Independent Living Research Utilization

We create opportunities for independence for people with disabilities through research, education, and consultation

Mind the Gap:
Using Your Data to Address Service Gaps

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Presenter:

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Today's Presenter

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- He/Him

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Today's Objectives

1. Learn what data is already available to your CIL.

2. Learn how to create a model of your service population.

3. Use that data to identify gaps and promote diversity in your staff and consumers.

Question:

What are some reasons to take a data-focused approach?

Why should we use data?

1. It provides objective assessments.

2. It helps us discover trends that may not be obvious.

3. It assists in mitigating bias, including racial and disability bias.

4. Data to support what your CIL already does and supports to anecdotal evidence.

Part 1: Inventory

What data do we have access to?

Quick Note: All Data is Biased

- All the data we will talk about today has some level of bias and underserved populations are often undercounted.

- This happens for many reason including how the question was formulated, if it was in plain language, and sampling methods.

Quick Note: All Data is Biased, cont.

When looking at any of the data we discuss today always ask the following questions:

1. **Who is asking the questions?** (Non-profit or for-profit business? State vs. Federal? Medical focused vs. Disability Focused?)

2. **How is it being asked?** (Are multiple formats being used? Plain Language?)

3. **Are there other reasons a group would be overlooked?** (For example, the recent census: NPR: The 2020 census had big undercounts of Black people, Latinos and Native Americans)

Types of Sources

Federal and Nationwide

Often considered the "standard" for demographics

- May not provide in-depth information on what your community needs. For example, local transportation usage.

- The Census becomes outdated the older it gets.

State, Local, and Internal

- Good at asking specific questions about your community.

- Vary wildly between states and their data collection processes.

- Greater need to watch out for bias.

Federal Sources

US Census

- Conducted every 10 years.

- Provides a top-level count but becomes less accurate as it ages.

American Community Survey (ACS)

- Conducted annual by the Census Bureau

- Offers in-depth insights in how people live.

Federal Sources, cont.

Center for Disease Control

- Provides updated information on state-by-state disability statistics.

- Includes information on COVID impact.

Administration for Community Living – PPR Comparisons

- All Part C PPRs are released by ACL and is useful at comparing CILs.

State/Local/Center Resources

State Data Sources

- Varies from state to state.

- The Department of Education, Department of Workforce Development often have valuable information for CILs.

State Surveys

- Community surveys conducted by cities, counties, or other organizations.

- State Plan for Independent Living Surveys

State/Local/Center Resources, cont.

Center PPR

- Offers a breakdown of who you serve and how you serve them

Internal Center Demographics

- A breakdown of who works, volunteers, or supports your CIL

How to pick your source

There is no one-size-fits-all approach to selecting a data source. It always starts with formulating questions you want to answer and narrowing your source.

Here are a few examples:

What is the employment level of people with disabilities compared to non-disabled individuals in my county?

- The US Census, or ACS are both excellent resources for this, offering comparative data at a top level.

How to pick your source, cont.

How many students with disabilities are leaving HS with a learning certificate in my state?

- Direct information from the state's Department of Education would be the best source, as federal surveys may not provide such in-depth data

How available is public transportation or paratransit in my county?

- Local data, state surveys, or state departments of transportation would be suitable sources.

Part 2: Build a Model

What is a model? Why use one?

- For the context of this presentation, I don't mean a visual model. Instead, I refer to a representation of what your community looks like.

- By analyzing data from federal and state resources, you can create a data-driven model that reflects the demographics and characteristics of your community.

- Once we have a model, we can compare where a CIL is, compared to their community.

Model 1: The Community you serve

This is typically the first model you will create. It involves gaining a general understanding of the community you serve. Often, this is achieved using federal data and can be narrowed down to the state, county, or city level. The goal is to identify key demographics or issues for comparison with your services and staff. Examples include:

1. Breakdown of race, disability, and age.

2. Veterans

3. Employment

4. Poverty

Example Model: South Carolina

South Carolina (from Census/ACS)

Veterans: 8.4%

Poverty: Disabled – 21% Non-disabled: 12.7%

Race

- White: 63%
- Black: 25%
- Other Race: 6%
- Two or More: 6%

South Carolina: Disability Specific

1 in 3 adults in South Carolina have a disability (CDC)

- 20% Cognitive
- 15% Hearing
- 26% Mobility
- 10% Visual
- 9% Self Care
- 18% independent living

Model 2: Who your CIL serves

The next step is to quantify who your CIL serves. The best source for this is your PPR, but be aware that your definitions of race, poverty, or disability may not match those used by other surveys.

In addition to PPR items also consider pulling the following:

1. Specific disabilities

2. Non-binary gender options

3. Benefits status

Example Model: Able Consumers

Racial breakdown

- White: 40%
- Black: 49%
- Hispanic/Latino: 7%
- Two or More Races: 1.5%
- Other: 1.7%

Disability Breakdown

Cognitive: 58%

Mental/emotional: 13%

Physical: 9%

Hearing: 0.7%

Vision: 1.5%

Multiple Disabilities: 13%

Other: 12%

Model 3: Your Staff

The final basic model is of your staff, which can also be extended to your board and volunteers. This model aims to assess how closely your staff mirrors those you serve, recognizing that shared lived experiences are essential for peer support.

What to collect:

1. As part of your PPR, collect information on whether they have a disability and if they are part of a minority community.

2. In addition, you may want to collect data on individual disabilities.

Note: I am not a human resource expert. Make sure you are consulting with HR if you need to ask any of these questions.

Example Model: Able Staff

Racial and Disability Breakdown

- Racial or Ethnic Minority: 35%

- Disability: 87% of staff have a disability
  - Breakdown (Made up for the example)
    - Cognitive: 12%
    - Mobility: 35%
    - Visual: 15%
    - Hearing: 5%
    - Psychiatric: 16%
    - Other: 17%

Part 3: Compare and React

What questions are we trying to answer?

Key Questions

1. Are we serving the entire disability community in our area?

   – Does data show we are leaving out part of the community? (Examples: Do we serve a higher percentage of people with physical disabilities than expected? Do we serve fewer people in the Hispanic community than we expected?)

What questions are we trying to answer, cont.?

Key Questions

2. Does our staff and board reflect who we serve?

   – Do we have a mixture of race, disability, life experience, etc. that reflects our community?

We can start to answer these questions by doing a comparison of our models.

Are we serving the entire community?

When addressing service gaps, this is one of the most critical questions.

Steps to determine this answer:

1. Pull your model for the community you serve and the model for who your CIL serves.

2. Compare numbers and identify discrepancies.

Are we serving the entire community, cont.?

Some Suggestions

1. Focus on finding gaps.

2. Consider what makes your CIL or service area unique that may affect those numbers.

3. Ask questions about how you are documenting items in your CIL system

Comparison: State Vs. Able

State Model

Race

- White: 63%

- Black: 25%

- Other Race: 6%

- Two or More: 6%

Disability

- 20% Cognitive

- 15% Hearing

- 26% Mobility

- 10% Visual

- 9% Self Care

- 18% independent living

Able Service Model

Race:

- White: 40%

- Black: 49%

- Two or More Races: 1.5%

- Other: 1.7%

Disability

- Cognitive: 58%

- Mental/emotional: 13%

- Physical: 9%

- Hearing: 0.7%

- Vision: 1.5%

- Multiple Disabilities: 13%

What does this show us?

Main Takeaways

- As a CIL, we serve a majority of people who are in the minority.

- More than half of our consumers have a cognitive disability, compared to 20% statewide.

- Less than 1% of our consumers have a hearing disability, compared to 15% statewide.

Potential Gaps and questions

- We have significant potential for growth in our services to people with hearing disabilities.

- Why do we serve so many people with cognitive disabilities? Is this common among other CILs?

- How can we leverage both these discrepancies?

- Does this look accurate based on what you know for your CIL?

Does our staff reflect our community?

This is the second key question. Keep the following in mind:

- **We are working with a much smaller sample size.** The change in one person on staff could change the entire makeup. If we have four people in management, a change of just one person could shift statistics by 25%.

- **We want a range of disabilities, life experiences, race, and other aspects of diversity.** You may decide to go against representing your community in your staff. For example, you may serve a very homogenous community but want your staff to be more diverse.

- **Keep long-term trends or outliers in mind.** Did we start a new program Is this an outlier? Example during COVID-19 our healthcare related services spiked.

Comparison: Community vs. Staff

Community (from PPR)

Racial Breakdown

- White: 40%
- Black: 49%
- Hispanic/Latino: 7%
- Two or More Races: 1.5%
- Other: 1.7%

Disability Breakdown

- Cognitive: 58%
- Mental/emotional: 13%
- Physical: 9%
- Hearing: 0.7%
- Vision: 1.5%
- Multiple Disabilities: 13%
- Other: 12%

Staff

- Racial or Ethnic Minority: 35%
- Disability: 87% of staff have a disability
  - Breakdown (Made up for the example)
    - Cognitive: 12%
    - Mobility: 35%
    - Visual: 15%
    - Hearing: 5%
    - Psychiatric: 16%
    - Other: 17%

Questions and Insights

1. Our racial breakdown is much closer to our state demographics than to the community we serve.

2. We have a diverse range of disabilities but may want more people with cognitive disabilities on staff.

   – This is also an area where we may need to dig deeper about how we categorize cognitive disabilities (Developmental, Intellectual, ADHD, TBI).

3. **This provides us with good long-term planning metrics.** In 2020, we had around 20% of our staff of a racial or ethnic minority, and in three years, we have increased it to 35% because we saw that we were not matching our community.

Next Steps: how to use your data

1. Look internally to changes.

   – Staffing, outreach focus, how demographics are collected

2. Look externally for partners

   – Can you address any trends by reaching out and connecting with partners?

3. Leverage your data for fundraising

   – Does your data show that you served one group very well? That is a highlight for fundraising

   – Does your data show an underserved area? You now have data to show why you are needed in that area

What other ways can you use this data?

Stay in touch

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Evaluation

Your feedback is important to us! Please take the evaluation survey clicking here or through the provided QR code.

Fireside Chat with Andy Arias

How can CILs/SILCs effectively leverage PPR and basic Census data to identify service gaps and underserved populations?

Could you elaborate on the methods for assessing staff and board representation of marginalized groups within organizations?

What practical strategies can you offer if there is a lack of resources to collect and analyze data?

IL-NET (CIL-NET and SILC-NET) Attribution

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