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Understanding and Evaluating Quality of Life for Individuals with Intellectual Disabilities: A Northwestern Vermont Population Study

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Introduction

There are 7-8 million individuals with intellectual or developmental disabilities living in the US.

- 91,795 of this population lives in Vermont[1,2]
- Historically marginalized and isolated community
- Socioeconomic, health-related, and emotional burden
- Public health-related disparity

Champlain Community Services (CCS): non-profit service provider and coordinator for 86 persons with intellectual disabilities in Northwestern Vermont

Objectives:

- Develop and apply measures to better understand and evaluate quality of life in the population CCS serves.
- Recommend improvement to CCS data collection and evaluation methods.
- Provide a basis for future recommendations to CCS services that are aligned to the needs of consumers.
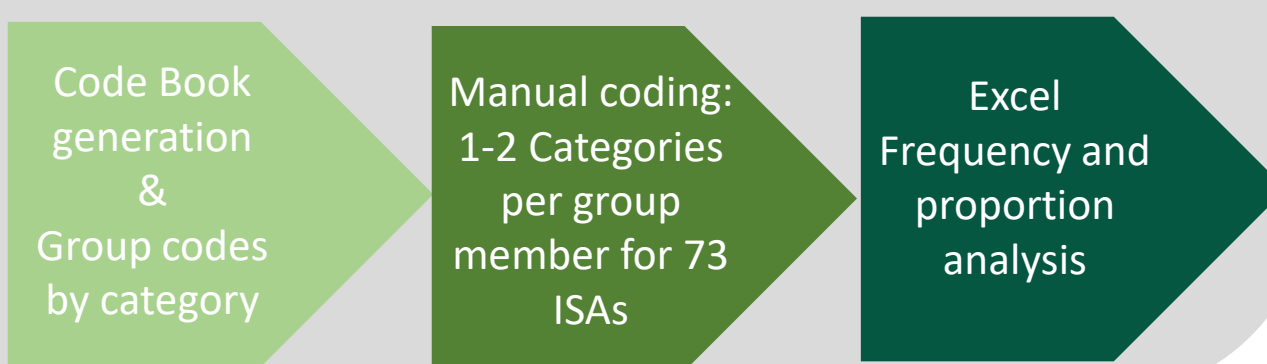
Methods

Data source: 73 Individual Service Agreements (ISAs)

Coded Categories

- Communication Strategy
- Desired Skills
- Employment Status
- Goals & Dreams
- Personal Healthcare
- Living Situation
- Social Factors
- Supervision
- Transportation

Trend and Outcome Analysis:

- Excel frequency analysis and figure development

Code Book generation & Group codes by category → Manual coding: 1-2 Categories per group member for 73 ISAs → Excel Frequency and proportion analysis

References

1. Brault MW. Americans with Disabilities: 2010. In: Bureau USC, ed2012:70-131.
2. Vermont So. Annual Report on Developmental Disabilities Services for State Fiscal Year 2017. *Disabilities, Aging and Independent Living* 2018; http://ddsd.vermont.gov/annual-report-dds-sfy2017. Accessed September 6th, 2018.

Results

Study Population:

- 73 CCS consumers with intellectual disabilities

Demographics:

- Sex: 62% male (n=45), 38% female (n=28)
- Age: not provided
- Race: not provided

Figure 1. Frequency analysis of grouped coding categories. Living Situation, Social, and Transportation were the most commonly reported code groups in ISAs.
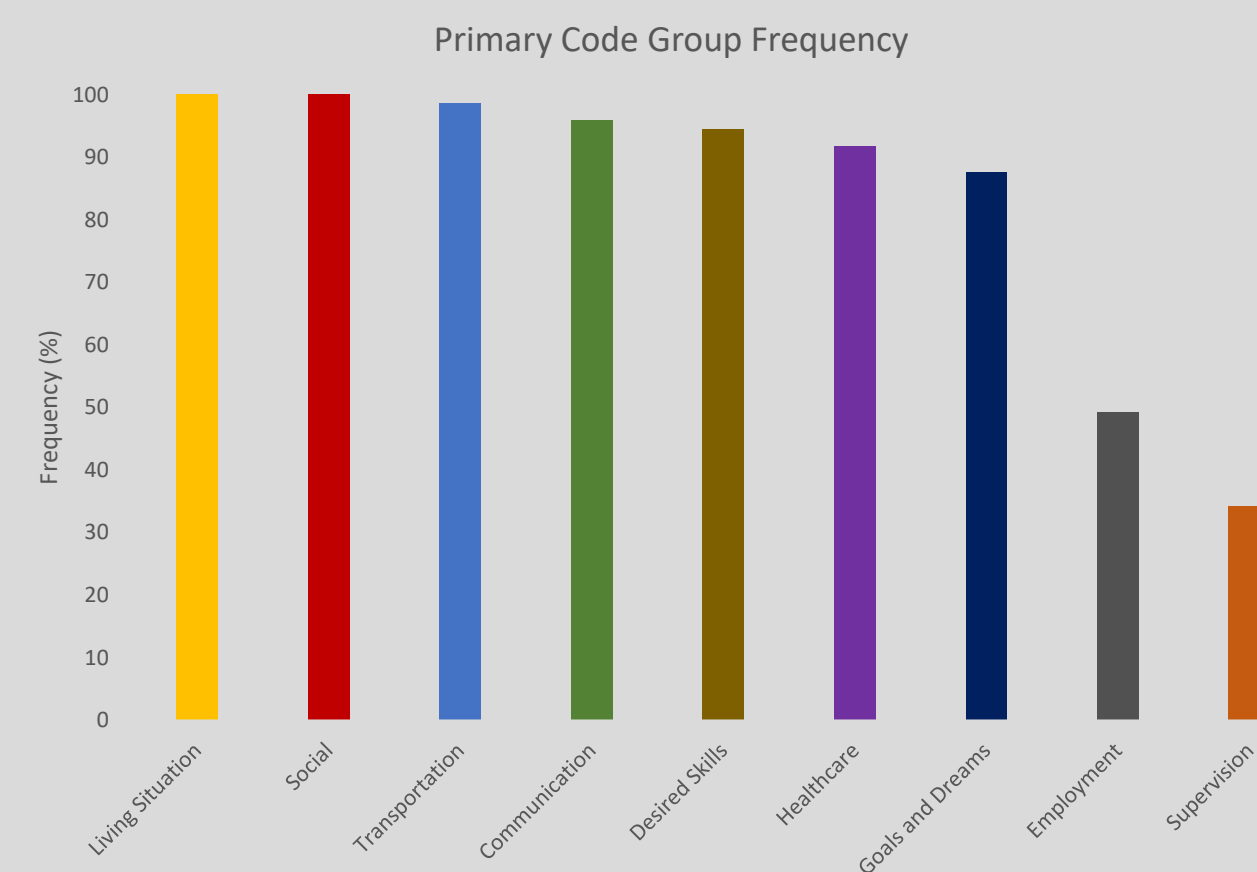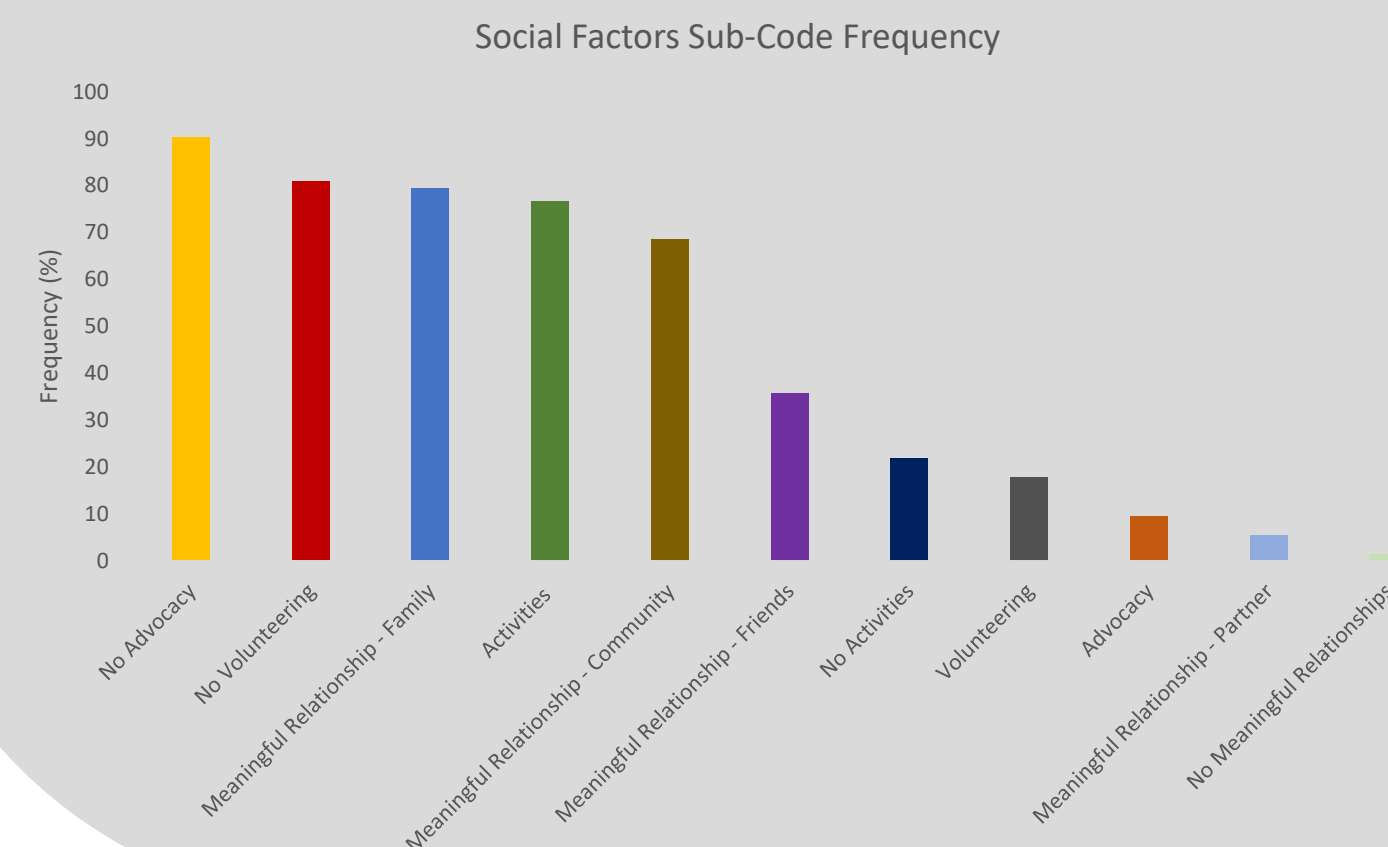

Primary Code Group Frequency

Figure 2. Living situation sub-code analysis. These data represent the percent of consumers (total n=73) that have each type of coded living situation. Mostly commonly, ISAs indicated consumers live at home or with a shared living provider.
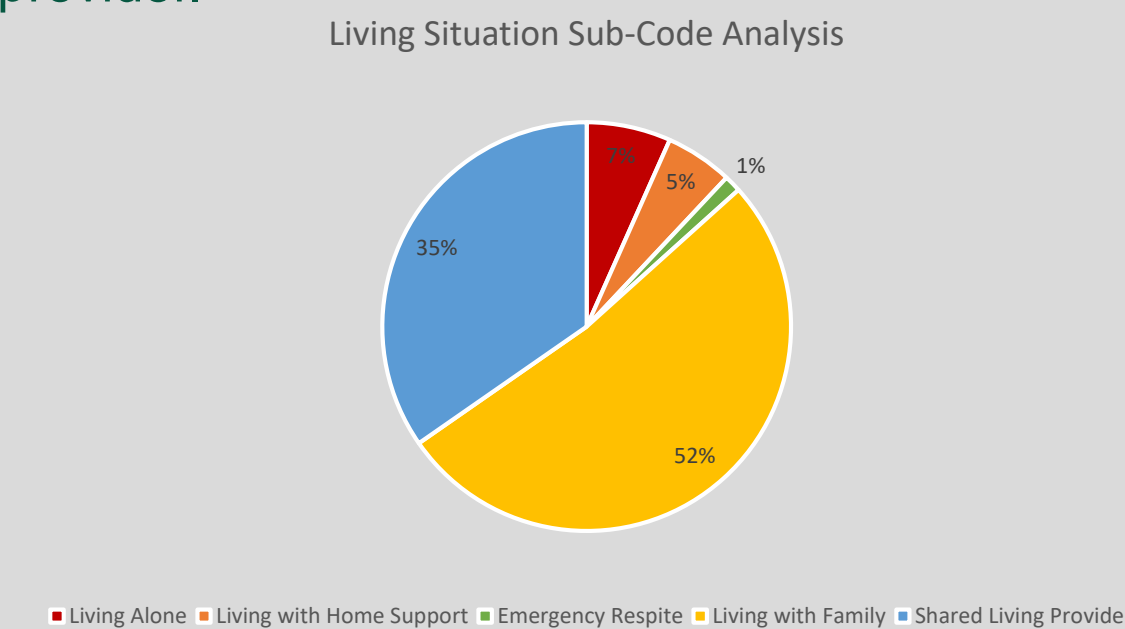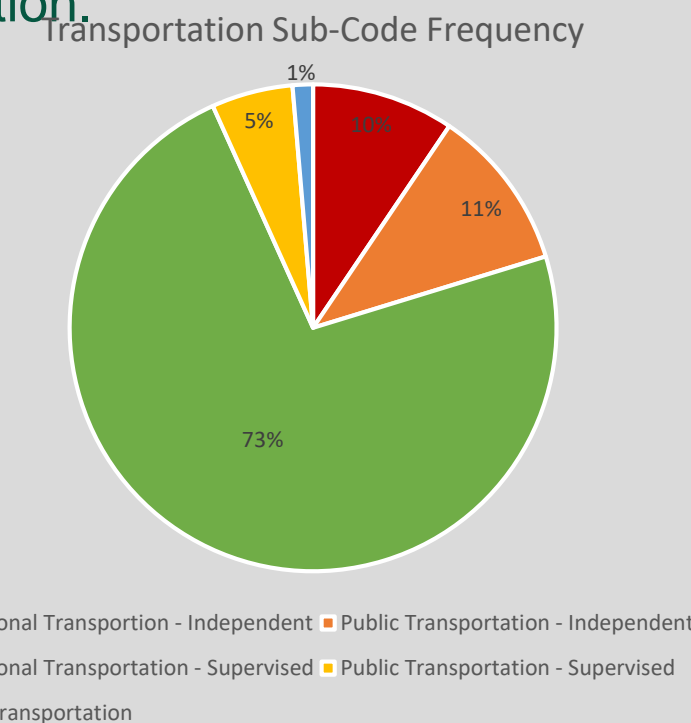

Living Situation Sub-Code Analysis

Living Alone • Living with Home Support • Emergency Respite • Living with Family • Shared Living Provider

Figure 3. Social factors sub-code analysis. ISAs most frequently indicated clients do not participate in advocacy or volunteering. Further, most clients report meaningful relationships with family and community, and are less likely to have such relationships with significant others.

Social Factors Sub-Code Frequency

Figure 4. Transportation sub-code analysis. These data represent the percent of consumers (total n=72) that use each coded type of transportation. Most commonly, ISAs indicated consumers use supervised personal transportation.

Transportation Sub-Code Frequency

Personal Transportation - Independent • Public Transportation - Independent
Personal Transportation - Supervised • Public Transportation - Supervised
No Transportation

Limitations & Conclusions

Limitations:
ISA data non-standard in format or content

- Reproducibility of coding
  - Inter-operator variability mitigated by one coder per category for all ISAs
  - Remaining variability of coding between research team members.

Conclusions:

- Heterogeneity in domains within each consumer's ISA
- The data set provides the first categorization of common themes throughout the CCS consumer base
- These data also establish a foundation for characterizing the quality of life of CCS consumers

Recommendations

- Development & integration of standardized measures to track changes in goals and accomplishments of consumers
- Further analysis of the provided data set to provide a basis for areas of focus for consumers

Quotes from Consumer ISAs

"Support staff will provide transportation and aid ... in her picking up of compost containers at her customer's homes, emptying the containers at the composting site, and returning the customer's containers."

"…loves living in downtown Burlington and the ease of independently doing things he enjoys. One part he enjoys about downtown is taking long walks early in the morning...to "watch the city wake up."

"… is an active member of her community and church, singing in the choir and committing herself to a number of volunteer efforts."