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Quality of Life Among Youth with IDD in Parent-Developed Residential Program

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Background

Individuals with Intellectual and Developmental Disabilities (IDD) routinely experience a lower quality of life than those without IDD. Further, the nature of residential settings has been shown to affect resident's quality of life. The study is tracking changes in quality of life for six young adults with IDD as they transition into an innovative housing program developed collectively by their parents. This new housing offers individuals their own apartments, while also providing access to communal spaces and support staff as needed.

Methods

Data sets will be collected and analyzed three times over a 26-month period. For this study, quality of life is being measured in three ways:

- (1) pre-post administration of the INICO-FEAPS Scale, and pre-post administration of a quantitative survey created for this purpose to parents and residents;
- (2) structured qualitative interviews of both parents and residents; and
- (3) measures of changes in goals identified in person-centered planning meetings, along with an analysis of the methods and processes used to create those goals.

To date, the first round of data collection has been conducted. Data was collected within one week after residents moved into their new apartments. In this way interviews captured information about residents recent lives pre-move, along with initial thoughts and feelings about their new living situation.

As part of a leadership placement at the CCIDS, I have recorded data from INICO-FEAPS surveys, assisted in analyzing survey data, identified themes and developed codes for qualitative data, and carried out preliminary analysis comparing goals identified in service plans and qualitative interviews.

Preliminary Analysis of Goals Reporting

Data can not yet be gathered to test for changes in goals post-move. Data has also not yet been gathered to analyze the person-centered planning processes used for identifying goals.

However, Table 5 demonstrates a comparison of goals identified by residents in their qualitative interviews against the goals identified in their most recent service plans. Five of the 32 goals collectively identified by residents in the qualitative interviews are reflected in service plans. Three of the five goals reflected in both the interview and service plans belong to one individual. Two individuals had one goal reflected, each. Three individuals had none of the goals stated in their interviews reflected in their service plans.

Number of Goals Identified in Qualitative Interviews	Number of Goals Identified in Service Plans	Number of goals from Interviews Reflected in Services Plans
32	25	5

Table 5. Comparison of numbers of goals identified in qualitative interviews vs. service plans.

"I would do nursing but I think it's a little off with my physical limitations – I would like to learn it, but I don't know if I could actually do a job with it... if I needed to take care of something I could at least understand what (the doctors) are talking about – you know, which I sometimes do, sometimes not."

Major Themes Found in Qualitative Resident Interviews

Pre-Move Living Situations

- Two respondents lived with their parents, 3 lived in elderly and disabled specific apartment complexes, and 1 lived in a home with a family. Respondents expressed a range of positive and negative associations with their previous living situations. See table 1 below.

Positives	Negatives
Enjoying family-style meals	Age-incongruent relationships (especially in the context of elderly housing)
Friendships with other residents	Loneliness
Independence	Lack of access to community (both physical and social)
Proximity to family members	Lack of independence
Access to the community	Over-reliance on support staff
	Inaccessibility of apartment

Table 1. Respondents feelings about previous living situation

Relationships

- Most relationships identified were tied to supports or the 'consumer' role in some way.
- Four of the 6 attended day programs before moving. Relationships made in these programs generally did not extend outside of day programs, though they were described as important.
- Romantic relationships were also tied to day programs, and also did not extend outside of them. Access to day programs, then, was synonymous with access to established romantic relationships.
- With one exception, important relationships created and maintained outside of a day program included only family members and family friends. The two of the three residents who previously lived in elderly housing additionally described older residents taking on "Grandmotherly" roles in their lives.

Initial Impression of New Residence Immediately Post-Move

- Residents overwhelmingly expressed positive impressions of their new living situation.
- The only negative initial impression revolved around missing former community.
- See Table 3 for the most common initial impressions.

Like	Dislike
Always having people around	Distance from friends
Responsibility	
Chores	
Helping around the house	
Communal meals	

Table 3. Initial impressions of new residence.

"I got – I had a lot of good friends – friends who have been there when I needed them the most during the day program."

Expectations for New Residence

- Though most recalled feeling initial skepticism when learning about the possibility of the move, respondents overwhelmingly reported positive expectations for their new residence.
- The themes and sub-themes which most often came up are found below in table 2.

Themes	Sub-themes
Independence	<ul style="list-style-type: none"> Managing Money Enhanced Decision Making Power Responsibility Community Engagement
Friendships and Social Connections	<ul style="list-style-type: none"> With other residents With wider community
Opportunities	<ul style="list-style-type: none"> Work Recreation Community Activities (both at and outside of home) Communal Cooking and Eating
Trying New Things	
Quality of Physical Space	

Table 2. Most common expectations for new residence.

"I couldn't believe it- that this was going to happen... this is happening and I love it."

"..Since I have to depend on (staff) so much it was like – well, do I want to depend on them so much that I absolutely can't live anywhere else?"

Statistical Analysis of INICO-FEAPS Scale

The INICO-FEAPS Scale was developed to quantitatively test quality of life of individuals with IDD. The scale gathers information from both the individual in question and someone close to them (in our case parents and guardians). Both the 'self-report' and 'other person' surveys consist of 72 questions, nine in each quality of life domain.

Table 6 presents the statistical results from a series of one-tailed t-Tests conducted on our data.

- Self-reported standard scores were higher than parent reports in all cases.
- Self-reported percentile scores were higher in all cases except for in the 'Rights' domain
- The difference between self- and parent reporting approached statistical significance in the 'Personal Development' domain at the .05 level
- The difference between percentile scores for self- and parent reporting overall was statistically significant at the .05 level

"I feel like, when I am outside I am just like in the present, because- the sun, the air, everything that makes me 'me' and helps me function- just a happy, thankful, happy-go-lucky guy."

Domain	Mean Standard Scores		Mean Percentile Scores		T-test Comparison of Parent and Self Mean Percentile Scores
	Self	Parent	Self	Parent	
Self Determination	11.8	11.2	65.3	62.3	t(5) = 0.16, p = 0.44
Rights	11.8	11.7	64.5	68	t(5) = 0.18, p = 0.43
Emotional Wellbeing	10.5	8.5	42.2	21.3	t(5) = 1.67, p = 0.08
Social Inclusion	10.5	8	53.7	33.5	t(5) = 0.94, p = 0.19
Personal Development	9.2	6.2	44	19.5	t(5) = 1.93, p = 0.056 **
Interpersonal Relationships	9.3	7	42.2	21.3	t(5) = 1.67, p = 0.08
Material Wellbeing	10.7	8	57	37.2	t(5) = 0.82, p = 0.23
Physical Wellbeing	10.2	9.7	59.3	51.2	t(5) = 0.50, p = 0.32
Overall QOL	59.3	33.5	59.3	33.5	t(5) = 2.1, p = 0.045 *

**Key: * = significant at .05 level
** = approaching significance**

Table 6. Standard and percentile scores, along with results from one-tailed t-Tests of self-report and parent-report INICO-FEAPS surveys

Conclusions and Next Steps

These initial findings describe the first of three rounds of data collected in this study:

1. Goals expressed by residents in our qualitative interviews and those present on their service plans are largely incongruent.
2. Residents on average rate their QOL higher than their parents do. Percentile scores reported by residents are significantly higher than those reported by their parents at the .05 level.
3. Residents are coming from a variety of residential backgrounds. Pre-move feelings were mixed, however initial reactions post-move have been overwhelmingly positive.

Two further rounds of data collection, along with a more in-depth analysis of the goal-setting process will take place in the coming months.