Tip Sheet for Ethical Youth Engagement

For researchers partnering with youth with neurodevelopmental disabilities

1 Design

Identify creative ways to collaborate and build relationships with youth.

Consider accessibility needs
(e.g., time for meetings/preferred format of communication)

2 Recruitment

Be creative to reach out and recruit youth outside of existing networks (e.g., community organizations).

Provide information about expectations/compensation, especially for what is done outside of project meetings.

Be open to have conversations about what partnership could look like.

Simplify application forms and use accessible/inclusive language. Offer support as filling out a form can be challenging for some.

3 Onboarding

Have regular conversations with youth partners to understand their goals (e.g., skills, experiences).

Provide trainings related to the assigned role (e.g., meeting facilitation, presentation, analysis).

Offer opportunities for youth to do a trial run based on their role's task and responsibilities.

Create opportunities and different options of roles and tasks to support youth's skills development for their CVs (e.g., use of different softwares, research skills).

Youth perspective

"I would say also the application process… the idea of filling out a long application was so daunting that I was just like, 'Is this even worth it?' It's such an academic thing. If someone doesn't come from an academic field like me, I have a really tough time organizing my thoughts into written words."

Ask how you can support during commitment and expectations outside project hours/meeting *(i.e. accommodations request)*.

Create safety measures and protocols so that youth partners know who to talk to in case they are feeling uncomfortable about anything and have available communication means (e.g., phone number of a coordinator).

4 — During the project

Be aware that a hierarchy between researchers and youth exists. Defining and seeing youth as experts can address this power imbalance.

Reflect compensation based on youth's values/needs (e.g., volunteer for younger youth, cash for students).

Start off each session/meeting with updates or debrief from when they last met.

Be intentional in naming youth as research partners and provide a variety of formats for them to provide feedback.

Show the contribution youth are making (e.g., changes made in the interview questions/documents).

Keep youth in the loop of what is happening in the project even when there are no tasks for them.

Youth perspective

"Even though I think we try to create safe spaces, sometimes I think there's an inherent shame of being neurodivergent or mentally ill or whichever that can make it difficult to speak up at times."

Apply good practices to create a safe and fun environment (e.g., ice breaker questions, independent youth advisor to talk to, multiple methods of participating).

Routinely ask if access needs would like to be modified (e.g., accommodations during working or school hours).

Treat all youth partners as equal partners alongside researchers.

Make sure everyone has a chance to speak by reaching out to younger youth partners and providing additional support to encourage participation.

Ask what type of gift card youth prefer or offer cash options rather than asking them to pick from selected gift card since they may require participants to spend more.

Youth perspectives

"After a year had passed, [for knowledge mobilization, the research team] invited us back to talk about our short stories [we had created in the project]. It was nice to have my film screened…I'm proud of all those accomplishments and I'm really happy that I was able to get to do that work."
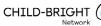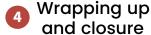
"I would have liked to have been involved all the way to the end, and know what's happening and know what conferences we're going to... Sometimes you just feel a little bit used for your knowledge and your lived experience..."

4 — Wrapping up and closure

Celebrate achievements.

Provide opportunities for knowledge mobilization.

Give credit/ recognize youth's contributions (e.g., co-authorship, reference, in-person get together).

Share information about what next steps are and provide an update until the end of the project.