Childhood disability as a double disadvantage? An empirical investigation into poverty measurement, poverty trends and policy impacts among children with disabilities across European welfare states

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Project abstract:

Child poverty rates are alarmingly high and have increased in many European welfare states. Simultaneously, the prevalence of children with disabilities has also been rising. In the existing literature, it is assumed that disabled children are more likely to grow up poor than non-disabled children. This begs the question whether the rising prevalence of disabled children accounts for the rising trends in child poverty, which can only be answered by means of 1) high-quality data and the ability to properly observe changes over time, 2) adequate poverty measures that accurately reflect disabled children's poverty risks, and 3) proper understanding of how welfare state policies affect poverty risks among disabled children. This project aims to disentangle the complex relationship between childhood disability and child poverty in European welfare states. Thereby, I will 1) conceptually improve poverty measurement for disabled children, 2) further our understanding of the costs incurred by disabled children, 3) analyse child poverty trends, and 4) investigate the role of welfare state policies in disabled children's poverty outcomes. To do so, I will draw on EU-SILC data for European cross-country comparative analyses and survey and interview data for a case study of Flanders. These insights will allow to understand the living conditions of (families of) disabled children and inform European welfare states on how to effectively target their social spending to those in need.

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1. Research Data Summary

List and describe all datasets or research materials that you plan to generate/collect or reuse during your research project. For each dataset or data type (observational, experimental etc.), provide a short name & description (sufficient for yourself to know what data it is about), indicate whether the data are newly generated/collected or reused, digital or physical, also indicate the type of the data (the kind of content), its technical format (file extension), and an estimate of the upper limit of the volume of the data.

Dataset Name	Description	New or reused	Digital or Physical	Only for digital data	Only for digital data	Only for digital data	Only for physical data
				Digital Data Type	Digital Data format	Digital data volume (MB/GB/TB)	Physical volume
		Please choose from the following options: • Generate new data • Reuse existing data	*Please choose from the following options:* • Digital • Physical	*Please choose from the following options:* • Observational • Experimental • Compiled/aggregated data • Simulation data • Software • Other • NA	*Please choose from the following options:* • .por, .xml, .tab, .csv,.pdf, .txt, .rtf, .dwg, .gml, … • NA	*Please choose from the following options:* • <100MB • <1GB • <100GB • <1TB • <5TB • <10TB • <50TB • >50TB • NA	
EU-SILC survey	Data collected by Eurostat: readily available microdata from the EU Statistics on Income and Living Conditions (EU-SILC), survey years 2017, 2021 and 2024.	Reuse existing data	Digital	Observational	.dta	<1GB	

Survey in Flanders	An online survey previously developed and distributed among parents of children with an autism spectrum disorder by Professor Nicky Rogge (Research Centre for Economics, KU Leuven), who is involved in the current project as co-promotor, will be used and distributed among parents of disabled and non-disabled children aged 2,5 to 21 years old living in Flanders.	Generate new data	Digital	Observational	.dta	<1GB	
Interviews with parents	In-depth interviews will be conducted with parents of children with disabilities among a selection of participants who completed the survey in Flanders.	Generate new data	Digital	Audio recordings and transcripts into textual data	.wav and .docx	<1GB	

If you reuse existing data, please specify the source, preferably by using a persistent identifier (e.g. DOI, Handle, URL etc.) per dataset or data type:

EU-SILC survey: I will use data previously collected by Eurostat for the readily available microdata from the EU Statistics on Income and Living Conditions (EU-SILC) survey. Cross-national analyses will be drawn from the EU-SILC, covering three different years: 2017, 2021, 2024, and the ad-hoc module on children's health and activity limitations (EU-SILC microdata: cross-sectional data up to 2022: DOI: 10.2907/EUSILC2004-2022V1).

Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? Describe these issues in the comment section. Please refer to specific datasets or data types when appropriate.

- Yes, human subject data

Survey in Flanders and interviews with parents: Since I will collect, process and store personal data and the research involves human participants (i.e. parents of children with disabilities), ethical approval from the Social and Societal Ethics Committee (SMEC) and PRivacy and EThics (PRET) platform of KU Leuven is required. Participants in the survey and in-depth interviews will need to sign the informed consent before they can participate in the study, in which the use and confidential treatment of the acquired data is explained. The privacy and ethics approval has yet to be obtained (G-2024-7951).

Will you process personal data? If so, briefly describe the kind of personal data you will use in the comment section. Please refer to specific

datasets or data types when appropriate.

- Yes

I will process and store personal data in the form of 1) readily available survey data of EU-SILC, 2) online survey responses and 3) audio recordings and interview transcripts.

EU-SILC survey: The microdata of the EU Statistics on Income and Living Conditions contain individual information on the personal, household and socioeconomic situation of European households, but the files released by Eurostat are pseudonymised and never contain direct identifiers (such as name, email address or detailed information on participant's residence). Moreover, information on individuals is reduced to ensure anonymity. Pseudonymisation is guaranteed by the removal of, for example, the respondent's address (only NUTS level 1 is provided), the exact date of the interview (grouped into quarters within a year), the household members' month of birth (grouped into quarters within a year), and their country of birth and citizenship (grouped into local/EU/other).

Survey in Flanders: The survey consists of self-reporting questions on child and family characteristics, parent's mental health, received informal and social support, time investment of parents, and parental employment. In the survey, no information that can identify the participants will be collected. Email addresses used to recontact the participants (for compensation, to inform them about the study results, and/or to participate in future research) will be stored separately from the survey responses. The collected data will be carefully handled, securely stored, and not distributed to third partners without pseudonymisation.

Interviews with parents: The interviews will consist of questions on the burden on households with disabled children regarding employment, time investment, maintaining and relying on significant relationships, family functioning, mental health and coping strategies. The interview transcripts will be pseudonymised, and original audio recordings will be deleted after finishing the transcribing. The participants' email addresses used to contact participants will be stored separately from the pseudonymised transcripts. As anonymity is hard to guarantee with regard to transcripts, I plan not to further distribute these data.

Does your work have potential for commercial valorization (e.g. tech transfer, for example spin-offs, commercial exploitation, …)? If so, please comment per dataset or data type where appropriate.

- No

Do existing 3rd party agreements restrict exploitation or dissemination of the data you (re)use (e.g. Material/Data transfer agreements/ research collaboration agreements)? If so, please explain in the comment section to what data they relate and what restrictions are in place.

- Yes

EU-SILC survey: Usage, storage and further dissemination of the readily available EU-SILC survey data are restricted by the terms of the contract with Eurostat. This contract will not allow further dissemination of the data. Interested parties can however apply themselves for the data used. EU-SILC is a commonly used dataset within the ReSPOND team of the Centre for Sociological Research. It is, similarly with other commonly used datasets, stored on the collectively managed (but secure) network drive KU Leuven BOX, along with data documentation, statistical coding and drafts of articles. Only those researchers who have signed the confidentiality declaration of EU-SILC have access to the specific folder containing the microdata. In the position as a researcher within the Centre for Sociological Research, I will sign a contract with Eurostat on the terms and preservation of data.

Survey in Flanders and interviews with parents: Survey and interview participants (parents of children with disabilities) will need to provide informed consent to allow me to work with the collected data. In order to protect these data, I will convert the audio recordings into pseudonymised transcripts, and the audio recordings will be deleted.

Are there any other legal issues, such as intellectual property rights and ownership, to be managed related to the data you (re)use? If so, please explain in the comment section to what data they relate and which restrictions will be asserted.

- No

2. Documentation and Metadata

Clearly describe what approach will be followed to capture the accompanying information necessary to keep data understandable and usable,

for yourself and others, now and in the future (e.g., in terms of documentation levels and types required, procedures used, Electronic Lab Notebooks, README.txt files, Codebook.tsv etc. where this information is recorded).

EU-SILC survey: Metadata is made available by GESIS for the EU-SILC survey data, containing study design, sampling methodology, weight construction and variable-level information. Relevant syntaxes developed in the project will be published on a public repository (Zenodo). A README file will be included, which details the version of the source data needed, the software version and the related publications.

Survey in Flanders: The documentation of group-level survey responses will be accompanied by a data list. The data list will contain the survey questions (including response options), recruitment procedure, list of organisations contacted to find eligible participants, number of participants, participant ID, setting/place, date and duration of filling in the questionnaire, and the informed consent. The steps taken to analyse the survey data will be documented.

Interviews with parents: Also for the in-depth interviews, a data list will be created, which will contain general information (interview ID, setting, date, duration, participant characteristics), the informed consent and the subjects discussed during the interviews. The steps taken to pseudonymise and code the qualitative data will be documented as well.

Will a metadata standard be used to make it easier to find and reuse the data? If so, please specify (where appropriate per dataset or data type) which metadata standard will be used. If not, please specify (where appropriate per dataset or data type) which metadata will be created to make the data easier to find and reuse.

- Yes

I will use the Data Documentation Initiative metadata scheme.

3. Data storage & back-up during the research project

Where will the data be stored?

EU-SILC survey: EU-SILC is a commonly used dataset within the ReSPOND team of the Centre for Sociological Research. The time-stamped master copy of the survey data is, similarly with other commonly used datasets, stored on the collectively managed (but secure) network drive KU Leuven BOX, along with data documentation, statistical coding and drafts of articles. Only those researchers who have signed the confidentiality declaration of EU-SILC have access to the specific folder containing the microdata. Copies of the data will be saved and stored on my personal network drive (I-drive). The I-drive is safely located on KU Leuven data servers, frequently backed up and suitable to store confidential data. The driver is only accessible through the KU Leuven VPN solution. Storage is governed by KUL ICTS.

Survey in Flanders: The survey data will also be stored on my personal network drive (I-drive). The participants' email addresses will be stored on the I-drive separately from the pseudonymised survey responses and will be deleted after the project.

Interviews with parents: The data collected through in-depth interviews (i.e. audio recordings and pseudonymised transcripts) will also be stored on my personal network drive (I-drive). The original audio recordings of the interviews will be deleted right after finishing the transcribing. The participants' email addresses will be stored separately from the pseudonymised transcripts and will be deleted after the project.

How will the data be backed up?

The I-drive is stored on the university's central servers and is frequently and automatically backed up.

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

The I-drive can store up to 128 TB.

How will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

EU-SILC survey: The data are securely stored on the network drive KU Leuven BOX and will be saved and stored on my personal network drive (I-drive). Only those researchers who have signed the confidentiality declaration of EU-SILC have access to the specific folder on the KU Leuven BOX containing the microdata. The further dissemination of the data is restricted by the confidentiality agreement with Eurostat, and the I-drive and KU Leuven BOX are only accessible through the KU Leuven VPN solution with the researcher's personal login and password.

Survey in Flanders and interviews with parents: The I-drive is safely located on KU Leuven data servers and suitable to store confidential data. It is only accessible through the KU Leuven VPN solution with the researcher's personal login and password.

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

The I-drive is free of charge. To access the KU Leuven BOX, a personal BOX account has to be requested. This costs €10 per year and will be covered with the allocated project budget.

4. Data preservation after the end of the research project

Which data will be retained for at least five years (or longer, in agreement with other retention policies that are applicable) after the end of the project? In case some data cannot be preserved, clearly state the reasons for this (e.g. legal or contractual restrictions, storage/budget issues, institutional policies...).

EU-SILC survey: In the position as a researcher within the Centre for Sociological Research, I will sign a contract with Eurostat on the terms and preservation of data. The personal data will be deleted after a certain time frame as agreed in the contract. Long-term storage of the survey data is organised at the level of the university.

Survey in Flanders and interviews with parents: The pseudonymised survey data and pseudonymised interview transcripts will be stored for at least ten years after the end of the project on the personal network drive (I-drive) of promotor Wim Van Lancker to make reproducibility and reuse of the data possible. The participant's email addresses used to contact participants will be deleted once the project ends. The audio recordings of in-depth interviews will be deleted once transcribing is finished.

Where will these data be archived (stored and curated for the long-term)?

EU-SILC survey: The datasets of EU-SILC are stored on the collectively managed secure network drive KU Leuven BOX.

Survey in Flanders and interviews with parents: The data will be stored for at least ten years after the end of the project on the personal network drive (I-drive) of promotor Wim Van Lancker.

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

There are no expected costs for data preservation.

5. Data sharing and reuse

Will the data (or part of the data) be made available for reuse after/during the project? In the comment section please explain per dataset or data type which data will be made available.

- Yes, in an Open Access repository
- No (closed access)

EU-SILC survey: Further dissemination of the EU-SILC survey data is restricted by the terms of the contract with Eurostat. This contract will not allow further dissemination of the data. Interested parties can apply themselves for the data used. Research papers will provide practical information and Stata syntaxes to replicate the results, if access would be granted by the owners of the data.

Survey in Flanders and interviews with parents: Documentation of the survey and interview data (data lists) will be made available in a public repository (Zenodo). As anonymity is hard to guarantee with regard to interview transcripts, I plan not to further distribute these data.

Relevant syntaxes developed in the project will be published on a public repository (Zenodo).

If access is restricted, please specify who will be able to access the data and under what conditions.

Documentation of the survey and interview data (data lists) and relevant syntaxes developed in the project will be made available in a public repository (Zenodo). This will allow researchers to replicate the research findings, if they acquire access to the underlying data, which cannot be disseminated further.

Are there any factors that restrict or prevent the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions)? Please explain in the comment section per dataset or data type where appropriate.

- Yes, Privacy aspects

EU-SILC survey: Further dissemination of the EU-SILC survey data is restricted by the terms of the contract with Eurostat. This contract will not allow further dissemination of the data. Interested parties can apply themselves for the data used. Research papers will provide practical information and Stata syntaxes to replicate the results, if access would be granted by the owners of the data.

Interviews with parents: As anonymity is hard to guarantee with regard to interview transcripts, I plan not to further distribute these data. The audio recordings will be deleted after transcribing the interviews and will not be shared with third parties.

Where will the data be made available? If already known, please provide a repository per dataset or data type.

Documentation of the survey and interview data (data lists) and relevant syntaxes developed in the project will be made available in a public repository (i.e. Zenodo).

When will the data be made available?

The data will be made available when the research results will be published.

Which data usage licenses are you going to provide? If none, please explain why.

NA

Do you intend to add a PID/DOI/accession number to your dataset(s)? If already available, you have the option to provide it in the comment section.

- No

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

There are no expected costs for data sharing.

6. Responsibilities

Who will manage data documentation and metadata during the research project?

Eef Gijbels, Julie Vinck, Wim Van Lancker

Who will manage data storage and backup during the research project?

Eef Gijbels, Julie Vinck, Wim Van Lancker

Who will manage data preservation and sharing?

Wim Van Lancker

Who will update and implement this DMP?

Eef Gijbels, and the PI has the end responsibility of updating and implementing this DMP

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