



# NATIONAL COLLABORATIVE FOR SUPPORTING FAMILIES

## The National Collaborative for Supporting Families with a Member with Intellectual and Developmental Disabilities

*The National Collaborative for Supporting Families brings together individuals and organizations representing various aspects of supporting families of people with intellectual and developmental disabilities (I/DD). Initial momentum was created during the May 2022 Supporting Families Summit, and the National Collaborative continues as a space for connecting around policy development, research, and grassroots advocacy to continue to inform and drive the National Agenda for Supporting Families.*

### History of the 2011 National Agenda on Supporting Families

As the field began thinking differently about supporting families, they recognized that people exist and have reciprocal roles within a family system. With the crucial impact of families on the lives of individuals with intellectual and developmental disabilities, policies and practices needed to start reflecting the family as part of the support system. To provide direction and guidance for such policy reform, a group of diverse national and state disability leaders met and developed recommendations on the types of supports families need to serve in this role at the Wingspread Conference Center in March of 2011. The resulting document, Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities (which can be found here: <https://bit.ly/3oGbWwa>), highlighted the importance of moving from "Family Support" as a program to "Supporting Families" as a paradigm and set of guiding principles for all that a system does to support a person in the context of their family and community.

### Highlights of the 2022 National Agenda on Supporting Families

 Click here to view: <https://bit.ly/3s6IIJV>

To celebrate all the accomplishments in the 10 years since the 2011 Summit at Wingspread, over 65 key national and state stakeholders came together in May of 2022 in Washington, D.C to share in their commitment to elevating the on-going needs and important role of families who are supporting members with developmental disabilities. This event was hosted by the National Community of Practice for Supporting Families, a partnership between the National Association of State Directors of Developmental Disabilities Services and the University of Missouri-Kansas City, Institute for Human Development, UCEDD, in partnership with the Administration for Community Living.

The following recommendations emerged from the 2022 Supporting Families Summit which are presented in the 2023 National Agenda for Supporting Families and used to guide the efforts of the National Collaborative for Supporting Families:

- Recommendation 1: Adopt a fluid, expansive (yet universal) definition of family that is driven by the person and can incorporate the many complex, unique iterations of the networks of mutual and reciprocal supports we call "family."

#### National Collaborative for Supporting Families:

A collaboration between the Community of Practice for Supporting Families, University of Missouri Kansas City Institute for Human Development (UMKC-IHD) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS)





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- Recommendation 2: Operationalize “family support,” with a common understanding of what that entails, to create consistent, clear and funded services that are responsive to the needs of all family members and their (potentially multi-faceted) role(s).
- Recommendation 3: Design and fund peer support as a critical service, including state specific funding for Family Support Programs.
- Recommendation 4: Redesign waiver services and supports to focus on quality-of-life outcomes, increase flexibilities, improve access and navigation, and ensure self-determination and self-direction (while also balancing the need to support the family).
- Recommendation 5: Develop more effective “front doors” that provide lifespan support, include life exploration and focus on outcomes.
- Recommendation 6: Ensure meaningful leadership roles of people and families with lived experience by professionalizing family and self-advocate roles and increasing mechanisms for capacity building and preparing organizations and systems to appreciate family leadership
- Recommendation 7: Fund and support a National Training, Research, and Resource Center for Family Support focused on Persons with IDD, to serve as an infrastructure for sharing resources and best practices, and to provide ongoing technical assistance and support for family organizations, state systems, and federal programs.
- Recommendation 8: Create a national, interagency task force on supporting families of people with ID/DD for research, funding, and advocacy.

### Forming the National Collaborative for Supporting Families

The National Collaborative for Supporting Families is an outgrowth of the interest and momentum for continued, shared efforts following the Supporting Families Summit. To prioritize the efforts and objectives of this collaborative, a survey was distributed amongst those who attended the Summit and associated events.

A meeting was held to discuss the formalization of the National Collaborative which included:

- An overview of the summary of the Supporting Families Summit held May 2022 and the resulting recommendations, which formed the National Agenda for Supporting Families report.
- Updates from the key areas for supporting families, including federal policy, state systems, grassroots advocacy, research, and best practices.
- A review of next steps for the National Collaborative for Supporting families, specifically related to disseminating information and elevating best practices.

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## National Collaborative for Supporting Families Steering Committee

In response to this feedback, the National Collaborative will form a Steering Committee, which will serve as a space for connection and information dissemination for systems change agents dedicated to enhancing supports for people with IDD and their families. The Steering Committee will convene quarterly, and members will serve as advisors for the Supporting Families Best Practice Series. Meetings for the Steering Committee will be January 2024 and April 2024 from 1-2:30pm CT.

## Supporting Families Best Practices Series

The Supporting Families Best Practice Series will introduce and elevate best practices related to supporting families. The series will be held quarterly in collaboration with the National Community of Practice for Supporting Families. Each session will feature a panel of individuals or entities who will address key recommendations from the National Agenda through their lens of grassroots advocacy, “practice level” implementation, states service systems, federal policies, and research.

The Best Practices Series will meet quarterly, each first Thursday of the month, 1-2:30pm CT, on:

- December 7, 2023 Topic: Enhancing the Peer Support Workforce for People with I/DD and their Families
- March 7, 2024 Topic: The Role of HCBS Waiver Services in Supporting Families
- June 6, 2024 Topic: Supporting Families to Navigate Services and Supports

To register for the Best Practice Series visit: <https://supportstofamilies.org/national-agenda/national-collaborative/>

Steering committee members will meet in the months following the series sessions to debrief the previous session and identify key practices or issues to address and subject matter experts to serve as panelists on the following series.

## Engagement Strategies

Information dissemination for the National Collaborative will occur through a designated page on [supportstofamilies.org/national-agenda/national-collaborative/](https://supportstofamilies.org/national-agenda/national-collaborative/). This page is a hub for resources and information related to the National Agenda on Supporting families, including Supporting Families Collaborative Information, National Supporting Families Best Practice Series, and information from the Summit and all associated events.

## Get Involved

If you're interested in getting involved with the National Collaborative, please follow this link to be added to the ListServ: <https://bit.ly/3tQ8oK2>

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