



Community-Based Support Services for People with Acquired Brain Injuries in the Fredericksburg Area

Final Report

INTRODUCTION

ICON Community Services proposed a service coordination model to utilize personal futures planning within the context of creating circles of support around the individual being served. The aim was to combine active collaboration among community professionals with an active supportive circle of those playing an integral role in the person's life to assist individuals with acquired brain injury to accomplish their personal goals.

The project ran from October, 1999 through June, 2001, with approximately 18 months of active service being provided, accounting for start-up and close-out activities. Within this time period, ICON was able to provide services to 39 individuals with another nine individuals interviewed and declining services at the time.

ICON presented a unique model that was entirely community-based, with no facility-based programming offered. Staff for the project maintained offices in their homes and went to the consumer to provide service and support. ICON's goal was to assist individuals in accessing, developing and utilizing natural supports in their environment to supplement and ultimately supplant, when possible, services provided by formal agencies. This would subsequently decrease their dependence on "the system." This required not only interaction with the individual utilizing ICON's services, but also a large effort to network with, get to know, educate and support a wide range of community organizations and businesses. In many instances (e.g., the library, local gyms, computer training centers) organizations were assisted in seeing how they were able to better include people with brain injuries in the programs and services they provide. In other cases (e.g., school systems, nursing homes) service providers were supported in providing services that more specifically addressed the needs of people with brain injuries.

This project is merely a first step in enhancing the accessibility to full inclusion and participation in their communities for people with brain injuries in the Fredericksburg/Planning District 16 area. Throughout the duration of the project, a great deal of time and effort was devoted in expanding the possibilities for this population, both within themselves and within the view of the larger public. It is sincerely hoped that whoever continues this contract builds on the foundations laid by ICON and avoids the well-traveled but less successful route of providing facility-based, prescribed programming.

ACCOMPLISHMENTS

- **Business Exchange** – ICON became a member of the Fredericksburg Business Exchange, a local consortium of businesspeople who meet weekly to share resources, networking and marketing strategies. Members present their businesses on a rotating basis from week-to-week. We presented the ICON service within Fredericksburg, and received quite positive feedback. As a result, we connected one participant with an employment agency, which led to a series of successful temporary job placements that demonstrated his employability. We also presented to the Exchange the idea of collaborating on a mentorship program, whereby people with brain injuries can learn skills on-the-job through shadowing. A great deal of interest was expressed in this concept, and we will probably continue to pursue this despite the termination of this contract. We have also obtained connections who may be interested in providing job leads, networking, working with us in increasing awareness, and collaborating on the mentoring project.
- **Transportation** – Care-To-Go – Through establishment of a contract with this transportation company, consumers of our services were able to attend classes, appointments, recreational activities, including a conference in Northern Virginia. This transportation was available throughout the City of Fredericksburg and the four counties we served.
- **Computer classes** – ICON collaborated with a computer instructor in the community to provide training for some of our consumers and staff. This allowed 1:1 and/or small group training on computers in integrated setting at a local community training center. Consumers were able to thus access training that exists in the community rather than wait for classes offered specifically for people with disabilities.
- **Gym** – At the request of several consumers who were no longer able to receive physical therapy, but still wanted to improve such things as stamina, strength, balance and flexibility, ICON forged relationships with two gyms in the Fredericksburg area. At the first, we worked individually with designated personal trainers to increase their level of comfort in working with individuals with brain injuries. At the second, we were able to arrange for trial memberships so that people who were not sure this was something they would be interested in could try it

for one or two months. The gym was then willing to work with us regarding discount memberships for our consumers. Unfortunately the contract ended before we were able to further this alliance. As a result of these efforts, however, one consumer was able to state he had finally found an activity that he could do with his family.

- **Inservice/Trainings** – Inservice presentations regarding brain injury and our services were conducted at the following sites: DRS, Mary Washington Hospital, Commonwealth Assisted Living, Spotsylvania Public Schools, Goodwill Industries, Fredericksburg Business Exchange, and at a local Naval Station. ICON staff also presented at the 2000 and 2001 Case Management Conference in Williamsburg, sponsored by Brain Injury Services, the 2000 International Williamsburg Conference, sponsored by MCV, and at the 2000 Journey Toward Independence. We were invited to present a poster session at the 2001 International Williamsburg Conference.
- **DRC** – ICON was able to develop a working relationship with the Disability Resource Center, the local Center for Independent Living. ICON staff served as co-facilitator for their empowerment group, which incidentally was comprised primarily of people with brain injuries, and we were able to use their facilities for meetings and to exhibit at their open house. We had entered into some planning and discussion regarding strategies to address the housing, transportation, and educational issues in the Fredericksburg area.
- **DRS** – One of the difficulties commonly facing people with brain injuries is that the nature of their disability frequently prevents them from meeting some of the criteria for accessing services from Department of Rehabilitative Services. This is often based on the perceived notion that these individuals are not "ready" for vocational rehabilitation or are too severely disabled to benefit from services. Deficits in memory, initiation, organization and planning often results in missed appointments and not following through with assigned tasks. ICON was able to introduce some compensatory strategies to address some of these issues for several consumers, as well as to meet with individual DRS counselors to enhance understanding of the nature of the disability resulting from brain injury. As a result, seven consumers were able to access DRS services and proceed along a positive path toward their vocational goals. At least three others had not been able to access or successfully utilize DRS services because of housing and/or mental health issues. ICON staff were able to assist in both coordinating available services and in supporting the individual in problem-solving as they tried to put some order and stability into their lives.
- **Community Services Board** – People with brain injuries tended to encounter the same difficulties here as with DRS regarding the perception that they were inappropriate for services. ICON staff was able to obtain Case Management Mental Health services for several consumers. We continued to participate on these individuals' teams in order to facilitate understanding of brain injury and foster the continuation of services.

- **Journey Toward Independence** – Five consumers were able to attend this brain injury conference which is held annually in Northern Virginia, and ICON staff presented a session on Person-Centered Planning and the project services being provided in Fredericksburg.
- **BIA Conference** – One staff and one consumer were able to attend this national conference held in Chicago in 2000.
- **Rhythms of Hope** – After seeing a performance by this dance troupe comprised of members with a variety of disabilities, one consumer was instrumental in bringing the dance company to Fredericksburg for a performance, and initiated efforts to bring dance classes to the area with the future possibility of developing a similar dance troupe in Fredericksburg.

CHALLENGES

- When ICON began this project, it was assumed that most of the persons for whom we would be providing supports were already connected with basic services, and that we would be acting as an adjunct, adding a community integration piece. What we discovered was a significant number of our consumers had been unable to access services from DRS because of what turned out to be a lack of understanding of brain injury. Consumers were deemed ineligible or inappropriate for services because they manifested behaviors that are the direct consequences of brain injury. For example, one consumer was deemed “not motivated” as a result of missing an evaluation appointment that had been set up for 7:30 in the morning. This particular individual had spent the past 1½ years at home, with very little activity other than sleeping, eating and watching TV. ICON staff was able to institute proper supports to assist him not only in getting to his subsequent evaluation appointment, but once he was accepted into a work placement, was able to provide necessary supports to make sure he got there on time. This was only required for the first two weeks, after which the consumer told us he was able to do it on his own, and has since been attending work regularly and on time. Another consumer had been told by his long-term case manager that she would no longer assist him in seeking housing, because he failed to follow through on the activities she assigned him to do. This individual had frontal lobe damage, and had great difficulty focussing his attention and initiating activity. ICON staff was able to assist him breaking the assigned tasks down into smaller, manageable pieces so he could begin to address them. This same consumer was deemed inappropriate for vocational services because he “does not have a vocational goal”. Again because of the brain injury, he was unable to focus, but in fact had a list of vocational goals. ICON staff was in the process of assisting him in prioritizing and deciding on which goal would be of most interest to him, a task one would have thought would have been within the purview of the DRS counselor. In yet a third example, a consumer was deemed ineligible for DRS services because he had a history of getting fed up with jobs and quitting. ICON staff was able to

connect him with a temporary employment agency. After several successful job placements, the consumer decided he was interested in a permanent job, and DRS was convinced he was a viable vocational candidate. As a final example, one consumer was deemed ineligible for referral to the Woodrow Wilson Rehabilitation Center because of behavioral issues.

In short, the most frequently expressed goal for the consumers we served was to be able to work. Since so many had been unable to access DRS services, ICON had to spend more time and energy than anticipated supporting people in getting the support they required from DRS.

- Similar issues were noted in working with the CSB. Consumers who had Mental Health or Substance Abuse issues were often unable to access CSB services, again because of difficulty on the latter's part in accommodating the behaviors characteristic of individuals with brain injury. Difficulties arose primarily around failures to keep appointments either because of memory of disorganization, lack of memory of the details of previous sessions, and inability to focus during a specific session or conversation. In two instances, ICON staff was able to intervene and assist consumers in being able to access CSB services.
- DRC – while dRC was a great source of support and assistance in ICON's endeavors, there were some instances of conflict and territory issues, particularly in the early months of the contract. A degree of this is inherent in the nature of interaction between a consumer-driven advocacy agency and professionals – there tends to be a sense of distrust on the part of the former toward the latter, and an assumption that the latter is not always acting in the best interest of consumers. In several cases in which both ICON and dRC were supporting an individual, communication was a challenge, the result being that the consumer received mixed messages regarding who was doing what. In one instance this resulted in a direct conflict, with the consumer "splitting" the staff from the two agencies. In a "surprise" meeting (arranged between dRC staff and the consumer at a time that ICON staff was scheduled to meet with the consumer), the consumer requested that ICON discontinue services, which we did. Ultimately, the consumer returned and requested ICON's support in a specific project. Unfortunately, this was toward the end of the contract so we were not able to provide this support.
- An initial challenge, which we anticipated at the outset, was the expectation of what our support services would entail. Many of the consumers we contacted had been disappointed in services they had received or expected to receive in the past. Most had received treatment and services that are based on the medical model, and thus had an expectation that support services would consist of someone coming in to do things for them or to do things to make them "better."
- Transportation – This has been an ongoing problem for the area in general with particular difficulty for people with disabilities. Transportation was fairly readily available within the city of Fredericksburg, but beyond those boundaries, little was

available, other than some systems in place for doctor's appointments. In at least two instances, ICON had to intervene with the public transportation service and advocate for providing appropriate service. ICON was able to contract with Care To Go to provide some transportation for consumers for leisure and social activities and running errands, in addition to transporting to medical appointments. However, this service was limited to the amount of money in the consumer fund for the duration of the project.

Through the advisory committee, ICON had begun to explore potential collaborations and strategies to either exert sufficient influence to motivate the various jurisdictions to better address the problem, or to develop systems (and apply for necessary funding) for a consortium of organizations to supply transportation. As this was a long-term project, the short term of the contract did not allow for a lot of progress in this area.

An additional challenge having to do with transportation was the ease with which this became a barrier to people with brain injuries. In two cases, lack of transportation was cited as the reason an individual could not make any progress, and in fact could not see the point of utilizing ICON supports. In the first case, the consumer's mother was unable to understand that ICON would be able to provide some transportation, while at the same time assisting her son in connecting with others participating in the activities in which he was interested, with the aim of him being able to share a ride with others in the community. (At one brain injury support group meeting, this resulted in a rather odd, circular conversation, with the mother repeatedly stating her son could not use ICON's services because there was no transportation, and ICON staff repeatedly stating there was transportation). Unfortunately, the son with the brain injury agreed with the mother, and declined services, although he had a strong desire to participate in various activities. In a second instance, a gentleman with a brain injury made transportation his primary goal, and was unwilling to explore any other interests or activities unless he could be guaranteed ongoing, free transportation. ICON staff continued to work with him at his home, and occasionally taking him to community sites (he had a counselor from CSB who provided regular transportation for recreation activities), and he had just begun to define some goals and focus on specific interests at the conclusion of the contract.

- One of the biggest challenges was the pressure to make some systematic, fundamental changes in a short period of time. Many people with brain injuries who were supported by ICON were very focused on what various service providers could give them, and what they could do to get "better", with less emphasis on what they wanted their lives to look like. Similarly, many people and agencies who had been providing supports, or whom people with brain injuries thought should be providing them supports, focused on what the consumers could not do, their challenges, and on a narrow range of options.

Many people within the community often did not what to expect when confronted with a person with a brain injury so they either ignored specific needs, or asserted they could not deal with people with brain injury.

Over the 18 months that the project was in full swing, the efforts of ICON staff on long-term issues were just beginning to bear fruit. Several consumers had come back to the project as it became clearer what we were trying to accomplish, and that this project encouraged people to really go after their life goals rather than limit themselves by their disabilities. We had built a level of trust among other service providers and agencies, and we had developed some strong collaborative relationships within the business community. ICON staff, and the project itself had gained a level of respect among other providers of brain injury services throughout the Commonwealth. Having laid a solid foundation, it is regrettable that the momentum has been lost in constructing a strong support system on this foundation.

- The most disappointing challenge ICON faced was the criticism we received, particularly from DRS, the funding agency, for hiring a person with a disability as the lead staff for the project. We were questioned about our initial hiring decision and whether we were aware of the nature of his disability (we were; we had discussed it at the interview, and worked out some accommodations). Early in the project, a local DRS counselor called to inquire if we had "compensatory strategies" in place for our staff because he had not given a consumer a list of items to bring to his DRS appointment (it turned out she had not given ICON staff a list of items to give to the consumer!). The initial performance evaluation for the project again questioned the wisdom of hiring a person with a disability for this position, and went so far as to identify previous agencies from which he had received services. The reluctance and/or inability to view this individual as a professional colleague, or to make judgments based on his performance rather than his disability status, was frankly, appalling. It is interesting to note that a DRS counselor from another jurisdiction, who did not "know" him, went out of her way to call ICON's Executive Director to commend him for his professional behavior, and his ability to spark some positive movement in an individual with a brain injury with whom they had been struggling for years.

WHAT WE LEARNED

- It is important, when introducing a new service, to focus a great deal of effort up front in ensuring that all stakeholders have a clear idea of the goal of the project. We would have done well to do a better PR job – produced more materials in various formats describing the project and the services we would provide, set up more meetings with people (in the community and within service agencies) in the beginning. Even though people stated they heard and liked what we proposed, in practice the expectation was often that ICON would operate as other services they had received or become familiar with. While ICON was eventually able to overcome

this, we might have progressed further in the short period of time we had if greater understanding and buy-in could have been obtained earlier in the process.

- Documentation – ICON needed to more quickly develop the proper system of documentation for the types of services we were providing. It was clear from the beginning that the traditional forms and documentation were not appropriate for services that follow the needs of the consumer rather than the dictates of the organization. While to some extent this was a work in progress, ICON should have utilized traditional documentation initially, presenting a stronger rationale as the service was developed for a change in documentation systems. In particular, stronger documentation of community development and networking was necessary, as was a method for recording supports provided by the community rather than the service provider, but as a result of the efforts of the provider. Since the nature of supports and formulation of services, goals and objectives often follows the format of the documentation utilized, providing innovative services and using traditional case-file documentation becomes quite difficult. At the same time the time-honored dictum that "if it's not written down, it didn't happen" holds true. This again points to the need to allow sufficient lead time to ensure proper administrative procedures and systems are in place prior to initiating services. ICON, in discovering a much larger desire for services than previous surveys of the Fredericksburg area had indicated, rushed into providing the service before making sure all of the appropriate forms were in place.
- Systems Change – Ultimately this was a project that promoted fundamental change in how support services are delivered to people with brain injuries in the community. This should have been more clearly emphasized up front and in the formulation of the project. This would have facilitated a greater understanding of our goals, and would have pushed us to be more deliberate and systematic in our approach to this form of service provision. Additionally, we would have been more explicit in defining the model under which we were operating, and been compelled to address the need for education regarding this model.

Respectfully Submitted,

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