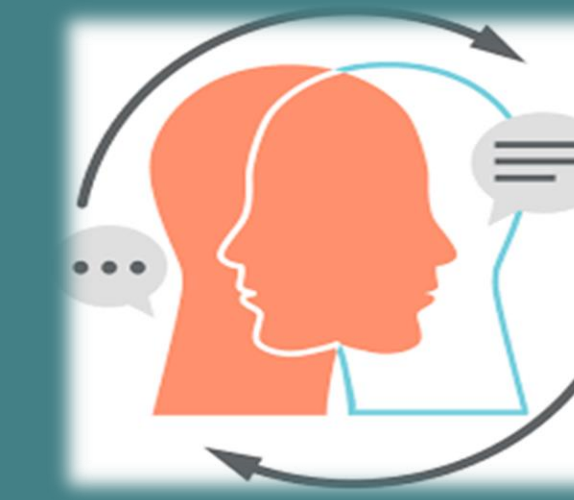




Feeling Heard & Seen: Communication Strategies As a Way to Connectedness

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Introduction

Many individuals in the IDD-MH population report feeling misunderstood by those that support them and in other social interactions. Among individuals identified with a debilitating disability or chronic illness, 85% experience loneliness and social isolation in the United States (Elflein, 2019). As a result, many individuals with IDD and the systems that support them may experience emotional distress that can present as property destruction, hitting others, or increasing volume of voice further warranting increased crisis response.

As a systemic model, START seeks to create mutual collaboration and common understanding between the START enrollee and systems of supports. This collaboration and common understanding fosters connection and communication to decrease crisis over time.

A qualitative study was created using strategy implementation and survey measures to evaluate crisis related to communication, distress associated with communication, and feelings of connection.

Objective & Aim

The study aims to explore experiences of caregivers' reported feelings of connection coinciding with the implementation of communication strategies. It is suspected that the overall feeling of connectedness will increase when systems have increased competency in communication interventions. The findings provide direction for START programs in targeting communication interventions to increase meaningful connection for the START enrollee.

In conducting this study, the START East Bay program considered how utilizing coaching visits could open the opportunity to identify individuals and systems that have the potential for planned coaching.

Methodology

Eighteen individuals were randomly selected as participants and were offered to receive planned implementation of communication strategies weekly over the course of six weeks. Of those eighteen, six accepted to be apart of the study. However, due to scheduling limitations only four START enrollees and their system completed the coaching visits and were surveyed on how that impacted the caregivers' reported feelings of connectedness and decreased crisis.

The Weekly Survey on Communication and Connection was used as a qualitative examination that evaluated crisis related to communication, subjective units of distress associated with communication, and feelings of social connection. Social/human connection was identified as the bond formed between people to build trust, feel valued and seen and defined by experiencing high quality interactions, genuine care, positive resonance, and kindness. The values of the PERMA model, particularly in Relationships and Meaning, were used to inform definitions of connectedness.

During coaching visits a Communication Interactive Booklet was used with three of the four participants, which emphasized verbal communication and interactive conversation on emotion, reflection, and future planning. One participant received a revised version of the Communication Interactive Booklet in the form of a visual binder due to non-verbal vulnerabilities.

Results

Distress and Connection Analysis

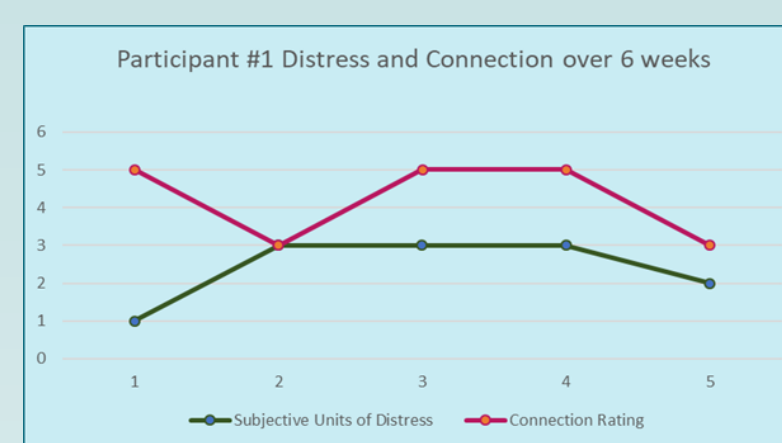


Fig. 1

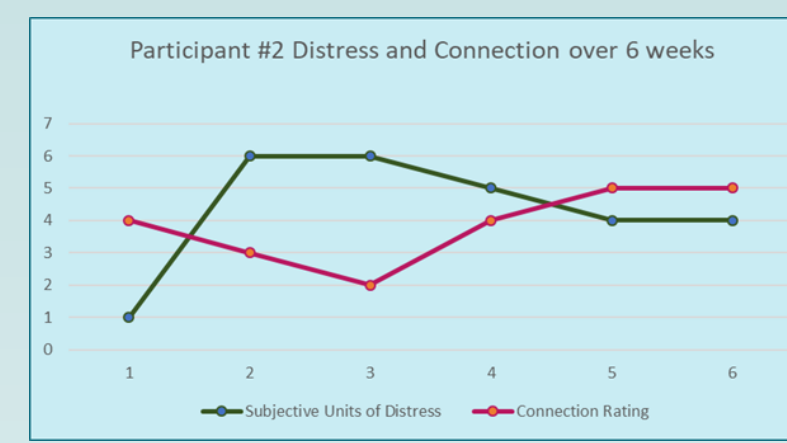


Fig. 2

The data gathered from the Weekly Survey on Communication and Connection indicated that as increased communication strategies were implemented with systems this led to an overall decrease in subjective units of distress (SUD) for the caregiver anticipating communicating with the START enrollee. Further, systems indicated that there was an increased feeling of overall connection to the individual they support as anticipated distress regarding communication decreased.

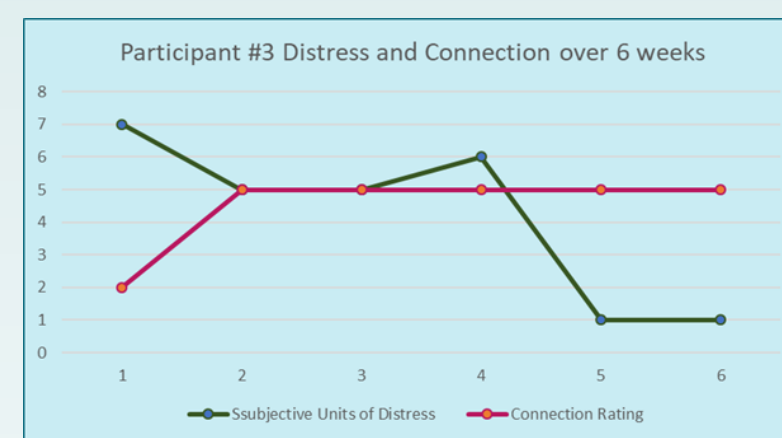


Fig. 3

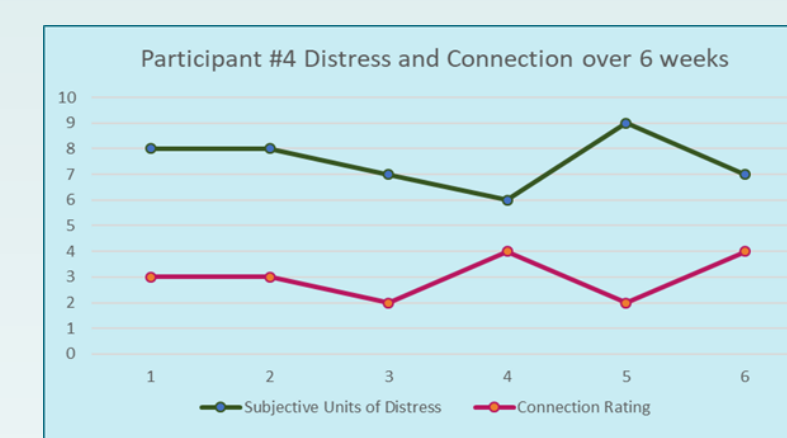


Fig. 4

X-Axis: Number of Coaching Sessions
Y-Axis: Rating of SUDs and Connection

Increased Understanding, Decreased Crisis



Fig. 5

Throughout each week of the study, our program gathered data on crisis that occurred relating to communication. Two of the four participants did not have any crisis situations occur relating to communication during the entire duration of the experiment. The other half of participants had crisis occur relating to communication at the onset of coaching visits being implemented. Then as visits continued each week, the crisis situations relating to communication decreased.

Of the six CA-START East Bay participants originally selected, four completed the Weekly Survey on Communication and Connection. Four engaged in consistent weekly coaching visits. Additionally, one individual who lives in a family residence was randomly selected to complete an updated Family Experience Interview Schedule (FEIS). This was conducted at the conclusion of the study to be compared to the FEIS completed at intake. This would evaluate if START therapeutic coaching and coordination services had a positive impact on feeling supported by mental health providers.

START East Bay explored three major hypotheses contingent on the implementation of consistent communication strategies given to systems over six coaching visits in accordance with the START Therapeutic Coaching Model.

1. That systems' anxiety around communication with the START individual would decrease
2. That crisis situations surrounding communication differences would decrease
3. That feelings of connection to the individual from the system would increase

Based on the data collected throughout the duration of the study, the above three hypotheses could be supported, as referenced by Figures 1-5. The X-axis indicates the number of coaching sessions completed and the Y-axis indicates the Subjective Units of Distress (SUDs) reported by the system and feelings of connection toward the START enrollee. A rating of one represents no feelings of distress or no feeling of connection, while a rating of 5 would be the maximum level of connection felt or 10 being the maximum level of distress felt by the system receiving coaching.

When reviewing the FEIS at intake to the updated FEIS after the conclusion of coaching, it was found that there was an overall increase in feeling supported by mental health providers – the average score going from 2.94 to 3.33. This indicates that families may experience an increased feeling of understanding and support by mental health providers when there is collaboration between START Coordination and START Therapeutic Coaching services. Further review will be conducted to update ecomaps for all participants.

Implications & Limitations

While we saw a general improvement regarding feelings of connection and feelings of distress around communication from systems, two of the participants had recent stressors relating to change in schedule and change in medication, that indicated higher rates of distress and smaller rates of connection at these points in the six weeks. This can be seen on Figure 3 at week four and on Figure 4 at week five.

Additionally, participants 1 and 2 had systems that were more actively engaged in coaching and implementing communication strategies. Figures 1 and 2 demonstrate the overall importance of how impactful planned coaching can be when the system demonstrates the capacity and motivation to participate fully in START Therapeutic Coaching services.

We hope to further expand this study by including more participants, gathering more FEIS data and information on the START enrollees' feelings of connection in conjunction with systems by utilizing the Social Connectedness Scale (SCS) before interventions were applied and at conclusion.

Conclusion

For START clinical teams, primary interventions consist of strengthening the supports' capacity to successfully engage individuals with IDD by focusing on understanding, building connection, improving relationships, identifying themes and interventions for crisis, and improving competencies.

Before coaching services were implemented half of the individuals selected experienced ongoing crisis related to communication differences which resulted in feeling unsupported, misunderstood, and a lack of connection or rapport between the START enrollee and their system. However, all participants identified distress relating to communication and a decrease in rapport and understanding the START enrollee. Once strategies were given to systems of support to address communication differences, a common understanding was made, bridging the gap in disconnection or detachment from the individual's experience.

The START East Bay clinical and coaching teams build system capacity through outreach, therapeutic coaching strategies, and training with the goal of sharing knowledge and resources. The team provided communication tools to the system and START enrollee to promote understanding, connection, and decrease crisis. By providing hands-on training to providers of direct support and caregivers it ensures there is a coordinated continuum of care in place to respond to arising needs. This level of intervention provides universal benefit to START service recipients as well as to service systems and communities.

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