institute for exceptional care

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**