# RECRUITMENT MANUAL:
# RESEARCH PRIORITIZATION STUDY
*Intellectual and Developmental Disabilities*

# Recruitment Manual Overview

*Version 2.0, last updated June 13, 2024*

The purpose of this document is to provide an overview of the recruitment process for the Research Prioritization: Intellectual Developmental and Disability Study. This document provides information and guidelines for PEDSnet and DBPNet teams at each participating institution to reference on the overall study, recruitment process, and contact information. Please reach out to the PEDSnet PMO with any questions regarding this document (PEDSnetresearch@chop.edu).

# A. Stakeholder-Informed Research Prioritization Services

## A1. Background

PEDSnet is a multi-specialty network consisting of 11 children's hospital health systems, dedicated to conducting observational research and clinical trials. Funded by the Patient-Centered Outcomes Research Institute (PCORI) Phase 3 Infrastructure Grant, PEDSnet is embarking on five Stakeholder-Informed Research Prioritization Projects.

The topic area for each project will be determined by the PEDSnet Steering Committee. Each project will develop a prioritized list of 10 research projects that will generate new evidence to have an immediate impact on patient health outcomes.

Led by the Engagement Core at Seattle Children's Hospital, PEDSnet will bring together patient and stakeholder engagement, crowdsourcing methodologies, data informatics and analysis, and project management during these studies to engage patients and families meaningfully in research and research decision-making to address critical knowledge gaps.

This recruitment manual focuses on the first project centered on the PCORI Priority Area of Intellectual and Developmental Disabilities (IDD), which will be conducted in collaboration with DBPNet.

The Developmental Behavioral Pediatrics Research Network (DBPNet) is a multi-center scientific and clinical research network that promotes coordinated research activities and addresses health issues for children with autism spectrum disorder (ASD) and other developmental disabilities. DBPNet offers a developmental behavioral pediatric research infrastructure that supports multidisciplinary research, focuses on the translation of research to practice, and provides an environment in which to train a new generation of developmental behavioral pediatrics researchers.

The five sites participating in this study were selected because they are members of both PEDSnet and DBPNet.

## A2. Study Design

Each Research Prioritization Project requires three recruitment groups: patients, parents, and clinicians. Each research prioritization project will engage youth, parents/caregivers, and clinicians to generate stakeholder-informed research priorities. The study team will use crowdsourcing methods to collect responses to study questions from participants. Detailed in this section is the five-step process that each project will adhere to.
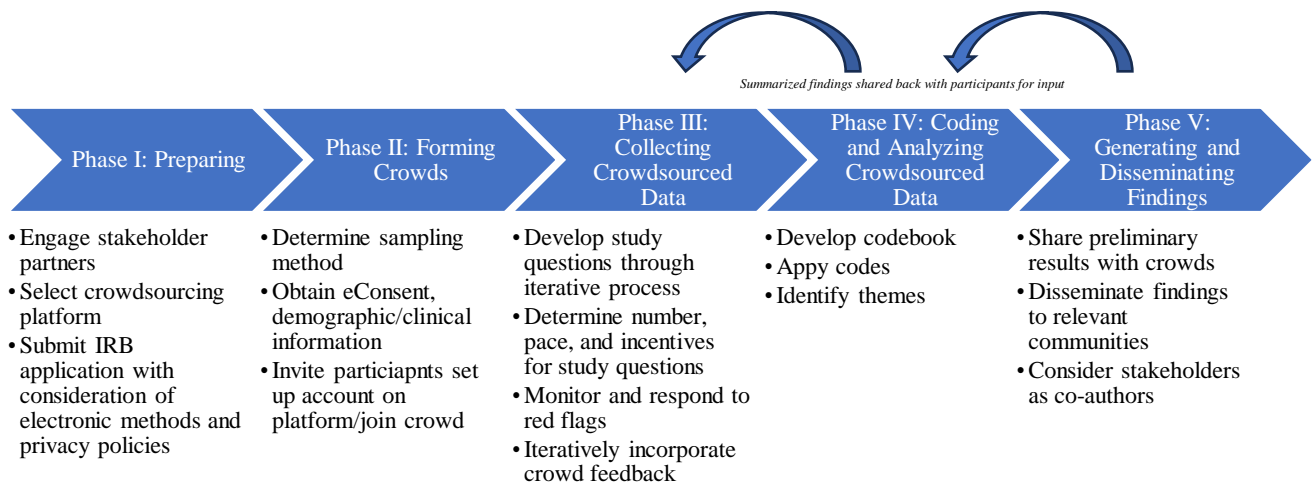
## Crowdsourcing methods

Crowdsourcing methods as defined by Sood et al. (2021) is a participative online activity that has four elements: an organization with a task to perform, a community, or crowd, uniquely qualified to contribute to the task, an online environment facilitating collaboration between the organization and the crowd, and mutual benefit for the organization and the crowd.

Utilizing Viva Engage as the online platform, participants will come together as a crowd to collaborate on identifying research priorities within the field of IDD. Viva Engage offers a downloadable mobile application, enabling participants to respond to questions at their convenience. Notifications alert participants to relevant questions or comments, ensuring timely engagement. Emotional inquiries prompt participants to share specific experiences and feelings in the moment.

Viva Engage fosters a sense of community, as participants remain within the same group throughout their involvement, allowing them to build upon shared experiences. Participants can express agreement by liking certain comments and feedback.

Crowdsourcing methodology follows a five-phase approach to collect data from participants.

### *Five Step Process*

*Summarized findings shared back with participants for input*

| Phase I: Preparing | Phase II: Forming Crowds | Phase III: Collecting Crowdsourced Data | Phase IV: Coding and Analyzing Crowdsourced Data | Phase V: Generating and Disseminating Findings |
|---|---|---|---|---|
| • Engage stakeholder partners<br>• Select crowdsourcing platform<br>• Submit IRB application with consideration of electronic methods and privacy policies | • Determine sampling method<br>• Obtain eConsent, demographic/clinical information<br>• Invite particiapnts set up account on platform/join crowd | • Develop study questions through iterative process<br>• Determine number, pace, and incentives for study questions<br>• Monitor and respond to red flags<br>• Iteratively incorporate crowd feedback | • Develop codebook<br>• Appy codes<br>• Identify themes | • Share preliminary results with crowds<br>• Disseminate findings to relevant communities<br>• Consider stakeholders as co-authors |

# B. Target Population

The study sample will include youth with a diagnosis of IDD (see specific diagnosis categories below), parents/caregivers of a youth with one of these IDD diagnoses, and clinicians and researchers who work with these patients. Each recruitment group will have specified criteria to meet. **All participant groups must be able to read and write comfortably in English and must be comfortable using a computer or smart device.**

## B1. Eligible Conditions for Study Enrollment

*Table 1: IDD Eligible Conditions Definition*

| Eligible Conditions |
|---|
| - Attention Deficit Hyperactivity Disorder (ADHD) |
| - Learning disabilities<br>    o Includes specific learning disabilities related to reading, math, writing disorders, including dyslexia and dysgraphia and Intellectual disabilities |
| - Autism Spectrum Disorder (ASD)<br>    o Includes Asperger's (AS) and Pervasive Developmental Disorder (PDD) |
| - Communication and language disorders<br>    o Includes expressive and receptive language delays, apraxia, etc. |
| - Intellectual disabilities |

## B2. Inclusion and Exclusion Criteria

*Table 2: IDD Minor Inclusion Criteria*

| Minor Inclusion Criteria |
|---|
| - Diagnosed with one or more of the eligible conditions |
| - Between the ages 13-18 |
| - Parent is not a study participant |

*Table 3: IDD Young Adult Inclusion Criteria*

| Young Adult Inclusion Criteria |
|---|
| - Diagnosed with one or more of the eligible conditions |
| - Between the ages of 19-24 |
| - Parent is not a study participant |

*Table 4: IDD Parent Inclusion Criteria*

| Parent Inclusion Criteria |
|---|
| -    Have a child diagnosed with one or more of the eligible conditions |
| -    Child is not a study participant |

*Table 5: IDD Clinician Inclusion Criteria*

| Clinician Inclusion Criteria |
|---|
| -    Work in at least one of the following professional disciplines:<br>     o  Neurodevelopmental Pediatrics<br>     o  Developmental-behavioral Pediatrics<br>     o  Advanced practice nursing in a developmental-behavioral pediatric setting<br>     o  Occupational therapy<br>     o  Speech therapy<br>     o  Pediatric psychology<br>     o  School psychology<br>     o  Neuropsychology<br>     o  Primary Care Pediatrics<br>     o  General Pediatrics<br>     o  Advanced practice nursing in a primary care setting |
| -    Experience working with patients who have been diagnosed with one or more of the eligible conditions |

## B3. Recruitment Goals

This study aims to recruit a minimum of 150 and a maximum of 300 total participants, including youth (aged 13-24), their parents/caregivers, and clinicians. Each site is expected to recruit at least 20-30 participants from each group, totaling 40-60 participants per site: 20 youth (aged 13-24) and parents/caregivers, and 20 clinicians.

*Table 6: Target Enrollment*

| Study Participants | Study Total | Estimated Recruitment Capacity Per Site |
|---|---|---|
| Youth/Parents/Caregivers | 100-150 | 20-30 |
| Clinician | 100-150 | 20-30 |

# C. Recruitment Process

## C1. Overview

This flowchart illustrates a high-level overview of the recruitment process. Each respective team is responsible for understanding their role in recruitment. For the detailed step-by-step instructions, please see below.

Figure 1: Recruitment Overview Process
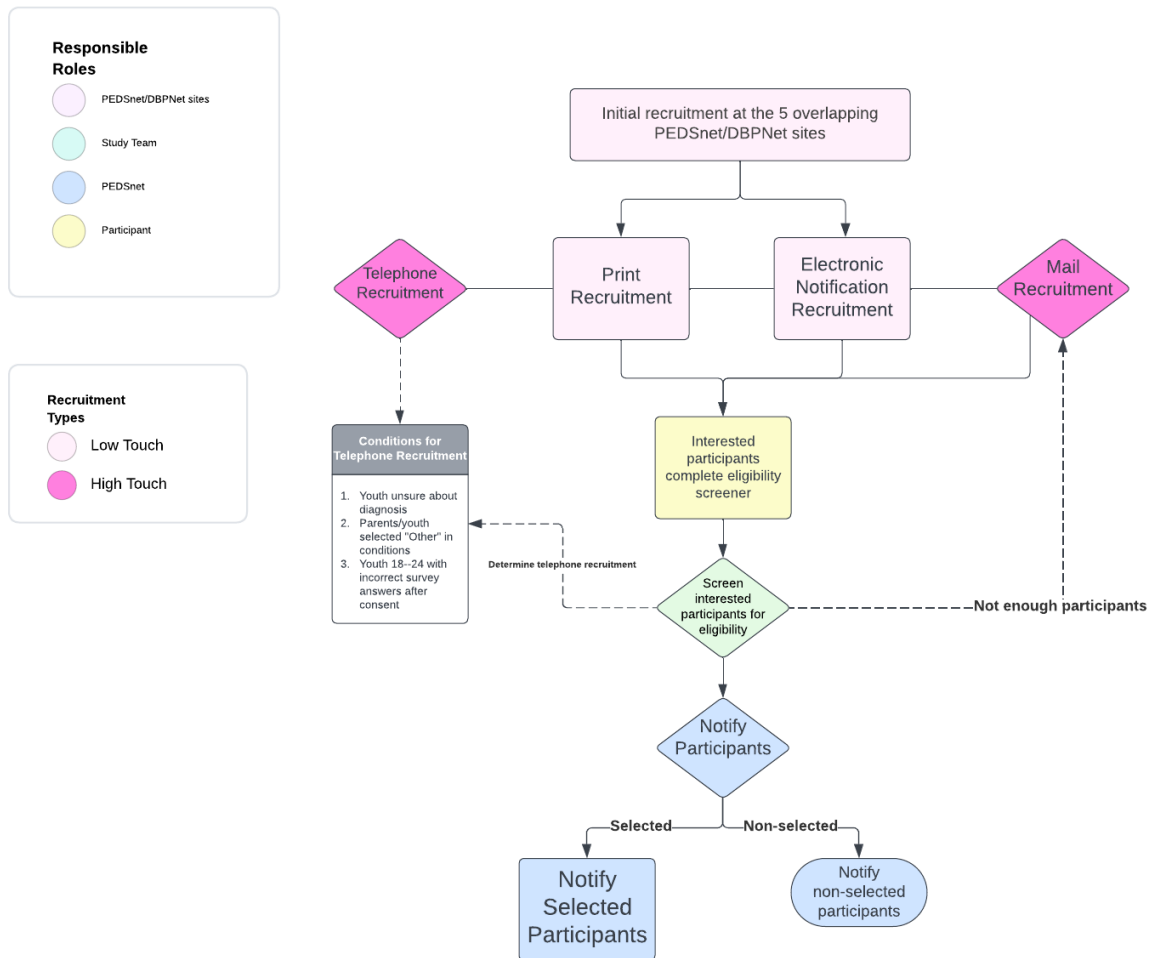


1. Coordinating Center provides recruitment materials to DBPNet site recruitment teams. DBPNet sites are responsible for conducting recruitment.
   a. The sites responsible for recruitment are: Children's Hospital of Philadelphia, Cincinnati Children's Hospital Medical Center, Colorado Children's Hospital, Stanford Lucile Packard Children's Hospital, and Texas Children's Hospital
2. DBPNet sites disseminate recruitment materials
   a. Each site has a recruitment goal of
      i. Minimum: 20 Youth/Parents and 20 Clinicians/Scientists
      ii. Maximum: 30 Youth/Parents and 30 Clinicians/Scientists
   b. Sites will recruit via email and through posting physical flyers in clinics
      i. Sites should send at least 2-3 email blasts spread out within 4 weeks to their patient listservs
      ii. For sites opting in to post flyers, sites should post flyer within 1 week of receiving recruitment materials
   c. We're asking sites to begin recruitment no more than 7 business days after receiving recruitment materials

d. With this being the first attempt at recruitment for the Research Prioritization projects the recruitment timeline will be dependent upon the number of interested participants at 4 weeks of receiving recruitment materials.
   i. PEDSnet PMO will monitor the screener and circulate reports with the number of eligible participants in each category from their site that have:
      1. Completed the screener; and of those
      2. How many are actually eligible
   ii. PEDSnet PMO and the DBPNet team will check-in with sites that have low rates of interest in the study as needed
e. Alternative Recruitment Methods:
   i. The PEDSnet CC will monitor response rates and eligibility among those that complete the screener. If, after 4 weeks, the response rate is not sufficient, sites may be asked to switch to high-touch recruitment methods of phone calls, direct mailings, or targeted emails.
   ii. The PEDSnet CC will contact potential participants via Telephone if one of the following conditions are met: (a) Interested youth select that they are unsure about their diagnosis in the eligibility screener, (b) interested parents/youth selected "other" for their condition, and (c) interested youth 18-24 with incorrect survey answers after consent.
3. Interested participants complete the eligibility screener.
4. PEDSnet CC will monitor responses from the eligibility survey. The core study team at CHOP will work together to ensure the study population meets diversity criteria. The recruitment process will continue until it is determined that there is sufficient enrollment in a category to move forward with starting up that "crowd.".
5. PEDSnet will notify all participants who completed an eligibility screener with further instructions on how to create and access the Viva Engage platform where they will respond to the study questions and interact with their fellow crowd members.

## C2. Recruitment Timeline

*Table 7: Research Prioritization IDD Recruitment Timeline*

| Approximate Due Date | Milestone |
| --- | --- |
| ~~May 17, 2024~~ | ~~Site recruitment staff attend survey kick-off calls~~ |
| July 24, 2024 | Low-touch site recruitment begins |
| August 19, 2024 | 4-Week Check-In |
| August 26, 2024 | High-touch site recruitment begins *(If needed)* |
| September 3, 2024 | Crowdsourcing Begins |

# D. Recruitment Materials

*As of July 23, 2024, the IRB at CHOP has granted approval for all recruitment materials presented in this manual. Please refrain from making any modifications to these materials, including emails.*

To start, we are asking all sites to begin with low-touch methods of recruitment. These methods include electronic and print. Electronic recruitment is required by all participating sites. Print is optional for participating sites. High-touch methods of recruitment will be dependent upon our 4-week check-in with sites. If at that time we would like to continue recruitment sites will be asked to engage in high touch recruitment methods. These methods include telephone and mail.

## D1. Low Touch

### Electronic *(Required)*
There are three recruitment emails for (1) parents, (2) clinicians, and (3) youth 18-24. Each recruitment email includes detailed information about the eligibility criteria along with a link that provides direct access to the eligibility screener via REDCap. Please refer to the appendices to view the email templates.

The parent recruitment email will also be used to recruit youth between the ages of 13-17 for the study. Parent involvement of interested youth is specified.

We encourage sites to utilize all available electronic recruitment methods, particularly relevant listservs. Some examples of the different avenues we will be using at CHOP:
- Patient and specialty listservs
- The Center for Autism Research listserv and newsletter blast
- This Week @CHOP, a weekly email blast sent out to all CHOP employees
- CHOP's Research Discovery Finder, which promotes studies on various multimedia screens throughout CHOP buildings
- Posting flyers in CHOP buildings

### Print *(Optional)*
Included in this manual are five flyers: 4 tailored for parents and youth, and 1 flyer designed for clinicians. Each flyer features the basic eligibility criteria and includes a QR code, offering direct access to the eligibility screener via REDCap. Please refer to the appendices to view the flyers visually.

Sites have the option to display flyers as deemed appropriately within their clinic. We have provided four variations of the parent-youth flyers to provide your site with the flexibility to utilize flyers as best seen fit in consideration of your clinic's patient population.

Each site will receive the five flyers in a zip filed attached to the same email that delivered this manual. If your site needs the flyer to be resent, please contact us at pedsnetresearch@chop.edu.

## D2. High Touch

### Telephone

Additional Telephone outreach may be conducted by the PEDSnet CC if the following conditions are met:
- *For youth participants who indicated they weren't sure about their diagnosis. If the youth is 13 – 17, we may be speaking to the parent*
- *For parents or youth who selected "other" in the conditions section*
- *For youth participants 18-24 who incorrectly answer questions on the Post-Consent Questionnaire used to confirm their consent*

For youth participants between the ages of 13-17 we will speak to the parent.

### Mail

Sites capable of mailing out flyers and recruitment letters to patients may be asked to do so if we are not meeting recruitment numbers with the low touch methods. Eligible participants will receive a printed copy of the recruitment email and relevant flyer. Additional information on this will be provided if necessary.

## E. Eligibility Screener

The recruitment screeners, including electronic consents and the eligibility and demographic questionnaires, will be conducted electronically through REDCap. These screeners will be accessible via QR code or link provided in the recruitment materials. There are two separate screeners: one for parent and youth participants, and another for clinician/scientist participants. Access to these screeners is restricted to PEDSnet PMO team members assigned to this project. To view the screeners, please refer to the following links:
- Parent and Youth Screener
- Clinician/Scientist Screener

### QR Codes and Links

*Table 8: Research Prioritization IDD Recruitment Timeline*

| Screener Types | |
|---|---|
| Parent and Youth | The QR code and link will bring all interested parents and youth to one page. The eligibility screener will group participants to ensure the |

| | proper information is collected for each interested group. |
|---|---|
| Clinician/Scientist | The QR code will bring clinician and scientist to a separate link |

## Parent and Youth Screener Overview

*Table 9: Parent/Youth Screener Overview*

| Instrument | Description |
|---|---|
| Overview | Provides study overview |
| Grouping | Participants choose their group |
| Pre-Consent Information | Informs participants about the process |
| eConsent Forms | Consent forms for different participants |
| Post-Consent Questionnaire (Youth 18 – 24) | Questions to confirm participant understanding |
| Eligibility | Asks about diagnosed conditions |
| Demographics | Collects demographic information |
| Email and phone communications | Collects contact information |

## Clinician

*Table 10: Clinician Screener Overview*

| Instrument | Description |
|---|---|
| Overview | Provides study overview |
| Pre-Consent Information | Informs participants about the process |
| eConsent Form | Consent form for participants |
| Eligibility | Asks about professional discipline and experience |
| Demographics | Collects demographic information |
| Email and phone communications | Collects contact Information |

# F. Notifying Participants

The study team at CHOP will be responsible for notifying participants if they have been selected to participate in the study or not.

Participants who are selected to participate will receive an email with instructions on creating an account on the crowdsourcing platform Viva Engage. The email will contain detailed instructions on how to set up the account to ensure participant anonymity. The CHOP research coordinators will carefully monitor the accounts and reach out to participants to modify them as needed if any identifying details are inadvertently used during the account setup process.

Selected participants will also receive instructions on providing their best mailing address so the study team can send their reloadable Visa debit card that they will receive payment on.

Once selected participants create their Viva Engage account, the CHOP study team will add each participant to their cohort group on Viva Engage. Participants will get an email notification to join their cohort group. Participants will only be added to their specific cohort group on Viva Engage.

Once all participants have created Viva Engage accounts, the study team will start posting questions.

# G. The Study Team and Contact Information

## G1. Key Personnel

For any questions related to this study, please contact pedsnetresearch@chop.edu, and a CHOP study team member can troubleshoot your questions to the appropriate members of the study team.

| PEDSnet Core Study Team |
|---|
| **Principal Investigator:** |
| Christopher Forrest *Forrestc@chop.edu* (CHOP) |
| **Co-Investigators:** |
| Erica Sood *Erica.sood@nemours.org* (Nemours) |
| Christopher Bartlett *Christopher.bartlett@nationwidechildrens.org* (Nationwide) |
| Eneida Mendonca *Eneida.mendonca@cchmc.org* (CCHMC) |
| **Project Manager:** Jill McDonald *Mcdonaldj5@chop.edu* (CHOP) |
| **Research Coordinators:** |
| Adya Maddox *Maddoxa1@chop.edu* (CHOP) |
| Aliyah Jones *Jonesgrifa@chop.edu* (CHOP) |
| Colleen Byrne *Byrnec@chop.edu* (CHOP) |

| DBPNet Core Study Team |
|---|
| **Co- Investigators:** |
| Nathan Blum Blum@chop.edu *(CHOP)* |
| Cy Nadler *Cnadler@cmh.edu* (Children's Mercy Hospital) |
| Elisa Muniz *Elmuniz@montefiore.org* (Montefiore) |
| **Project Manager:** David Pearlman *Pearlmand@chop.edu* (CHOP) |

## G2. Study Team Roles and Responsibilities

| Study Team Roles and Responsibilities |
|---|

| Team Member(s) | Task |
|---|---|
| CHOP Coordinating Center | Recruitment material development, regulatory approvals, progress tracking, and managing the crowdsourcing platform. All participant payments will be issued directly to each participant by the CHOP Coordinating Center. |
| Core Study Team Members | The CHOP Coordinating Center organized a Core Study Team consisting of clinicians, researchers, informaticians, and parents. The Core Study Team finalized the study protocol and recruitment materials and developed the crowdsourcing questions. |
| Recruitment Site PI and Recruitment Site Project Manager/Research Coordinator | The Recruitment Site PI and PM/RC will be responsible for sending out recruitment |
| PEDSnet Site Project Manager | The PEDSnet Project Manager at each site will add recruitment team members to the PEDSnet Master IRB protocol. The Coordinating Center at CHOP will email the PEDSnet Site Project Manager the list of local recruitment members that need to be added to the IRB. |

# Appendix

## Flyers

### Flyer A

**DOES YOUR CHILD HAVE A DEVELOPMENTAL CONDITION? WE WANT TO HEAR FROM YOUR FAMILY!**



**Contribute To Research That Will Help Children**

Researchers want to know the areas of care that matter most to you about your child's condition.

**ELIGIBLE CONDITIONS**
- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

**DETAILS**
- Looking for youth between ages 13 to 24 years OR parents of eligible youth
- Participation is entirely online
- Compensation provided to participating youth and parents
- Participating parents will answer personal questions based on their child's condition; youth will answer questions about themselves

**INTERESTED?**

Fill out this brief survey using the QR code provided or by accessing this link:
**https://redcap.link/57691epe**

If you have any questions, please contact Aliyah Jones by emailing pedsnetresearch@chop.edu

TAKE THE SURVEY HERE

PEDSnet
A Pediatric Learning Health System

DBPNet
Developmental Behavioral Pediatrics Research Network

*Flyer B*

# DOES YOUR CHILD HAVE A DEVELOPMENTAL CONDITION? WE WANT TO HEAR FROM YOUR FAMILY!



## Contribute To Research That Will Help Children

Researchers want to know the areas of care that matter most to you about your child's condition.

### ELIGIBLE CONDITIONS

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

### DETAILS

- Looking for youth between ages 13 to 24 years OR parents of eligible youth
- Participation is entirely online
- Compensation provided to participating youth and parents
- Participating parents will answer personal questions based on their child's condition; youth will answer questions about themselves

## INTERESTED?

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If you have any questions, please contact Aliyah Jones by emailing pedsnetresearch@chop.edu



TAKE THE SURVEY HERE



PEDSnet
A Pediatric Learning Health System

DBPNet
Developmental Behavioral Pediatrics Research Network

*Flyer C*

# DOES YOUR CHILD HAVE A DEVELOPMENTAL CONDITION? WE WANT TO HEAR FROM YOUR FAMILY!



## Contribute To Research That Will Help Children

Researchers want to know the areas of care that matter most to you about your child's condition.

### ELIGIBLE CONDITIONS

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

### DETAILS

- Looking for youth between ages 13 to 24 years OR parents of eligible youth
- Participation is entirely online
- Compensation provided to participating youth and parents
- Participating parents will answer personal questions based on their child's condition; youth will answer questions about themselves

## INTERESTED?

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TAKE THE SURVEY HERE

PEDSnet
A Pediatric Learning Health System

DBPNet
Developmental Behavioral Pediatrics Research Network

*Flyer D*

# DOES YOUR CHILD HAVE A DEVELOPMENTAL CONDITION? WE WANT TO HEAR FROM YOUR FAMILY!



## Contribute To Research That Will Help Children

Researchers want to know the areas of care that matter most to you about your child's condition.

### ELIGIBLE CONDITIONS

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

### DETAILS

- Looking for youth between ages 13 to 24 years OR parents of eligible youth
- Participation is entirely online
- Compensation provided to participating youth and parents
- Participating parents will answer personal questions based on their child's condition; youth will answer questions about themselves

## INTERESTED?

Fill out this brief survey using the QR code provided or by accessing this link:
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If you have any questions, please contact Aliyah Jones by emailing pedsnetresearch@chop.edu



**TAKE THE SURVEY HERE**



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# WE WANT TO HEAR FROM YOUNG ADULTS LIKE YOU!



## Contribute To Research That Will Help Other Young Adults

Researchers want to know which topics you think are most important to research.

### ELIGIBLE CONDITIONS

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

### DETAILS

- Looking for young adults between ages 18 to 24 years
- Participation is entirely online
- Compensation provided to participating youth
- You will answer personal questions about yourself and your experiences

### INTERESTED?

Fill out this brief survey using the QR code provided or by accessing this link:
**https://redcap.link/57691epe**

If you have any questions, please contact Aliyah Jones by emailing pedsnetresearch@chop.edu



TAKE THE SURVEY HERE

# WE WANT TO HEAR FROM YOUNG ADULTS LIKE YOU!



## Contribute To Research That Will Help Other Young Adults

Researchers want to know which topics you think are most important to research.

### ELIGIBLE CONDITIONS

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

### DETAILS

- Looking for young adults between ages 18 to 24 years
- Participation is entirely online
- Compensation provided to participating youth
- You will answer personal questions about yourself and your experiences

### INTERESTED?

Fill out this brief survey using the QR code provided or by accessing this link:
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Research Network

*Flyer G*

# WE WANT TO HEAR FROM YOUNG ADULTS LIKE YOU!



## Contribute To Research That Will Help Other Young Adults

Researchers want to know which topics you think are most important to research.

### ELIGIBLE CONDITIONS

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

### DETAILS

- Looking for young adults between ages 18 to 24 years
- Participation is entirely online
- Compensation provided to participating youth
- You will answer personal questions about yourself and your experiences

## INTERESTED?

Fill out this brief survey using the QR code provided or by accessing this link:
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If you have any questions, please contact Aliyah Jones by emailing pedsnetresearch@chop.edu



TAKE THE SURVEY HERE

**PEDSnet** A Pediatric Learning Health System

**DBPNet** Developmental Behavioral Pediatrics Research Network

*Flyer H*

**PEDSnet** — A Pediatric Learning Health System

**DBPNet** — Developmental Behavioral Pediatrics Research Network

## Do you work with youth with developmental conditions? We want to hear from you!

**DETAILS**

Researchers from PEDSnet and DBPnet are recruiting clinicians and scientists for an online research study to identify research priorities and inform future projects.

**ELIGIBLE DISCIPLINES**

- Developmental Pediatrics
- Occupational or Speech Therapy
- Psychology
- Primary Care/General Pediatrics
- Advanced Practice Nurses

**INTERESTED?**

Fill out this brief survey:
**https://redcap.link/9zhwk7g4**

*If you have any questions, please contact the study team by emailing pedsnetresearch@chop.edu*

**CONDITIONS OF INTEREST**

- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Communication and Language Disorders
- Learning Disabilities
- Intellectual Disability

IRB 16-012878

## Recruitment Emails

*Email for recruiting parents and youth (13-17):*

**Subject Line:** CHOP Study Looking for Participants! Does your child have a developmental condition? We want to hear from your family.

## You can contribute to research to help children!

**Does your child have:**
- **Attention Deficit Hyperactivity Disorder**
- **Autism Spectrum Disorder**
- **A communication or language disorder**
- **Learning disability**
- **Intellectual disability or Developmental Delays**

**We want to hear from your family!**

Researchers at **CHOP** and other children's hospitals are looking to find out what research questions you would like answered about the condition your child has.

Participants will answer questions related to their experiences on an online platform. Participants will also be able to respond to other's comments.

If you want to participate, please fill out the following survey. The survey will open with more details on this study and then take you to a consent form. If you are willing to participate, signing the consent form and proceeding is consenting to be screened for participation.

We are also recruiting youth for this study! If your child is interested, please have them fill out a separate survey. For youth aged 13-17, we will ask you, the parent, to read and sign a consent form on their behalf. Once you have consented, your child will read an assent form. If they are interested in joining the study, signing the assent form and proceeding will screen them for participation. ***Please note – we want participants with many conditions and experiences. Thus, not everyone who fills out the survey will be invited to participate in the project***: https://redcap.link/57691epe

For families where both parents and youth express interest, we will select either the parent or the youth for participation, but not both from the same family.

Please feel free to reach out to the study team via email with any questions at pedsnetresearch@chop.edu

Thank you for your consideration!
*Email for recruiting youth (18-24):*

**Subject Line:** CHOP Study Looking for Participants! We want to hear from young adults like you!

# You can contribute to research!

Researchers at **CHOP** and other children's hospitals are looking to find out what research topics are most important to you. This study will be done completely online and participants will be paid.

Participants will answer questions related to their experiences on an online platform. Participants will also be able to respond to other's comments.

**If you'd like to participate, you should have one of the following diagnoses:**
- **Attention Deficit Hyperactivity Disorder**
- **Autism Spectrum Disorder**
- **A communication or language disorder**
- **Learning disability**
- **Intellectual disability or Developmental Delays**

If you want to participate, please fill out the following survey. The survey will open with more details on this study and then take you to a consent form. If you are willing to participate, signing the consent form and proceeding is consenting to be screened for participation. You may want to take this survey when a parent or guardian is around in case you have any questions.

***Please note – we want participants with many conditions and experiences, so not everyone who fills out the survey will be invited to participate in the project***:
**https://redcap.link/57691epe**

Please feel free to reach out to the study team via email with any questions at
pedsnetresearch@chop.edu

Thank you for your consideration!

*Email for recruiting clinicians and scientists:*

**Subject Line:** Recruiting participants for a study on research priorities for youth with developmental disorders

## Improve Intellectual or Developmental Disabilities through collaborative research

Are you a clinician or researcher in one of the following disciplines:

· **Developmental Pediatrics**
· **Occupational or Speech Therapy**
· **Psychology**
· **Primary Care/General Pediatrics**
· **Advanced Practice Nurses**

**We want to hear from you!**

Researchers from **PEDSnet** and **DBPnet** are looking to recruit clinicians and researchers that work with youth with intellectual or developmental disabilities for an online research study where participants answer a series of questions related to their experiences to help identify research priorities and inform future research projects

The attached flyer and linked eligibility screener contain additional information regarding eligibility for participation. The eligibility screener will begin with a consent form that we ask you to read. If you are willing to participate, signing the consent form and proceeding to the survey is consenting to be screened for participation in the survey. *Please note – not everyone who fills out the screener will be invited to participate in the project*: **https://redcap.link/9zhwk7g4**

Please feel free to reach out to the study team via email with any questions at pedsnetresearch@chop.edu

Thank you for your consideration!