, burnout, attachment problems, relationship problems, divorce, emotional neglect, difficulty setting your own boundaries, difficulty with your own emotions, wrong choice of study, wrong career choice, etc.?

22.

Are there differences visible for the child if it has a mother with autism, a father with autism or if both parents have autism?

23.

What are the consequences of a parent's autism diagnosis for the child? Does a diagnosis improve care to the child? Does it improve possibilities for acceptance?

24.

How has contact with their parents with autism developed over the years? Do children of parents with autism have contact with their parents in a different way than children whose parents do not have autism?

25.

How do those involved appreciate the contact and is there a difference? Does the (adult) child of a parent with autism value the contact differently from the parent with autism? Are there differences or similarities in this appreciation compared to parents without autism?

26.

How does contact develop and what effects are visible if there is a grandparent (or grandparents) with autism? How is the contact with the grandchildren, for example? How does the grandparent with autism value the contact, how does the child (now parent) value this contact and how does the grandchild value this contact?

27.

What percentage of the children of parents with autism have a partner with autism later in life?

28.

What experiences do children of parents with autism have with mental healthcare?

29.

When a child of autistic parents interacts socially with an individual with autism, how does that affect the (adult) child? How do adult children of autistic parents experience interactions with individuals with autism?