

Summary of Comments on Goal One: Leadership and Advocacy

Feedback on Goal One is generally positive, with strong support for its focus on self-advocacy, systems change, and valuing lived experience. Respondents especially support compensating people with disabilities for their expertise, noting it is meaningful and long overdue. Toolkits, mentorship, and storytelling were seen as practical ways to build advocacy skills, and the emphasis on community inclusion, person-centered supports, and leadership development across a range of needs was well received.

Respondents raised concerns about access and inclusion. Several noted the need for stronger enforcement of rights and questioned how compensation may affect Medicaid benefits. Others highlighted gaps for people who cannot easily self-advocate, including individuals with significant support needs, children, and families navigating the education system. Suggestions included expanding outreach, strengthening partnerships, and providing clearer guidance on implementation to ensure the goal is accessible and effective for all.

Feedback on Goal Two is generally positive, with strong support for its focus on systems change, collaboration, and addressing needs across the lifespan. Respondents value the emphasis on listening to people with disabilities, strengthening community living, expanding employment opportunities, and planning for future needs like housing and disaster preparedness. Many also appreciate the focus on youth transition, family engagement, and building a more connected system through partnerships and stakeholder input.

A few respondents shared questions and suggestions to strengthen the plan. These included how the proposed changes will align with ongoing state efforts, opportunities to make systems easier to navigate, and the importance of continued partnership with state agencies and community organizations. Some also noted the value of expanding outreach to families and ensuring clear, available services.

What people liked about the plan:

Respondents appreciated that the plan is thorough, clear, and well-organized, with realistic and achievable goals. They valued the strong focus on empowerment, self-advocacy, and supported decision-making, along with an emphasis on communication, collaboration, and listening to people with disabilities and families across the lifespan.

They also liked that the plan is comprehensive, outlines key priority areas, and builds connections across systems. The inclusion of public input and the commitment to compensating people with disabilities for their expertise were seen as especially meaningful. Overall, the plan is viewed as thoughtful, sincere, and designed to improve awareness and quality of life.

What they did not like about plan:

Respondents shared a few areas where the plan could be strengthened. Many noted opportunities to improve access and awareness, including making public input more ongoing and easier to participate in. Some suggested simplifying language (like reducing or defining acronyms) and providing clearer information about how to access services. A few also asked for more clarity on how current system changes, waivers, and funding realities will connect to the plan, noting that clearer guidance would help people navigate changes with more confidence.

Respondents also highlighted opportunities to expand focus in key areas, including supports for children, workforce stability, and helping families earlier before they reach crisis. There was also interest in ensuring the plan reaches people who may not be well connected to services. Overall, feedback points to strengthening communication, inclusion, and system capacity to build an already solid foundation.

Who else should we partner with:

Respondents identified a wide range of potential partners, with a emphasis on cross-system collaboration. Key partners include state and local entities such as HHS, the Department of Education, Department of Corrections, county agencies, Disability Access Points (DAPs), ADRCs, and housing authorities. Many also highlighted the importance of working with Managed Care Organizations (Wellpoint, Molina, Iowa Total Care) and service providers across employment, residential, and community-based supports.

There was also strong support for partnering with advocacy organizations, families, and people with lived experience, including groups like The Arc, NAMI Iowa, and family leadership programs. Respondents emphasized the value of engaging parents (especially of young children), self-advocates, peer support networks, and community partners, as well as universities and healthcare systems. Overall, feedback encourages broad, intentional partnerships that bring together agencies, providers, and lived experience to improve coordination, innovation, and system impact.

How can we develop better relationships with others in the community who may not know us?

Build awareness through consistent, clear communication and outreach, such as simple newsletters, social media, and public forums. Use plain language, reduce jargon, and share real-life stories to make information relatable and meaningful.

Meet people where they are by engaging in communities, schools, provider settings, and local events, including rural and underserved areas. Strengthen relationships by connecting with providers, families, and community groups, maintaining a visible and approachable presence, and creating opportunities for open and inclusive engagement.