

Lifelong Needs after Acquired Brain Injury: A Case Study in Enhancing Community Awareness

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Editor's Note: *This article has been peer reviewed for general issues of relevance to life care planners and not the efficacy of the specific protocol described.*

Abstract. *The high prevalence of aggressive and high-risk behavior after acquired brain injury (ABI) presents a variety of clinical challenges in the treatment milieu. These challenges become even more vivid when full community inclusion is the ultimate goal of treatment. There can be a number of challenges when community inclusion is practiced at its strictest interpretation, and rehabilitation professionals, including life care planners, must understand these issues.*

The following article addresses these issues as they present themselves in an adult male with an ABI and severe unwanted behavioral issues. These issues had been an obstacle to his autonomy until his community support structure encouraged an increased level of participation in the community that allowed him to pursue the activities of his choosing to increase his quality of life. The ultimate result is a significant decrease in the frequency of severe unwanted behavior. A more comprehensive utilization of a characteristic interaction style and community education are key components to interventions which address the true lifelong needs that an ABI presents to families, funders, and clients themselves. These components can also have implications for the development of an effective life care plan for individuals with ABI.

Introduction

The advent of managed care and stricter medical guidelines related to length of stays in hospitals and post-acute rehabilitation programs after illness or injury has produced significant changes in the field of medicine (Newman & Reed, 1996). A comprehensive and thorough analysis of the needs of individuals with acquired brain injury (ABI) underscores the importance of examining life care planning in this population. This paper will discuss the importance of such pursuits in the context of the lifelong nature of ABI residuals. The cost-containment paradigm emphasized within a managed care environment often results in hospital stays being shorter, insurance claims that are harder to make, and post-injury rehabilitation expectations reduced. Furthermore, the expectations of care providers as to the length of medical treatment may become biased due to contingencies focused upon the management of finances.

A prime example of quality of care being compromised often occurs in the context of an individual's recovery from an ABI. While a small percentage of individuals with ABI can

recover physically within a given window of time that may fit in line with traditional managed care cost-containment models, the vast majority of these types of injuries are not resolved in a few short months (biausa.org, 2004). Care providers often find themselves wondering why many behavioral or neurological issues still present themselves months or even years after the incident. This rather elongated form of recovery is one that care providers are not accustomed to, and, as a result, they may tend to become very rigid in the ways that they react toward survivors with ABI who present post-injury behavioral issues. Given the expansive nature of behavioral challenges, an effective life care plan should address the needs that the individual would face through the span of his or her life through collaboration with an array of different treatment providers. The formulation of an effective care plan would then delineate treatment recommendations and expectations for the individual.

In general, community's expectations contribute to statements like, "He (or she) should know better," or "Why is he (or she) still doing that?" The truth of the matter is that behavioral issues persist because the brain does not heal as quickly as a broken limb or a laceration on the skin. Medical science teaches us to expect healing of a bone to occur within a set time frame or resolution of a cut to the skin to take a certain number of days. This line of thinking is then generalized to those experiencing an ABI. When an individual's behaviors do not follow this logic, frustration can be the result. This frustration is exacerbated when the problems that are experienced are behavioral and these issues are harder to manage or understand than speech or gait abnormalities. The latter are more socially acceptable, whereas explosive outbursts and unexpected profanity are not.

The reality of the situation has been presented very cogently by McMorrow and McMorrow when they state that "there is a need to encourage recognition that promoting independence among many persons with brain injury is a huge undertaking that often will entail the course of a lifetime" (McMorrow & McMorrow, 2002, p. 9). This is consistent in many ways with a life care plan that serves to outline services for an individual with ABI to promote or maximize their independence over the course of their lifetime. The community as a whole needs to come to grips with this assessment in order to be able to address all of the issues that will present themselves throughout the course of treatment in community-based settings and beyond. Expectations related to recovery need to be adjusted based upon the lifelong nature of the problem. It is not the case that the individual with ABI will follow a predicted course of recovery, learn a set of strategies that will be applied throughout his or her life, and present no further issues. These expectations are not realistic and can lead to a number of false beliefs related to treatment outcome (McMorrow & McMorrow, 2002). The life care planner is uniquely qualified to collaborate with the treatment providers and identify future care expectations, making adjustments as recommended, over the individual's lifetime.

Inpatient settings for ABI rehabilitation have long encountered requests related to lengths of stay and recovery process as it relates to their clients. The majority of these requests come from insurance case managers or medical directors in charge of overseeing post-acute rehabilitation care. However, questions related to the prognosis of a behavioral or cognitive deficit are difficult to answer in the initial stages of the assessment process. The population of individuals with ABI and neurobehavioral problems presents even bigger challenges to professionals and family members. Although the residuals from these injuries are easier to spot, they exact a greater toll on those around the individual with the brain injury.

A great deal of the clients served in neurobehavioral rehabilitation programs has some form of frontal lobe injury (Arco, 2004). Injury to this portion of the brain has numerous behavioral correlates and different types of behavioral disturbances and topographies can

occur. Krauss (2004) outlines these issues by stating, "These frontal lobe issues include irritability, lability, impulsivity, disinhibition, aggression, poor motivation, poor self-regulation of behavior, poor judgement and insight, risk taking, or sexual disturbances. Some of these symptoms are separated out for purposes of discussing assessment and treatment, but clinically, they often occur together, as in a more generalized frontal lobe syndrome" (p.1). **Aggression** is common following an ABI, particularly in the early stages where rehabilitation efforts can be challenged significantly. It can range from mild verbal displays to physical aggression and a more thorough behavioral analysis of the aggressive behavior is needed. Only then can an appropriate behavioral intervention be put into place which may also have long-term implications for life care planning.

Aggression is an issue that can have a variety of underlying causes. For example, if it is part of a frontal lobe syndrome, the treatment protocols may be different than if the underlying cause is presumed to be psychosis, mood disturbance, or seizure disorder. "This is often not obvious, and treatment may be trial and error. Polypharmacy [the use of more than one medication] may be unavoidable in the complex patient, and it is best to obtain a consultation" (Krauss, 2004, p. 2).

Direct injury to the frontal lobe of the brain is known to produce a great deal of disinhibition and a variety of behavioral problems. Agitation related to frontal lobe injuries has been noted in 35-96% of patients during the acute phase of recovery. Reports from post-acute settings suggest this issue occurs in 31-71% of cases. The correlates of these injuries are widespread and many patients (up to two-thirds of the cases) develop significant changes in certain personality traits that pose great barriers to interpersonal relationships, irrespective of the severity of the injury or the age at the time of injury (Kraus, 2004). It would be impossible to predict when a given client will no longer experience behavioral issues related to their injury, yet this seems to be the expectation from many seeking behavior intervention services after an ABI. The belief commonly held is that all residuals from an ABI are expected to be resolved within a certain period of time. When they are not, a special sort of "selective understanding" is present. In general, our society is much more accepting of an individual whose gait is unsteady due to a brain injury versus someone demonstrating erratic or deviant behavior. For example, able-bodied individuals will tend to help individuals with gait impairment with opening doors or any other area of their lives where the physical problem makes life more difficult. The same commonly is true for memory problems or speech anomalies. It is much easier to observe understanding and compassion with these ABI residuals as opposed to behavioral ones. As service providers, our frustration tolerance and desire to help these individuals is a lot more problematic. There seems to be an impression that the individual is capable of self-control, but chooses not to take responsibility for doing so. The community's views can be quite strong at times.

Requests to restrict access to certain establishments appear from time to time from local business owners related to persons with ABI who display unwanted behaviors in their places of business. However, a number of these individuals and others in the community have compassion and understanding and will do all that they can to accommodate the client with sporadic behavioral issues. There are also situations where clients are barred from entering certain establishments after displays of inappropriate behavior are observed. Sometimes these requests are understandable given the magnitude of the behavior observed and other times, in these authors' opinions, they are unfounded and are based on irrational beliefs or expectations. If we as clinicians, family members, rehabilitation professionals, or others involved in neurobehavioral rehabilitation have clinical assurance that an individual can safely access the

community, it is our duty to advocate for these basic rights. We need to be prepared to educate the community related to neurobehavioral needs and effective interaction styles to use when certain issues arise. Without this education, our communities will continue to hold distorted views about individuals with unwanted behavior as the result of their brain injury.

A recent situation underscores the issue. An office manager in a local business asked a client to quit his volunteer “job.” The position involved greeting others as they entered the office and informing certain staff when their appointments had arrived. The client in question had a very lively personality and was accustomed to greeting attractive females by complimenting them on their looks. He would commonly state, “You look very pretty today.” The only problem was that he tended to repeat these statements more than once. There was no profanity, harassment, or suggestive language involved in his greetings at all. Those close to this young man were surprised at the employer’s decision to terminate his volunteer position. The same greeting from someone without a brain injury would likely not raise an eyebrow. This is just one example of a pervasive issue encountered along the path to building independence in clients with neurobehavioral problems.

In the authors’ opinion, the main goal in rehabilitation should be to foster as much independence for individuals as they can safely manage day to day. These efforts pay off in the long run by enabling the person to achieve a greater sense of control in his/her life and reducing the responsibility placed upon others. In our view, everyone wins in this proposition. Given this fact, it is hard to understand why there is so much resistance at times when sporadic behavioral issues do arise. These points are all illustrated through the case of a gentleman with extensive behavioral needs and concomitant community involvement on a daily basis. His experiences in the community embody some of the challenges and the rewards mentioned above as they relate to community involvement and increased autonomy.

Case Study: *Latka’s Story

(* name changed to protect privacy)

Latka is a 46-year-old Caucasian male immigrant. He acquired a traumatic brain injury (TBI) in 1987 as a result of an automobile accident. When the accident occurred, Latka was thrown through the vehicle window and landed on the curb of the road, fracturing his skull. He was ultimately admitted to the Center for Comprehensive Services Personal Intervention Program in 1994 due to behavioral outbursts and extreme risk. His prior placement had requested that he leave due to repeated issues of placing himself at risk by sitting down in the middle of the freeway in front of the facility and screaming. He had also resided at rehabilitation facilities in Michigan prior to his transition to the program.

Latka has exhibited multiple instances of paranoia in various situations and contexts where his verbal behavior involves statements about others poisoning his food or placing unclean items in it. Individual physical features of persons interacting with him tend to trigger these episodes of paranoia at times. Features such as sunglasses or skin color have evoked paranoid responses to staff members and others. Latka is also very paranoid about receiving assistance from individuals who are African-American; therefore, ethnicity, quite frequently, is a trigger for behavioral outbursts. Any assistance from African-Americans is suspicious to him due to invalid assessments that he is being poisoned, and pills are being placed in his food. Features such as hair color and eye color may also precipitate paranoia about the person due to geographical ethnicity. Because he is originally from a foreign country and of an orthodox religion, he perceives certain physical characteristics to be representative of Croatians or

Muslims. This is a periodic barrier to any form of therapy due to prejudices that carried over from his home country.

In the authors' opinion, persons with ABI often engage in behaviors that appear to be manipulative to procure items or incentives as a form of counter-control. Latka has been known to engage in these verbal behaviors to gain access to tangible items such as cigarettes and money. He may tell a trusted staff member that their supervisor does not like how the staff member works, or that the supervisor believes the staff member is lazy. These confabulations are usually in response to feedback that Latka received that he did not like, or did not serve his purpose. On occasion, he has also been known to report negative behaviors in which a preferred staff member has engaged in an attempt to get coworkers or other staff to distrust the staff member in question. At other times, he expresses his dislike of certain staff members by telling certain trusted persons about wrongdoings within the company, such as taking money, food, staff members clocking each other in and out, or using company cars to go home and sleep. Other paranoid confabulations include his belief that cooks in a particular restaurant are placing pills in his food in an attempt to poison him, or that African-American staff members have urinated in his shampoo because of their dislike for him. He also perseverates with staff members by explaining that he does not receive particular program incentives as prescribed, such as money, and insists that he is not lying by performing the sign of the cross and engaging in crying to gain sympathy from staff. These multiple forms of verbal manipulation can go unnoticed even by staff members who work with him on a daily basis. It is still a great question whether these behaviors are manipulative or just representative of the severity of the cognitive deficits that he experiences.

The authors feel that one of the most frequently observed problem behaviors in persons with an ABI are verbal outbursts. These outbursts are often in response to feedback, but can also serve an attention getting function. When Latka engages in verbal outbursts, his behavior escalates rapidly from controlled to aggressive. He will often show signs of agitation, such as grimacing, when receiving negative feedback. At other times, he will simply begin a verbal outburst by yelling at the top of his lungs. The content of these verbal outbursts is normally racially motivated and typically involves staff members with whom he is in contact with on a daily basis. The syntax of these verbal outbursts usually includes simple noun-verb phrases such as, "You, Out!," "You, Go," or simply, "AFRICA" when his anger is focused on African-American staff members. Most of the time, he engages in multiple behaviors while escalated during verbal outbursts. These other behaviors include physical aggression, property destruction, and urination on objects representative of the person with whom he is displeased.

In terms of property destruction, Latka has engaged in multiple forms of problem behavior. The behaviors that he displays when upset encompass the following: destruction of name plates on doors, tearing up schedules, tearing boards off of walls, kicking desks, overturning desks, throwing trash cans, urinating on doors, and defecation on behavioral contracts. Though these behaviors are all within his repertoire, they are not all present during every outburst and are often triggered by verbal instruction from staff. While engaging him in this instruction, his behavior escalates from control to aggression; similar to the characteristics displayed before verbal or physical aggression. When there is a break in the feedback, however, he scans his surroundings for an object which can be easily manipulated to intimidate the other individual. While these behaviors rarely cause physical harm to other individuals, the emotional strain felt by both Latka and the individual can cause barriers to therapy that may be difficult to overcome.

One of the more interesting behaviors that Latka engages in during the course of a day is

his insistence on rigid daily routines and compulsive behaviors that border on being obsessive. Any deviation from his daily routine will be met with possible verbal or physical aggression, property destruction, or non-compliance to prompts. When first meeting Latka, his appearance is a bit disheveled and his hygiene is questionable. Upon entering his apartment, though, one can find an array of intricacies that allow for examination of an organization compulsion. All clothing is neatly ordered and folded, shoes placed perfectly side-by-side, spotless countertops and tables, and a bathroom that must be cleaned up to specifications before he will shower in the stall or use the toilet. Along with the showering, the water temperature for a shower must also meet his specifications. This procedure often takes 5-10 minutes. After this comprehensive ritual, there is usually only five minutes before the hot water runs out, which prevents him from completing his showering routine daily due to the water being “cold to the plate in my head.” This anxiety about having no hot water prevents him from showering daily, and also allows him to confabulate that he showers twice daily. Other examples of his insistence on constancy involve his preference for food. Food that has been prepared by African-American staff members is often refused; the same as coffee prepared by African-Americans. His preference for coffee, which he consumes at a minimum of five cups a day, is selective to only two establishments, Denny’s, and a preferred local coffee shop. Coffee made within the residence is not consumed. Even driving routes must be constant to ensure appropriate behavior. In one instance, a new staff member attempted to take a different route to the local Denny’s, and was met with a behavioral outburst severe enough to stop the vehicle, de-escalate him and continue on the usual predetermined route.

Latka also engages in numerous verbal problem behaviors. Two of the more interesting verbal behaviors with which he has exhibited are perseverative complaining and constant pessimism. Upon engaging him in conversation, the content of the verbal exchange focuses solely upon the negative aspects of the day’s events, even if confabulated. This involves not only verbal perseveration to sway the credibility of staff members, but also involves a self-report that his days are filled with no activities, no help from staff, he receives no money from staff, and constant illness. This verbal behavior is not just daily, but is involved in each and every encounter with staff or clinical members providing services. Ignoring or differentially reinforcing such negative statements is met with escalation of verbal and physical aggression, until attention is focused on the negative statements. On the other hand, he is very appropriate with members of the community, and persons who do not participate in direct service to him.

The other verbal behavior, which has harmed his ability to establish rapport with staff members, is a constant verbal repertoire consisting primarily of pessimistic statements. Each encounter with Latka is marked by a noticeable content of pessimism, including feeling that people do not help him, no one likes him, and his situation is “100% bad.” When a clinical team member asked him to identify at least one good thing that happened to him only two days after his birthday, he responded that, “nothing good has happened in 17 years.” In actuality, he had been taken for coffee, taken to lunch, and had been made dinner by a preferred staff member with whom he does not often interact. The following day, he had also been taken to breakfast by members of the clinical team who had worked with him previously. In addition, he had also been told “happy birthday” and received cards and well wishes from numerous staff members and clients. In spite of kind words and birthday wishes, he responded that the last seventeen years have been terrible and he is a “pessimist 100%.” Another example of his pessimism stems from his daily activities at the facility in which he resides. During the course of a week, sessions are sometimes cancelled or a very low number of residents participate in any given group. These factors allow him to express the belief that “all sessions are cancelled” or that the

facility is in fact not engaging residents in rehabilitation activities. For this reason, he believes that the facility in which he resides is “broken,” not helping people, and the staff members at the facility are “lazy.”

With regard to elopement, he has been known to endanger both himself and others when escalated. Many of these instances begin with escalation from control to either verbal or physical aggression, and lead him to escape from the residence in which he resides and attempt to take his own life by lying down in the middle of a major highway. When escalated to this point, he refuses all prompts to remove himself from danger. At these times he is putting not only himself, but the staff members and community members who are driving by, at risk. Latka has also been known to leave the residence and go to places in the community and ask to have the police or ambulance service called to assist him with his needs. Along the same lines, he has also been known to throw groceries and other objects from residences into major roadways in his community, again endangering community members who are driving by.

Latka’s memory deficits are sometimes difficult to pinpoint. He can remember the names of people he has worked with and places he has resided, the work he has done at these facilities, traumatic or emotional events that have happened to him, preferred staff members, location of preferred establishments, and the monetary value of products purchased. He also believes he has resided at the facility for seventeen years when in fact he was admitted only ten years ago. Although to the layperson it may seem that he has forgotten his placement at the two previous residences during the initial seven years after his injury, he can remember the names of both facilities and the estimated time of stay. He must be prompted constantly to address his daily schedule, but remembers the exact times of which each activity occurs. In some instances, these memory deficits also serve the function of encouraging naïve staff members to allow him to engage in activities or procure incentives that he has already received.

Latka’s inclusion into the life of the community has been a long and arduous process filled with barriers. The process has taken years to fully integrate him into a community that is accepting of persons with disabilities. Presently, his daily routine takes him from supervision in the residential facility to being unsupervised in numerous establishments within a quarter mile distance of his residence. He patronizes several local coffee shops and restaurants, and goes freely to other establishments throughout the course of his day. In each of these situations, he is appropriate with members of the community, and is often given discounts for his daily patronage. Many of the workers at places he visits have known him for quite some time and readily engage him in conversation.

Advocacy : Impacting Community Views

It is clear from the preceding case study that Latka experiences a number of cognitive and behavioral deficits that impact his ability to interact with others and to get his needs met in a manner that is satisfactory to him. Figure 1 shows the extreme durability of the behaviors that he displays.

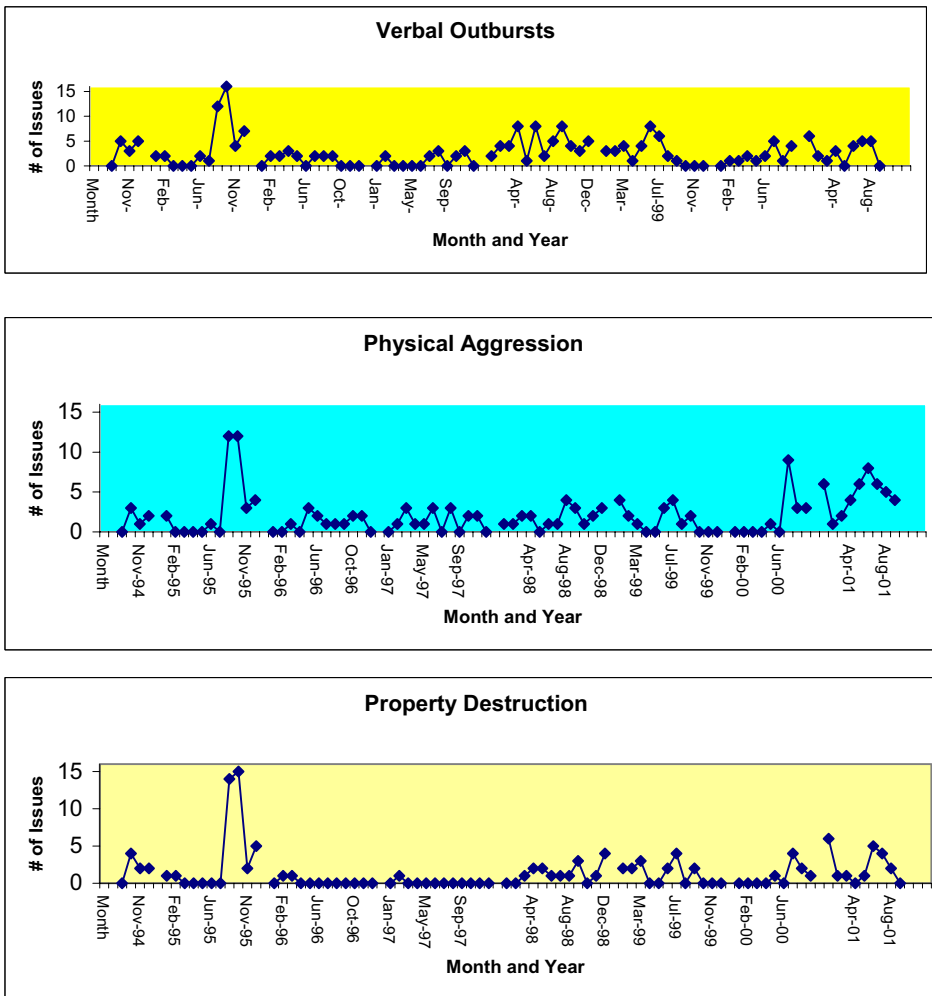


Figure 1: Sample behavioral data for Latka over 8 years.

The incredible aspect of this data is that it spans the course of 8 years. Though there were periods of time with notable decreases in the frequency of unwanted behaviors, the fact remains: these issues do not go away on their own. What we as rehabilitation professionals are striving for here is to influence the way that the community looks at these profound deficits in order to increase their understanding of the deficits and the way that they impact this man's life. The process is one of reciprocity and education and we advocate that it serves as a model for inclusion for individuals with ABI and behavioral issues. A model that can be incorporated into a life care plan for individuals with similar neurobehavioral problems and needs.

The multitude of significant deficits described here contributes to Latka's problem behaviors in many ways. Not only does the language barrier play a huge role, but his rigidity and concrete thinking make interacting with him a challenge. The big thing to remember here is that we need to adjust the expectations that we have of non brain-injured individuals to accom-

moderate for the issues that present themselves in social ways (behaviorally). We need to remember that memory deficits, not purposeful intention, contribute to physical aggression in that forgetting times when incentives are given increases the probability that he will be aggressive toward staff members. Poor hygiene skills may result from tactile sensitivity or an inability to smell, **not** a refusal to be clean. The presence of verbal/physical aggression and property destruction often disrupts behavioral programs due to the escalated state that he is in. These issues present themselves due to lack of appropriate skills to communicate in other ways, not an insistence to be rude and aggressive. In many instances, Latka is given the incentive he desires to avoid escalating him further, thus it is **our** behavior that may produce the aggression as opposed to his when we do not deliver as we have in the past. In addition, the paranoid statements exhibited by Latka have posed problems for both staff members and community establishments in dealing with him on a daily basis. This barrier is only overcome by communication with numerous people to educate related to **why** he makes these statements. The statement “wrong pizza” had been misunderstood by a local patron for years. The patron had taken this to mean that the food that he was serving was bad and that Latka was informing him of this. It had to be explained that these behaviors were not due to disdain for the restaurant, but rather a past learning history of others putting medications into his food. This has produced strong suspicions whenever his meal looks strange to him at any time.

We as service providers working with Latka have established a relationship with the community that promotes and ensures a safe and open relationship. Staff members and therapists contract with clients to utilize community outing programs to ensure that they are encountering situations in the local community that are similar to what they will encounter when they discharge to their home communities. Throughout these trials, we observe whether skills that they were being taught generalize to the community. This community integration program consists of first going with the client to observe appropriate behavior in each establishment. In some cases, the clients are then shadowed to the sites to make sure they are appropriate by themselves. We then work with the community establishments to respond promptly to each and every instance of inappropriate behavior. These meetings take the form of discussion and problem solving when issues occur. Many community establishments come to know the clients by name and will inform us of how they are doing in the community. This working relationship with the community allows Latka and other clients like him to increase their community interaction and develop multiple productive relationships with others. Another positive aspect of this relationship involves expanding clients’ worlds by allowing them a variety of interactional experiences.

These community integration programs have been implemented and monitored in Latka’s case over the course of many years by numerous staff members and therapists. Latka often invites therapists and staff members along on outings, not to ensure safety, but rather as companions of his in the community. Therapists and staff members utilize these times to reinforce socially appropriate behaviors and decrease socially inappropriate behaviors. We find ourselves continually advocating for clients if socially inappropriate behaviors do arise. In Latka’s case, community establishments have communicated inappropriate behaviors and utilized the working relationship to decrease the instances of future occurrences of these issues.

In summary, the successful rehabilitation of persons with ABI and behavioral challenges is a difficult one, with multiple players (client, family, treatment team, community resources, etc.) and variables to consider for life care planning. The rehabilitation process is met with difficulties at the managerial or financial level in which the rising culture of managed care may attempt to reduce the length or quality of care that is provided. Yet, as care providers we must

not be swayed by this cultural movement in the medical and insurance community. Instead, we must strive to provide exceptional care, and, if effective, should be able to co-exist in a climate of budget cuts and time constraints on length of treatment. Exceptional care is a multifaceted and multidisciplined endeavor that requires caregivers to believe that change can occur, engage in regular training on new treatment approaches, and maintain a constant grasp of the clinical and experimental published literature. This is not unlike some of the general tenets of effective life care planning. Although we are suggesting that many care providers might need to go beyond what they are currently doing, this extra effort is justified by the life enhancing changes that persons with ABI could experience. As care providers, is that not what we owe to these individuals? Community inclusion efforts as we, the authors, see them are best summarized as follows: The process is one of reciprocity and education and we advocate that it serves as a model for inclusion for all individuals with ABI and subsequent behavioral issues.

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