What is IIDDEAL and What is it About?

- IIDDEAL stands for: **Individuals with IDD Engaged, Aligned, and Leading: Outcomes that Matter.**

- **IIDDEAL** started January 2022 and will end December 2023.

- IIDDEAL includes:
  - people with IDD
  - family care partners
  - clinicians
  - insurers/government

- IIDDEAL helps these groups agree on the most important health and life results and approaches.

- In IIDDEAL, these groups of people are called **stakeholders**.

- IIDDEAL is a project that **brings stakeholders together to build**:
  - trust
  - understanding of each other and the ability to come to agreements
  - learnings so that future **patient-centered outcomes research (PCOR)** is more meaningful and inclusive of stakeholders.
What is the IIDDEAL Work Product?

- IIDDEAL will produce a Health Outcomes Framework about what these important health and life results are.
  
  - The Framework will help make future **patient-centered outcomes research (PCOR)**:
    
    - include what’s important to people with IDD
    
    - be easier for clinicians, insurers, and government to support.

Is IIDDEAL a Research Project?

- No, IIDDEAL is not a research project. But it will help with future research.

- Researchers who care about **PCOR** and want to learn the perspective of stakeholders sometimes participate in IIDDEAL meetings.

- Most research on IDD doesn’t ask people with IDD what is most important to them.

- **Patient-centered outcomes research (PCOR)** is different.

- **PCOR**: 
  
  - learns from patients and care partners about what results matter to them
  
  - compares different treatments to see which improves a person’s health and life results more.
How is IIDDEAL Being Paid For and Who is Participating?

- The Patient-Centered Outcomes Research Institute (PCORI), Eugene Washington PCORI Engagement Award funded the first phase of IIDDEAL (IIDDEAL-1).
  - IIDDEAL-1 included around 60 stakeholders (self-advocates, care partners, clinicians, and payers/government representatives).
- Arnold Ventures is funding the second phase, IIDDEAL-2.
  - IIDDEAL-2 will include 72 more people. It will not include insurers or government stakeholders.
- Lead organizations include: Augusta University, IEC, Brandeis University
- This project depends on the expert advice and participation of the multi-stakeholder Advisory Council and Core Team members.

What Activities Were Done in IIDDEAL So Far?

We invited stakeholders through:

- Disability groups
- Advocates
- Personal contacts
- Professional groups like ones for doctors and nurses
- State and federal agencies
- Healthcare groups
- Research partners
We made sure to include stakeholders with different backgrounds:

- Race/ethnicity
- Life stage/age
- IDD condition
- Communication preferences
- Gender
- Geography (where they live)

Our stakeholder activities included:

- one-on-one meetings with self-advocates about their health stories.
- an illustrator (artist) drawing their health stories.
- meetings with stakeholder groups.
- review and feedback on the meeting summaries.

What Did Stakeholders Share in the Group Meetings?

- Self-advocates talked about their priority (most important) outcomes, like “Physical Health, Reduced Pain, and Improved Energy.”

- Care partners talked about more priorities, like resources they need to support their person with IDD.

- Clinicians were asked about how they could support important outcomes. They told us what tools they need to do that well.
• Insurers and government talked about:
  
  o How they can use these outcomes in their programs. They told us what they need to do that well.

• Stakeholders were invited to be co-authors of the meeting summary(ies).

What Is Finished So Far?

• IIDDEAL-1 stakeholder meetings are done.

• IIDDEAL-2 one-on-one meetings with self-advocates are done.

What Else Is Planned?

• IIDDEAL-2 stakeholder discussion meetings:
  
  o Self-advocates (January-February 2023)

  o Then care partners (March-April 2023)

  o Finally clinicians (April-May 2023).

• Multi-Stakeholder Consensus Meeting in September 2023
  
  o Meeting will be in person in Washington DC.

  o 4-5 persons from each stakeholder group will be there.

  o They will create the Health Outcomes Framework recommendations.
• The draft Health Outcomes Framework will be made public in October 2023 so people and groups can give their opinions about it. This is called public comment.

• The final Health Outcomes Framework recommendations will be made public in December 2023.

• We will write papers about engagement strategies. We will make them public in December 2023.