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11-2019

## Collaboration with Parent-Run Organization, a Support Agency and Adults with Developmental Disabilities to Improve the Quality of Life

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# Center for Community Inclusion and Disability Studies

## Collaboration with Parent–Run Organization, a Support Agency and Adults with Developmental Disabilities to Improve the Quality of Life

Alan Kurtz, Ph.D. and Janet May, M.Ed.

### Background

A group of parents were dissatisfied with existing residential supports for their adult children with developmental disabilities. They created a residential alternative characterized by:

- A town and neighborhood location where residents would have easy community access;
- Six one-bedroom apartments as well as shared space;
- Opportunities for shared meals and healthy food;
- Many opportunities for social interaction within residence;
- Opportunities for skill-building;
- Support from an agency;
- Financial support from state and local resources; and
- Funded as a Private Non-Medical Institution (PNMI)

### UCEDD’s Role – Evaluating the Model

The Center for Community Inclusion and Disability Studies (CCIDS) was asked by the parent organization to evaluate their model. We proposed the following:

- Pre-Post Quality of Life Survey (INICO FEAPS).
- Structured Interviews of parents and residents prior to their move and one year after their move.
- Review of Person-Centered Planning Documents.

In addition, CCIDS staff made recommendations to the parent organization and support agency after the first year.

CCIDS and the parent organization are currently seeking funding to conduct another round of data collection and to support training to the support agency.

### Pre-Post INICO-FEAPS Quality of Life Scores by Domain Self and Parent(s)

Domain	Self Percentile Pre-Score	Self Percentile Post-Score	Self # with Increase	Self # with No Change	Self # with Decrease	Parent(s) Percentile Pre-Score	Parent(s) Percentile Post-Score	Parent(s) # with Increase	Parent(s) # with No Change	Parent(s) # with Decrease
Self-Determination	65.3	76.3	3	3	0	62.3	78.7	4	2	0
Rights	65	78.5	4	2	0	68	70.5	3	1	2
Emotional Wellbeing	42.2	43.3	2	1	3	21.3	57.8	4	2	0
Social Inclusion	53.7	37.7	1	0	5	33.5	19	1	1	4
Personal Development	44	47.2	3	1	2	19.5	34.5	5	0	1
Interpersonal Relationships	42.2	50.5	2	2	2	21.3	34.3	5	0	1
Material Wellbeing	57	60.8	2	1	3	37.2	70.83	6	0	0
Physical Wellbeing	59.3	47	3	2	1	51.2	47	3	2	2

### Conclusions from Quality of Life Survey

Parents tended to rate their adult children’s quality of life lower at the time of the move than residents.

- ★ Both parents and residents tended to rate the residents’ **Overall Quality of Life** higher after they lived at the residence for a year. Both parent and resident scores were higher in year two in the following domains of **Self-Determination, Rights, Interpersonal Relationships, Emotional Wellbeing, Personal Development,** and **Material Wellbeing.**
  - ★ Mean scores for **Social Inclusion** decreased significantly both in the parent and resident versions of the survey. Combined with the higher scores in **Interpersonal Relationships,** the results suggest that social interaction greatly increased for residents but that most of their interaction took place within the residence and not the larger community.
- Both parent and resident scores indicated a perceived decline in residents’ **Physical Wellbeing.** This was at odds, however, with what most of the residents and parents reported in their interviews.

### Resident Perceptions of the Program

- Liked being in town and close to activities.
- Most liked spending time in the shared spaces and eating with other residents.
- Everyone enjoyed getting to cook one night a week for the group and the quality of the food.
- Most learned some skills and became more independent.
- Community participation was often a group activity.
- All felt it was a good experience, including two who moved out.
- Liked their apartments.
- Felt less dependent on families.

### Parent Perceptions

- ◇ Residents were happy, had grown and become more independent.
- ◇ The quality of the food was good although several parents worried about weight gain.
- ◇ Better relationships with family including less dependence on parents.
- ◇ Very satisfied with the staff who were hired to work at the residence and with low staff turnover.
- ◇ Dissatisfied with funding that made it difficult to provide individualized supports, especially in community settings.

### Ongoing Issues and Concerns

- ❖ Two residents moved out because it was not a “good fit.”
- ❖ Inadequate number of staff sometimes made it difficult for people to do the things they wanted to do.
- ❖ Social interaction appeared to increase but participation in broader community appeared to decline.
- ❖ Person-centered planning and other planning goals were seldom consistent with the goals expressed by residents in their interviews.
- ❖ Inconsistent planning processes.

### Recommendations

- Provide training to support staff on authentic person-centered planning.
- Provide training to support staff on making community connections and utilizing natural supports.
- Continue to measure quality of life and use the result to improve the model.