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Increasing community integration and inclusion for people with intellectual disabilities

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ABSTRACT

Historically residential facilities for individuals with intellectual disabilities have served the role of segregation and congregation with no real focus on integration into the community. More recently the focus has been to get people out of residential institutions and into community-based living settings. This work examines an approach to changing the systems and culture at a large residential facility to create higher rates of transitions to community-based living settings. A multi-phased systematic implementation approach is discussed in which each successive phase builds upon the previous phase. This approach creates opportunities for community integrated activities and then utilizes these community contexts as functional learning opportunities. Results are evaluated in the areas of community presence, community participation, community integration and community inclusion. Data indicate significant increases in each of these areas based on changing the facility focus, simplifying the intrusive accountability systems, aligning resources and teaching staff how to utilize support plans more efficiently to teach skills in functionally appropriate community integrated activities.

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1. Introduction

Historically, integration of individuals with intellectual disabilities (IDs) into the community was discouraged and avoided based on the theories of treatment at the time. Consequently, individuals were separated, congregated and isolated, sent away to institutions with separate schools and work

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options (Mirfin-Veitch, Bray, & Ross, 2001). This has proven to be ineffective from a treatment standpoint and leads to individuals with ID feeling devalued, disadvantaged, and treated like eternal children (Martin, 2006). Over the years there has been a plethora of treatment techniques that promised to ameliorate these issues with varied results. More recently avid movements to transition individuals with ID to community-based living settings and ''de-institutionalization'' efforts have not produced uniformly better results for everyone (Mansell, 2006). A consistent factor in both the rate of moving into a community-based setting and remaining in a community-based setting is individual level of ability. Myers, Ager, Kerr, and Myles (1998) found the more significant an individual's disability the fewer opportunities he/she has to participate in community activities. White and Dodder (2000) found that adults with higher levels of adaptive behavior have greater levels of community integration. Further complicating these issues for individuals with significant ID is the increased prevalence of comorbid behavioral challenges that effect social skills and abilities (Matson, Minshawi, Gonzalez, & Mayville, 2006). Finally, quality of life data continue to indicate that quality of life remains poor for individuals with significant ID and the higher the ability level of the person the higher they score on quality of life measures (Perry & Felce, 2003; Singh et al., 2004). Therefore, functional skills acquisition becomes paramount for individuals with significant ID to assist them in moving from a residential setting into a community-based living setting.

Traditionally, learning opportunities offered to individuals with ID have occurred in artificial contexts such as segregated day programs and isolated sheltered workshops. This has been especially true for individuals living in residential facilities. These isolated, segregated operations gave little credence to the functionality and contextual fit of the learning opportunities provided. Skills training programs often focused on individual deficits and ignored the relevance of the training to the individual and his/her true goals. Individuals with less significant ID and higher adaptive abilities have more success in gaining and maintaining community-based living options. This leaves individuals with more significant challenges to reside in residential facilities. Therefore it is imperative for residential facilities to have a keen focus on increasing individual functional ability. The traditional scattered ''shotgun'' approach to skills training with the hope of hitting some of the individual skills needed is an inefficient and ineffective approach to teaching specific community-based skills. Unfortunately, this is often the approach utilized for individuals with ID who live in residential facilities. Foci of supports for individuals with ID has shifted to enhancing individual quality of life including providing the supports, learning opportunities, and real-life activities which enable individuals to experience inclusion and to become meaningful contributors to the larger society (Carr, 2007). Treatment orientation for individuals living in residential settings should be movement to the next level of care which is often community-based living. Support strategies must focus on where the person wants to live and then design relevant functional learning opportunities to support the person to achieve their desired goal. This helps to eliminate the scattered ''shotgun'' approach to skills acquisition by facilitating realistic person driven objectives and interventions that assist the person to meet their individual goals.

Teaching in a traditional academic classroom setting can be effective for individuals with ID and can improve academic skills (Cole, Waldron, & Majd, 2004). A newer more innovative approach to traditional classroom teaching for adults with ID is the utilization of psychosocial habilitation treatment malls to deliver contextually appropriate functional learning opportunities (Thorn, Bamburg, & Pittman, 2007). However, traditional classroom settings have limitations regarding learning context as they cannot always occur in real-life settings in the normal rhythm of life. Classroom based learning opportunities are beneficial and necessary for some people, but only serves as the basic foundation upon which to build skills. Regardless of the teaching methodology, learning techniques can be further enhanced when learning opportunities occur across multiple contexts, particularly real-life community-integrated contexts. This is a crucial factor for individuals with significant ID who need to learn practical functional skills and partake in real-life activities and experiences in order to transition to a more independent life. Positive behavior support (PBS) literature has embraced and championed the concept of learning in natural contexts, keenly focusing on the ecological validity and social validity of treatment strategies (Carr et al., 2002). Matson and Boisjoli (2009) identified 56,320 peer reviewed journal articles on the topic of ID published from 1979 to the first quarter of 2008. However this research has given little attention to systems and supports to capitalize on skills development during recreational activities (O'Reilly, Lancioni, & Kierans, 2000). These less formal activities can serve a crucial role in the formation of natural learning

contexts. More effectively utilizing the times after traditional teaching opportunities enhances the focus on learning across settings and creates a learning milieu. This therapeutic milieu is based on a wellness treatment model which creates an environment conducive to personal and functional growth for the person (Singh et al., 2006). This creates learning opportunities across settings in real-time and real-life situations and facilitates a wider array of contexts in which to learn and practice new skills.

In this study our aim was to design a functional system in a large residential facility that would increase community integrated learning opportunities. This was conducted with particular focus on increasing successful transitions to community-based living settings. For this work community-based living setting is defined as a home in an integrated community with 6 or less individuals living in the home and includes all scenarios within that parameter including living in a home or apartment alone. The initial component was the creation of a therapeutic milieu that would facilitate learning across times and settings. The second component of this framework was to impart efficiency in the arduous accountability systems that often hinder community integrated activity opportunities in residential facilities. Third was to identify and simplify utilization of functional skills from the individual support plans. The final component was teaching, generalizing and practicing of skills in real-life activities in natural contexts. Analysis of the results on rates of community integration is discussed as well as other areas measuring community-based activities. Finally, limitations of the study and relevant issues for future research are examined.

2. Methodology

2.1. Setting

This study was implemented at a large residential facility supporting individuals with ID. This is a long standing residential facility established in 1921 and in its early years operated as a typical ‘‘institution’’ of its day going as far as being almost totally self-sufficient with working farms, livestock, and even a fully functional dairy operation. The evolution of the facility has traversed a great distance from those early years. However, at the time of this study the facility operated as many residential facilities do with limited community involvement utilizing terms such as ‘‘outing’’, ‘‘van ride’’ and ‘‘furlough’’. These activities had little value or meaning to the individuals supported and provided limited opportunity to acquire skills that would benefit them in the transition to a community living setting. This culture resulted in unintended but continued community isolation and separation for the individuals supported.

2.2. Participants

At the onset of this study there were 556 individuals living in the facility. The participants included 1.6% ($n = 9$) of the individuals having a mild intellectual deficit, 5.7% ($n = 32$) of the individuals having a moderate intellectual deficit, 12% ($n = 69$) of the individuals having a severe intellectual deficit, 75% ($n = 418$) of the individuals having a profound intellectual deficit and 5% ($n = 28$) of the individuals classified as unspecified intellectual disability. This breakdown indicates 87.6% ($n = 487$) of the individuals fall into the severe or profound range of intellectual disability constituting significant ID. Additionally, there were 315 males and 241 females. Individual ages ranged from 18 years to 91 years with a mean age of 54. Length of residency at the facility ranged from 22 days to 77 years with a mean length of residence being 28 years. Diversity of race at the facility included 75% ($n = 418$) White, 24.5% ($n = 136$) African American, 0.18% ($n = 1$) Indian and 0.18% ($n = 1$) Native American.

Table 1 highlights participant demographics including gender, race, and level of intellectual disability separated by age ranges for further analysis.

2.3. Research design

This research was longitudinal in nature and examined the effects of increasing community integrated learning opportunities on rates of community integration and community inclusion indices. Baseline data was gathered from the facility’s existing databases for rates of transitions for the

Table 1
Participant demographics by gender, race, and level of intellectual disability separated by age ranges.

Age range	N	Gender		Intellectual level[a]					Applicable race			
		Male	Female	Mild	Mod.	Sev.	Prof.	Unsp.	White	African American	Indian	Native American
0–21	4	1	3	0	0	1	2	1	3	1	0	0
22–45	138	86	52	2	6	10	116	4	92	44	1	1
46–65	306	175	131	5	15	38	234	14	236	70	0	0
66+	108	53	55	2	11	20	66	9	87	21	0	0
Total	556	315	241	9	32	69	418	28	418	136	1	1

[a] Intellectual levels = mild intellectual disability, moderate intellectual disability, severe intellectual disability, profound intellectual disability and unspecified intellectual disability.

2-year period prior to implementation of this study. This baseline data was then compared to the 2-year post-implementation data reviewing effects on transitions from the large residential setting to small community-based living settings. Additionally, a 3-month baseline assessment of the frequency of community integrated activity opportunities was collected prior to implementation. Data were collected during 6-month implementation phases and then compared to the 3-month baseline and assessed for treatment durability during a 9-month maintenance phase assessment.

2.4. Definitions

Terms related to community involvement are often used interchangeably, and definitions vary, and are conceptualized differently (Clement & Bigby, 2008). Therefore, we will define four distinct categories of community involvement to articulate an approach for systems change. First is "community presence" which incorporates the basic concept of physically being in a community integrated setting and occupying the same social space as non-disabled people. Second is "community participation" which includes interacting in the community and participation in regular community integrated activities. Successful participation brings a person from simply going to a place in the community to socially interacting with people in the community in the normal rhythm of life. Third is "community integration" which involves a full amalgamation of a person's life into the community. Often considered the pinnacle of community initiatives, community integration encompasses more aspects of an individual's life and is culminated in their living setting. Fourth is "community inclusion" which encompasses acceptance, a sense of belonging, and builds upon social relationships in the community. Community inclusion encompasses a greater emphasis on community connectedness and is formed on the foundation of social inclusion (Lloyd, Tse, & Deane, 2006). Although definitions are necessary for discussion it is important to note that in practical application an individual is not hindered by the need to progress sequentially through a hierarchy of categories.

2.5. Procedures

This study was implemented in phases to build foundational layers in which community integration and inclusion could be fostered and successfully occur via a large residential setting. Implementation occurred in successive phases including creation of the therapeutic milieu (phase-1), increasing community presence (phase-2), and increasing community participation (phase-3). Each phase was structured in 6-month increments which included restructuring of processes, training staff and data collection. Phase-2 and phase-3 were further broken down into two 3-month implementation components.

2.5.1. Creation of the therapeutic milieu

As stated earlier the goal of therapeutic milieu development is to create an environment conducive to personal and functional growth for the person. The concept of the therapeutic milieu holds that every interaction between an individual and staff has therapeutic potential. Specifically, in a residential setting this should take the primary form of learning opportunities. Preliminary efforts to

create a therapeutic milieu centered on generalizing skills learned in traditional academic classroom settings during the day to the individuals' home environment in the evenings. Staff were trained to identify skills from the individuals' day programs that could be reinforced in the home milieu in the evening after traditional teaching times. Staff were also taught how to align and link skills from the support plan to an appropriate context for implementation. Individual cards were then designed as a quick reference for each person as to what skills to reinforce during the therapeutic milieu. Staff were then mentored to competency to implement skills reinforcement and generalization in contextually appropriate activities in the home. Competency was achieved by independently identifying what skills they were reinforcing from the individual's day training during the activity observed and why they were reinforcing that skill with that person in that context. Staff were then trained to identify further elements from the individuals' support plans, beyond the day training objectives, identifying skills that could be reinforced during the home-based therapeutic milieu. Staff were again mentored to competency in independently stating what they were reinforcing and why, as they implemented the contextually aligned activity. This expanded the utilization of the therapeutic milieu to a person's entire support plan. The therapeutic milieu concept additionally served as a catalyst to direct support workers to better understand their role in teaching individual skills. Both staff and individuals supported are part of the therapeutic milieu creating an environmental and cultural change for everyone involved (Singh & Tosh, 2005). Direct support staff began to see positive results of their efforts toward teaching new skills increasing the social and ecological validity of support plans.

2.5.2. Community presence

Although simple presence in the community is not considered the gold standard, it was the preliminary implementation focus as it serves as the foundation for a larger community involvement continuum. The goal of any community involvement initiative should be to address some of the common issues that impact interpersonal connections and relationships including proximity, reciprocity, mutually reinforcing events, and choice (Kennedy & Itkonen, 1996; Pottie & Sumarah, 2004). In the pursuit to achieve this goal, initial system barriers encountered included resources including transportation, money and staffing constraints. Therefore, the first 3 months of implementation focused on resource realignment and redistribution to facilitate increased opportunity for community presence for all individuals regardless of level of ability or support needs. This included improving vehicle assignment and increasing availability, improving access to money, and modifying staffing patterns to facilitate ease of community presence. The existing protocols and processes related to community "outings" were focused on maintaining business controls such as accountability for resident funds, accountability for use of facility vehicles, and knowledge of the whereabouts of each resident and staff at all times. This onerous system was dismantled and eliminated so spontaneous activities in the community could occur with no prior approval. Essential data features were maintained with a primary focus on system efficiency.

The second 3 months of this phase focused on staff training initiatives implemented to teach staff the value of community presence and presence in community integrated activities for individuals with ID. Staff were further taught the basic concepts of functional learning context and the differences in teaching skills based on living in a residential setting versus teaching transportable skills focused on community living abilities. Additionally, incidental teaching techniques were taught to further support functional context and set the stage for implementing individualized skills from the person's support plan in community integrated activities. Supplemental staff supports at this phase included removing the rigid daily staff assignments and "grouping" system to provide staff more flexibility to accommodate individual preferences for presence in community integrated activities.

2.5.3. Community participation

The next phase of implementation focused on promoting more individual involvement and participation while in the community. In a study reviewing and ranking items individuals with intellectual disabilities most wanted, increased community involvement was expressed more frequently than any of the other factors analyzed (Kampert & Goreczny, 2007). Therefore, during the first 3 months of this 6-month phase staff were trained to facilitate activities which transcended from people simply going to a place in the community to socially interacting with people in the community.

Staff were taught the value of individuals with ID participating in routine activities in the community and functionally interacting in integrated settings, leading to increased community-based abilities. Additionally, staff were taught how to identify potential community integrated learning opportunities and link these to individual's likes and preferences.

During the final 3 months of this phase the most important aspects of staff education was implemented consisting of teaching staff to more effectively utilize individual support plans. This began the linkage of the individuals' preferences, to the community-based learning opportunity context and finally to the skill acquisition components of the persons support plan. Building on the principles of the therapeutic milieu, staff were taught to identify a functional skill from the individuals' support plans to be generalized and implemented based on the context of the community integrated activity preferred. The individuals' quick reference cards were updated and utilized for each person identifying what skills to reinforce during the community integrated activity. Staff were mentored to facilitate each community integrated activity as a functional learning experience via the linkage to the person's support plan. True participation in community integrated activities creates an endless continuum of functional learning opportunities in which an individual can learn and practice new skills, and staff can capitalize on skill reinforcement, generalization and incidental learning opportunities.

3. Results

Residential facilities traditionally have arduous, controlling systems and resource allocations that hinder community presence opportunities for individuals living at the facility. The simplification of these processes and the reallocation of resources to support community presence opportunities resulted in a substantial increase in the number of people exploring and experiencing community integrated activities. Further adding to this was basic staff education in the principles of community presence and incidental teaching techniques. Fig. 1 represents the impact of resource realignments and basic staff education initiatives on community integrated activity opportunities. This data indicates a 105% increase in community integrated activities for the first 3 months of phase-2 implementation compared to baseline and a 111% increase for the second 3 months of phase-2 when compared to the baseline data. Overall the data from the phase-2 segment reflect a 109% increase in the number of people experiencing community integrated activities over the baseline evaluation data.

Additional staff education to more effectively utilize individual support plans and identify functional skills to be generalized in the community context further increased the frequency of

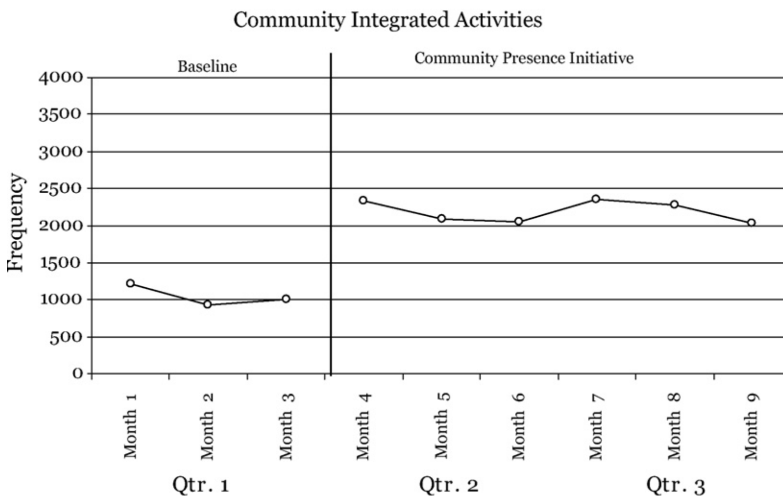

Fig. 1. Total community integrated activities after community presence initiative implementation as compared to baseline.

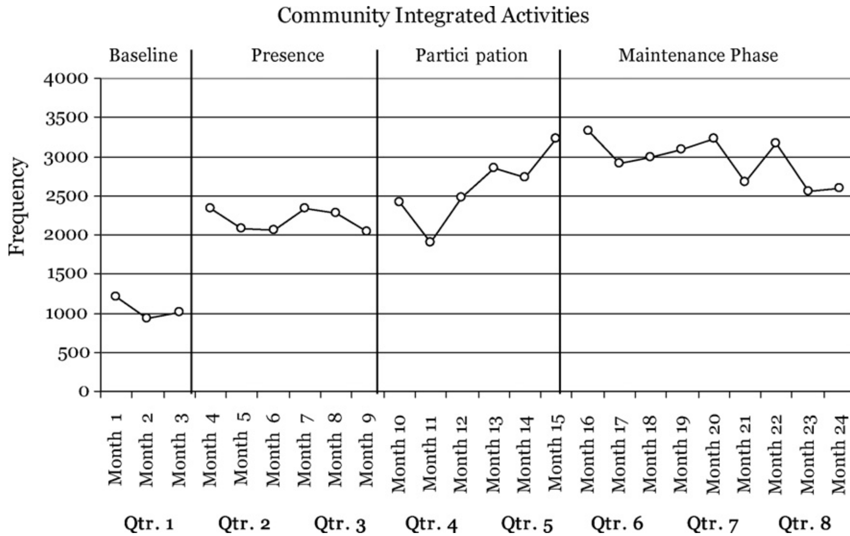

Fig. 2. Total community integrated activities after community presence and community participation initiative implementation as compared to baseline.

community integrated activities. This was an expansion of the therapeutic milieu beyond the home setting and created a plethora of contextually appropriate learning opportunities. These participation initiatives further increased community integrated activities for individuals. Fig. 2 represents how these community participation initiatives impacted the number of community integrated activities. This data reflects an additional 9% increase (116% over baseline) in the first 3-month segment of phase-3. For the final 3 months of phase-3 the focus was on true utilization of the support plans and further expanding the therapeutic milieu. This resulted in an additional 75% increase over phase-2 and a 180% increase over baseline in the number of people experiencing community integrated activities.

The quality of life oriented Personal Outcome Measures designed by The Council on Quality and Leadership (The Council) was utilized to capture elements of community participation (Council on Quality and Leadership, 2000). These measures assess whether an outcome, as defined by the person, is present or not creating a "yes" "no" dichotomous variable that can be aggregated for analysis (Gardner & Carran, 2005). The instrument itself captures community participation elements via the specific outcomes "people participate in the life of the community" and "people interact with other members of the community". The outcome "people participate in the life of the community" evaluates how actively people join and share in community activities as well as choice of and access to community resources. The outcome for 'people interact with other members of the community' assesses meaningful interactions with people in the community not associated with the service provider as well as types of interactions and social involvement. The increases in these two outcomes are represented in Fig. 3. Quarters four and five represent participation data collected during the phase-3 initiative and quarters six, seven and eight represent participation data collected during the maintenance phase of this study. Quarter three data represent participation data collected prior to the implementation of phase-3 and serves as a baseline for individual participation in community integrated activities.

Living in integrated environments and being included and connected to their community is often considered the gold standard for individuals with ID. Hence, the true measure of this work is community integration and community inclusion. The results of this endeavor indicate that by increasing community presence and participation and capitalizing on individualized functional skills learned in community integrated activities, individual transitions from a residential setting to community-based settings significantly increased.

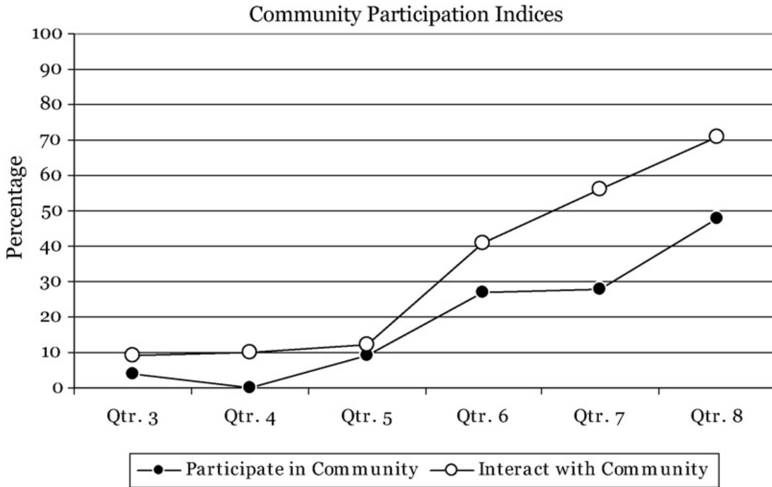

Fig. 3. Indices of community participation outcomes interacting with members of the community and participation in the community.

Fig. 4 indicates the annual rate of transitions and the number of transitions per month to community-based living settings. This data represents the 2 years prior to implementation of this framework, the data for the 15 months of implementation and the 9 months post-implementation. Years 2004 and 2005 serve as the baseline for transitions from a large residential setting to smaller community-based living settings. This study was initiated in early 2006 and data reflect the increase in the rate of transitions during implementation of this work and the durability of the increase during the maintenance phase.

Living in a community-based environment does not automatically equate to success. Individuals without adequate functional skills who are thrust into a community living setting may become more isolated and segregated and can be relegated to living on the fringes of the community. Community inclusion encompasses acceptance and a sense of belonging, and builds upon social relationships in

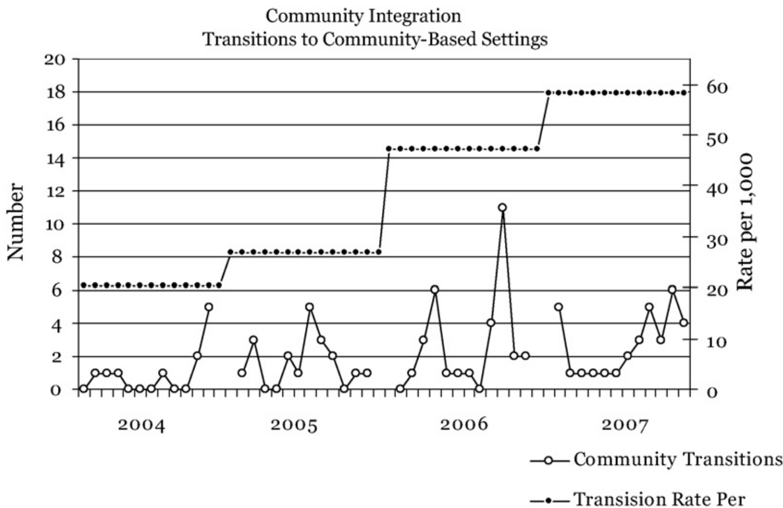

Fig. 4. Total community integrations to community-based living settings with annual transition rate. Rate = total number of transition divided by census time 1000.

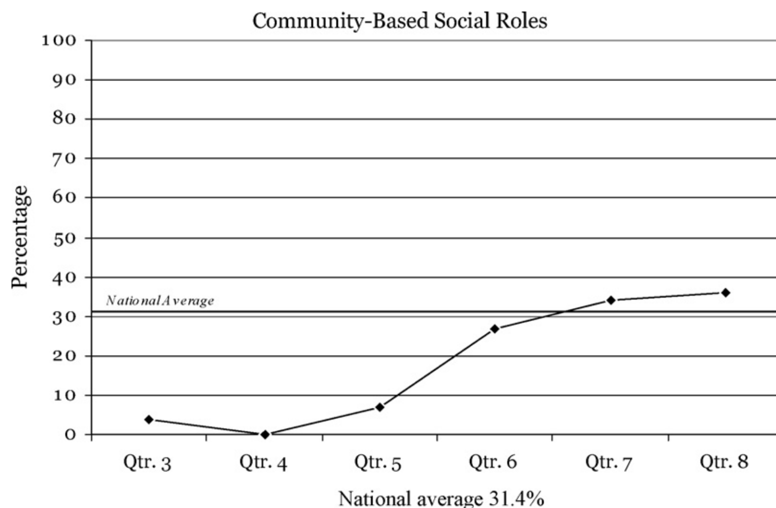

Fig. 5. Percentage of social role outcomes per quarter compared to the national average. National average 31.4%.

the community. It also includes a greater emphasis on community connectedness and is formed on the foundation of social inclusion (Cummins & Lau, 2003). The results of this study indicate that increased functional skills enhance relationship opportunities by creating a sense of ability and commonality in social settings. Increased functional skills in areas such as social interaction, safety, dining etiquette, money management, etc. enhance social relationships by highlighting abilities and unifying common interests.

Fig. 5 represents data measuring indices of social inclusion based on the presence of the outcome for "people perform different social roles". This data indicates that by increasing community presence and participation and improving functional skills learned and practiced in a community context, inclusion-based community roles in social activities increased. Data represented in quarter three serves as a baseline for community inclusion reflecting data collected prior to the implementation of phase-3. Quarters four and five represent data collected during the phase-3 initiative and quarters six through eight represent outcome-based inclusion data collected during the maintenance phase of this study. These data indicate an increase in inclusion elements during phase-3 implementation but further show a cumulative increase effect during the maintenance phase. Additionally, this data compares the data collected during this study to the national average of individuals with ID from the Council's database which includes over 7000 interviews.

4. Discussion

Literature has indicated that the higher an individual's ability level the more access they have to community activities. This work highlights the advantages of creating a therapeutic milieu fostering learning and practicing functional skills in real-life activities and how this translates to increased community integration success for individuals with significant ID. The data indicate significant increases in the areas of community presence, community participation, and community integration and the improvement in various elements of community inclusion based on the application of this framework. Of particular note are the data results for community integration as this study indicates significant increases in rates of community transitions based on the three phases of implementation, building successive layers in which to create community integration success. Further, results indicate that a large residential facility can promote and enhance community-based options for individuals by changing the custodial focus, simplifying the intrusive accountability systems, aligning resources, and realigning the goal of the facility, which is teaching skills that will enable transition to a community-based living setting, and training staff to utilize each of these effectively.

This study focused more on systems and staff culture evolution and employed a multi-component approach to achieve this goal. In doing so limitations emerged in that some of the scientific and statistical rigor was compromised for a more applied approach. There are many aspects of this framework that need more systematic research to validate individual components to discover areas for manipulation and improvement. Therefore, future directions may include recreating single elements of this study with more scientific and statistical rigor to drill down on specific issues that effect community integration success. An example of this is evaluating each system change separately examining where a facility can make the most impact on community-based opportunities.

From the applied approach, this conceptual framework can be enhanced with more focus on chaining skill acquisition opportunities together. This work has focused on creating opportunity and facilitating a staff culture to teach a skill in natural contexts. Although the community integrated activities typically had multiple destinations the primary focus was on teaching one skill while participating in the community integrated activities. The next step is to organize community integrated activities as a sequence of opportunities in which individuals can chain learning events together in a rhythm of life activity. An example would be a community integrated activity that included going to the bank (money management), then going to a restaurant (dining skills), and then shopping at a local store (social skills). The chaining of these activities could further enhance the rate of skill acquisition and increase community integration success.

Finally, future directions for this research include a more detailed evaluation of the durability of the community transitions from this study based on no readmission to a residential facility. Additionally, further examination of indices of community inclusion should be examined to determine both the level of inclusion maintained and what factors influenced increases and decreases in elements of community inclusion.

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