

DMP title

Project Name Towards empowering support of parents of young children on the autism spectrum - DMP title

Grant Title G0D3722N

Principal Investigator / Researcher Ilse Noens

Project Data Contact Gert-Jan Vanaken, gertjan.vanaken@kuleuven.be

Description Raising autistic children is not self-evident. Parents of young children with autism are often confronted with daily challenges, resulting in uncertainties regarding their roles and responsibilities in parenthood. By a timely diagnosis and intervention, clinicians may provide some initial guidance: sharing knowledge on autism and adapted parenting practices is key to early intervention. However, lived experience of other parents and insights from neurodiversity theory may give rise to the question of whether such early intervention from professional experts is doing full justice to the many layers of autism as a phenomenon and the diversity of roles and responsibilities of parents in particular. Therefore, this project's central question is how clinicians can support parents of a young child with autism in their multiple roles and responsibilities in an empowering way. First, we aim to gain a layered insight into the roles and responsibilities of parents of young autistic children from different perspectives. Using qualitative methods, we will analyze perspectives from (a) the academic literature on early interventions, (b) parents with lived experience, and (c) neurodiversity scholars. Building on this layered insight, we aim to co-create and test a group-based intervention for parents of young autistic children in collaboration with an advisory group consisting of parents, clinicians and neurodiversity scholars.

Institution KU Leuven

1. General Information

Name applicant

Ilse Noens

FWO Project Number & Title

G0D3722N

Towards empowering support of parents of young children on the autism spectrum

Affiliation

- KU Leuven
- Universiteit Antwerpen

2. Data description

Will you generate/collect new data and/or make use of existing data?

- Generate new data

Describe in detail the origin, type and format of the data (per dataset) and its (estimated) volume. This may be easiest in a table (see example) or as a data flow and per WP or objective of the project. If you reuse existing data, specify the source of these data. Distinguish data types (the kind of content) from data formats (the technical format).

WP	Raw vs. processed	Type of data	Format	Volume	How created
WP1 (review of literature)	no new data generated				
WP2 (interviews with parents)	Raw	Audio-recordings of interviews	.mp3	estimated 4 GB (files of about 20 interviews)	Face-to-face interviews with parents of autistic children

		Notes	on paper	20 pages	Descriptive and reflective notes made during face-to-face interviews
	Processed	Transcripts	.rtf	estimated 4MB	Pseudonymized transcription of audio-files of the interviews
		Notes	.docx	estimated 0.5MB	Digitalisation of hand written notes
		Qualitative data analysis documents (incl. coding)	.nvp	estimated 20 MB	Import and coding of interview transcripts in Nvivo
WP 3 (interviews with neurodiversity scholars)	Raw	Video-recordings of interviews	.mp4	estimated 3 GB (files of about 10 interviews)	Online interviews via videoconference
		Notes	on paper	10 pages	Descriptive and reflective notes made during video interviews
	Processed	Transcripts	.rtf	estimated 2MB	Pseudonymized transcription of video-files of the interviews
		Notes	.docx	estimated 0.25MB	Digitalisation of hand written notes
		Qualitative data analysis documents (incl. coding)	.nvp	estimated 10MB	Import and coding of interview transcripts in Nvivo
WP 4 (cocreation of workshops)	Raw	Video-recordings	.mp4	estimated 2 GB	Online or offline videorecordings of three focus groups
		Notes	on paper	10 pages	Descriptive and reflective notes made during discussion sessions and focus groups
	Processed	Data analysis documents	.nvp	estimated 10MB	Import and coding of interview notes Nvivo
		Notes	.docx	estimated 0.25MB	Digitalisation of hand written notes
WP 5 (proof-of-concept study)	Raw	Questionnaires	on paper	estimated 60-120 pages (12 participants, 10 pages per participant)	paper questionnaires completed by participants before and after intervention
		Audio-recordings of interviews	.mp3	estimated 4GB	Interviews with participants in proof-concept interventions

		Field notes	paper	10 pages	Descriptive and reflective notes made during intervention
	Processed	Questionnaires	.xlsx	Dataset with responses from 12 participants	Digitalisation of questionnaires
		Transcript of relevant interview fragments	.rtf	estimated 4MB	Pseudonymized transcription of audio-files of the interviews
		Qualitative data analysis documents	.nvp	estimated 20MB	Import and coding of interview transcripts in Nvivo
		Notes	.docx	estimated 0.25MB	Digitalisation of hand written notes

3. Legal and ethical issues

Will you use personal data? If so, shortly describe the kind of personal data you will use. Add the reference to your file in KU Leuven's Register of Data Processing for Research and Public Service Purposes (PRET application). Be aware that registering the fact that you process personal data is a legal obligation.

- Yes

Privacy and ethical approval (SMEC) will be obtained for all studies.

Depending on the study we will collect: name; e-mail address; address; telephone number; audio/video-recordings of interviews/focus groups; gender; age; educational level; number of children; autism diagnosis; questionnaires on perception of intervention and parental self-efficacy

Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? If so, add the reference to the formal approval by the relevant ethical review committee(s)

- Yes

We will submit an ethical application to at the Social and Societal Ethics Committee KU Leuven (SMEC)

Does your work possibly result in research data with potential for tech transfer and valorisation? Will IP restrictions be claimed for the data you created? If so, for what data and which restrictions will be asserted?

- No

Do existing 3rd party agreements restrict dissemination or exploitation of the data you (re)use? If so, to what data do they relate and what restrictions are in place?

- No

4. Documentation and metadata

What documentation will be provided to enable reuse of the data collected/generated in this project?

For each study we will generate documentation which will be stored together with the collected data (see below for storage location). This documentation will consist of SMEC application, including the informed consent process and the study protocol, which entails recruitment procedures and interview/focus group guides. For each of the qualitative studies, a single Word-

document will be kept describing the contextual variables and field notes for each interview/focus group. Also, during the research project itself we will keep a logbook concerning pseudonymisation (linking transcripts to identifiable persons). For each study a codebook will be generated in NVivo during qualitative data analysis.

In particular for WP 5 (proof-of-concept intervention) a detailed set of instructions for interventionists will be generated on how to deliver the different modules of the intervention. After effectuating the intervention, these instructions will be complemented with field notes made during the intervention and with reflections based on the quantitative and qualitative evaluation of the intervention in this work package.

Will a metadata standard be used? If so, describe in detail which standard will be used. If no, state in detail which metadata will be created to make the data easy/easier to find and reuse.

- No

See above.

5. Data storage and backup during the FWO project

Where will the data be stored?

Since we will collaborate with researchers from other research units and groups, pseudonymized electronic data will be stored on the shared OneDrive for Business offered by KU Leuven for active use during the project. Only directly involved researchers will have access to this shared folder. All researchers will be using multifactor authentication with the KU Leuven Authenticator app.

The password-protected logbook which links the pseudonymized data to identifiable persons will be stored separately on the J Drive of the research unit.

Non-pseudonymized data such as audio/video files and contact information will only be stored on the J Drive in accordance with regulations on the storage of personal information in non-European cloud services.

Paper data (informed consents; questionnaires) will be archived in a locked closet in the office of the researcher at the Parenting and Special Education research unit.

How is backup of the data provided?

Electronic data will be stored within OneDrive with automatic back-up procedures.

During the research project, manual back-ups will be made by one of the researchers on the (shielded) J: drive of the research unit, which is being automatically, daily backed-up as well.

Is there currently sufficient storage & backup capacity during the project? If yes, specify concisely. If no or insufficient storage or backup capacities are available then explain how this will be taken care of.

- Yes

OneDrive provides a capacity 2TB which largely suffices this project's needs as specified above.

What are the expected costs for data storage and back up during the project? How will these costs be covered?

No additional costs expected.

Data security: how will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

Pseudonymized electronic data will be stored on the project's OneDrive for active use during the project. All researchers will be using multifactor authentication with the KU Leuven Authenticator app.

The password-protected logbook which links the pseudonymized data to identifiable persons will be stored separately on the shielded, shared network Drive (J:) of research unit.

6. Data preservation after the FWO project

Which data will be retained for the expected 5 year period after the end of the project? In case only a selection of the data can/will be preserved, clearly state the reasons for this (legal or contractual restrictions, physical preservation issues, ...).

All pseudonymized and anonymized data will be stored for at least 10 years in accordance with the KU Leuven research data management policy. Irrelevant personal data such as the audio/video files of the interviews and focus groups, the logbook linking transcripts and questionnaire responses to identifiable persons and participants contact details will not be kept after finalising the respective studies.

Moreover, notes on paper will be saved together with the interview transcripts in Word files as soon as possible. Once the notes have been saved electronically, paper notes will be destroyed.

Where will the data be archived (= stored for the longer term)?

After finalising the project, data and documentation will be stored on a shared, but password-protected university drive (J:drive) for durations specified above, after which they will be destroyed. We opt for a shared drive in order for data to be kept available even if individual researchers would leave the university.

What are the expected costs for data preservation during the retention period of 5 years? How will the costs be covered?

As the size of all data files is fairly small (<100MB) compared to the available shared storage space of the J:drive (100GB), no additional costs are expected.

7. Data sharing and reuse

Are there any factors restricting or preventing the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions)?

- Yes. Specify:

The raw qualitative data (i.e. transcripts) cannot be shared, because the data are only pseudonymized and participants did not give their informed consent to share these data. Participants only consent to using excerpts of the interview for scientific publication.

Which data will be made available after the end of the project?

Documentation, codebooks generated during qualitative data analysis, and questionnaire data from WP5 will be made available upon motivated e-mail request and transferred via secured email connection.

Where/how will the data be made available for reuse?

- Other (specify):

Upon motivated request data will be shared via secured email.

When will the data be made available?

- Immediately after the end of the project

Who will be able to access the data and under what conditions?

Access will be considered after a request is submitted explaining the planned reuse. Only uses for research purposes will be allowed and commercial reuse will be excluded. Researchers have to comply with the confidentiality rules for the given data. As stated above, pseudonymized data will only be made available upon publication of all results on this part of the data.

What are the expected costs for data sharing? How will the costs be covered?

None

8. Responsibilities

Who will be responsible for data documentation & metadata?

Gert-Jan Vanaken will be the main responsible, supervised by Ilse Noens & Kristien Hens.

Who will be responsible for data storage & back up during the project?

Gert-Jan Vanaken will be responsible, supervised by Ilse Noens & Kristien Hens.

Who will be responsible for ensuring data preservation and reuse ?

Ilse Noens and Kristien Hens will be responsible for data preservation and reuse after the project will have ended.

Who bears the end responsibility for updating & implementing this DMP?

The PI (prof. Ilse Noens) bears the end responsibility of updating & implementing this DMP.