

**Prolonged engagement, outsiders perspectives,  
and an ethic of friendship. The search for  
sustainable and fruitful knowledge production  
processes in the care for people with severe  
intellectual disabilities.**

Dr. Gustaaf Bos

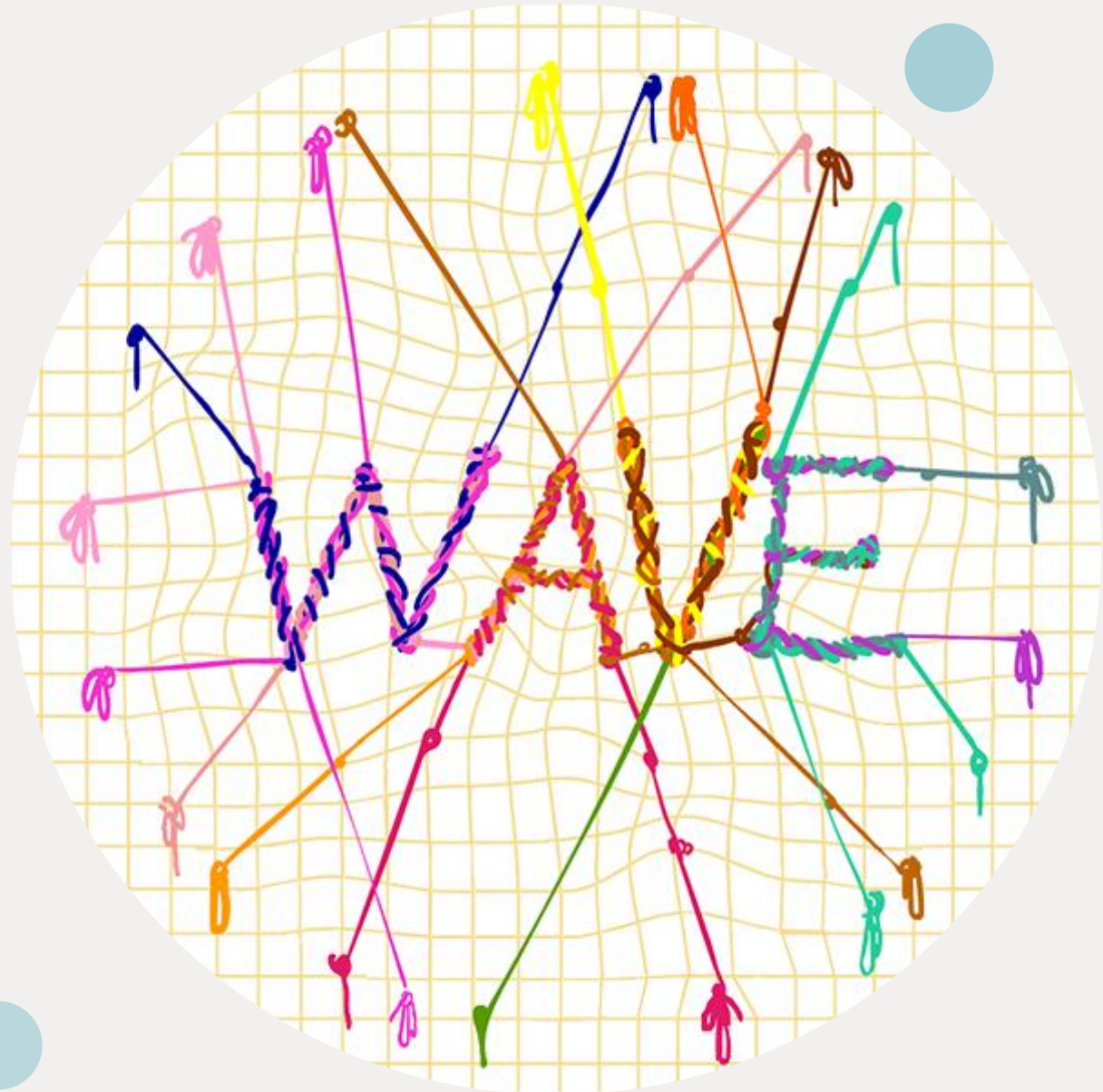
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# Project WAVE

- Short impression: <https://en.projectwave.nl/>
- WAVE is a 3-year research project (2019-2022) which offers experimental-relational space to investigate, explicate, discuss and perform a personal, intuitive and ethically driven way of relating to and caring for people with SID and challenging behavior. In our research we speak of 'protagonists', 'insiders' and 'outsider-researchers'.
- Getting to know each other in different ways ... by gradually interweaving outsiders' perspectives.
- Outsider-researchers and insiders search together for other, unconventional ways of creating (new) perspective(s) on protagonists and insiders, in order to stimulate improvement. By w(e)aving these perspectives sustainably into daily care practice(s) we hope to 1. improve QoL and 2. stimulate mutual learning/acting in similar situations and in vocational education (CoP).



# Vulnerability and Strength in families with a child with complex, 24-hour care needs



## Kwetsbaarheid én kracht

@kwetsbaarheidenkracht

Dit onderzoek gaat over goede zorg voor en betrokkenheid bij gezinnen met een zorgintensief kind. Ho

## Short background

- This 3-year research project (2021-2024) explores the collaboration between families with a child with complex care needs care professionals and care systems. The aim is not only to get a broad, in-depth understanding of this collaboration, but also to promote it and make it more sustainable.

## How?

- By following 9 families in their everyday complexity for 18 months. In the following 18 months, based on our fieldwork, we will develop tools that aim to benefit the collaboration with these families.
- Focus on family/system rather than individual

# Different roles & perspectives

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## **Gustaaf:**

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Project leader and researcher, different projects

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Background information

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## **Alistair:**

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Multiple perspectives: researcher and 'insider'/own situation studied

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Background information

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## **Vanessa:**

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Multiple perspectives: researcher and outsider in outsider project because of 'insider' role

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New member in WAVE

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Background information

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# Challenging research practices



PROLONGED ENGAGEMENT  
(DIFFERENT LEVELS)



OUTSIDERS BECOMING  
INSIDERS



ETHIC OF FRIENDSHIP