



Work Together NC

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IDD Leaders Summit

Replication Guide



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Table of Contents

Pg. 1	Purpose of the Guide & Purpose of the Summit
Pg. 2	Section 1: Planning the Summit
Pg. 3	Format Options; Pre-Work for Participants
Pg. 4	Planning Timeline
Pg. 5-6	Making the Summit Feasible & Sustainable
Pg. 7	Messaging & Framing: “Beyond Charity”
Pg. 8	Media & Storytelling Strategies
Pg. 9-10	Section 2: Sample Agenda (Full Day)
Pg. 11	Section 3: Facilitation Tools
Pg. 12	Section 4: Breakout Discussion Templates & Breakout Room 1
Pg. 13	Breakout Room 1: Probes
Pg. 14	Breakout Room 2
Pg. 15	Breakout Room 2: Probes
Pg. 16	Section 4: Post-Summit Follow-Up
Pg. 17	Appendices





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I/DD LEADERS SUMMIT: REPLICATION GUIDE

Purpose of This Guide

- This guide provides a step-by-step model for any community to convene nonprofit leaders, self-advocates, and system partners to strengthen collaboration across I/DD services. It is based on a tested summit model and includes discussion templates, facilitation tools, and customizable prompts that allow local organizers to adapt the event to their service landscape.

Purpose of the Summit

Communities should tailor the summit purpose to local needs, but most events aim to:

- Identify strengths, gaps, and opportunities across the lifespan
- Strengthen relationships between organizations
- Develop shared priorities and actions
- Promote cross-sector collaboration
- Create momentum toward systems-level improvements

Template purpose statement (customize):

- The purpose of this summit is to convene I/DD leaders from across our community to identify shared priorities, surface actionable solutions, and build stronger connections that will support people with I/DD to live, work, learn, and belong.



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Section 1: Planning the Summit

Core Partners & Planning Team

Assemble a planning team of 2–8 people representing:

- I/DD nonprofits
- Advocacy or self-advocacy organizations
- Providers (employment, residential, day, clinical, etc.)
- Families or family support networks
- Local government or funders (optional)

Planning team responsibilities:

- Set the agenda
- Determine the invite list
- Facilitate outreach
- Prepare materials
- Lead day-of logistics

Invite List

A balanced summit includes participants from:

- Community-based I/DD nonprofits
- State or county-funded providers
- Advocacy coalitions
- Self-advocates and family members
- Schools or transition teams
- Employers or employment partners
- Mental health or healthcare partners
- Local government, LME/MCO, or managed care representatives

Goal: ~30–60 participants for optimal discussion



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Format Options

- Half-Day Summit (3–4 hours) — Includes one breakout cycle
- Full-Day Summit (5–6 hours) — Includes two breakout cycles
- Pre Summit Zoom (3–7 days before the In-Person Summit)
 - A Pre-Summit Zoom helps participants get to know one another and gain a clear understanding of what each organization brings to the table, setting the stage for more efficient and productive conversations during the event. It is also an opportunity to orient participants to the chosen theme/goals of the event. See Appendix C for potential breakout room discussion prompts.

Pre-Work for Participants

Send 1–2 weeks before the summit:

- Purpose and agenda
- Names and descriptions of participating organizations
- A pre-survey (see Appendix A), which can be used to determine priority breakout room topics.



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Planning Timeline

Timeline	Tasks
8-12 weeks before	<ul style="list-style-type: none">- Select host organization(s)- Form planning committee (4-8 people, diverse roles)- Select date, time, venue (2-4 breakout rooms)- Identify priority topic areas- Begin recruiting breakout facilitators
4-6 weeks before	<ul style="list-style-type: none">- Develop invitation list (I/DD nonprofits, providers, advocacy groups, self-advocates/families, housing/transportation/workforce partners, county agencies, LME/MCOs)- Send invites + collect RSVPs- Finalize facilitators- Prepare breakout materials
2-3 weeks before	<ul style="list-style-type: none">- Assign participants to breakout rooms- Confirm accessibility supports (ASL, captioning, dietary, mobility, etc)- Plan lunch/refreshments
1 week before	<ul style="list-style-type: none">- Send final agenda + room assignments- Prepare facilitator packets- Assemble printed templates or digital packets



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Making the Summit Feasible & Sustainable

1. Start Small (and That's a Win)

Communities do not need a large budget, a formal coalition, or a large turnout to make this summit meaningful.

- Gathering 5–10 people is enough to start building shared understanding & momentum
- A short, half-day (or even 2-hour) convening is appropriate for a first summit
- The goal is connection and alignment, not a polished product.
- Relationships built at small tables often lead to bigger systems change over time.

2. Funding the Summit (Low- or No-Cost Options)

Many I/DD Leader Summits can be hosted with little or no direct funding. Consider:

- Charging a nominal or sliding scale registration fee to cover costs (\$25-40)
- Small community grants (local foundations, community foundations, United Way)
- County or municipal funds (disability services, community engagement, workforce development)
- Faith-based organizations offering space or food as an in-kind contribution
- Sponsorships from local employers, banks, healthcare systems, or housing developers
- Cost-sharing among participating organizations
- In-kind support (meeting space, printing, food, facilitation)

This summit is about coordination and shared priorities — not launching a new program — making it an easy lift for funders to support.



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Making the Summit Feasible & Sustainable (Cont.)

3. Suggested Host Locations

Look for accessible, familiar, and low-cost spaces, such as:

- Churches, synagogues, mosques, or faith-based community centers
- Public schools, community colleges, or universities
- Libraries or town halls
- Nonprofit offices or community centers
- Workforce development boards or chambers of commerce

Ensure the space is physically accessible and welcoming to self-advocates and families.

4. Outreach & Recruitment Strategies

Effective outreach is relational and community-driven:

- Personal invitations to trusted partners
- Asking self-advocates and families who should be in the room
- Leveraging existing coalitions, listservs, or advisory groups
- Partnering with schools, transition coordinators, and case managers
- Sharing invitations through advocacy and parent networks
- Using plain language and a clear purpose in all outreach

Emphasize that this is a working conversation—not a conference or training.



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Messaging & Framing: Beyond “Charity”

How this summit is framed matters. Effective messaging highlights that disability inclusion is a community investment, not charity.

Key framing concepts:

- Disability services are an economic investment
- Employment supports create workers, consumers, and taxpayers
- Strong disability systems strengthen the local workforce
- Inclusive communities benefit everyone
- People with disabilities bring assets, skills, leadership, and innovation

Suggested Talking Points

- “When people with disabilities work, communities grow.”
- “Investing in disability services strengthens our local economy.”
- “Inclusion is infrastructure.”
- “People with disabilities are contributors—not costs.”

These talking points are useful for outreach emails, funder conversations, and media engagement.



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Media & Storytelling Strategies

Sharing stories helps build momentum and attract future partners.

Consider:

- Inviting a local journalist to attend part of the summit
- Incorporating a “storytelling room” for your summit, where consenting participants are recorded to tell their story in 2-5 minutes, which could be compiled for a media campaign
- Centering self-advocate stories (with consent)
- Highlighting collaboration and shared priorities—not individual organizations
- Using quotes and photos (with permission) for social media
- Framing stories around **solutions, innovation, and community impact**

Optional prep:

- A short press release or media pitch
- 3–5 shared messages aligned with summit priorities
- One or two stories that illustrate systems-level challenges and opportunities



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Section 2: Sample Agenda (Full Day)

Welcome & Introductions (10–15 min)

- Quick overview of purpose
- Ground rules (collaboration, curiosity, respect, time awareness)
- Round-robin or table introductions

Context Setting (10 min)

Provide a brief overview of:

- Work Together NC's website, serving as a one-stop resource hub for IDD providers (this could also be covered in the pre-Summit if desired)
- Local I/DD landscape
- Why collaboration matters
- Desired outcomes for the day

Breakout #1 — To Adulthood (60–75 min)

- Participants work in small groups (4–7 people) on topics related to planning for the transition to adulthood (or an alternative chosen theme)– discussing three areas:
 1. Strengths in the local system
 2. Challenges (gaps, barriers)
 3. Innovation Opportunities (emerging solutions)
- Participants vote on prioritized action items and then generate an action statement.

Report Out (20–30 min)

Each group shares their action statements.

Break (10 min)





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Section 2 (Cont.): Sample Agenda (Full Day)

Breakout #2 – Through Adulthood (60–75 min)

- Participants work in small groups (4–7 people) on topics related to lifespan needs (through adulthood– or an alternative chosen theme)– discussing three areas:
 4. Strengths in the local system
 5. Challenges (gaps, barriers)
 6. Innovation Opportunities (emerging solutions)
- Participants vote on prioritized action items and then generate an action statement.

Report Out (20–30 min)

Each group shares their action statements.

Lunch / Break (Optional)

Closing & Next Steps

- Summarize key insights and next steps
- Announce follow-up meeting dates
- Encourage ongoing collaboration





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Section 3: Facilitation Tools

Guidelines for Dialogue

- **Stay action-oriented.** Be specific — who will take action, how, and when? Focus on concrete steps that move ideas forward.
- **Ground discussions in useful reality.** Avoid extremes of over-idealizing or doom-and-gloom thinking. Instead, ask: Given the barriers, what CAN be done?
- **Remain curious and open.** Listen to understand, not just to respond. Be willing to shift perspectives based on new information.
- **Step up, step back.** Contribute when you have something to add, and make space for others to do the same.

Dot Voting Guidance

- Paper: Print red, blue, and yellow dots; participants vote on action posters.
- Digital: Use Miro or Figma





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Section 4: Breakout Discussion Templates

Breakout Room #1

- Identify roles [introduce facilitators, identify a timekeeper]: 5 minutes
 - Facilitator: Your role is to guide and prompt action-driven discussion, ensuring the focus isn't on one particular organization but on what we can all do together
 - Timekeeper: Your role is to remind everyone how much time remains throughout the discussion, ensuring enough time at the end for a concluding statement
- Introductions: Name, Organization, Role [Person with lived experience, care partner, professional?]: **5 minutes**
- As a group, fill out the following chart. The specific topics can be adapted based on the local area's priority needs.

Cliff #1: To Adulthood

Potential Topics: Employment, Transportation, Community Participation/Safety, Postsecondary Education

[20 minutes]

Define Strengths – what is working?

Define Challenges – what is not working?

For each challenge, what is an Innovation Point or opportunity?

- **Challenge:**

- **Opportunity:**

[20 minutes]

Identify Actions

Then, use dots to code the actions!

Red = high impact, high effort
(time/funding/resources)

Blue = low resource, low effort
(time/funding/resources)

Yellow = opportunities for Collaboration /
Collective Impact

<p>Probes:</p> <p><i>What challenges has your organization encountered in efforts to address [topic area]?</i></p> <p><i>What are the biggest barriers preventing people with IDD from accessing [topic area] in North Carolina?</i></p> <p><i>What gaps exist in the current systems (e.g., services, policies, funding) that are hindering access to this area for people with IDD?</i></p>	<p>Probes:</p> <p><i>What strategies or initiatives have shown the greatest success in improving access to [topic area] for people with IDD?</i></p> <p><i>Have there been any innovative models or solutions that you believe could be replicated or expanded across the state?</i></p> <p><i>Are there examples of specific policies or practices that have improved access or quality of services? What made them successful?</i></p>	<p>Probes:</p> <p><i>With consideration to the barriers that exist (funding, resources, etc), what concrete actions would make a difference?</i></p> <p><i>How can we better hold the system accountable to highlight gaps/ advance advocacy priorities? Who are the key stakeholders (government, private sector, advocacy groups) that need to be involved in addressing these issues, and how can we bring them together?</i></p> <p><i>Are there existing programs or services that are duplicating efforts in [topic area]? If so, where?</i></p> <p><i>How can we better coordinate efforts to avoid redundant initiatives or misalignment of resources?</i></p> <p><i>Where do you see opportunities for organizations to streamline services, share resources, or work together more effectively? Looking at the organizations in this room – are there opportunities for increased collaboration around shared needs?</i></p> <p><i>What would meaningful collaboration look like in this area? How can we better align efforts and create more coordinated action across different sectors?</i></p>
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[10 minutes]

In closing...

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Come up with a statement that summarizes the priority advocacy actions and key insights generated from the conversation. Assign one or two people to be the “accountability partner” to monitor the group’s progress, checking in at least monthly.

Be specific. For example:

*As a result of today’s summit, _____ [WHO] will do _____ [WHAT]
_____ by _____ [WHEN]. _____ [WHO] will be our accountability partner.*

Breakout Room #2

1. Identify roles [introduce facilitators, identify a timekeeper]: **5 minutes**
 - a. Facilitator: your role is to guide and prompt action-driven discussion, ensuring the focus isn't on one particular organization but on what we can all do together
 - b. Timekeeper: Your role is to remind everyone how much time remains throughout the discussion, ensuring enough time at the end for a concluding statement
2. Introductions: Name, Organization, Role [Person with lived experience, care partner, professional?]: 5 minutes
3. As a group, fill out the following chart. The specific topics can be adapted based on the local area's priority needs.

Cliff #2: Through Adulthood

Potential Topics: Housing/Community Living, Workforce Crisis/Aging Caregivers, Adult IDD Service Navigation (Registry of Unmet Needs/1915i & Waiver)

[20 minutes]

Define Strengths – what is working?

Define Challenges – what is not working?

For each challenge, what is an Innovation Point or opportunity?

- **Challenge:**

- **Opportunity:**

[20 minutes]

Identify Actions

Then, use dots to code the actions!

Red = high impact, high effort
(time/funding/resources)

Blue = low resource, low effort
(time/funding/resources)

Yellow = opportunities for Collaboration /
Collective Impact

<p>Probes:</p> <p>What are the biggest barriers preventing progress in this area?</p> <p>How do current policies, funding structures, or service models contribute to these challenges?</p> <p>Who is most impacted by these challenges, and what are their most urgent needs? What are some root causes of this issue that are often overlooked?</p> <p>How do these challenges affect individuals, families, and caregivers in both the short and long term?</p>	<p>Probes:</p> <p>Where have we seen success stories or promising models in this area?</p> <p>What creative solutions have organizations, communities, or states implemented to address this challenge?</p> <p>How have technology, policy changes, or community-driven efforts helped make a difference?</p> <p>Are there any unexpected partnerships that have led to positive outcomes?</p> <p>What lessons can we learn from other sectors or similar advocacy movements?</p>	<p>Probes:</p> <p>Who are the key stakeholders working on this issue, and how can we better align efforts?</p> <p>Where do we see duplication of efforts, and how can we work smarter?</p> <p>What cross-sector partnerships (e.g., healthcare, education, workforce, housing) could strengthen our impact?</p> <p>How can self-advocates, families, and caregivers play a more active role in shaping solutions?</p> <p>What data or evidence could help unify efforts and drive collective action?</p> <p>What are small, immediate changes that could make a tangible difference?</p> <p>What systemic, long term changes need to be advocated for?</p> <p>How can we better use existing resources instead of waiting for new funding?</p> <p>Are there policy adjustments, process improvements, or communication strategies that could be implemented quickly?</p> <p>How can we leverage volunteers, students, or community partnerships to fill gaps in support?</p> <p>What simple messaging or awareness efforts could help shift perceptions and mobilize action?</p>
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[10 minutes]

In closing...

Come up with a statement that summarizes the priority advocacy actions and key insights generated from the conversation. Assign one or two people to be the “accountability partner” to monitor the group’s progress, checking in at least monthly.

Be specific. For example:

As a result of today’s summit, _____ [WHO] will do _____ [WHAT]
 _____ by _____ [WHEN]. _____ [WHO] will be our accountability partner.



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Section 5: Post-Summit Follow-Up

1. Summarize Outputs (1–2 Weeks)

- a. Priority actions Breakout #1
- b. Priority actions from Breakout #2
- c. WHO/WHAT/WHEN commitments
- d. Next meeting dates

2. Establish a Working Group

- a. 3–5 volunteers to steward progress. 1–2 assigned as the accountability partners.

3. Maintain Momentum

- a. Quarterly follow-ups
- b. Celebrate early wins
- c. Share updates across organizations
- d. Annual review of action plan





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Section 6: Appendices

Appendix A — Pre-Summit Survey

1. What is one challenge your organization is facing related to supporting people with I/DD to live and work in the community?
2. What is one thing working well?
3. What collaborations/supports would help?
4. What is one question you hope the summit addresses?

Appendix B — Materials Checklist

- Printed templates
- Dot stickers
- Flipcharts or whiteboards
- Name tags
- Lunch/snacks
- Sign-in sheet
- PowerPoints (Slides for Pre-Summit and In-person Summit included [HERE](#))

Appendix C– Pre-Summit Break-Out Room Discussion Prompts

1. Introductions [1 Minute max]:
 - a. Name
 - b. Role (Parent? Person with lived experience? Professional?), & Organization (if applicable)
2. Provide an example of when you or your organization observed or helped address cliff #1 or cliff #2 for an individual or group. [3 Minutes max]*

*Without sharing any protected client information

3. If time: each person shares – what do you hope to get out of the summit?