

Building Community Capacity: Providing CILs Tools for Promoting and Documenting Changes in Programs, Practices, and Policies

Glen W. White, Ph.D., Jerry Schultz,
Ph.D., Christina Holt, M.A., Jeff Gordon,
Ph.D., and Sara Obermeier, M.A.

Community Living Summit
Sept. 19-21, 2016
Alexandria, Virginia



Statement of the Problem

- Laws passed to help increase community participation (e.g., FHAA, ADA, Olmstead)
- Disability Integration Act (S. 2427) being discussed by Congress to create community-based alternatives to institutionalization
- Passage of laws and regulations does not guarantee community participation of intended beneficiaries



Statement of the Problem

- 450+ Centers for Independent Living in the US have helped consumers increase independence
- CILs have anecdotal reports of how consumers' increase in independence in the community
- However, in 2003 the OMB assessment concluded “results not demonstrated” due to lack of evidence on IL outcomes

•Reference: http://www.dars.state.tx.us/reports/2014_Greenlights/GreenLight2/findings.html

Project Framework

INTERVENTION PACKAGE

Curriculum Training in Related Skills

- Assessing needs and resources
- **Analyzing problems and goals**
- **Developing strategic and action plans**
- **Developing an intervention**
- Increasing participation and membership
- Advocating for change

Technical Assistance, Peer Support, & Online Resources

- Analyzing information about problems & goals
- Establishing a vision & mission
- Developing & using strategic action plans
- **Implementing effective interventions**
- **Assuring technical assistance**
- **Documenting progress**

ANTICIPATED OUTCOMES

Short-Term

- Community Actions
- Development Activities

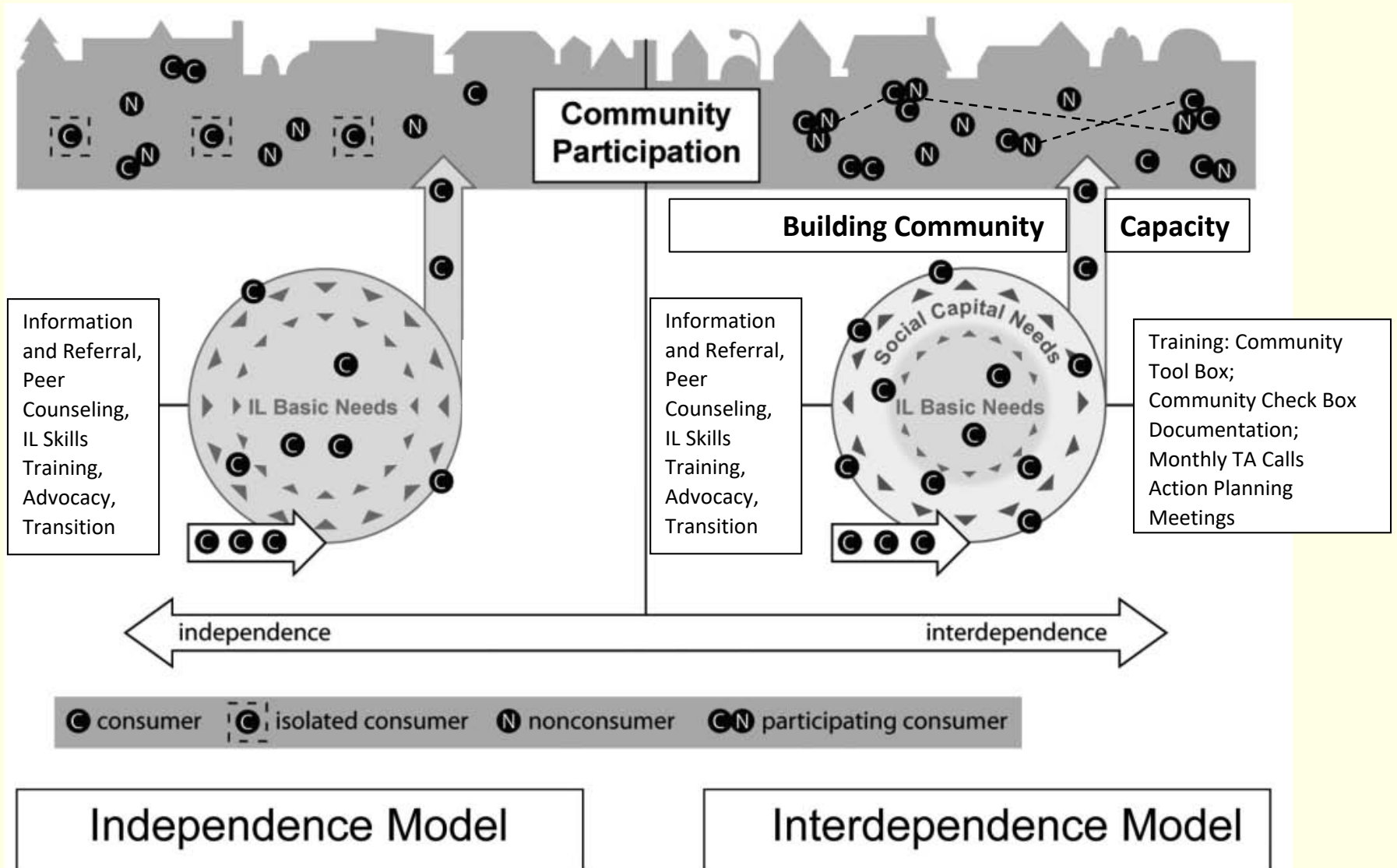
Intermediate

- Community & System Changes

Long-term

- Increased community participation & enhanced QOL for PWD

Independent Living and Transition into the Community



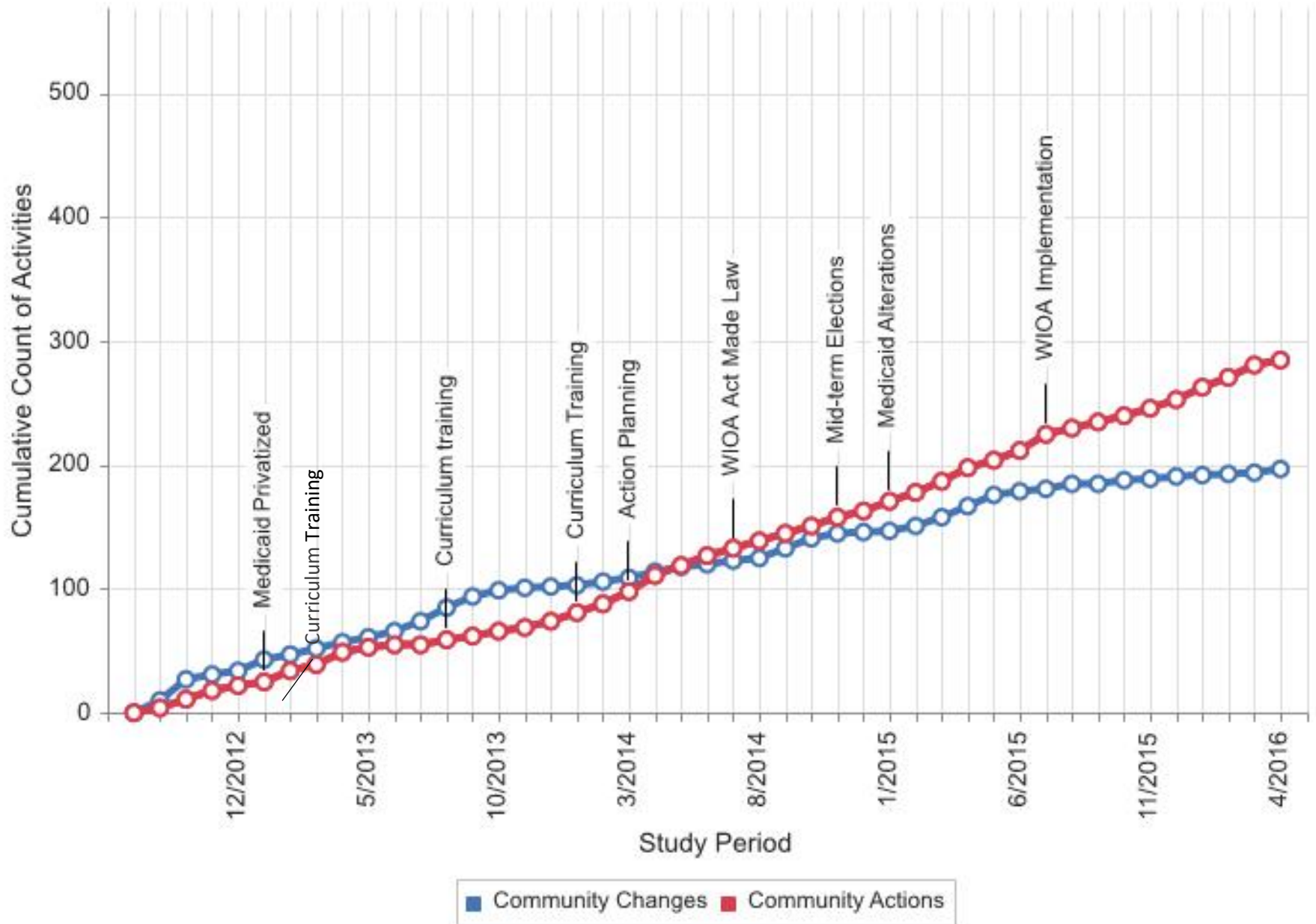
...“Expand society’s capacity to provide full opportunities and accommodations for its citizens with disabilities.”

–from NIDILRR Mission Statement

- CILs, ADRCs, and AAOAs have an important role to play in building this capacity for people with disabilities and those aging into disability
- Robust and sustained data are needed to help document community actions and community change
- Partnerships with stakeholders are needed to help interpret the meaningfulness of change and to help with knowledge translation of this work

Community Changes and Actions by 9 Participating CILs

8/1/2012 - 4/30/2016



Contextual Factors Affecting Rates of Change

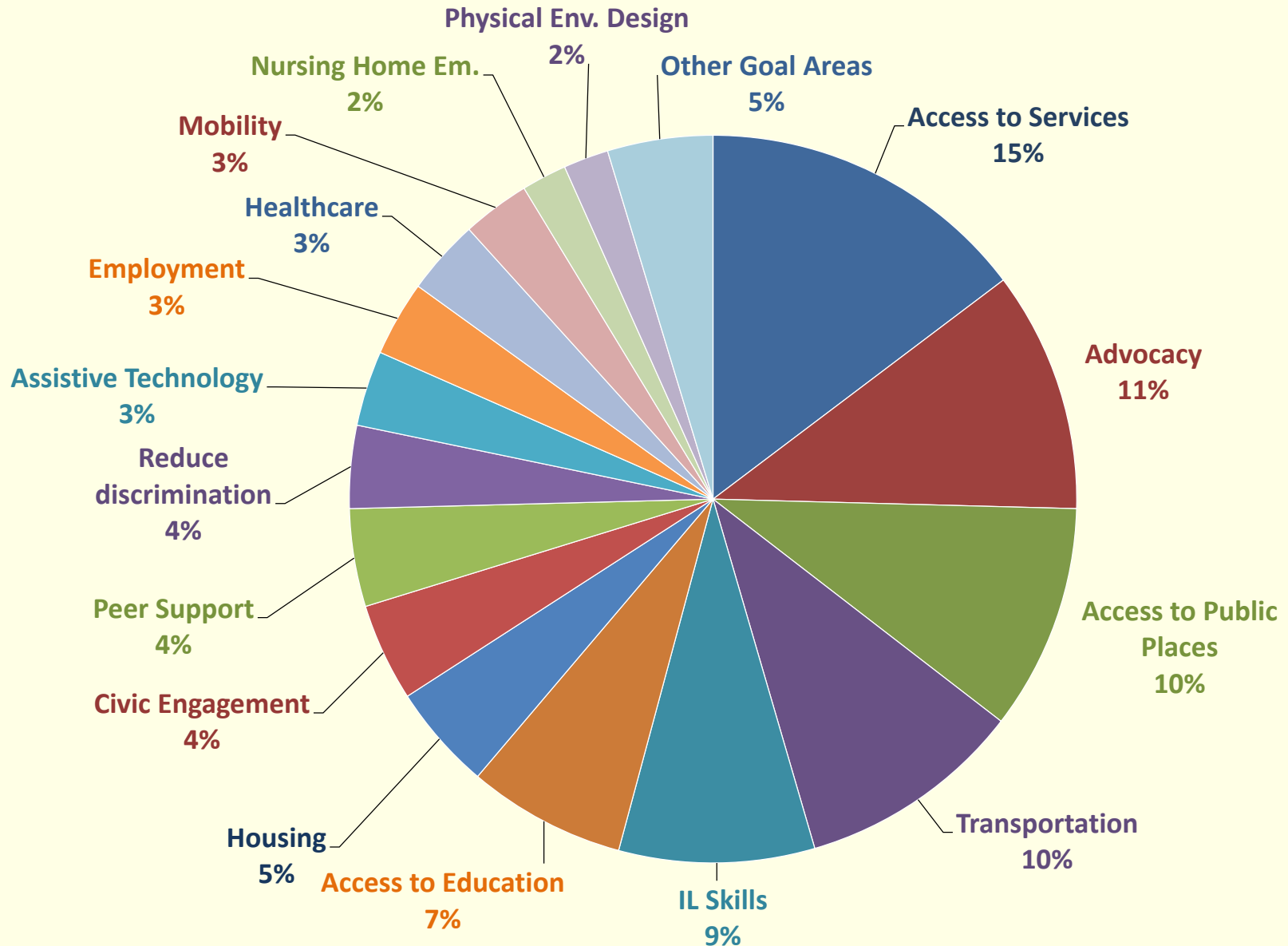
- Staff and leadership changes
- Funding changes (increase, decrease, source of funds)
- New initiatives and expanding service areas
- Medicaid expansion

“[There is] frustration with serving consumers while at the same time trying to build a long-term focus. It is really difficult with limited resources.”
- CIL staff member

“It’s hard to get out and do new stuff when you’re trying to hang on to what you’ve got.” - CIL staff member

Community Changes by Goal for 9 Participating CILs

N = 197



Value of Using Data

“There is a need to bridge the gap between qualitative and quantitative data so that the difference the CIL is making can be made explicit. [You] must be able to describe what you are doing to funders and why it is working better than the person in line behind you who also wants funds.” (CIL staff member, June 2015)

“[We use] the site (*Community Check Box*) to become more familiar with what [our CIL] has accomplished in the past, which will provide guidance for what to do in the future.” (New CIL staff member, June 2015)

Impact on Programs, Practices & Policies

The use of more impactful community strategies by CILs increased by 27% after training ($p = .032$)

- Sept 2013: CIL advocacy led to change in state law to allow communities better options for financing their transportation services. *(Modifying policies)*
- Oct 2014: CIL met with county assessors to assure accessible voting sites, and that PWD could exercise their right to have someone with them while voting. *(Modifying access and barriers)*
- Apr 2015: New parking tags were issued to signify van parking due to CIL efforts to prioritize these spaces. *(Modifying access and barriers)*

Project Implementation Lessons Learned

- Continuous formal and informal contacts helped keep CIL partners involved
- Payment to CILs was necessary but not sufficient
- Ensure that those entering data report all relevant activities related to community action and change (not just those with which they were personally involved)

Promising CIL Practices

- Use needs assessments to focus community change implementation
- Review action plans regularly for relevance and renewal
- Build relationships with stakeholders in housing, transportation, healthcare and other domains to expand capacity and change efforts
- Develop and nurture learning communities
- Develop and empower advocacy groups to amplify staff capacity
- Provide partner organizations with advice and support to implement disability-related programs, policies, and practices

Recommendations

- Build CIL staff competencies for community change
- Develop and support collaborative partnerships and implement plans for community action and change
- Fund CIL staff to implement and document community action and change efforts
- Provide additional CIL funding to offer seed resources to stimulate community action and change

“If you want to bring a fundamental change in people's belief and behavior...you need to create a community around them, where those new beliefs can be practiced and expressed and nurtured.”

Malcolm Gladwell, from “The Tipping Point: How Little Things Can Make a Big Difference”



Source: Fair use photo

On the phone:
Catherine Graham,
MEBME -
Executive Director,
South Carolina
Spinal Cord Injury
Association,
Columbia, SC

