



THE NEURODIVERGENCE CLINIC RESEARCH CENTER

THE NDC RESEARCH KIT

GENERAL INFORMATION

What is The Neurodivergence Clinic Research Center (NDCRC)?

NDCRC is a free and secure tool that helps willing volunteers work with eligible researchers and their studies on neurodivergence. NDCRC is a research project and a list of willing individuals who are interested in neurodivergence research. These individuals are called NDCRC Volunteers. NDCRC provides a tool that allows you to provide your opinion or experience as it relates to a neurodivergence research study.

What is Neurodivergence?

Neurodivergence describes the existence or mind-body experience of being neurodivergent. It is a broad term and encompasses the state of being of anyone whose neurocognitive function differs from societal standards, i.e., from the neurotypical.

Are there any benefits, costs, or risks of joining NDCRC as a Volunteer?

As a NDCRC Volunteer, you might be able to get involved with research that helps improve the health and well-being of our society. Even now, many research studies end too early since there are not enough volunteers to take part. Also, there are many people who want to join research studies, but do not know how.

How will you benefit from joining NDCRC as a Volunteer?

- Reduce the time you spend looking for research studies or figuring out how to take part in research.
- Improve your chances of being matched with research studies that interest you.
- Help you learn more about your community's research, resources, or about your area of interest.
- Help you be a part of an international group of volunteers that might help improve the health of others and impact the future of research for everyone.
- Benefits society as this research may increase general knowledge or improve access to new or different treatments or health practices.

There is a chance that there may be no benefit to you for joining NDCRC. Also, NDCRC cannot guarantee that you will be contacted by a researcher for any specific research study, either now or in the future.

There is a very small risk that some of your profile information may be released without your permission, but NDCRC takes many steps to keep your personal information private, secure, and confidential until you allow NDCRC to release it. You may get emails from researchers using NDCRC when your anonymous profile is added to their research studies. You may always remove yourself from NDCRC. There is no cost to join NDCRC.

Who can join?

Anyone can join NDCRC as a Volunteer. You do not have to be diagnosed with a health condition to be a NDCRC Volunteer. If you decide to join, you may register for yourself or someone else when you start the Volunteer registration form. A parent, legal guardian, or caretaker can register someone under the age of 18. They can also register an adult that is not able to enter his or her own information.

What do I have to do to join?

Joining NDCRC is easy! It should take less than 2 minutes. If you decide to sign up, you will receive a questionnaire in which we ask a few questions about yourself, like your age and contact information. You will also be able to enter details about your health. All of this information will be stored securely and will be kept confidential as described below and in the NDCRC Privacy Statement.

You do not have to answer all the questions in the questionnaire. Only the information that you choose to enter will be a part of your profile. You can remove yourself from NDCRC at any time.

What happens once I register?

Once you join NDCRC your non-identifiable information becomes part of a pool of data. Researchers search through this pool when looking for data about their studies. These studies will be reviewed by an Institutional Review Board (IRB). IRBs look at the risks and benefits of each research study.

To limit access to your information, researchers will send you a Research Kit to you through NDCRC's secure web system. This takes form of an email message that NDCRC will send to the email address connected to your NDCRC profile.

If you want to learn more about our neurodivergence study, or want the researcher to contact you, you can contact us through the website Contact page. At that time, the researcher may share more details with you about his or her study. Remember that by joining NDCRC, you do not have to take part in any study. You may choose not to respond to a researcher message at any time.

NDCRC will perform quality and evaluation metrics on an on-going basis. Part of that process may involve collecting non-identifiable information about your contact and enrollment status in researchers' studies. This will help us see how useful this tool is to NDCRC's researchers and institutions.

[NDCRC Disclaimer](#)

NDCRC does not promise that your data will be included in studies through the NDCRC system. NDCRC supports only neurodivergence-specific research.

[How is my information protected?](#)

NDCRC respects your privacy and takes privacy very seriously. Your personal information will be sent and stored in a secure system. Please see the NDCRC Privacy Statement for more details.

NDCRC will never sell, rent, or lease your personal information.

[What if I change my mind about being part of NDCRC?](#)

You may request to remove your personal information from NDCRC at any time through the website Contact page.

[What if my contact and/or health information has changed?](#)

You will be able to request a change or update to your profile information at any time through the website Contact page.

[Who is involved in NDCRC?](#)

NDCRC has been developed through a collaboration between Bellagio Psychotherapeutics of Alpharetta d/b/a Stresshacker LLC, a Georgia Corporation. NDCRC is supervised by Dr. Mark R. Zuccolo, Executive Director of The Neurodivergence Clinic. NDCRC is privately funded.

[Does NDCRC provide mental health care services?](#)

No. NDCRC does not provide any medical or healthcare products, services, or advice. If you have any questions about your mental health care, please see the Diagnosis, Coaching, and Treatment section of our website.

VOLUNTEER AGREEMENT

By agreeing to this Volunteer Agreement, you willingly agree to let NDCRC use and share your personally identifiable information on your NDCRC profile as described here and in the NDCRC Privacy Statement. You also agree to let NDCRC access, keep or share your registration information if required to do so by law or in the good faith belief that it is necessary to:

- Enforce the terms of this Volunteer Agreement or the site's Terms of Use
- Respond to your requests for customer service
- Comply with federal, state, or local legal process

By finishing the registration process, you represent and warrant that you live at the address you indicate in the registration form, are at least eighteen years of age, and that you possess the legal right and ability to enter into this Volunteer Agreement. You affirm that when you register with NDCRC, you will provide accurate information about yourself. You agree that if any information you provide is inaccurate, NDCRC may keep you from accessing NDCRC. If you register someone who may not be able to register themselves (including individuals under the age of 18, or someone who is unable to register without your assistance), you assert that you are their legal guardian, parent or caretaker and agree to the terms outlined in this agreement.

If you agree, your profile will be added to the NDCRC volunteer registry as soon as you submit this form.

Thank you for learning more about NDCRC!

[Do you have questions or concerns?](#)

For general questions, please visit the website [Contact page](#).

VOLUNTEER INFORMED CONSENT

Name:

Date of Birth:

Address:

Email Address:

- I confirm that I have read and understood the information sheet for the study.
- I have had the opportunity to consider the information.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
- I understand that data collected during this study will be processed in accordance with the NDCRC Privacy Statement.
- I understand that my consent form will be retained and kept in a secure digital folder.
- I understand that I am entitled to access the information I have provided at any time while it is in storage as specified above.
- I consent for my interview to be audio / video recorded if I so request. The recording will be transcribed.
- I agree with my questionnaire answers and/or reflections being modified with changes to any details that may lead to identification of myself or anyone else involved in the research.
- I consent to verbatim quotes being used in publications; I will not be named (and a pseudonym will be used) but I understand that there is a risk that I could be identified by those who know me/my history.
- I understand that whatever I say in the questionnaire or reflective writing is confidential unless I tell the researcher that I or someone else is in immediate danger of serious harm, or the researcher sees or is told about something that is likely to cause serious harm. If that happens, the researcher will contact me and tell me about what could happen if I continue to talk about it and explore how I would prefer to deal with the situation. The researcher will encourage me to seek support from elsewhere to help me make the situation safer. If the researcher feels unsure that I will go and get support, they will talk to me

about what they need to do and what might happen next. In an extreme case where a child (or any other vulnerable person including the interviewee) is at serious risk, and I choose not to seek help/advice the researcher has a duty to disclose this to the relevant agencies.

- I understand that exploring my phenomenological experiences may lead to emotional discomfort. I understand that I will be offered a de-brief session with a psychotherapist following the research interview if I choose.
- I understand that I will not benefit directly from participating in this research.
- I understand that should I disclose possible criminal offences that have not been investigated or prosecuted, in the questionnaire, the researcher may report the matter(s) to relevant agencies.
- I understand that disguised extracts from my interview may be used to inform future psychotherapy practice within the Code of Ethics guidance of the profession.
- I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of the people I speak about.
- I understand that the questionnaire and reflective writings are designed for the purposes of the research and may not produce any beneficial effects relating to my health or well-being.

Name of Participant (print):

Date:

Signature:-----

RESEARCH QUESTIONS

Please type your answers in the space provided.

1. Can you tell me about your neurodivergence?

a. How did it present as a child?

b. What does it feel like for you?

c. How does it affect your life now?

d. How did/do other people relate to you?

2. What did you think/believe about yourself as a child (with ND behaviors in mind)?

a. What do you believe about yourself now?

3. What was like for you in school and at home?

a. Did you feel different?

b. If so, in what way?

c. What support (if any) did you get?

d. Did you have friends/meaningful relationships?

4. When did you start having psychotherapy? (if you never did, skip this question)

a. What did you try (if anything) previously to having Psychotherapy?

b. Can you remember what you wanted to get out of Psychotherapy?

c. Did you try other modalities or therapies?

5. What was Psychotherapy like for you/how did your therapist work with you?

a. Have you had any particularly negative experiences with therapy, which you feel are associated with your ND? If so, please can you say a little about these?

b. Have you had any particularly positive experiences with therapy associated with your ND? If so, please can you say a little about these.

c. With hindsight, did your ND create any specific challenges for you in therapy? If so, can you please say a little about these.

6. Did you have clear, defined goals/outcomes to work towards in Psychotherapy relating to ND?

a. Can you remember what they were?

b. Did you find this helpful or unhelpful?

c. Please feel free to add any additional insights or comments.