



The Arc of Illinois

Rooted in Reality: A Statewide Call for IDD System Change

Impact:

In Year 1, we aim to capture the real, unmet needs of people with IDD and their families across Illinois through eight regional events and a statewide summit. By collecting direct input and video documentation from individuals, families, and provider communities we'll build a public-facing report and dashboard to drive targeted policy change. Alongside identifying gaps and challenges, we'll also highlight what's working well across the state to help replicate effective practices. A focused waiver access study will ensure family voices shape reform. This work lays the groundwork for a unified, data-driven movement rooted in lived experience.

Year 1 Objectives:

- **Statewide Listening & Data Collection Tour**
 - Host **8 regional, in-person events** across Illinois - from Cairo to Rockford - equally split across rural, urban, and suburban settings.
 - Use a standardized **data collection survey** as well as video documentation to gather firsthand experiences, unmet needs, and system gaps from:
 - Individuals with IDD (with supports as needed)
 - Family Caregivers
 - People currently living in provider settings (group homes, CILAs, ICFs)
 - Individuals currently living in State Operated Developmental Centers (SODCs)
 - Focus areas: housing, waiver access, transition support, employment, behavioral health, social connection, safety, dignity, and service gaps.
- **Launch Statewide Policy + Lived Experience Summit (Chicago or Springfield)**
 - Culminating event bringing together all stakeholders: families, self-advocates, providers, policy leaders, researchers, and advocates.
 - Present synthesized findings from regional events.



- Facilitate solution-driven breakout sessions to generate aligned action across sectors.
- **Data Analysis & Reporting**
 - Partner with University of Illinois Chicago (UIC) to analyze qualitative and quantitative findings.
 - Build a **public-facing dashboard and interactive report** that breaks down needs by region, demographic, and service type.
 - Identify at least **5 high-impact recommendations** to influence state planning, waiver redesign, and rate reform.
- **Waiver Access & Navigation Study**
 - Deep dive into barriers to accessing or understanding the Medicaid waiver system (across all entry points: PUNS, ISCs, schools, families, and providers).
 - Partner with self-advocacy mentors and family support groups to ensure tools are accessible and inclusive.
 - Align findings with Going Home Coalition, DDD, and ICDD to build united reform recommendations.

Year 1 Outcomes:

- First **statewide, user-informed report** detailing unmet needs for individuals with IDD and families, with breakdowns by age, geography, and living situation.
- Established **regional feedback infrastructure** that can be updated annually and replicated by partners.
- 8 regional events hosted with high attendance and cross-sector representation.
- 1 large-scale statewide Summit with over 300 participants.
- UIC-analyzed dataset and report used to shape state policy priorities.
- Waiver Access Recommendations Report delivered to key state agencies and policymakers.



- Foundation laid for launching **Year 2 targeted reforms, pilot programs, and legislative asks** based on community-defined priorities.

Year 1 Deliverables:

- **Community Data Collection Tool** (paper and digital; inclusive language)
- **Unmet Needs Statewide Report** (with region-specific snapshots)
- **Public Data Dashboard**
- **Waiver Access Barriers Report**
- **Advocacy + Awareness Infographic** (for families and community allies)
- **Recorded Webinars** for use by coalition members, providers, and families