Plan Overview

A Data Management Plan created using DMPonline

Title: DigAble: A participatory multi-methods study of media interventions and policies that match capacities and needs for neurodiverse youth

Creator: Carlo Schuengel

Principal Investigator: Carlo Schuengel, Ina Koning

Data Manager: Pieter Bas Schutte

Affiliation: ZonMw (Nederlands)

Funder: Netherlands Organisation for Scientific Research (NWO)

Template: 1 - VU DMP template 2021 (NWO & ZonMW certified) v1.4

ORCID iD: 0000-0001-5501-3341

ORCID iD: 0000-0003-0305-0487

Project abstract:

While recognition and respect for neurodiversity is growing, the impact of large societal shifts, such as digitalization, is felt disproportionally by a broad group of neurodivergent youth (including borderline to mild intellectual disability-MID, autism and ADHD). Already facing an uphill battle with education, peer relationships, work, services, and accessing care and welfare, COVID-19 made it worse. Many activities moved online (either as first or second options), which was a boon for some but a bane for many neurodivergent youth. Media-lessons and -interventions for the general youth population have been developed but it remains unclear what interventions are suitable for neurodivergent youth. We therefore investigate the needs and capacities of neurodivergent youth, their parents, educators, carers, and managers in this sector and how these should be matched with support (WP1). Based on systematic review, we distil and match practice elements for evidence on differential effects (WP2). Finally, we co-create a decision tool so that youth, their families, school and care organizations, and professionals arrive at interventions and policies which they need most and are most promising (WP3). Scientific breakthroughs are achieved by understanding the links between needs and capacities of neurodivergent youth and which specific practices most effectively support themselves in this rapidly digitalizing society and their (professional) caregivers and educators. Societal breakthroughs are achieved by well-founded choices between reasonable adjustments and interventions and by grounding policies in more realistic expectations of the effects of interventions to offset inequities.

ID: 152721

Start date: 01-06-2024

End date: 31-05-2026

Last modified: 02-06-2024

Grant number / URL: 406.23.PPO.036

Copyright information:

The above plan creator(s) have agreed that others may use as much of the text of this plan as they would like in their own plans, and customise it as necessary. You do not need to credit the creator(s) as the source of the language used, but using any of the plan's text does not imply that the creator(s) endorse, or have any relationship to, your project or proposal

DigAble: A participatory multi-methods study of media interventions and policies that match capacities and needs for neurodiverse youth

0. General information

0.1 Document version & date

Version 2.0
Date: 27 / 05 / 2024

0.2 Project title

DigAble: A participatory multi-methods study of media interventions and policies that match capacities and needs for neurodiverse youth

0.3 Project summary

While recognition and respect for neurodiversity is growing, the impact of large societal shifts, such as digitalization, is felt disproportionally by a broad group of neurodivergent youth (including borderline to mild intellectual disability-MID, autism and ADHD). Already facing an uphill battle with education, peer relationships, work, services, and accessing care and welfare, COVID-19 made it worse. Many activities moved online (either as first or second options), which was a boon for some but a bane for many neurodivergent youth. Media-lessons and -interventions for the general youth population have been developed but it remains unclear what interventions are suitable for neurodivergent youth. We therefore investigate the needs and capacities of neurodivergent youth, their parents, educators, carers, and managers in this sector and how these should be matched with support (WP1). Based on systematic review, we distil and match practice elements for evidence on differential effects (WP2). Finally, we co-create a decision tool so that youth, their families, school and care organizations, and professionals arrive at interventions and policies which they need most and are most promising (WP3). Scientific breakthroughs are achieved by understanding the links between needs and capacities of neurodivergent youth and which specific practices most effectively support themselves in this rapidly digitalizing society and their (professional) caregivers and educators. Societal breakthroughs are achieved by well-founded choices between reasonable adjustments and interventions and by grounding policies in more realistic expectations of the effects of interventions to offset inequities.

0.4 At which VU Faculty is this project situated?

- Faculty of Behavioural and Movement Sciences (FGB)

0.5 Your contact details

Name: Carlo Schuengel
Roles: Conceptualization, Methodology, funding acquisition, supervision, Writing - Review & Editing, Management and coordination responsibility for the research activity planning and execution
Telephone number: +31 205988905
E-mail: c.schuengel@vu.nl
ORCID: https://orcid.org/0000-0001-5501-3341
University: Vrije Universiteit Amsterdam
Faculty: Faculty of Behavioural and Movement Sciences
Department: Clinical Child and Family Studies

0.6 List other people involved, including those at partner organisations in the project (if applicable)

Vrije Universiteit Amsterdam:
Ina Koning, h.m.koning@vu.nl
Sander Begeer, s.m.begeer@vu.nl

Iuliia Chaplinska
Sophie Mary
Windesheim Hogeschool:
Peter Nikken, p.nikken@windesheim.nl
Svenja Büttner, s.buttner@windesheim.nl
Hogeschool Leiden:
Hendrien Kaal, kaal.h@hsleiden.nl
Rogier de Groot, groot.de.r@hsleiden.nl
Universiteit Utrecht:
Helen Vossen, h.g.m.vossen@uu.nl
Regina van der Eijnden, r.j.j.m.vandenEijnden@uu.nl

0.7 Funding organisation & grant number (if applicable)

Funding organisation: NWO
Grant number: NWA.1540.21.004

0.8 Project code (if applicable)

n.a.

0.9 Consulted data management expert(s)

Name; Wendy Hugens
E-mail: w.hugens@vu.nl
Date of consultation: May 19, 2024

1. Data description

1.1 Will you collect and/or process personal data in this project?

- Yes

1.2 Will you use existing data? If yes, what is their source?

No

1.3 Will you collect or produce new data? If yes, please describe how.

Work package 1: Needs and capacities of neurodivergent youth and their (professional) caregivers in relation to digitalization
A scoping review will be conducted. A survey will deliver quantitative and qualitative data through open-ended and closed questions within an ongoing study (InKaart) . A descriptive survey using purposive sampling will be conducted. Following these results, focus groups will be held with youth with different forms of neurodivergence and (professional) caregivers and educators.
As a result, for WP1 we expect to generate the following data:
a. Bibliographic data from identifying, screening, and including publications and data extracted from the included studies. Search queries will be stored as text/doc files. Bibliographic data will be stored and archived in tagged text formats. Codebooks will be stored as spreadsheet documents (xls). Extracted data will be stored in spreadsheets (xls). Typically, based on initial numbers of 10.000 potential records, data files of such type do not exceed 100 Mb.
b. Data from responses to survey questions. Survey data will be stored in csv (analyzed; archived), spss (raw; processed; analyzed),

and excel (analyzed) formats. Typically, data files of such type for around 1,000 participants do not exceed 1 Mb.

c. Data from focus group interviews. Interview data will be stored as audio files in mp3 format (raw; archived) and transcripts as text/doc files (processed; analyzed) . Codes will be exported into excel format (xls; processed; analyzed). Typically, data files of such type for around 20 participants do not exceed 2 Mb.

Work package 2: Distillation of practice elements in media interventions for youth and evaluation of evidence and inclusiveness

The objectives will be pursued through systematic research synthesis, first by conducting a scoping review for objective a, and then by employing the distil-and-match approach for quantitative synthesis.

a. Bibliographic data from identifying, screening, and including publications and data extracted from the included studies. Search queries will be stored as text/doc files. Bibliographic data will be stored and archived in tagged text formats. Typically, based on initial numbers of 10.000 potential records, data files of such type do not exceed 100 Mb.

b. Manuals and other documentation on media interventions. Manuals and documentation will be stored in the original formats in which these were obtained, which will usually be some document format such Word or pdf. Given that some of this documentation use graphical elements and expecting 200 manuals at maximum, we expect that data files in total will remain under 1 Gb.

c. Data extracted from bibliographic records, articles, and manuals. Codebooks will be stored as spreadsheet documents (xls; processed; analyzed). Extracted data will be stored in spreadsheets (xls; processed; analyzed). Typically, data files of such type do not exceed 1 Mb.

d. Intraclass correlations. Distill-and-match analyses will consist of calculating various sets of intraclass correlations. These will be tabulated and will typically take up under 1 Mb of storage.

Work package 3: Co-create an adaptive decision tool resulting in recommendations and actions for implementation and dissemination

The objectives will be pursued through describing and combining the findings of WP1 and WP2, and quantitative (questionnaire) and qualitative (focus groups) methods for establishing consensus and collecting experiences and opinions on the adaptive decision tool.

a. Data from responses to survey questions in the rapid Delphi study. Survey data will be stored in csv (analyzed; archived), spss (raw; processed; analyzed), and excel (analyzed) formats. Typically, data files of such type for around 1,000 participants do not exceed 1 Mb.

b. Data from focus group interviews. Interview data will be stored as audio files in mp3 format (raw; archived) and transcripts as text/doc files. (processed; analyzed). Codes will be exported into excel format (xls; processed; analyzed). Typically, data files of such type for around 20 participants do not exceed 2 Mb.

1.4 Describe the population/participants/subjects that will be studied

For Wp1, parents of neurodivergent youth will be surveyed through the In Kaart participant registry. For Wp1, also professional caregivers and teachers will be recruited who work with neurodivergent youth. Furthermore, neurodivergent youth will be recruited for focus groups.

For Wp3, participants for the rapid online Delphi will be recruited from stakeholder groups of neurodivergent youth, caregivers, and practitioners. Also for the focus groups, participants will be recruited from these populations.

1.5 Do you process any of the following (personal) data?

- Name
- Contact details
- Information about family and personal relations

1.6 Do you process the personal data based on informed consent?

- Yes, using digital consent
- Yes, through a physical form

1.7 On what legal ground will the data processing take place if it is not based on informed consent?

- Not applicable, I use informed consent

1.8 Does the data collection include any of the following types of personal data?

None of the above

1.9 If your research involves special categories of personal data (previous question) and you will not use explicit informed consent, what is the legal ground for the exemption?

Not applicable

1.10 What kinds of outputs will you produce in this project? Please describe these data assets.

The following types of data assets will be produced:

Raw data
Data asset: interview recordings
Description: structured interviews recorded on audio
Format: .mp3

Processed data
Data asset: interview transcriptions
Description: automatically transcribed interviews by Amberscript
Format: .doc; .txt

Data asset: checked interview transcriptions
Description: manually checked transcriptions
Format: .doc; .txt

Data asset: scores on relevant variables
Description: spreadsheet with scores on variables that we're studying
Format: .sps;.xls;.csv

Analysed data
Data asset: graph
Description: visualisation of results
Format: .png

Other
Data asset: interview protocols / labjournals / codebooks
Description: description of how interviews are carried out / metadata
Format: .doc; .txt

Data asset: informed consent forms / processing agreement / consortium agreement
Description: physical forms signed by participants / document legal agreements
Format: physical documents

Data asset: key file
Description: reidentification participant number + contact details
Format: .xlsx

Data asset: code
Description: R syntaxes used to clean and analyse the scores on relevant variables, including documentation on what the syntaxes do
Format: .txt

1.11 How much digital data storage will your project require?

- 0 - 50 GB

An estimate of 80% will be raw data, the remainder will be processed data and secondary outputs.

1.12 Will you collect physical data? If yes, please describe these.

Not applicable

1.13 Will you take measures to ensure data quality? Please describe these, if applicable.

For data processing steps that rely on human judgments (e.g., study screening, study extraction, interview coding), reliability checks will be conducted and reported.

2. Legal and ethical requirements, codes of conduct

2.1 What legislation applies to your research project? Please tick the relevant boxes for your project.

- General Data Protection Regulation (GDPR)/ Algemene Verordening Gegevensbescherming (AVG)

The research protocols for work packages 1 and 3 in which personal data are processed will be submitted for review with the ethical review committee of the Faculty of Behavioural and Movement Sciences (VCWE FGB). This procedure includes a review by the faculty's privacy champion, who assesses the procedures and materials for informed consent and the data management plan. The framework for this assessment is the NETHICS code of ethics and the GDPR (see https://vu.nl/en/employee/behavioural-and-movement-sciences-getting-started/the-scientific-and-ethical-review-board-vcwe).

Because for WP1 data will be shared by VU from the participant register In Kaart with Hogeschool Leiden, a datasharing agreement will be drafted and agreed with advice from the privacy champion and legal office. Part of this process will be to write a data protection impact assessment (DPIA).

2.3 Do you require approval of an ethical committee for this project? If yes, please indicate which ethical committee and whether you have obtained approval for this project.

- Yes

Ethics Committee: VCWE
Approval status: Not yet
Review code:
Approval date: n.a.

2.4 Will you work with data for which intellectual property and/ or confidentiality are an issue? If yes, please describe.

- Yes

Bibliographic data obtained from providers such as Web of Science, Scopus, and Lens are copyright protected and cannot be made publicly available.

Intellectual ownership will be managed in accordance with the consortium agreement for this project. Standard NWO clauses for intellectual ownership have been agreed by the partners.

In brief, results are owned by the partner who generates the results. For results that are generated jointly, shared ownership will be established in writing. For details, we refer to the consortium agreement.

2.5 Do you plan on generating a marketable product from your research project? if yes, please describe

- No

3. Storage and back-up during the research process

3.1 What measures will you take to secure and protect data during the research process? Please describe, for each

separate data asset you described for question 1.10, how you will ensure data security, where the data assets are stored & backed up, and who has authorization to access the asset.

The data classification for integrity and confidentiality for several data assets is high due to the copyright protection of bibliographic data and intervention manuals and due to the sensitive nature of part of the personal data and their indirect identifiability.

For this reason we will primarily use YODA. YODA is a platform that supports research data management throughout the entire research cycle: from safe and easy storage and sharing of data during the research process, to sharing of data within research groups and projects and, ultimately, to research data archiving and publication. This platform is maintained by SurfSara under a processing agreement with Vrije Universiteit Amsterdam.

For recovery of data, YODA provides versioning and file restore requests.

During the collection of survey data, data will be temporarily held in storage with Qualtrics, in accordance with the processing agreement that VU has with Qualtrics. To increase security, survey responses will be copied to YODA and after verification, the buffer storage at Qualtrics will be emptied.

Access to YODA can only be obtained through multi-factor authorization with Surf Research Access Management (SRAM) and will be managed by the PI (Schuengel) and co-PI (Koning).

All data referring to persons will be pseudonymized, with identifying keys being encrypted with a password and stored on a separate location.

Access to the folders on YODA will be provided to the work package leaders (WP1: De Groot; WP2: Schuengel; WP3: Koning) and co-leaders (WP1: Koning/Buttner; WP2: Nikken; WP3: Vossen) and to the researchers for these work packages. Each user will receive a brief training in secure data management and sign a confidentiality agreement.

3.3 Which tools are used in the collection, processing or storage of data during research?

- Amberscript/Transcript Online
- Atlas.Ti *
- Microsoft Teams
- Open Science Framework (OSF)
- Qualtrics
- R (software) *
- Research Drive (Surf)
- Sharepoint
- SPSS
- Yoda
- Zivver

3.5 Is it necessary to transfer the (physical or digital) data assets to other locations or research partners? If yes, please describe how you secure the file transfer.

- Yes

Interview recordings will be made on encrypted audiodevices from TO3 and after collection, directly transferred to YODA by USB cable.

3.7 Do you transfer personal data outside of the European Economic Area (EEA)? If Yes, please provide additional information

- No

4. Data archiving and publishing

4.1 Which data assets will be archived and which will be published?

All data assets will be archived, except for interview audio files, which after transcription will be deleted.

Data assets that do not contain personal data nor copyright protected material will be published. This includes extracted

bibliographic data and search queries.

4.2 Where will you archive your data assets?

The data will be archived in VU YODA (https://portal.yoda.vu.nl/).

4.4 For how long will the data be available in the archive?

In accordance with the FGB Data archiving regulations, all data assets will be archived for at least 10 years

4.6 Where will you publish your data assets?

Publication of data assets will take place through OSF.

4.8 How will you ensure your dataset gets a persistent identifier (e.g. a DOI-code)?

The Data Publication Platform of VU assigns each data package a DOI.

4.9 Will you register your datasets in an online registry other than PURE? If yes, where?

Publication of the data packages is done through the YODA portal at DataCite Commons (https://commons.datacite.org/doi.org?query=client.uid:delft.vudata).

4.10 Are there restrictions to data publishing? If yes, please specify the reasons and list the data assets you do not wish to share publicly.

Bibliographic data obtained from providers such as Web of Science, Scopus, and Lens are copyright protected and cannot be made publicly available. We will explore the alternative use of OpenAlex as the source for bibliographic information, as data obtained from OpenAlex can be freely shared under the CC0 license. Secondary bibliographic information, obtained through extracting study information and data mining, will be made publicly available.

Survey data from youth and caregivers cannot be made publicly available, because even deidentified, pseudonymized data are likely to contain identifying information through the combination of rare neurodevelopmental conditions and demographic data. These data will therefore only be made available on request.

Survey data from the Delphi study surveys will be made publicly available, given that these data are deidentified, pseudonymized, not sensitive, and unlikely to be amenable to identification of respondents.

Focus group interview recordings and transcripts will likely contain sensitive and potentially identifying information, and will therefore not be made publicly available

4.12 When will you share the data? If not immediately after completion of the project, please specify the reasons.

Data will be shared for reuse as soon as articles are published.

4.13 Please indicate the license and/ or terms of use under which you share your data.

If data are made available, it will be under the CC BY 4.0 license.

5. Documentation

5.1 What documentation will accompany the data?

Work package 1: Needs and capacities of neurodivergent youth and their (professional) caregivers in relation to digitalization

a. Bibliographic data from identifying, screening, and including publications and data extracted from the included studies. Documentation will consist of search strings, in- and exclusion criteria, a PRISMA flow chart, and a codebook. This documentation will be captured in text documents (txt, doc). Metadata recording will be in accordance with the PRISMA-ScR (PRISMA extension for scoping reviews).

b. Data from responses to survey questions. Documentation will consist of the survey questions in proprietary .qsf format for exporting and importing surveys in Qualtrics and in word (doc) format, syntaxes for cleaning data, constructing variables, and analyzing the data for reporting (txt). A logbook of analyses will be kept and saved as a text (txt). Metadata will be in accordance with the journal article reporting standards for quantitative research (JARS-Quantitative) of APA (https://apastyle.apa.org/jars/quantitative).

c. Data from focus group interviews. Documentation will consist of topic lists in documents (doc). The qualitative coding project will as a whole be exported in the interoperable .QDPX format. This format is a QDA-XML standard for exchanging projects between different CAQDAS (Computer-Assisted Qualitative Data Analysis Software) packages. A logbook of the steps in the qualitative analysis will be kept and saved as a text (txt). Metadata recording will be in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ; https://doi.org/10.25504/FAIRsharing.6mhzhj).

Work package 2: Distillation of practice elements in media interventions for youth and evaluation of evidence and inclusiveness

a. Bibliographic data from identifying, screening, and including publications and data extracted from the included studies. Bibliographic data from identifying, screening, and including publications and data extracted from the included studies. Documentation will consist of search strings, in- and exclusion criteria, and a PRISMA flow chart. This documentation will be captured in text documents (txt, doc). Metadata recording will be in accordance with the PRISMA-ScR (PRISMA extension for scoping reviews).

b. Manuals and other documentation on media interventions. A logbook of the collection of these materials will be kept and saved as a text (txt).

c. Data extracted from bibliographic records, articles, and manuals. Codebooks will be stored as spreadsheet documents (xls). This documentation will be captured in text documents (txt, doc). A logbook of the extraction will be kept and saved as a text (txt). A logbook of the collection of these materials will be kept and saved as a text (txt). Metadata recording will be in accordance with the PRISMA-ScR (PRISMA extension for scoping reviews).

d. Intraclass correlations. Documentation will consist of the syntaxes (txt) for the computation of intraclass correlations and descriptive data. A logbook of analyses will be kept and saved as a text (txt). Metadata will be in accordance with the journal article reporting standards for quantitative research (JARS-Quantitative) of APA (https://apastyle.apa.org/jars/quantitative).

Work package 3: Co-create an adaptive decision tool resulting in recommendations and actions for implementation and dissemination

a. Data from responses to survey questions in the rapid Delphi study. Documentation will consist of the survey questions in proprietary .qsf format for exporting and importing surveys in Qualtrics and in word (doc) format, syntaxes for cleaning data, constructing variables, and analyzing the data for the Delphi rounds and reporting (txt). A logbook of interim and final analyses will be kept and saved as a text (txt). Metadata recording will be in accordance with the reporting guidelines for Delphi studies as proposed by Spranger et al. (2022; https://doi.org/10.1016/j.zefq.2022.04.025).

b. Data from focus group interviews. Documentation will consist of topic lists in documents (doc). The qualitative coding project will as a whole be exported in the interoperable .QDPX format. This format is a QDA-XML standard for exchanging projects between different CAQDAS (Computer-Assisted Qualitative Data Analysis Software) packages. A logbook of the steps in the qualitative analysis will be kept and saved as a text (txt). Metadata recording will be in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ; https://doi.org/10.25504/FAIRsharing.6mhzhj).

5.2 What metadata will accompany the data?

All datasets will be accompanied by metadata in accordance with the DataCite MetaData Scheme (https://doi.org/10.25504/FAIRsharing.me4qwe)

5.3 What methods, software or hardware are needed to access and use your data?

We seek to conduct statistical analysis on the survey data using open source software, in particular using R. Our strategy will be to fully document the versions used of R, RStudio, and the analysis packages. Furthermore, the analysis code will be fully annotated.

For the qualitative data analysis, we will export the data project in Atlas.ti to the interoperable .QDPX format. This format is a QDA-XML standard for exchanging projects between different CAQDAS (Computer-Assisted Qualitative Data Analysis Software) packages.

6. Data management responsibilities and resources

6.1 Who will be responsible for management of the data assets during the project? Please specify their name, position, role in the project, and faculty/ institution/ group.

Name: Carlo Schuengel
Roles: Conceptualization, Methodology, funding acquisition, supervision, Writing - Review & Editing, Management and coordination responsibility for the research activity planning and execution
Telephone number: +31 205988905
E-mail: c.schuengel@vu.nl
ORCID: https://orcid.org/0000-0001-5501-3341
University: Vrije Universiteit Amsterdam
Faculty: Faculty of Behavioural and Movement Sciences
Department: Clinical Child and Family Studies

6.2 Who will be responsible for management of the data assets after completion of the project (e.g. the project lead/ dedicated data manager/ department head)? Please specify their name, position, role in the project, and faculty/ institution/ group.

Name: Carlo Schuengel
Roles: Conceptualization, Methodology, funding acquisition, supervision, Writing - Review & Editing, Management and coordination responsibility for the research activity planning and execution
Telephone number: +31 205988905
E-mail: c.schuengel@vu.nl
ORCID: https://orcid.org/0000-0001-5501-3341
University: Vrije Universiteit Amsterdam
Faculty: Faculty of Behavioural and Movement Sciences
Department: Clinical Child and Family Studies

6.3 For data that are only available upon request, what methods will be used to handle requests for access and how will data be made available to those requesting access?

The registrations of the data packages are linked to the ORCIDs of the authors, allowing requests for data use to be directed at the authors.
If access is requested for verification purposes, encrypted data will be made available through a secure download link and a decryption key will be provided separately by e-mail, on the condition of signing a non-disclosure agreement.
If access is requested for reuse, a data sharing agreement will be closed between VU and the user.

6.4 What resources (for example financial and time) will be dedicated to research data management? Please estimate their cost.

No costs are foreseen for storage and archiving, because the size of the datasets is expected to remain below the 500 Gb threshold that VU uses before charging costs.
The project budget includes € 10.000 for data management support, which is primarily meant to cover the cost of managing survey data collected through In Kaart and NAR.