Culture of Gentleness: A Promising Practice for Supporting Vulnerable Individuals

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Introduction

The majority of people with developmental disabilities who are supported by public programs live good lives with minimal distress. Their services and supports enable them to live interdependently and to achieve their personal goals. However, a small minority of individuals are so traumatized by their disability, their social situation, and their inadequate support systems that they are extremely vulnerable and reactionary to their environments and everyone in those environments. They are at risk to themselves, to others, and a high cost to the public program. Historically, these individuals would have been put into institutions with no opportunity to develop the pro-social skills that they need to become stable and productive individuals. In most situations, the institutions, themselves, only exacerbated the individuals' problems. Fortunately, public policies no longer support institutionalization. All individuals should have the opportunity to experience good lives in the community. In order to support these extremely vulnerable individuals, the Culture of Gentleness Model was developed.

Culture of Gentleness: Building a Foundation of Support

The Culture of Gentleness Model, while grounded in solid behavioral counseling theory (antecedent based intervention; response interruption/redirection; errorless learning; visual supports), is not an intervention, per se. Rather it is a way of interacting and supporting an individual in order for him/her to feel safe. With safety comes the potential for emotional and psychological stability and growth. The Culture of Gentleness is about being intentional in interactions with others and being sensitive to how the other is feeling and reacting. A basic belief of the Model is that when individuals are in distress, they need to have others in their lives who will nurture and help them through the difficulty. They do not need to be punished or ignored or lectured. A mantra that is central to the Model is: "I need to be at my best when you are at your worst".

Most counseling and intervention strategies focus on what needs to be changed within an individual; what are the individual's deficits and how to reduce or ameliorate them. The Culture of Gentleness Model places a focus on the development and deepening of relationships which are at the foundation of all human growth and recovery. The Model focuses on changing the system of care rather than fixing the individual. The Model focuses on the development of companionship and a sense of community through the following six key elements:

1. *Safety*: Everyone must be physically and emotionally safe in order to grow, learn, heal, and recover.
2. *Unconditional Positive Regard*: Everyone needs to be loved and valued in good times and in bad.
3. *Uplifting Interactions*: Everyone needs uplifting interactions to feel safe and valued.
4. *Reduced Demands*: Everyone needs to have positive events outweigh negative demands in order to feel safe and valued.
5. *Structure and Predictability*: Everyone needs structure and predictability to feel safe.
6. *Transition*: Everyone needs predictable and anxiety-free transitions to thrive.

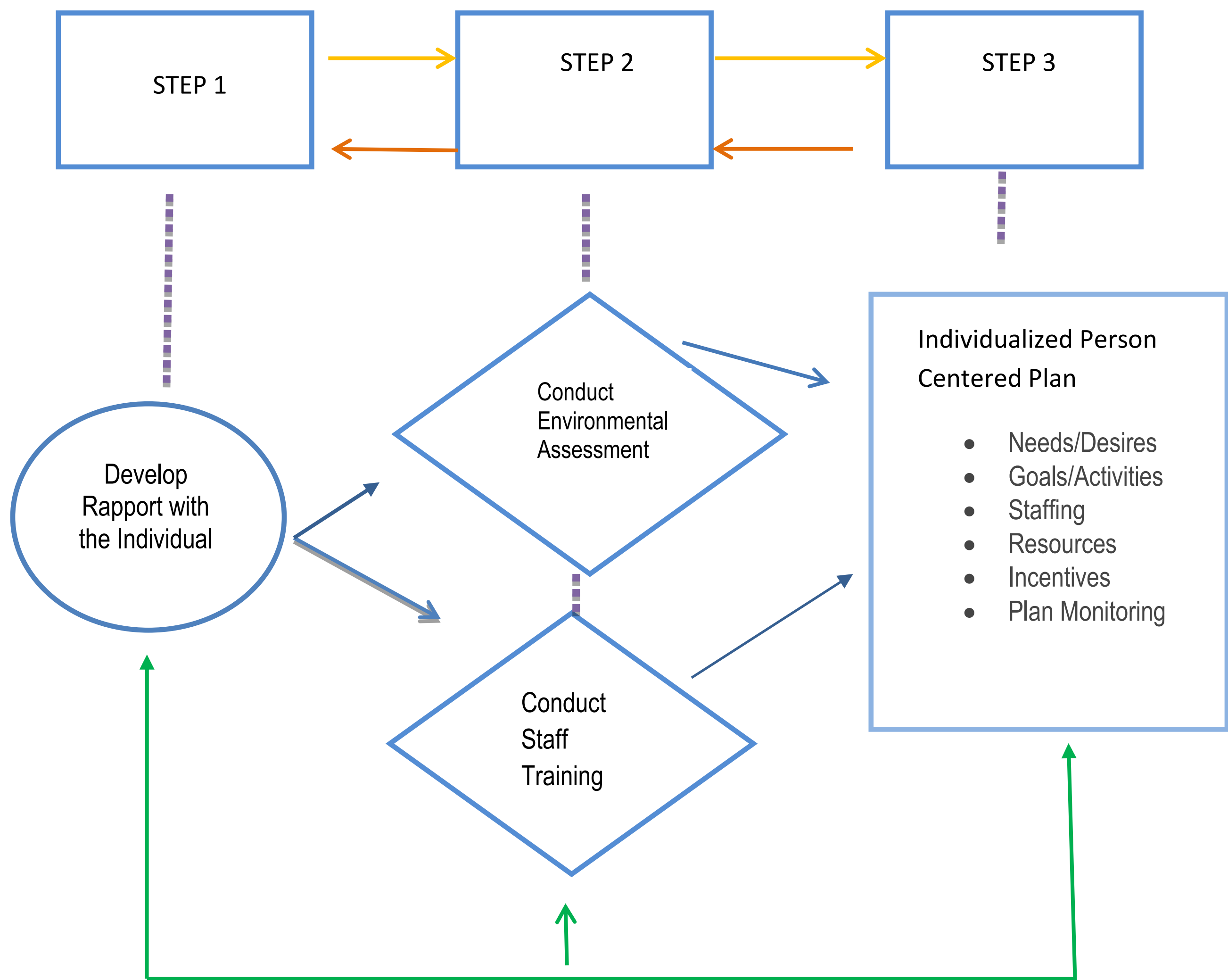
Figure 1 below illustrates the process of creating a foundation of support for the individual. Step One in the process is the development of rapport with the individual. Rapport creates the emotional environment within which the individual feels safe - a necessary prerequisite for growth and learning. Rapport is developed through the caregiver interactions with the individual; how words, touch, eye

contacts and personal presence are conveyed. How this is implemented with each person will vary depending upon what is learned about the individual through the gathering of the individual's history and personal story.

Step Two in the process is assessment and training. The environmental assessment determines what could be causing stress within the individual's environment. The staff assessment determines the skill building needs of the direct caregivers and their supervisors. Training and ongoing monitoring are provided to support the caregivers (and thus the individual).

Step Three in the process is the development of a comprehensive person centered plan that addresses the individual's needs and desires, sets goals and activities, identifies the staffing plan, resources, incentives for staff and the individual, and creates a plan for monitoring success.

Culture of Gentleness Model



To assess the impact of the Culture of Gentleness Model on vulnerable individuals served by the Community Mental Health system a retrospective analysis of the histories, interventions, and outcomes for a group of individuals served between 2009 and 2013 was conducted.

Methods

Sample

Seventy-one adults with a primary diagnosis of developmental disability and a secondary mental health diagnosis were included in the sample. Participants in the study lived in 25 different Michigan counties with the majority (43%) residing in the southeast corner of the State, followed by the southwest corner. No participants resided in the Upper Peninsula. All participants have been recipients of community mental health services since childhood. Table 1 presents the demographic characteristics of the sample.

Table 1: Demographic Characteristics of the Sample (N=71)

Variable	Statistic
Gender	66.2% male
Age (mean)	29 years (range = 10-57 years)
Race	74.6% Caucasian 15.5 % African American
Diagnosis	42.3 % autism spectrum disorder 14.1% mood/anxiety disorder 23.9% psychosis 8.5% bipolar 2.8% impulse control 8.5% unknown etiology
Severity of Disability	32.4% mild 28.2% moderate 25.4% severe
Residence	57.1% specialized residential 31.4% group home 4.2% family home

Procedure for Individual Identification for Culture of Gentleness Model Services and Supports

Individuals are referred to the Center for Positive Living Supports (CPLS) which is housed within the Macomb Oakland Regional Center (Macomb County, Michigan). The Center staff developed and they implement the Culture of Gentleness Model of services and supports. Staff services and supports include:

- Consultation and assessment of the individual's needs and the environment in which he/she resides as well as an assessment of caregiver skills
- Assessment of the organizational ability to support the individual
- Training of caregivers and other support staff in the basic principles of a Culture of Gentleness
- More advanced practicum training for leadership staff in implementing and supporting a Culture of Gentleness
- Development of a plan of supports based on the assessments
- Mobile supports including on-site coaching and mentoring of caregivers
- Follow-up monitoring and support.

The Center staff consists of a licensed psychologist, social worker, trainer, provider consultant, and highly skilled paraprofessionals. Individuals who are at risk for more restrictive interventions including placement in more restrictive settings due to their social/emotional behaviors are the primary candidates for CPLS services and supports.

Model Implementation

Data Sources and Analysis

Data was collected on services provided to each participant by CPLS (assessments, plan development), services provided to staff by CPLS (trainings, technical assistance, monitoring), and participant outcomes (pre/post data on 911 calls, incident reports, self injurious behavior, physical intervention, and changes in setting and staff). Data was collected on standardized protocols and recorded into an excel database.

Descriptive statistics were generated for each variable (frequencies, percentages, means, and standard deviations). To assess the impact of the Model on participant outcomes t-tests were conducted comparing pre/post means for each outcome variable. Significance testing was set at alpha = .01.

Results

Staff Services and Supports

Participant Outcomes

On average CPLS staff provided 11 days of intense intervention to the 71 individuals. However, the range of intense intervention was extremely broad from 2 – 135 days per individual. As shown in Table 2, with the exception of self-injurious behavior, there was a reduction in negative outcomes post intervention. However, only the reduction in 911 calls, placement changes, and staff changes were statistically significant. There was a significant difference in the scores for 911 calls ($t(20)=2.77$, $p=.012$).

Similarly for placement change, there was a significant difference in the pre/post scores ($t(31)=6.15$, $p=.000$). Finally, for staff change, there was a significant difference in the scores ($t(70)=3.22$, $p=.002$).

Table 2: Participant Outcomes Pre/Post Intervention

Variable	Pre-intervention	Post-intervention
911 calls	n=166 ; mean=2.5	n=17; mean=.71*
Incident Reports	n=364; mean=19.5	n=175; mean=10.0
Self injurious behavior	n=122; mean=3.0	n=143; mean=4.0
Physical Intervention	n=186; mean=9.9	n=38; mean=2.6
Placement Change	n=250;mean=3.1	n=7; mean=.22**
Staff Change	n=13;mean=1.1	n=4; mean=.44**

*p=.01; **p=.001

Individual Stories

Chris

Chris was adopted at the age of one. His mother had been addicted to drugs and alcohol and was mentally disabled. As a result, he experienced many challenges of fetal alcohol syndrome. Easily over stimulated and impulsive, he often engaged in dangerous activities.

At age 11, Chris accidentally set himself on fire. He suffered severe burns and was disfigured from the waist up. After enduring over 30 surgeries and months of hospitalization, he suffered sexual and physical abuse while receiving neurological rehabilitation. This abuse significantly attributed to dangerous sexual driven behaviors.

Placed in multiple institutions for aggressive and self-injurious behavior, Chris seemed to have pervasive feelings of inadequacy, worthlessness, and guilt. He and his parents were also fearful about placement because so many had failed in the past.

Thankfully, his parents and guardian worked diligently with the CMHSP on his community placement and supports. A transition plan was developed that focused on staff training needs, home management, limits, boundaries and structure. Since Chris was a high risk for elopement, the Center assisted with all facets of his placement.

Technical assistance was provided to plan the budget, location, security safeguards, and monitoring of his new home. The Center also assisted with his move by providing six days of mobile training/crisis response services. The mobile mentor helped the caregivers focus on building a relationship with Chris as well as increasing their confidence and skill level.

Structure, engagement and environmental control were crucial to success. Staff meetings and consultations continued for the next year and a half with ongoing training and support. This was critical as Chris continued to challenge his caregivers. In the first year, he refused to go to school and had two occasions where elopement put him at serious risk. Despite all of it, his team remained strong and positive.

Three and a half years later, Chris is reaping the benefits. Today, he is funny, relaxed, entertaining, and feels valued by others. He loves being with (and emailing) friends and family, has a job he adores, goes fishing, plays sports, and is involved in a variety of activities in his community and his church.

Chris has even been successful in significantly reducing the amount of medication he takes on a daily basis. Rather than desiring to hurt himself, Chris now enjoys helping others and living without locked doors.

Michael

Michael lived at home until he was 21. His mother had been told he was developmentally delayed and things would get better in his teen years. Instead, they became more challenging. Despite her best efforts, when he was moved into a new home, he became aggressive and violent to the point he was handcuffed and hospitalized several times. This proved to be a very difficult transition for Michael.

The Center's Mobile Training/ Crisis Response Team was brought in to assist, providing hands-on mentoring and training. Demands on Michael were reduced, a structure was established, and creating a feeling of safety became the priority. Over time, caregivers learned to identify and prevent areas of struggle, work through challenges and as relationships blossomed, his anxiety diminished.

Today, Michael has two roommates and has lived in the same home since 2009. He leads an active life playing basketball after school, taking daily walks around his neighborhood, and listening to music. He has a great sense of humor, keeps his caregivers smiling, and blows kisses to Mom whenever he sees her.

Michael's mother is living a more relaxed and fulfilling life herself. She has the time to do things she was not able to do when he lived with her. She reports that when visiting her, Michael will indicate when he wants to return to his own home. This gives his mother a sense of peace.

Rima

Rima was hospitalized as an adolescent and her family feared for her safety from mutilative self-abuse, aggression, and property destruction. She had lived in other community settings and she was not successfully supported which resulted in her placement at Mt. Pleasant Center. When she lived at the Mt. Pleasant Center, her family feared its closure and was terrified at the thought of her being placed back in the community

She swallowed all types of objects, which frequently resulted in medical attention and surgery. She could have died many times. She once pushed a refrigerator across a room when she was upset. She went through four providers in her first six months after leaving Mt. Pleasant Center.

The Center provided extensive supports over 16 months to Rima and her family. Many key areas were addressed, including trust between the family and the professionals charged with supporting her. Numerous trainings occurred with her family, service provider and clinical staff with critical attention paid to her potentially explosive periods. By stabilizing staff and creating trust with her family, relationships deepened, and Rima began to feel safe.

Today, Rima and her family have developed a trusting and valued relationship with the service provider and her caregivers. She is much happier today, often laughing and smiling. She is kept busy with many activities and is engaged in her community. She has a paying job and her family enjoys relaxed weekly visits. Rima has personally hosted her large extended family at her home for holiday celebrations.

Preston

Preston has a long history of psychiatric and institutional admissions dating back to 1981. His family life was not stable, and his grandmother assisted in raising him. He was placed on Mellaril and Stelazine when he was in the 2nd grade and placed in foster care. With a diagnosis of schizophrenia, he was admitted to Kalamazoo Psychiatric Hospital when he turned 18.

From there, he was placed in the Mt. Pleasant Center in 1999 for ten years. Following its closure, Preston made his first move into the community in over 25 years. He lived in the community for a year, and was placed back at Kalamazoo Psychiatric Hospital after having auditory hallucinations and increased aggression that was exacerbated by medication refusals.

The Center became involved in 2011 and helped develop a transition plan for Preston's long-term placement back into the community. Substantial technical support coordinated clinical services prior to his discharge. He was moved to a new home in Ann Arbor with the help of the Mobile Training/Crisis Response Team. Mentoring and training assisted in managing medication refusals, along with other challenges.

By learning to structure Preston's activities with the normal flow of the day, with a consistent staff and approach, Preston has now built very strong relationships with his caregivers. His service provider continues to support ongoing training and close monitoring. Today, Preston is doing well without any elopements, psychiatric hospitalizations, 911 calls, or physical interventions reported. He is active in his community where he enjoys bowling, shopping, festivals and long walks.

Discussion

Training

The findings from this retrospective study of 71 individuals with very challenging behaviors support CPLS as a promising (and emerging) evidence based practice. When looking at participant outcomes, the CPLS model was extremely effective in reducing problem behaviors among the individuals served. That is not to say that all problematic behaviors were totally eliminated, as that is not the nature of human behavior. However, all individuals were able to live in less restrictive and safe environments, without trauma-inducing staff interventions as a result of CPLS. Key to the improved outcomes for all individuals

was having well trained, stable, and consistent staff who provided supports and services in a safe, caring, and consistent environment. In fact, both placement and staff stability were significant predictors of positive individual outcomes. The personal stories of three individuals served by CPLS reinforce and personalize these quantitative findings.