Institute for Exceptional Care (IEC, www.ie-care.org) is a nonprofit organization dedicated to transforming healthcare for people with intellectual and/or developmental disabilities (I/DD). IEC was founded by healthcare leaders who have both led national efforts to transform healthcare payment and care delivery, and the lived experience of caring for affected loved ones. We partner with affected adults and many disability organizations. IEC focuses on addressing gaps in the financing and payment for healthcare and other necessary support services, in coordination across service sectors such as clinical and home- and community-based supports, and in the cultural and clinical preparedness of practitioners and payers to serve the I/DD population.

We appreciate the IACC’s broad acknowledgement of these priorities. However, we recommend that the IACC consider more specific federal action in a number of areas and ensure that people with I/DD can have meaningful input on all policies and programs.

- The IACC acknowledges the need for strengthening the HCBS sector, and financing/payment for both HCBS and clinical services. The Department of Health and Human Services has multiple opportunities to take concrete action to do so. For example, the Centers for Medicare & Medicaid Services could set explicit expectations for States to address HCBS infrastructure in their 1115, state plan amendments, or other Medicaid related waivers, particularly as related to use of available enhanced FMAP funds under the American Rescue Plan. Similarly, CMS could fund through the CMS Innovation Center the creation of state-specific common resources that all HCBS providers could use, such as technical or business management assistance.

- The IACC promotes greater investments in autism research. Comprehensive and accurate data are a critical foundation for research that can inform day-to-day decision making by clinicians or payers. Federal agencies could invest in improving the ability for healthcare decision-makers to identify autistic people across the lifespan, who are often not labeled as such in typical electronic medical records or insurance claims.

- The IACC also misses an opportunity to acknowledge and develop recommendations on the role of other federal healthcare entities, including TRICARE, which provides insurance coverage for active duty military personnel and that has conducted recent evaluations of applied behavioral analysis for autistic members; traditional Medicare and Medicare Advantage health plans; Medicaid; Affordable Care Act insurance exchanges and regulations; and the Federal Employee Health Benefits Program, which is an influential purchaser of private health insurance. All of these federal purchasers and regulators can focus more attention on identifying autistic beneficiaries within their populations and addressing their needs and goals.

- The IACC supports the development of more technology solutions to support autistic people. Yet companies offering new interventions struggle to create sustainable business models due to the fragmented nature and inadequate levels of financing and payment for autism and other I/DD related services. In too many cases, entrepreneurs default to relying in part or whole on direct-to-consumer sales, which likely exacerbate disparities in care, as people and families of means are more likely to learn of these interventions and be able to afford them. The IACC could call for the creation of an industry forum that could help healthcare purchasers and regulators coordinate review, approval, and payment for such interventions.

Thank you for the opportunity to comment.