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PDS-Personality Protocol

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We use this protocol and it's working

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Abstract

Early developmental precursors of Borderline Personality Disorder (BPD) have been the focus of little empirical work, despite BPD being recognized as a leading contributor to disability, burden, and increased mortality. Interpersonal dysfunction and identity disturbance are hallmark symptoms of BPD that can be traced to early childhood. Yet, our understanding of how these core features of the disorder develop, interact over time, and lead to BPD is limited by a lack of longitudinal research that begins during this early, critical developmental period. The current study charts the developmental trajectories of interpersonal dysfunction and identity disturbance from early childhood into young adulthood, examining how they interact with environmental factors and are associated with neural circuitry aberrations, to predict BPD in early adulthood. In this study, we leverage 17 years of previously collected longitudinal data from the Preschool Depression Study (PDS), along with newly collected data in adulthood to study the development of interpersonal and identity dysfunction. This NIMH-funded study of 348 young children enriched for emotional dysfunction offers an unparalleled opportunity to understand specific developmental precursors and timing for BPD.

We will examine: (1) whether specific developmental periods of early childhood and adolescent impairment in these constructs provides predictive utility for young adult interpersonal dysfunction and identity disturbance, (2) how these constructs prospectively and uniquely relate to young adult BPD, as opposed to depression, and the moderating effect of specific environmental factors; and (3) the additional predictive role of neural correlates of these constructs in onset of BPD.

Eligibility

- 1 Participants were limited to those who participated in the Preschool Depression Study (N=348), in addition to their young adult peers (N=348), for a total possible sample size of N=696.
- 2 **Inclusion Criteria**
 - Prior participation in the Preschool Depression Study OR young adult peer of participant in the Preschool Depression Study (at least 18 years old).
 - Ability to understand, speak, and read English sufficiently.
- 3 **Exclusion Criteria**
 - Currently incarcerated.
 - Lack of consent from participant.
 - Inability to understand, speak, or read English sufficiently.
 - Less than 18 years old.
- 4 **Subjects with the following conditions were excluded in the original Preschool Depression Study:**
 - Known mental retardation.
 - History of a Pervasive Developmental Disorders (Autism, Asperger's, PDD NOS).
 - Major medical illness.
 - History of head injury or loss of consciousness >5 minutes.
 - Have been in a group home, an out-of-family foster placement or institutionalized.

Recruitment

- 5 Multiple methods were used to contact participants and encourage them to participate in this wave of the study. This was the first wave of the study in which all study participants were young adults and were not participating with their parent. We attempted to accommodate this young adult population by using text and email for recruitment as well as allowing them to schedule themselves via Bookings if they chose. The following methods were used for recruitment. Hard-to-reach participants were contacted 20-30 times through these different methods.
 1. Initial text and email containing study information and Bookings link.
 2. Phone calls and voice mails and continued texts and emails.
 3. Phone calls and emails to alternate contacts (primarily the parent or guardian who participated with the participant in prior waves).
 4. Cards and newsletters sent to last known address.
 5. Public records searches to find phone numbers and addresses when the previous contact information was no longer valid.

Scheduling

6 Microsoft Bookings

The study used Microsoft Bookings to facilitate scheduling of the initial Self-Assessment and the Peer Assessment. Participants were emailed and/or texted links to schedule themselves for study sessions. Participants were given the option to reach out to study staff to schedule the session for them if they had any issues using the Bookings link. Study staff would also manually schedule hard-to-reach participants if they responded to phone calls or texts. Participants were instructed to only include their email address and no other identifying information when scheduling on Bookings. After scheduling, participants would receive confirmation emails and Zoom links directly from the study email address.

Self-Assessments were expected to take up to 4 hours to complete, but participants were given the option to schedule a 2, 3, or 4 hour time block on Bookings. Interviewers would then schedule follow-up sessions as needed if the assessment could not be completed in the initial time block. Peer sessions were scheduled for 1 hour.

Self Assessment

7 Consent

Participants were consented to the study using an IRB approved consent through the eConsent framework in REDCap. The eConsent was either shared via Zoom or by a special survey link sent to the participant's email. Participants accessing Zoom on a computer were able to sign via Zoom using the Remote Control function. Participants who joined the Zoom call from a phone or tablet would complete the survey link via their email address. Participants heard a consent script read by the interviewer before signing and were given the opportunity to read the consent form in full if they wished. Interviewers shared the consent form via Zoom and would scroll through corresponding parts of informed consent document while reading.

8 Beginning the Interview

8.1 Pre-Interview Check In

Complete the Pre-Interview Check In survey with the participant: *"Before we get started, I'll need to know where you are right now and the best way to reach you in case of an emergency."*

- a. Present Time and Date
- b. Address
- c. Best way to get in touch
- d. Emergency contact

9 Life Story Narrative

9.1 Read initial instructions exactly as written:

"The next part of the assessment is going to be about you and the story of your life. We are interested in hearing your story, including parts of the past as you remember them and the future as you imagine it. The story is selective; it does not include everything that has ever happened to you. Instead, we will ask you to focus on a few key things in your life. There are no right or wrong answers. I will guide you through a series of questions and turn my camera off while you are answering. You will have about five minutes to answer each one.

Please know that our purpose in doing this interview is not to "figure out what is wrong with you" or do some kind of clinical/psychological analysis. The interview is for research purposes only, and its main goal is to simply hear your story. We are collecting life stories to understand the different ways in which people's lives unfold, and how they live and understand who they are.

Do you have any questions before we begin?"

9.2 In the upper righthand corner, select "View" and then ****make sure Gallery is selected**** and select "Hide Non-video Participants" so the recording shows only the participant.

9.3 **Tell me about yourself** (5 mins)

a. *****START RECORDING*****

- i. Set Zoom to record video – Let participant know!!
- b. Read instructions exactly as written: *"We would like to begin by hearing a little about you. We want to get to know you a bit better, and it's also helpful to have something to refer back to during the interview. So, how would you describe yourself as a person? There is no wrong answer. I will set the timer for 5 minutes. Let me know when you are ready to begin."*
 - i. Copy and paste question into zoom chat: **How would you describe yourself as a person?**
 - ii. When participant tells you they're ready: *"Okay, your time will begin when I turn off my camera."*
- c. Turn camera off and mute yourself
- d. Set timer for five minutes
 - i. If participant speaks for less than 2 minutes, provide the following prompt: *"Please elaborate on what you were saying."*
 - ii. If participant stops speaking again, wait 30 seconds, turn camera back on, and move on to the next prompt.

- iii. If participant stops speaking *past 2 minutes* (e.g., 2:45), wait 30 seconds from the time they stop talking/asking for you to come back, and then turn camera back on and move on to the next prompt.
- e. Turn camera back on

9.4 **Low point in life** (5 mins)

a. Read instructions exactly as written: *"Thinking back over your entire life, please identify a time that stands out as a low point, if not the lowest point in your life story. Please provide as much detail as you can about it. What happened, where and when, who was involved, and what you were thinking and feeling? Why was this particular moment so bad and what might this say about you or your life? I will set the timer for 5 minutes. Let me know when you are ready to begin."*

i. Copy and past question into zoom chat: **Thinking back over your entire life, please identify a time that stands out as a low point, if not the lowest point in your life story. Please provide as much detail as you can about it. What happened, where and when, who was involved, and what you were thinking and feeling? Why was this particular moment so bad and what might this say about you or your life?**

ii. When participant tells you they're ready: *"Okay, your time will begin when I turn off my camera."*

b. Turn camera off.

c. Set timer for five minutes.

i. If the participants protests doing this, tell them that the event does not really have to be the lowest point in their life but merely a very bad experience of some kind.

ii. If participant speaks for less than 2 minutes, provide the following prompt: *"Please elaborate on what you were saying."*

iii. If participant stops speaking again, wait 30 seconds, turn camera back on, and move on to the next prompt.

iv. If participant stops speaking *past 2 minutes* (e.g., 2:45), wait 30 seconds from the time they stop talking/asking for you to come back, and then turn camera back on and move on to the next prompt.

d. Turn camera back on

9.5 **High point in life** (5 mins)

a. Read instructions exactly as written: *"Thinking back over your entire life, please identify a time that stands out as a high point, an especially happy, joyous, exciting, or wonderful moment. Please provide as much detail as you can about it. What happened, where and when, who was involved, and what you were thinking and feeling? Why was this particular moment so good and what might this say about you or your life? I will set the timer for 5 minutes. Let me know when you are ready to begin."*

i. Copy and paste question into zoom chat: **Thinking back over your entire life, please identify a time that stands out as a high point, an especially happy, joyous, exciting, or wonderful moment. Please provide as much detail as you can about it.**

What happened, where and when, who was involved, and what you were thinking and feeling? Why was this particular moment so good and what might this say about you or your life?

ii. When participant tells you they're ready: *"Okay, your time will begin when I turn off my camera."*

b. Turn camera off

c. Set timer for five minutes

i. If participant speaks for less than 2 minutes, provide the following prompt: *"Please elaborate on what you were saying."*

ii. If participant stops speaking again, wait 30 seconds, turn camera back on, and move on to the next prompt.

iii. If participant stops speaking *past* 2 minutes (e.g., 2:45), wait 30 seconds from the time they stop talking/asking for you to come back, and then turn camera back on and move on to the next prompt.

d. *****STOP RECORDING***** - Let participant know!!

9.6 LSN Wrap-Up

a. Turn camera back on and check in with participant: *"Thank you for sharing some of your story with us. We're all done with that portion of the interview. Before we continue on, would you like to take a break?"*

b. Go back to "View" in the upper righthand corner and unselect "Hide Non-video participants".

9.7 If any suicidal ideation/abuse concerns arise, follow Staff SI/Safety Protocol and contact Study PIs and/or Clinical staff.

1. Complete Safety plan if needed
2. Provide our list for psychosocial resources
3. Document in REDCap under "SI and Safety Planning"

Clinical Interviews

10 SCID-5-AMPD Module I

Interviewers administered the SCID-5 AMPD Module I using the following steps. Responses were coded in REDCap and interview was recorded via Zoom.

10.1 Administer SCID-5-AMPD: *"Now we'll be starting another portion of the interview. I'll be asking you about your thoughts, feelings, and behaviors. These questions will be just be about you in general, there's no particular timeframe to think about. Ready to begin?"*

Begin in "SCID AMPD Overview" and end with "SCID AMPD Intimacy"

- 10.2 Wrap up: *"Thank you so much for sharing with me. We're all done with that portion of the interview. Before we continue on, would you like to take a break?"*
- 10.3 If any suicidal ideation/abuse concerns arise, follow Staff SI/Safety Protocol and contact Study PIs and/or Clinical staff.
1. Complete Safety plan if needed
 2. Provide our list for psychosocial resources
 3. Document in REDCap under "SI and Safety Planning"
- 11 **SI and Safety Planning**
- Interviewers asked participants 2 items modified from the MDD section of the SCID to assess for suicidal ideation in the past month and during their entire life. Any reports of SI were assessed and safety planning was completed if necessary.
- 11.1 Ask the following 2 questions as written.
- a. **In the past month, have things been so bad that you thought a lot about death or that you would be better off dead? Have you thought about taking your own life?**
 - b. **Has there ever been a time when things have been so bad that you thought a lot about death or that you would be better off dead? Have you thought about taking your own life?**
- Answer the following questions about Passive and Active SI and Non-suicidal Self-Injury (NSSI) in the past month and lifetime based on the direct questions asked or any other reports accumulated throughout the interview.
1. **Did the participant endorse any PASSIVE suicidal ideation in the last month?**
 2. **Has the participant ever attempted suicide?**
 3. **Was a safety plan created?**
- 11.2 Additional question will open up if a participant says "Yes" to either of the above items. **Have you done something about it? (What have you done? Have you made a specific plan? Have you taken any action to prepare for it? Have you actually made a suicide attempt?)**
- 11.3 Further assess and safety plan as you would normally in response to SI.
- 11.4 Answer the following questions about Passive and Active SI and Non-suicidal Self-Injury (NSSI) in the past month and lifetime based on the direct questions asked or any other reports accumulated throughout the interview. Complete the remainder of this section now or at the end of the interview (if you prefer to see if SI comes up in other sections)
1. **Did the participant endorse any PASSIVE suicidal ideation in the last month?**
 2. **Has the participant ever attempted suicide?**

3. Was a safety plan created?

12 SCID-5-CV

SCID-5-CV was administered via NetSCID. The interview was recorded using Zoom.

12.1

Go to NetSCID and login with your username and password. Click "Administer NetSCID-5"

12.2

Select the following modules under Module Selection, and make sure NetSCID-5 Clinical Version is selected from the drop-down menu:

- Mood Episodes & Disorders (A & D)
- Anxiety Disorders (F)
- Obsessive-Compulsive Disorder & Posttraumatic Stress Disorder (G)
- Adult Attention-Deficit/Hyperactivity Disorder (H)

12.3

Click "Start New Interview"

12.4

*****START RECORDING***** - Let participant know!!

12.5

Introduce NetSCID: *"Now we'll be starting another portion of the interview. It's possible you've already answered some of these questions or similar ones at the beginning, but I may need to ask again just to make sure I have the correct information. When possible, I'll simply confirm information you've already provided and move through any repeated questions quickly. Ready to begin?"*

12.6

Begin in "Mood Episodes and Disorders" Section and end after "Adult Attention-Deficit/Hyperactivity Disorder" Section. You may pause throughout the interview if you or the participant needs a break. Be sure to save your progress on NetSCID during any pauses so you do not lose any information.

12.7

When you have completed the ADHD section, be sure to press "End" to mark the interview as complete. If you do not do this, NetSCID may not let you open a PD interview for your participant.

12.8

*****STOP RECORDING***** - Let participant know!!

12.9

Say *"Thank you so much for sharing with me. We're all done with that portion of the interview. Before we continue on, would you like to take a break?"*

13 SCID-5-PD

SCID-5-PD was administered via NetSCID. The interview was recorded using Zoom.

- 13.1 Go to NetSCID and login with your username and password. Click "Administer NetSCID-5"
- 13.2 Select the following modules under Module Selection, and make sure NetSCID-5 Personality Disorders is selected from the drop-down menu:
 - NetSCID-5 PD
- 13.3 Click "Start New Interview"
- 13.4 *****START RECORDING***** - Let participant know!!
- 13.5 Administer NetSCID: *"Now we'll be starting the final portion of the interview. It's possible you've already answered some of these questions or similar ones at the beginning, but I may need to ask again just to make sure I have the correct information. When possible, I'll simply confirm information you've already provided and move through any repeated questions quickly. Ready to begin?"*
- 13.6 Begin interview. You may pause throughout the interview if you or the participant needs a break. Be sure to save your progress on NetSCID during any pauses so you do not lose any information. You can also pause the video recording just remember to restart it.
- 13.7 *****STOP RECORDING***** - Let participant know!!
- 13.8 Say *"Thank you so much for sharing with me. We're all done with the interview! Before you go, let's talk about the other portions of the study quickly."*

End of Self Assessment

14 Participant Surveys/Questionnaires

- 14.1 Remind participant of the following: *"I'm going to send a link to your surveys. We ask that you try to complete all of them within 2 weeks. You will be paid upon completion or at the end of the 2 weeks, whichever comes first. Your survey responses will NOT be monitored in real time, so if you need immediate assistance at any point while completing them, we more than likely will not be able to get you the help you need as quickly as you might need it. However, we will be periodically reviewing surveys, and if you disclose any thoughts of suicide, harming yourself or others, or that someone is*

harming you, we will follow up with resources for you. If you ever need immediate assistance, please call 911, go to your nearest emergency room, or call or text 988."
*"Remember to schedule the assessment with your peer if you have not already done so, ideally within one month of your Self Assessment we just completed today. Ideally you would pick a close friend and coordinate a time that is convenient for both of you to join a Zoom call simultaneously. If you cannot think of a friend to invite, the order of preference for another peer would be sibling and then extended family member (like a cousin or relative *close in age to you*). Your peer MUST be 18 or older!"*

- 14.2 Ask participant for feedback about assessment and let them know they can call or email us with questions any time! Thank them for their time and end the call. Congrats, you just finished an interview! 😊
- 14.3 Send participant their survey link via email.

Peer Assessment

15 Peer Consent

Peer participants were consented to the study using an IRB approved consent via the eConsent framework in REDCap. The eConsent was either shared via Zoom or by a special survey link sent to the peer's email. Peers accessing Zoom on a computer were able to sign via Zoom using the Remote Control function. Peers who joined the Zoom call from a phone or tablet would complete the survey link via their email address. The Breakout Room function in Zoom was utilized to allow peers to consent privately while on the Zoom call.

16 Beginning the Peer Session

- 16.1 Peer Contact Information: Collect current contact information and information necessary for peer payment.
- 16.2 Peer Pre-Interview Check In
 - 1. Ask the participant and peer's relationship to one another.
 - 2. Ask how long they've known each other. You'll enter the number in months.
 - 3. Complete the Pre-Interview Check In survey with the peer AND participant: *"Before we get started, I'll need to know where you both are right now and the best way to reach you in case one of us gets disconnected."*
 - a. Present Time and Date
 - b. Address
 - c. Best way to get in touch

d. Confirm participant emergency contact info is the same from their self-assessment – if it is different collect that information. You DO NOT need an emergency contact for the peer.

17 Peer Discussion Set-Up

17.1 In the upper right-hand corner, select "View" and then ****make sure Gallery is selected**** and select "Hide Non-video Participants" so that way the recording shows only the participant.

17.2 *****START RECORDING***** - Let peer and participant know!!

17.3 Read initial instructions exactly as written: *"For the next 20 minutes, we would like you to talk to one another about three topics. First, you will have the chance to talk about a favorite memory you share together. Then, each of you will have the chance to talk about something you need help or support with. Lastly, we'll ask you to talk about something fun: planning a vacation or weekend trip together. I will read you specific instructions before you begin each task. My camera will be turned off while you are discussing. Do you have any questions before we begin?"*

18 Memory Task (5 mins)

18.1 Read instructions exactly as written: *"For the first 5 minutes, we would like you to discuss with one another a favorite memory that you share together. Try to include as many details as possible, such as where it was, when, what you were doing, and who else was involved. Talk just as you normally would. I will set the timer for 5 minutes and turn my camera back on when the time is up. Let me know when you are ready to begin."*

18.2 Copy and paste question into zoom chat: **Talk about a favorite memory you share together. Try to discuss as many details as possible, such as where it was, when, what you were doing, and who else was involved.**

18.3 When participant/peer tell you they're ready: *"Okay, your time will begin when I turn off my camera."*
Turn off camera.

18.4 Set timer for 5 minutes

i. If participant/peer speak for less than 2 minutes, provide the following prompt: *"Please elaborate on what you were saying."*

ii. If participant/peer stop speaking again, wait 30 seconds, turn camera back on, and move on to the next prompt.



- iii. Participant and peer may get way off topic – let them, we can still code that!!

18.5 Turn your camera back on.

19 **Support Task (10 mins)**

19.1 Read instructions exactly as written: *"During the next 10 minutes, we would like you to talk with each other about a problem or issue that you need help or support with. You can discuss anything about the problem. It is up to you who goes first, but please try to make sure you each get a chance to discuss your problem. You can spend as much time as you want on each person's problem. Talk just as you normally would. I will set the timer for 10 minutes and turn my camera back on when the time is up. Let me know when you are ready to begin."*

19.2 Copy and paste question into zoom chat: **Talk with each other about a problem or issue that you need help or support with. It is up to you who goes first, but please try to make sure you each get a chance to discuss your problem.**

19.3 When participant/peer tell you they're ready: *"Okay, your time will begin when I turn off my camera."*
Turn off camera.

19.4 Set timer for 10 minutes

- i. If participant/peer speak for less than 8 minutes, provide the following prompt: *"Please elaborate on what you were saying."*
- ii. If participant/peer stop speaking again, wait 30 seconds, turn camera back on, and move on to the next prompt.
- iii. Participant and peer may get way off topic – let them, we can still code that!!

19.5 Turn your camera back on.

20 **Plan a Vacation/Weekend Trip Together (5 mins)**

20.1 Read instructions exactly as written: *"For the last 5 minutes, we would like you to plan a vacation or weekend trip together. Try to discuss as many details as possible, such as where you will go, when, what you will do there, and who else you may want to invite. Talk just as you normally would. Have fun and dream big! I will set the timer for 5 minutes and turn my camera back on when the time is up. Let me know when you are ready to begin."*

- 20.2 Copy and paste question into zoom chat: **Plan a vacation or weekend trip together. Try to discuss as many details as possible, such as where you will go, when, what you will do there, and who else you may want to invite.**
- 20.3 When participant/peer tell you they're ready: *"Okay, your time will begin when I turn off my camera."*
Turn off camera.
- 20.4 Set timer for 5 minutes
- If participant/peer speak for less than 2 minutes, provide the following prompt: *"Please elaborate on what you were saying."*
 - If participant/peer stop speaking again, wait 30 seconds, turn camera back on, and move on to the next prompt.
 - Participant and peer may get way off topic – let them, we can still code that!!
- 20.5 *****STOP RECORDING***** - Let peer and participant know!! Turn your camera back on.

21 Post-Discussion Surveys

- 21.1 Read instructions: *The last thing I'll have each of you do is complete a short 10-question survey about the discussion you just had. It should take about 3 minutes to complete for each of you. I'll start with [Peer's Name] – I'll send [Participant's Name] into a breakout room so you can answer the questions privately, and then I'll enter the breakout room and have you complete the survey, [Participant's Name]. Whenever you're not completing the survey, please just hang tight and wait for the other to finish. We'll go back to the main room at the end for some final instructions."*
- 21.2 Place Participant in a Breakout Room.
- 21.3 In Peer's REDCap file, open the PEER Post-Discussion Survey and complete.
- Share your screen with peer.
 - You can either read the questions out loud and fill in the survey for the peer, or you can give them remote control access and have them complete it. Just make sure they understand what the survey is asking, and specify that it's asking about the conversations they *just* had during the discussion activity.
- 21.4 Join the Breakout Room (leave Main Session) with Participant: *"Okay [Peer's Name], hang tight for*

a second while I complete the survey with [Peer's Name]. We'll all meet in the Main Session at the end!"

- 21.5 Click on Breakout Rooms in the bottom menu on your Zoom screen. In the upper righthand of the pop-up, click "Join" and then "Yes." This will leave the peer in the Main Session to come back to later.
- 21.6 In participant's REDCap file, open the PARTICIPANT Post-Discussion Survey and complete.
 - i. Share your screen with participant.
 - ii. You can either read the questions out loud and fill in the survey for the participant, or you can give them remote control access and have them complete it. Just make sure they understand what the survey is asking, and specify that it's asking about the conversations they *just* had during the discussion activity.
- 21.7 After the survey is finished, click on "Breakout Rooms" in the menu at the bottom of your Zoom screen, then in the bottom righthand corner of the pop-up click on "Close All Rooms." You and the participant should come back to the Main Session within a few seconds.

End of Peer Assessment

- 22 Inform peer about surveys and that they should be completed within 2 weeks: *"[Peer's Name], 'I'm going to send a link to your surveys via email. We ask that you try to complete all of them within 2 weeks. You will be paid upon completion or at the end of the 2 weeks, whichever comes first. You will receive \$30 for completing them. 'Your survey responses will NOT be monitored in real time, so if you need immediate assistance at any point while completing them, we more than likely will not be able to get you the help you need as quickly as you might need it. However, we will be periodically reviewing surveys, and if you disclose any thoughts of suicide, harming yourself or others, or that someone is harming you, we will follow up with resources for you. If you ever need immediate assistance, please call 911, go to your nearest emergency room, or call or text 988.'"*
- 23 Remind Participant to complete their surveys if they have not done so yet, OR praise them if they have already completed them: *"[Participant's Name], it looks like you still need to complete your surveys. Just a reminder you'll have until [2 weeks post-Self Assessment, look on calendar]. (If it's already past their 2-week mark: [Participant's Name], it looks like you didn't quite complete all of the surveys we sent you. I know it's past your 2-week mark, but if you're able to get those done in the next few days and email us you've completed them, we can still pay you!)"* OR *"[Participant's Name], it looks like you completed all of your surveys! That's so great, thank you for doing that. Any feedback you'd like to give?"*



- 24 Ask participant and peer for feedback about assessment and let them know they can call or email us with questions any time! Thank them for their time and end the call. Congrats, you just finished the final session for this participant!
- 25 Send Peer their survey link via email.