Institute For Exceptional Care (IEC)
Process Guardrails

1. Each IEC advisory committee, whenever possible, should have a minimum 1/3 participation by self-advocates.
   - Each should include not only self-advocates with degrees and professional credentials, but self-advocates with a wide range of lived experiences, disability labels, cultural diversity and preferences, and other characteristics
   - This is in keeping with the strong precedent set by DD Councils, which similarly advise state-level policy makers.

2. All efforts should be made to ensure that committee meetings are language- and communication-accessible with Plain Language versions of materials provided as needed.
   - If traditional methods of meeting and working are inaccessible for self-advocates or seem to conflict with the 1/3 baseline, alternative ways of doing the work should be developed and used.
   - IEC should model the language and communication accessibility that clinicians are being asked to employ.

3. All public-facing materials produced by IEC advisory committees/groups should be available in accessible formats, including Plain Language versions.

4. Wherever possible, IEC advisory committees’ work and recommendations (e.g., professional trainings) should be aimed broadly at people with neurodevelopmental disabilities rather than specific diagnostic groups.
   - When more specificity is needed, recommendations should target specific functional or service needs, medical conditions, or accommodation/support needs, rather than diagnostic labels or perceived “functioning” levels.

5. All IEC committee work should be informed by the learnings of the social model of disability and the disability rights movement, which stems from 40+ years of research and practice.
   - This work is rooted in community inclusion, the civil rights of people with disabilities, and the fostering of high expectations for this population.
   - IEC’s efforts should promote and embody these ideals.
6. **IEC should never conflate oral speech, intellectual disability, behavioral or medical needs, or co-occurring conditions with "severity," as we know that the population of people with neurodevelopmental disabilities is much too complex for such assumptions.**
   - People can look very different and have similar needs or may look very similar and have very different needs.
   - IEC should never aggregate people into high or low functioning categories.

7. **IEC should promote the appropriate goals of medical care, as well as the social, educational, and clinical service goals that are important to those being served.**
   - Specifically, the goals should support the ability to live happy, healthy, self-determined lives as people with neurodevelopmental disabilities—not to reduce the appearance of their disability(ies).
   - IEC should pair its intellectual work with persons’ civil rights which must include a focus on fulfilled, happy lives rather than cure or the fitting in to society’s expectations or norms.

8. **IEC should respect and promote the respect of individuals’ preferences for person-first language vs. condition-first language in their communications with persons with IDD.**
   - This is best accomplished by asked the individual what they prefer.

9. **Improving the experience of health care for persons with IDD should be integrated at every level of IEC’s work.**

10. **IEC should be transparent in its work and ensure that performance data is available to all stakeholders**