Institute For Exceptional Care (IEC)
Process Guardrails

Self-Advocates on Committees:
- One third of the people who are on IEC advisory committee should be self-advocates.
- The self-advocates should not all have the same backgrounds.
- They should have different disability labels, different lived experiences, and different cultures.
- People of color and diverse preferences should be included.

Full Inclusion in Committee Meetings:
- Complicated parts of the meeting should be explained using Plain Language so that everyone understands.
- Everyone should be able to communicate the way they prefer. Choices, like typing instead of speaking, should be available so that everyone can.
- If the meetings are not accessible for all of the self-advocates, IEC should find new ways of getting the work done.

IEC Committee Work:
- IEC’s work and recommendations should focus on all people with IDD, not specific types of IDD like autism.
- If the committee work has to be more specific, labels and diagnoses should not be used. The focus should be on accommodations or support needs.

Written Materials in Pain Language:
- Written materials that are seen by the public should also be in Plain Language.
- Each part of the website should have a Plain Language version.
Community Inclusion and Respect:
- A lot of research and practice has been done for people with IDD to be fully respected and fully included in the community. That experience should guide IECC’s work.
- IEC should promote full inclusion and respect in all that it does.

Avoid Assumptions and Labels:
- **Assumption** means a belief that something is true.
- IEC should never make assumptions about a persons’ abilities because of their speech, intellectual disability, conditions, or needs.
- IEC should discourage labeling of people.
- IEC should never use words like *severely impacted* or less severely impacted as a way to describe a person’s condition. **Severely impacted** is used by some people to assume how much conditions effect a person’s life and independence.
- IEC should never view or describe people as high or low functioning.

Promote the Right Goals:
- **Promote** means to encourage and advocate for something.
- IEC should promote the right goals for good health care and services for people with IDD.
- The goals should be what are important to people with IDD. They should include the goals of living a happy, healthy, self-determined life as a person with IDD.
- The goals should not include trying to make the person fit in to what society expects everyone to look like and do.

Respect for Individual Preferences:
- IEC should respect how people with IDD would like others to refer to them.
- IEC should promote others to respect how people with IDD would like others to refer to them.
- Some prefer **person-first language**, such as *A Person with IDD*. Some prefer **condition-specific language**, such as *Autistic Adult*.
- IEC should promote asking the individual what they prefer.
**Sharing Data:**
- **Data** is a collection of information and facts.
- IEC will be collecting data to measure how well providers, therapists, clinics and hospitals give health care.
- The data will help to understand how good the care is.
- IEC should make that data available to everyone including people with IDD.

**The Health Care Experience:**
- All of IEC’s work should include making the experience of health care better for people with IDD.