Significant data limitations prevent an accurate analysis of the distribution of CILs: Recommendations for change

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Significant Data Limitations Prevent an Accurate Analysis of the Distribution of Centers for Independent Living: Recommendations for Change.

In a project designed to update analysis of the distribution of Centers for Independent Living (CILs) in rural America, we encountered several limitations in the data as made available through the 704 reporting systems. The move of the Independent Living Administration (ILA) into the Administration on Community Living (ACL) may present an opportunity to address the data limitations discussed in this brief.

Disability affects nearly 1 in 5 people living in the United States (Brault, 2012). CILs provide essential services to support community inclusion and participation of people with disabilities across the United States. Recent research efforts using a Geographic Information System (GIS) to analyze the distribution of CILs across the nation has revealed significant limitations in how CIL program data are collected and reported. Structuring CIL data collection to be compatible with a GIS analysis has potential to improve future program policy and decision-making.

Why GIS?

Geographic Information Systems (GIS) offer a dynamic method for evaluating and analyzing the distribution of CILs across the country. GIS is a tool that can help analyze, visualize and manage a wide range of data, usually in the form of a map. Used across the fields of public health, community development, and health management, GIS has proved valuable for service delivery and policy development across a wide range of industries. Analysis in a GIS would help the ACL and ILA evaluate CILs by helping to answer key questions such as:

• What is the distribution of CILs across the nation?
• How are CIL services distributed throughout the nation?
• Where are gaps in CIL services located across the country? (ie. How many counties in the U.S. remain unserved by CILs?)
• How many people with disabilities live in these service gaps?
• What implication does an accurate understanding of the distribution of CILs and the population of people with disabilities have on the mechanisms by which CILs access resources (i.e. funding)?
However, as CIL data are currently managed, analysis using GIS is highly unreliable. Structuring data for use in a GIS will allow a more accurate, reliable and robust data analysis to assist policymakers with the distribution and allocation of CIL resources to best support people with disabilities across the nation. An example of the type of analysis and visualization that could be achieved using GIS is found in the map at the end of this document.

**Scope of the problem:**

Current CIL data are collected via the 704 reporting tool, which collects data on such aspects as number and types of consumers with disabilities served, types of services rendered, program and financial planning objectives, and much more. However, these data present significant limitations for a GIS analysis as they are currently collected, structured and published. In this brief the Research and Training Center on Disability in Rural Communities (RTC: Rural) states these data limitations, their problematic effects, and provides specific recommendations for future data collection.

**Data limitations:**

Data for this analysis was accessed through the RSA Ad Hoc Query tool. As the data are currently collected and published, there are major data constraints that limit the effective use of GIS for program evaluation and analysis. See the side box for more detailed information about CIL data collection.

1. **Inconsistent data and reporting:** Many CILs may have to report data on two different reporting forms because they are the recipients of funding from multiple sources. This leads to increased room for reporting error and duplicate data. It is therefore difficult to get complete and consistent data for all centers. For example:
   a. Center names are inconsistently reported across both forms.
   b. County level service data are collected only for centers who complete the 704 part II report form. Since not all centers complete this form, data about national county level service distribution is incomplete.

2. **Lack of location information:** Location data must be available to work in a GIS and place centers and their service areas on a map. However, the locations (such as addresses) of centers are not reported out through the query tool.

3. **Missing data:** Many CILs operate satellite or branch offices in addition to their main office. The data do not have any information about the location of these additional centers. This is problematic because location data are needed to confidently represent CIL service sites and their distribution across the nation.

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**704 DATA COLLECTION**

Data on Centers for Independent Living are collected via the 704 reporting tool using two separate forms. The 704 Part I form is completed by Statewide Independent Living Councils (SILCs) and includes data on CILs that are funded via Designated State Entities (DSEs) using part B funds. The 704 Part II form is completed by CILs that are funded directly by the federal government using Part C funds. Some centers receive both Part B and Part C funding and are therefore reported in both forms.

In the past, data collection has been managed through the Rehabilitation Services Administration (RSA). However, with the move of the Independent Living Administration (ILA), which manages grants awarded to CILs, to the Administration on Community Living (ACL), this is likely to change.
These data limitations demonstrate the risk for poorly informed decision-making. Inaccurate data can paint an inaccurate and unreliable picture of CIL service delivery. Visualizations and more detailed descriptions of the limitations can be found in our project update report.

**Recommendations:**

Adopting the following recommendations to the data collection process will produce more reliable data for analysis and a clearer picture of CIL service distribution.

1. **Create unique IDs:** Create a unique identification number (ID) for each reporting CIL. This unique ID should be different from a grant number, as many centers receive multiple grants. Creating a unique ID number for individual CILs will also improve data consistency by standardizing and linking information across multiple reporting mechanisms.

2. **Improve data consistency:** Adopt consistent reporting requirements across all reporting forms, or synthesize reporting into a singular form. For example, use consistent names or unique IDs for reporting CILs and collect the same location data (i.e. counties served) across all reporting forms.

3. **Collect location information:**
   a. Collect CIL location data for main and satellite offices and identify them accordingly with their unique IDs.
   b. Collect county level data for all CILs, regardless of reporting form or funding source.

4. **Link to geographic identifiers:** Link location information data to geographic identifiers (GNIS IDs) used by the U.S. Census to seamlessly link to all county and place (city) census data for a more robust analysis.

**FUTURE RESEARCH**

Beyond answering the questions listed above, structuring CIL data collection to facilitate an analysis in GIS opens up opportunities for future research. For example:

1. What is the distribution of CIL services relative to other programs managed by the ACL, such as the No Wrong Door (ADRC) program?

2. Previous research has shown that not all CILs are federally funded (Innes, 2000) and are therefore not tracked through the 704 reports. How many of these CILs exist and what is their distribution across the nation?

**Conclusions:**

The movement of ILA into the ACL presents an opportunity to address these limitations. To start, updating and adopting a data collection process that supports analysis with GIS can: (1) increase reliability and accuracy of data reporting tools; (2) reduce data constraints that limit reliability and robustness of program evaluation; (3) provide an accurate map of the current distribution of CIL services, all of which are important for planning and managing the distribution and allocation of services to support people with disabilities across the U.S.

This brief is a groundwork presentation of limitations encountered while working in a GIS with the available 704 data and some recommendations for future data collection. More detailed information about the data used and our preliminary analysis is forthcoming in a technical report. In the interim, more information can be found in a project report linked to throughout this document.
References


The map above is an example of a map created in a GIS using currently available 704 report data. The map shows the locations of CILs across the nation by funding stream. In addition the map shows counties served by CILs across the nation. However, because of the data limitations discussed in this brief, the data visualized in this map are unreliable. Were the data presented in this map reliable, we could confidently identify unserved counties across the nation.

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