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QUALITY AND COORDINATION OF CARE FOR PERSONS WITH BRAIN

INJURY IN THE COMMUNITY: DEVELOPING A SURVEY

by

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A Thesis Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Master of Science

in Occupational Therapy

at

The University of Wisconsin-Milwaukee

August, 2012

ABSTRACT

QUALITY AND COORDINATION OF CARE FOR PERSONS WITH DISABILITY:
DEVELOPING A SURVEY MEASURE

by

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The University of Wisconsin-Milwaukee, 2012
Under the Supervision of Dr. Mark V. Johnston, PhD

Background: Because of increasing demand on primary care physicians and a
complex, fragmented, healthcare "system", people now must coordinate their own
healthcare and services. In response, care coordination has become a clinical specialty,
typically done by nurses or social workers. People with disabilities (PWD) also must
coordinate their care, including health and disability-support services, knowing who to
call, advocating for themselves, and scheduling appointments, among other things. Such
demands can be particularly problematic after brain injury, which may impair abilities to
prioritize, coordinate, manage, and schedule activities. Coordinating services requires
participation of the PWD, and supportive significant others (SSO). At present, no
validated measures exist which characterize the activities that PWD and SSO do to
ensure quality, coordinated care or that identify gaps in needed services.

Purpose: Purposes of this thesis were: To continue development of a
questionnaire on care coordination; to evaluate its clarity, acceptability, and content

validity; and to collect an exploratory description of care coordination experienced be people with TBI and their SSO in the community.

Methods: We completed development of the Care and Service Coordination and Management (CASCAM), an exploratory survey with structured quantitative questions and open-ended items, with versions for both the PWD and a SSO. Participants were primarily in the chronic phase of rehabilitation after brain injury. Quantitative results are primarily analyzed using descriptive methods. Interrelationships among items were also examined. Qualitative analyses identified major themes expressed in response to open-ended questions.

Results: Content validity was established through verifying that the CASCAM successfully addresses issues related to care and service coordination which apply directly to people with brain injury and their SSO. Participants expressed 7 important themes in the qualitative analysis. The internal consistency of major groups of reported care coordination activities ranged from .774 to .945.

Discussions: Care coordination is an essential instrumental activity of daily living for PWD living in the community. The level of internal consistency found strongly suggests that it is possible to provide a summary measure of coordination activities. Further research is needed to develop measures of care coordination to support efforts to improve our fragmented "system" of care.

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LIST OF ABBREVIATIONS

ABI- Acquired Brain Injury

ACIC- Assessment of Chronic Illness Care

ADL – Activities of Daily Living

AHPPPAL- Assessment of Health Plans and Providers by People with Activity

        Limitations

BIA- Brain Injury Association

CC- Care coordination

CCM- Chronic Care Model

CINAHL- Cumulative Index to Nursing and Allied Health Literature

CPCQ- Client Perceptions of Coordination Questionnaire

CTM- Care Transition Measure

EBSCOhost- Elton B. Stephens Company Online Database

IADL- Instrumental Activities of Daily Living

IRB- Institutional Review Board

MDD- Major Depressive Disorder

PACIC- Patient Assessment of Chronic Illness Care

PAM- Patient Activation Measure

PCP- Primary Care Physician

PTA- Post Traumatic Amnesia

PWD- Person With Disability

SSO- Supportive Significant Other(s)

SPSS- Statistical Package for the Social Sciences

TBI- Traumatic Brain Injury

Introduction

The Problem

"Acquired Brain Injury (ABI), particularly of the traumatic brain injury (TBI) type, is one of the leading causes of death and lifelong disability in North America" (Greenwald, Burnett & Miller, 2003, p. S3). Survivors often must go through years of intensive rehabilitation in order to return to the activities and occupations that they once enjoyed performing independently. Recovery is a long, enduring process, where attempts to return to work or school may continue even two years (or more) after the initial TBI (Bell, Temkin, Esselman, Doctor, Bombardier, Fraser & Hoffman, 2005). The trauma to the brain can cause a wide range of physical, cognitive, and behavioral impairments which significantly impair the individual's ability to live independently, maintain personal relationships, and engage in leisure activities (Ponsford, Harrington, Olver & Roper, 2006). After sustaining a severe injury such as a TBI, it is well known that these individuals often have a much harder time performing daily tasks such as bathing, dressing, meal preparation, driving, and participating in paid employment (Turner, Ownsworth, Cornwell & Fleming, 2009). An aspect often overlooked is one's ability to manage and coordinate everything that is going on in their life. This includes not only the management of daily tasks and productive activities, but also the coordination of different health care, rehabilitative, and independent living services that they require, and even things like scheduling therapy appointments.

Throughout the last few years, individuals who have sustained a TBI have been decreasing in length of stay for inpatient rehabilitation, which has caused post-acute TBI

therapy to become even more vital in assisting patients to return to their homes and perform their desired occupations (Kim & Colantonio, 2010). During inpatient rehabilitation people with brain injuries often are treated by a large team of health care professionals, including occupational, physical, and speech therapists, among others. However, it has been seen that people with TBI often have difficulty in carrying on what they have learned in the rehabilitation center back into their community (Ponsford et al., 2006). These same individuals tend to live for many decades still post-injury, so it is important to think that just because someone has been discharged, does not mean that their rehabilitation has ended (Fleming, Tooth, Hassell & Chan, 1999; Teasell, Cullen & Bayley, 2005). Many people who have had a TBI must continue to work hard both physically and mentally in order to fully integrate into the community and life style they would like for themselves and their families. In addition, these individuals are often not alone in their efforts. They usually have a family member or significant other who provides them motivation, support and assistance. It is always crucial that any close family members or significant others be incorporated into treatment sessions, as they too must be educated in how to assist the person with TBI in performing various tasks involved with coordinating one's care and services.

Purpose

The broad purpose of this research, both past, present and future, is to continue development of a questionnaire, known as the Care and Service Coordination and Management (CASCAM) questionnaire; to test its clarity, acceptability, and content

validity; and to collect an exploratory description of care coordination and management experienced by people with traumatic brain injuries and their supportive significant others. More specifically to this current thesis, the purpose is to determine: (1) which care and service coordination and management activities are most (or least) time consuming; (2) how certain care coordination activities correlate with one another in terms of frequency; (3) and what specific care gaps are faced by people with brain injury and their SSO when coordinating care and services.

Background

Every year, about 1.5 million Americans sustain a TBI in the United States (Bell et al., 2005). They are a leading cause of disability in young Americans, as about 230,000 people who have had a TBI in the U.S. each year are admitted to an acute care hospital and survive until discharge (Bell et al., 2005; Ponsford et al., 2006). The most common cause by far of TBI is as a result of motor vehicle accidents, accounting for more than 50% of all head injuries, with falls, violence, and sports collisions also being heavy contributors (Pedretti, 2006; Wagner, 2001). In addition, it has been reported that individuals with a TBI who were involved in motor vehicle crashes sustained more severe injuries than those who were associated with assaults, falls, or other causes (Bushnik, Hanks, Kreutzer & Rosenthal, 2003). Greenwald et al. (2003) found that men are three times more likely than women to sustain a TBI, with the highest rate of injuries occurring in young men between the ages of 15 and 24. It is also important to point out that "although the incidence of TBI is greater in younger patients when compared with

the elderly, older TBI victims usually show greater severity of injury, and higher

mortality rates" (Wagner, 2001, p. 247). Moreover, older individuals with TBI have been

found to have poorer outcomes than younger patients, as measured by the Glasgow

Outcome Scale (GOS), as well as having longer lengths of stay and lower rates of

functional gain (Pennings, Bachulis, Simons & Slazinski, 1993).

Definition of Terms

Activities of Daily Living (ADL)- "Activities that are oriented toward taking care of one's

own body" (adapted from Rogers & Holm, 1994, pp. 181–202) (OTPF, 2008, p. 631).

Care Coordination- It has been said that "care coordination is a complex set of functions

that can be difficult to define and measure" (McAllister, Presler & Cooley, 2007, p. 725).

In fact, one literature review identified more than 40 separate definitions for the term care

coordination (McDonald, Sundaram, Bravata, Lewis, Lin, Kraft, McKinnon, Paguntalan

& Owens, 2007). Matlow, Wright, Zimmerman, Thomson and Valente (2006) defined

care coordination as "the process of orchestrating the sequence and timing of

interdependent actions". This involves "assessment, planning, implementation,

evaluation, monitoring, support, education, and advocacy" for the individual with a

disability (Matlow, et al., 2006, p. 85).

Community Activities- "Engaging in activities that result in successful interaction at the community level (i.e., neighborhood, organizations, work, school)" (OTPF, 2008, p. 633).

Instrumental Activities of Daily Living (IADL)- "Activities to support daily life within the home and community that often require more complex interactions than self-care used in ADL" (OTPF, 2008, p. 631). Care coordination is an instrumental activity of daily living.

Preventative Health Services- Services to prevent future health problems, to plan how to manage future health problems, or to keep past health problems from occurring again. This is also a major theme in the coordination of care.

Supportive Significant Others (SSO)- Family or close friends who provide advice and assistance to the individual with a disability. These supportive and significant others often help to coordinate care and needed services for the person with a disability and also must often deal with the stress and frustration accompanying these care coordination activities.

Wellness/ Wellness Programs- Wellness programs go beyond treatment of disease or sickness. They aim to enhance the overall health of people: physically, mentally, emotionally, and socially. In addition, wellness programs work with individuals to help

them achieve a healthy lifestyle and to feel good every day. This may be done by helping

a person to exercise more, to maintain a healthy diet, to quit smoking, to drink less, to

lessen fears or anxieties, or in many other ways that help people to have long-term quality

of life (description from the CASCAM, see Appendix B for more).

Written Care Plan- A very important document in care coordination, which outlines the

tasks and responsibilities of all those involved in caring for a person. It is a summary or a

list of major care and service needs and identifies who is responsible for performing these

services. For example, it may be called a home care plan. Sometimes it includes a home

exercise plan (description from the CASCAM, see Appendix B for more). Often, care

plans cover several, if not all, of the following care needs: Health/medical and nursing

care; rehabilitative therapy services; routine personal care such as feeding, grooming, and

so on; educational service needs; and social needs.

Traumatic brain injuries are sometimes classified under the larger umbrella

known as acquired brain injuries (ABI), which refers to an injury to the brain that occurs

after one's birth (Ben-Yishay & Diller, 1993). Acquired brain injuries are then separated

into traumatic and non-traumatic brain injuries. Pedretti (2006) defines a traumatic brain

injury as "damage to brain tissue caused by an external mechanical force with resultant

loss of consciousness, post-traumatic amnesia (PTA), skull fracture, or objective

neurological findings that can be attributed to the traumatic event on the basis of

radiological findings or physical or mental status examination" (p. 839). Some examples of non-traumatic brain injuries include strokes and diseases of the brain (Ben-Yishay & Diller, 1993).

The term brain injury can be a bit misleading though, as it may seem to be a quite precise term, when in fact the injury produced can have a great variety of manifestations. TBI is clearly an injury to the head or brain, which classifies it as a central nervous system injury (Ben-Yishay & Diller, 1993). A TBI can be categorized into two different types shortly after sustaining injury: primary or secondary. A primary brain injury is one that occurs at the moment of impact, as an initial result of the trauma to the head (Pedretti, 2006). In contrast, a secondary brain injury has effects that are seen several days to weeks after the initial injury (Pedretti, 2006). This progressive type of injury worsens in the first few hours and days before starting to get better, and is often due to brain swelling, loss of perfusion, and decreased delivery of oxygen to both healthy and damaged tissue. This means that a secondary brain injury can also affect neurons that were not initially involved with the actual traumatic event (Pedretti, 2006).

A brain injury can also be referred to as being either an open or closed injury, with an open injury referring to having skull penetration, whereas a closed head injury has no penetration. One large risk resulting from an open injury is the threat of infection and contamination. These injuries can be further broken down into more categories, called focal and multifocal (diffuse) injuries. A focal injury occurs as a result of a direct blow to the head after a collision with an external object, a fall, the penetration of the head from a weapon, or a collision of the brain with the inner portions of the skull

(Pedretti, 2006). These result from direct force to the head and brain and are usually fairly visible to the naked eye. Research suggests that focal brain injuries often cause intracerebral and brain surface contusions, especially in the inferior and dorsal-lateral frontal lobes, as well as the anterior and medial temporal lobes, and the inferior cerebellum at times (Pedretti, 2006). Whereas a focal injury results from direct force, multifocal, or diffuse injuries, often result from acceleration, deceleration, and rotational forces on the brain (Pedretti, 2006). Diffuse axonal injuries due to acceleration and deceleration are perhaps the most common type of syndrome seen with TBI, along with damage to the forebrain. These variable forces tend to be transmitted to the surface, as well as deeper portions, of the brain and often cause both wide and microscopic damage to someone's brain (Pedretti, 2006). Common causes of multifocal and diffuse injuries are motor vehicle, bicycle, and skateboard crashes, but falls from any high surface may also be attributed (Pedretti, 2006). Two examples of what could be considered multifocal injuries are concussions and diffuse axonal injuries. A diffuse axonal injury often results from overstretching of an axon's membrane as a result of the head rapidly accelerating or decelerating, which in turn causes injury (Lundy-Ekman, 2007, p. 470). "This injury allows excessive calcium influx, producing cytoskeletal collapse that disrupts anterograde axonal transport", which eventually cause the axon to break (Lundy-Ekman, 2007). This type of injury typically occurs in the superior cerebellar peduncle, corpus callosum, and midbrain (Lundy-Ekman, 2007). Someone who has had a TBI will usually have a combination of some sort of both focal and diffuse brain injuries, depending on how the initial injury occurred (Pedretti, 2006). Pedretti (2006) states that "in best-case scenarios,

there is a minimal amount of secondary brain damage and functional disability that occurs as a result of brain swelling, hypotension, hypoxia, and systemic injury" (p. 840).

An individual's resulting level of function and specific impairments depend highly on the area of the brain injured, the type of injury sustained, and length of post-traumatic amnesia (PTA) (Lundy-Ekman, 2007). PTA can be best defined as the length of time between when an individual initially sustains a brain injury and then later regains ongoing memory of daily events and orientation (Pedretti, 2006). Post-traumatic amnesia is "the single best measurable predictor of functional outcome" (Pedretti, 2006, p. 843), although it can be misleading because amnesia is just one part of the initial recovery process. Stuss, Binns, Carruth, Levine, Brandys, Moulton and Snow (1999) helped to re-conceptualize PTA in that post traumatic confusion should be considered a more reliable outcome measure than the length of amnesia. Regardless of what measure is used, it is believed that no two head injuries are neuropathologically alike (Teasell et al., 2005).

Common Symptoms/ Clinical Picture

Bell et al. (2005) stated that traumatic brain injuries are the most common injuries to the central nervous system that result in prolonged disability. Some of the physical symptoms displayed by a person who has had a severe TBI include: decorticate or decerebrate motor rigidity, abnormal muscle tone, spasticity, ataxia, decreased endurance, postural deficits, limitations in range of motion, visual deficits, muscle weakness, absence of primitive reflexes, and reduction in or absence of sensation, among many

others (Pedretti, 2006). In addition to these symptoms, secondary physical problems such as cardiorespiratory deconditioning often occur as a result of prolonged bed rest, immobility from physical impairments during long hospital admissions, and physical inactivity (Hassett, Moseley, Tate, Harmer, Fairbairn & Leung, 2009). These symptoms and problems can serve as a partial blocking effect into previous vocational and leisure activities and can increase the individual's risk of secondary health conditions, such as heart disease, as well as the economic burden associated with the injury (Hassett et al., 2009).

Although these symptoms cause a high level of disability within one's life, the cognitive symptoms associated with TBI are usually more seriously disabling in the long term. The subsequent damage which typically occurs to the frontal, temporal, and limbic areas of the brain cause these individuals to show poor judgment, decreased executive functions, memory deficits, slow information processing, attentional problems, and poor divergent thinking (Lundy-Ekman, 2007).

Bombardier, Bell, Temkin, Fann, Hoffman and Dikmen (2009) state that "depression is arguably the most prevalent and disabling psychiatric condition associated with TBI" (p. 231). In fact, research has shown that between 15.6% and 26.5% of individuals who have sustained a TBI meet criteria for major depressive disorder (MDD) within only a few months after their injury, with numbers only increasing with time (33%-42% within first year and 61% within 7 years) (Bombardier et al., 2009). In this same study, it was reported that people with TBI are associated with significantly higher rates of planning to commit suicide, as well as 8 times more likely to attempt suicide, and

3 to 4 times more likely to complete suicides, than those belonging to the general population and non-brain injured control participants. An important factor to consider also is that depression after a brain injury tends to increase over time after injury, contrary to most other serious injuries, where depression decreases over time. It is hypothesized that this subsequent depression associated with TBI may be due to other cognitive symptoms associated with the disability, like poorer cognitive functioning, increased aggressive behavior and anxiety, greater functional disability, and poorer global recovery (Goverover, Johnston, Toglia & DeLuca, 2007).

It was explained in this same study that another cognitive symptom associated with TBI, lack of self-awareness, is among the greatest obstacles in brain injury rehabilitation. In fact, lack of self-awareness has been reported as being one of the most frequent cognitive impairments observed in adults with TBI, occurring in about 76% of individuals (Goverover et al.; Sherer, Bergloff, Levin, High, Oden & Nick, 1998). They went on to say that lack of awareness has the potential to impair the individual's comprehension regarding their own deficits on their ability to function in daily activities, to benefit from rehabilitation services, and to successfully return to work. The impairment of self-awareness and self-regulation frequently also cause the individual to have problems associated with executive functioning, as well as the inability to anticipate difficulties, recognize errors or monitor their performance during an activity (Goverover et al., 2007).

In addition, Ownsworth and McFarland (1999) reported that memory loss is another frequently experienced cognitive problem by those who have sustained a TBI,

which has to do with lack of self-awareness in a large part. In a study by Vanderploeg, Crowell and Curtiss (2001) it was demonstrated that most memory loss due to TBI is in fact a resulting problem of encoding loss. That is, the individual is unable to store the information in their memory to begin with. The subsequent goal neglect brought on through these deficits can be very frustrating for people with TBI and tends to compromise their functional independence (Levine, Robertson, Claire, Carter, Hong, Wilson & Duncan, 2000). Even a concussion, which is considered a mild traumatic brain injury, can cause long-term behavioral effects (Lundy-Ekman, 2007). "A concussion is distinguished by a brief loss of consciousness, a transitory posttraumatic amnesia, or a brief period of confusion following head trauma" (Lundy-Ekman, 2007, p. 471). After sustaining a concussion, some people may have lingering effects up to one year after the initial injury, which is commonly known as post concussion syndrome (Lundy-Ekman, 2007).

Traumatic brain injury causes problems with engagement and success in life, most often with paid employment and serves as a general occupational disruption. These resulting cognitive problems that someone often goes through after receiving a brain injury are one of the primary reasons why these individuals have such difficulty in the areas of independent living, social competence, and vocational endeavors (Ben-Yishay & Diller, 1993).

Significance and Relevance to Occupational Therapy

Brain injury often presents as occupational disruption. Because of this, having a family member, significant other, caregiver, or health professional who can assist these individuals in doing things like scheduling appointments, going to and from therapy, and going through paperwork can be extremely helpful for the PWD. However, increasing quotas and higher demands on health care providers have forced many people to put elements of the coordination of their care into their own hands, or increasingly into the hands of family members and caregivers (McAllister et al., 2007). This puts an even higher amount of stress onto someone who is already dealing with disease or disability either personally, or through a loved one or significant other. Having to navigate the health care system, schedule appointments and attend therapy sessions, along with everything else that is going on in one's life can be frustrating and confusing to any person, let alone someone who has had a brain injury.

This topic is of particular concern to the field of occupational therapy in that care coordination is an instrumental activity of daily living (IADL), and as such, should be addressed by an occupational therapist (ACOTE Standards and Interpretive Guidelines, 2010). Although care coordination is not usually something that occupational therapists always think about; they tend to conduct care coordination for their patients when needed, perhaps without even consciously being aware of it. Like most IADLs, care coordination is required on an intermittent basis, but is extremely meaningful and sometimes essential. This is particularly true during transition phases in one's life, such as transitioning to inpatient and/or acute care, or to outpatient and chronic care.

Furthermore, this research and subsequent questionnaire and results can be very beneficial to any individual with a brain injury, as well as their SSO, by identifying problems in qualitative care. If successful, these individuals will be able to coordinate their own care services, or else be able to identify which areas of his/her care need to be further coordinated, whether through the medical system or with the assistance of a SSO. The result will be that the PWD will be able to do things like schedule appointments, navigate the healthcare system, and advocate on their own behalf. In doing so, one will hopefully be able to reduce the amount of stress perceived while interacting with medical and rehabilitation staff and will increase their overall mood, as well as functional independence.

In addition, the topic described involves areas of meaningful, independent living that can assist the person(s) with TBI to be able to accomplish various tasks related to care coordination, which in turn will improve aspects related to ADLs, other IADLs, and multiple other activities and occupations. This then has the potential to lead to a societal impact in hospitals, communities, and families. In the hospital, health care professionals will be presented with a clearer understanding of the difficulties that people with brain injury and their SSO experience, and transition and treatment plans can be adjusted accordingly. In the community, these individuals will be able to better receive the care and services that they need with a lesser amount of burden, leading to more time to do the things that they enjoy in the community. In the family, supportive significant others will have a diminished amount of stress, burden, and personal effort, as well as a greater

awareness of what their loved one is experiencing. As a result, families will have more time to spend with each other. For these reasons, this research is being conducted.

Literature Review

Care Coordination

Health care occurs in multiple systems, and often involves assessing, planning, implementing, evaluating, monitoring, supporting, educating, and advocating, no matter which system (Matlow, Wright, Zimmerman, Thomson and Valente, 2006). Care coordination also occurs over multiple systems, as it is an interdisciplinary approach that is person centered and assessment based in order to combine health care as well as social support services. As Chair (2009, cited in Gaikwad, 2009, p. 8) suggests, "the individual's needs and goals are assessed and a care plan developed to address those needs and goals".

There are several key aspects involved with the coordination of such care and services. An individual must have a general understanding of important services that they need for their condition(s), as well as what services are available to meet such needs and which needs require self-management. Care coordination also includes making sure that the person with TBI and/or their caregiver want to participate in the program, have a personal relationship with the care management educator, and then actually receive information and encouragement from that educator. These care coordination services should be provided by a chronic care manager, who often is a physician, but often also

include a physician's assistant, nurse practitioner, or social worker (S. 1340, 2007). This act additionally suggests that any other health care providers involved with the patient should work together with and collaborate with the physicians or other chronic care manager.

Working as a health care team often results in better decisions being made for the PWD, as well as a further understanding of what else he/she is going through. This in turn negates the need for the individual with brain injury to continually repeat information to each healthcare provider that they encounter. However, probably most importantly, the family and patient must be important team members throughout the process and should be included in major decisions by the care team (AAP, 2005).

Often times, care coordination involves the topic of co-occupation, which is when more than one person shares a common occupation. People with disabilities frequently share occupations with a family member, significant other, or caregiver when the PWD is unable to independently complete the occupation(s). Subsequently, it is important that all individuals involved work well together to accomplish the co-occupation, focusing on their abilities to work together. This is why a supportive significant other must be included in evaluations, goal planning, and important care team meetings. But ultimately, without a primary care physician, it is very unlikely that a person's services can be determined, as the physician is often the core of the medical care coordination.

As mentioned, only a few professions have historically taken on the role of a care coordinator. This may be because these professions typically involve a certain skill set

which also aligns well with care coordination. A care coordinator must have the time to fully participate in the team process of care coordination, as well as time to learn about various systems and services, and build relationships with other health care professionals and the patient and their families. This can prove to be difficult for many primary care physicians in that they are often very busy every day, allowing for little extra time to conduct the timely process of coordination of services. This is why other health care professionals at times act as the primary care coordinator. Not much has been written on the core functions that must be required of someone in order to fit the care-coordinator role, as well as possible requisite training and methods for implementing and evaluating this service (McAllister et al., 2007). However, some health care professionals have described the skills that they feel are often needed in order to coordinate care, including: knowledge of resources, knowledge of the healthcare field, teaching skills, computer skills, organization, scheduling skills, assertiveness, observation skills, and advocacy. In addition, it is crucial as a care coordinator to exhibit empathy, compassion, understanding, and communication (McAllister et al., 2007).

With that said, it is also crucial to recognize what some common barriers to the coordination of care are. These may include: funding issues, lack of transportation, insurance coverage, attitude of the family, attitude of the patient, and distance from hospital/health care center, among others. Kroll and Neri (2003) indentify that frequent barriers include: insufficient communication among providers, lack of time and effort from physicians in coordinating care, and a lack of disability-specific knowledge from other providers. These barriers can cause many consequences to care coordination, and

have been reported as being directly correlated with quality of care by the patient, including lower levels of patient satisfaction (Matlow et al., 2006). These same researchers also found that "poor coordination is associated with increased medical errors, morbidity, and mortality" (p. 85), and that in contrast, "better coordination of care is associated with higher levels of perceived health status and receipt of preventive services".

Things like team organization, back-up plans, and various methods of communication have been reported as making care coordination easier on a personal level, in order to enhance access to services and resources, promote optimal health and functioning of the PWD, as well as improving their quality of life (McAllister et al., 2007). This same article states that "care coordination has the potential to greatly increase the overall value of primary health care" for people with disabilities and their families, because it has an impact on clinical, functional, satisfaction, and cost or resource outcomes (p. 726).

McAllister et al. (2007) identified six separate domains which are involved in the coordination of one's care needs: patient activation, delivery systems design, decision support, clinical information systems, community linkages, and health policy. In order to educate someone on how to potentially help to coordinate their own care needs, one must integrate these six domains, with the addition of custom domains when working with individuals whom have had brain injuries. This same study identified that a variety of different methods to providing these domains through care coordination have evolved within primary care, but they can be generally categorized as either designated or

delegated. However, there is often the unfortunate reality that the PWD and SSO must coordinate care without any help from others.

-Designated Approach: All care needs that emerge during a time-limited office visit are distributed across a group of available staff.

-Delegated Approach: "In a delegated approach to care coordination, care needs are assigned to a specific coordinator or staff person who is designated to provide some care-coordination services" (McAllister et al., 2007, p. 729).

- Facilitative Approach: A different model of care coordination, known as facilitative care, has been said to be more effective and sustainable. Facilitative care coordination is thought to be a more team-based method to providing needed services. In this model, care coordination tasks and services are shared across the entire team, including the family, clinicians, and the person or persons with the special responsibility for ensuring coordination of care (McAllister et al., 2007). One major advantage to this approach is that the various coordination tasks and responsibilities are spread out across the entire care team, rather than lying squarely on the shoulders of the already overly busy physicians. But no matter what method of care coordination is chosen, it is always of the utmost importance to ensure that the PWD and/or SSO is an active member of the team and that they

are able to learn and remember what is needed in order for their care coordination services to be met.

Another important aspect of care coordination involves memory, especially from the PWD and/or SSO on how to perform their care coordination activities. Cicerone, Mott, Azulay and Friel (2005) performed a review on cognitive rehabilitation that referenced a number of different areas involved with memory and cognition. Their research suggests that the use of externally directed assistive technology memory aiding devices such as pagers, lists, and voice recorders can significantly "benefit people with moderate to severe memory impairments" (Cicerone et al., 2005, p. 948), which includes many individuals who have had a TBI or ABI. Interestingly, Powell, Heslin and Greenwood (2002) found evidence that suggests that even several years after an individual sustains a TBI, functional gains can still be made in terms of self-organization and psychological rehabilitation while working in an outreach treatment group in the community. This is another point that helps the prospective idea of using a survey to help identify problems in one's care coordination and implement changes to improve the individual's care.

Measures of Care Coordination

The Assessment of Health Plans and Providers by People with Activity Limitations (AHPPPAL):

When developing a survey to measure one's level of care coordination, it is important to first understand any previous measures of care coordination. The Assessment of Health Plans and Providers by People with Activity Limitations (AHPPPAL), developed by Mathmatica, focuses on primary care and healthcare. It is a lengthy modification of the Medicaid Consumer Assessment of Healthcare Providers and Systems (CAHPS), which was "revised to address the needs of adults with physical, sensory, and/or cognitive disabilities" (Palsbo & Mastal, 2011, Abstract section, para. 1). One major point of interest for this measure of care coordination is that it can be administered to anyone, including individuals with disabilities, and also can be administered in various forms, most notably over the phone. The AHPPPAL Survey was tested with three different Medicaid plans in California, summing a total sample of 1086 participants enrolled in Medicaid due to a disability. This observational study found that the disability caused a larger bias on health plan ratings, as well as specialist ratings, than demographic factors did (Palsbo, Diao, Palsbo, Tang, Rosenberg, & Mastal, 2010). In addition they also wrote that "self-reported activity limitations incorporating standard questions from the survey can be used to create a disability case-mix index and to construct profiles of a population's activity limitations" (p. 1339).

But just as almost all other research has its strengths and weaknesses, so too does the AHPPPAL. The survey may prove to be too long for certain individuals, therefore

causing them frustration. The topic of community services is exceptionally varied, and free-response options in the survey prove to also be a limitation. Although the survey asks whether the respondent had someone help them complete all of the items, there seems to be no other mentions of attendant care and needed home supports. In addition, the narrowed equipment questions regarding medical supplies and mobility and breathing equipment does not allow the AHPPPAL to cover all categories of needed equipment.

After reading through the rest of the survey, many similarities and differences are noticeable. Both the AHPPPAL and the CASCAM have well-worded items which help to obtain valuable information regarding recent healthcare experiences. Some of the other similarities between the two surveys include: health plan/written care plan items; transportation items; care coordination items (although the AHPPPAL does not cover the topic in depth); functional activity limitation items; and demographic/diagnostic information.

In terms of differences, the AHPPPAL covers the role and actions of respondent's primary care physicians more in depth, as well as medications, and reproductive health. It also presents with a higher number of broad questions than the CASCAM, particularly due to the specificity in respondent diagnoses the CASCAM covers. Lastly, the CASCAM covers community activities, and goes more in depth into the topics of attendant care/needed home supports, as well as equipment.

Patient Assessment of Chronic Illness Care (PACIC):

Another important reference to the topic of chronic illness care and coordination is the Patient Assessment of Chronic Illness Care (PACIC). Glasgow, Wagner, Schaefer, Mahoney, Reid and Greene (2005) conducted development and validation of the PACIC, which they describe as "designed to complement the ACIC by providing a patient perspective on receipt of chronic care model-related chronic illness care. The PACIC collects patient reports of the extent to which they have received specific actions and care during the past 6 months" (p. 437). The survey started out with 20 items, but was later improved in order to sufficiently cover diabetes management. Additional items need to be added for other serious chronic conditions, as well as a flexible set of items for patient-centered, individual items, which most likely would need to be qualitative in nature. But no matter the specific set of items, it is useful as a brief, validated self-report to determine the extent in which patients with chronic illness receive care that correlates with the Chronic Care Model (CCM), which can be defined as "care that is patient-centered, proactive, planned and includes collaborative goal setting, problem-solving and follow-up support" (Glasgow et al., 2005, p. 436). This evidence-based model of care turns away from the reactive acute-oriented care and focuses on reviews of literature in order to provide individuals with effective, efficient care. Glasgow et al's (2005) study, involving a sample of 283 adults, focused on the six key dimensions of CCM: organization of health care; clinical information systems; delivery system design; decision support; self-management support; and community resources. They reported that the written version of the PACIC takes on average about two to five minutes to complete, whereas the version

taken over the phone can take between seven and eight minutes. Each item is scored on a 5-point scale, ranging between 1, meaning no/never, and 5, meaning yes/always. The 20 questions could be grouped into five broader groups, of which each was scored by averaging the five items in their contents, with the overall score being an average of all 20 questions. Upon analysis, Glasgow and his colleagues found that the PACICs 5 scales, as well as its overall score, have good internal consistency. Moderate correlations were found between the PACIC and age and gender, number of chronic conditions ($r= 0.13$), as well as primary care and patient activation ($r= 0.32-0.60$), and was unrelated to education. Due to the inter correlations among the different scales, the research team pointed out that some respondents may not be able to recognize differences among subscale constructs. With that said, an advantage of the PACIC is that these futile items can be removed for situations where deemed appropriate to do so, thus lessening confusion, as well as time, for the respondents.

Client Perceptions of Coordination Questionnaire (CPCQ):

A third relevant questionnaire to this common topic of care coordination involves the Client Perceptions of Coordination Questionnaire (CPCQ), which addresses care and service needs in a primary medical care setting in Australia. Though it does not address a more complex healthcare setting like the one here in the United States or focus solely on people with disabilities, it is still evident that there is overlap as well as relevance to the CASCAM.

The CPCQ is one of the first instruments made to incorporate information from multiple services delivered by multiple agencies, over time, and for all health problems in

a short, self-administered instrument (McGuiness & Sibthorpe, 2003). It was developed

through iterative item generation, within a framework of six domains of coordination

(identification of need; access to care; patient participation; patient-provider

communication; inter-provider communication; and global assessment of care), and

addresses four sectors of health care provision (overall care; general practitioner care;

nominated provider care; and carers). These items are expressed as questions, regarding

how often specific aspects of care were experienced by the respondent (i.e. How often did

you….?) in order to collect information across providers and over time (McGuiness &

Sibthorpe, 2003). Originally, the instrument was to be used primarily with elderly

individuals with chronic health problems, but later expanded to 32 items and can now be

completed by either the patient or their carer. McGuiness and Sibthorpe (2003) found that

out of the six scales described earlier, "the first four scales were satisfactory, but the

client scales were inadequate with poor internal consistency, and convergent and

discriminant validity. People with chronic pain syndromes had significantly worse

experiences for almost all items, supporting construct validity" (p. 309). But seeing as

how this was one of the first instruments to attempt to measure coordination of

healthcare, it provides an excellent starting point for further development in the topic.

Some of the CPCQs strengths include its ease of completion, transferability, and

construct validity. In contrast, problems with collecting data regarding the respondent's

contributions to coordination highlight the lack of theoretical development in this area

(McGuiness & Sibthorpe, 2003).

The CPCQ has provided many other survey developmental teams with starting points, including the CASCAM. Some of the areas addressed in the instrument (transportation, coordination, satisfaction of care, and access to services) have been included in the CASCAM. These include several items that take on the same item response style as the CPCQ, in order to collect information across time, as well as types of health services.

Care Transition Measure (CTM):

The CTM was developed in order to determine the quality of care transitions across healthcare settings, focusing on being patient centered, rather than provider centered, due to the fact that most measures addressing care transition of care coordination and continuity focus exclusively on the primary care physician (Coleman, Smith, Frank, Eilertsen, Thiare & Kramer, 2002).

Upon completion of the draft CTM, Coleman et al. (2002) asked both patients and their caregivers to review each item, as well as four members of the research team who each belonged to different professional backgrounds. These professional experts compiled the instrument's items into four domains afterwards: Information Transfer; Patient and Caregiver Preparation; Support for Self-Management; and Empowerment to Assert Preferences. Upon review of the original instrument, the research team found that a single version of the CTM could not account for the different possible transitions that occur, prompting the development of three separate versions: hospital to home; hospital to home with home skilled nursing care; and hospital to skilled nursing facility to home, with or without home skilled nursing care, although these are not the only important

transitions to an individual in the healthcare system. In addition, the CTM changed to include several types of item responses, as the team found that the same Likert-style response type was not suitable to all instrument items. After these changes, "the face validity and comprehensiveness of the CTM was well received by both patients and clinicians" and that "there is no similar transition measure to the CTM to facilitate a direct comparison" (Coleman et al., 2002, p. 6). This helps to show that the instrument may be able to help fill an important gap in health system evaluation for individuals in that it is successfully able to measure the quality of care delivered across many settings from which they may receive care.

These well calculated, thoughtful changes to the CTM helped to back the instrument with a multitude of strengths. One of the first that may come to mind is that the measure is derived from real experiences, both positive and negative, from patients and their caregivers, as opposed to many other measures. As can be seen by the multiple changes made to the instrument, the research team held the insights, reactions, and opinions of the patients in high regard, and these responses served as a major guide for development. It was also found that "the CTM domains represent more than just a process of care measure. These domains reflect less tangible yet critical components of transitions that include fear and anxiety, empowerment, and caregiver support" (Coleman et al., 2002, p. 7). But ultimately, the CTM should be considered a strong and effective measure in that it was developed using both qualitative and quantitative approaches.

As with the other previous measures, the CTM served as inspiration for the creation of the CASCAM. Some of the similarities include using various item response

styles, rather than just Likert-style, in order to best suit all types of questions; comparing CASCAM items to relating instruments because of the absence of a gold-standard comparison; asking experts, as well as knowledgeable respondents, to review CASCAM items; and making more than one version of the questionnaire in order to better approach the different experiences of future respondents.

Tailored Caregiver Assessment and Referral (TCARE):

The TCARE is a manual-style protocol that was created in order to assist care managers who work with older adults and their family caregivers (Montgomery, Rowe, & Jacobs, 2010). It was designed using the Caregiver Identity Theory, which emphasizes caregiving as being a systematic process of identity change. This change significantly influences the amount of stress and burden which a caregiver experiences (Montgomery et al., 2010). The TCARE uses six core care coordination and management elements: Conduct an Assessment; Interpret Assessment; Identify Appropriate Goals, Strategies, and Services; Consult with the Caregiver; Develop a Care Plan; and Conduct Follow-Up and Evaluate Progress. The table below describes the amount of subjective face validity transferability that exists between these elements and the coordination of care and services for people with brain injury.

Table *1*

Transferability of TCARE Elements of Care Management to the Care Coordination of Stable, Independent People with Brain Injury in the Community

TCARE Element of Care Management	Degree of Transferability*	Comments Regarding Transferability
Conduct an Assessment	1	Whereas the TCARE process stresses that the assessment must be conducted in person, care and service management for individuals with brain injury in the community can also be done over the phone or through email. However, both of these topics emphasize that an initial assessment of needs must be completed to identify strengths and signs of concern.
Interpret Assessment	2	Interpretation of the assessment allows one an overview of the needs and services which are likely to be required. But the coordination of care and services for people with brain injury in the community tends to focus more so than the TCARE on which things that the PWD finds most important and cares about most. Thus, at a glance it tends to include the desires of the PWD more.
Identify Appropriate Goals, Strategies, and Services	1	While the TCARE attempts to identify goals that will most benefit the caregiver, our model of service coordination focuses more so on the PWD.
Consult with Caregiver	1	While the TCARE emphasizes that the plan of care be decided to feed to the caregiver's strengths and needs, coordinating care and services for people with brain injury attempts to tailor the plan to the PWDs strengths and needs. Although some amount of tailoring to the caregiver may be done if the PWD is very low functioning, it is important to keep in mind that many people with brain injury in the community have no caregivers at all.
Develop a Care Plan	2	Both models stress the importance of using a care plan to mutually decide upon goals, strategies, and services that are most appropriate. It also is used as a road map for everyone working together and can be used to monitor, evaluate, and reflect progress. But whereas the TCARE focuses on including the caregiver, our model attempts to include the PWD in the process of creating a care plan as much as possible.
Conduct Follow-Up and Evaluate Progress	1	The TCARE seems to conduct follow-ups and evaluations at a level of progression which our model would like to attempt to achieve as well (every 90 days). Both ideas stress the importance of follow-ups in order to re-evaluate how things are going, but often times it is difficult to do so with people with brain injury in the community.

0= Not Transferable; 1= Partially/Slightly Transferable; 2= Mostly Transferable; 3= Completely Transferable

In short, it appears that the elements of TCARE that transfer most to the stable, independent living TBI community are those of interpreting an initial assessment, and developing a plan of care. This may be because the actions of care coordination itself tend to more so rely on planning, communication, and brainstorming with others, which these two areas seem to include more than the other elements. The methods of actually conducting initial assessments and implementing strategies, however, seems to be what differs between these two topics. This is why the elements of TCARE that include conducting an assessment and conducting follow-ups may be the areas of least transferability to care coordination for people with brain injury in the community.

The Patient Activation Measure (PAM):

The final care coordination measure that was researched, and found that it also overlaps with the CASCAM in several areas, was the Patient Activation Measure (PAM). The topic of patient activation includes education, self-management, and care coordination. A patient who is activated is one who is knowledgeable of their condition and diagnoses, demonstrates the necessary skills to manage their condition, and also has the confidence and ability to collaborate with providers and access needed services (Fowles, Terry, Xi, Hibbard, Bloom, & Harvey, 2009). It is "a measure of activation that is grounded in rigorous conceptualization and appropriate psychometric methods" (Hibbard, Stockard, Mahoney and Tusler, 2004, p. 1006). This instrument relies heavily on the principles of the Chronic Illness Care Model (Bodenheimer, Lorig, Holman, & Grumbach, 2002), which emphasizes patient-orientated care, as well as patient/family integration into the care team, similar to the ideas of care coordination. In addition, those

who receive chronic and ongoing care must play an important part in maintaining their own functioning, and a major role of health care professionals should be to encourage these individuals in this activation (Hibbard et al., 2004). These researchers also implemented into their instrument the idea of being engaged and active in one's own care, as well as the relationship between self-efficacy, preventive actions, and health outcomes.

Hibbard and her colleagues administered their instrument via telephone interviews to participants with their 75-item PAM, as well as a limited set of demographic and health status questions. Upon analysis, it was found that the PAM appears to be valid and reliable in measuring activation. "The measure has strong psychometric properties and appears to tap into the developmental nature of activation. Because the measure is highly reliable at the person level, it is possible to use it on an individual patient basis to diagnose activation and individualize care plans" (Hibbard et al., 2004, p. 1023). With that said, it can be seen that the PAM may be useful for both creating interventions and in evaluating already implemented ones.

Because the ideals behind the PAM align very closely to those of the CASCAM, it is evident that the methods used by Hibbard et al. (2004) should also be used for the CASCAM. This includes both of the instruments processes of development. The PAM was developed over four stages, similar to the CASCAM. In addition, performing the interviews over the telephone is easy and convenient for most respondents. As a result, this option too is included into the CASCAM. Over time, the PAM has been revised in order to reduce the number of items, and has done so with a 22 item full version and 17

item short form version, with no loss of reliability or validity (Hibbard et al., 2005). This was done through using Rasch psychometric methods, which is an area of future development that may be appropriate in order to shorten the length of the CASCAM without losing precision.

But while the PAM assesses an individual's knowledge, skill, and confidence for self management (Hibbard et al., 2005); it lacks items to determine exact care gaps. Although it touches on care coordination, the PAM does not capture the full essence of an individual's experiences. Rather, it can be used for a quick, concise estimation of the amount of confidence an individual has related to the coordination of their care.

In summary, the following describes shortcomings of the measures related to care coordination which were described previously, prompting further appropriateness for the use of the CASCAM.

- The Assessment of Health Plans and Providers by People with Activity Limitations (AHPPPAL): This very long assessment only briefly addresses care coordination. Furthermore, the AHPPAL does not address the SSO and his or her contributions, opinions, and experiences related to the coordination of services for the PWD.

- Patient Assessment of Chronic Illness Care (PACIC): The PACIC provides patient's perspectives on receipt of Chronic-Care Model related chronic illness

care. However, this short measure does not address activities relating to searching for or attempting to access services.

- Client Perceptions of Coordination Questionnaire (CPCQ): The questionnaire does not address complicated health care systems, such as the one in the United States.

- Care Transition Measure (CTM): Used to determine the quality of care transitions, the CTM applies to people with brain injuries and their SSO at times of transition, such as from hospital to home. However, the topic of care coordination goes far beyond that of the transition of care and services.

- Tailored Caregiver Assessment and Referral (TCARE): Although the TCARE effectively takes the SSO and/or caregivers into account, it subsequently lacks sensitivity to the considerations of the PWD for decisions. As such, it is limited in focusing on tailoring care to the caregiver's strengths and weaknesses.

- The Patient Activation Measure (PAM): This measure emphasizes family involvement, prevention, and education. However, it lacks items to determine exact care gaps faced by the PWD and any SSO. Furthermore, it provides only a basic estimation of the PWD's confidence related to experiencing coordination of care and services.

As a result, the CASCAM is effective to be used for care and service coordination and management over the previously described measures in that it addresses the following:

- Differences between complex medical and independent living needs

- Difference of experiences between PWD and SSO

- Experiences related to care coordination across all stages of recovery

- Opportunities for PWD and SSO to describe experiences in their own words

- Consideration of PWD and SSO experiences and opinions equally

- Exact and detailed care gaps faced by the PWD and SSO

Written Care Plan

One of the major goals of care coordination "is achieved in part through the development and implementation of a specific care plan by a variety of service providers and programs in an organized matter" (Gupta, O'Connor & Quezada-Gomez, 2004, p. 1517). Care plans are beneficial in that they allow for the documentation of any important history, as well as needs, services, corresponding therapeutic and educational interventions, and contact information to important members of the care team. Written care plans essentially provide the who, what, where, when, why, and how of service needs for patients (Individualized Health Plan, 2011). In addition, the written care plan ensures that the duplication of services and confusion about goals, treatments, and

responsibilities are prevented throughout the entire care coordination process (McAllister et al., 2007).

The person with TBI should receive an individualized written care plan including which needs they have, what services are required (and have or have not been met), any potential barriers to receiving services, as well as what skills and knowledge are needed in order to access them. This care plan helps to prioritize goals for the PWD, determine interventions to reach those goals, and decide which individuals will work with the PWD in certain areas of the plan. The care plan is developed by the patient's treatment team, along with the input of the patient and their family, in order to fully determine the individual's status and specific needs (Montana Department of Public Health and Human Services, 2011, p. 1). "An initial plan of care must be developed prior to the person's enrollment. Subsequent plans of care must be completed at least annually or when the consumer's condition warrants it" (Montana Department of Public Health & Human Services, 2011). This continuous process of revamping the care plan allows anyone associated with the care of that individual to quickly learn, at a glance, what events, medications, developments, and interventions have taken place over the duration of services for the patient (Dellefield, 2006). As a result, incoming health care providers will not then repeat any routine tasks or questions for the patient, subsequently lessening any inadvertent stress. In addition, the patient, along with their SSO, should be provided with a copy of the plan. It must be revised based on the changing care needs and services that the individual requires at that point and time through individualized guidance and informational supplies. However, at the same time, "the care plans must be thorough, yet

brief enough to be useful" (Sox, 2011, p. 1). This will ultimately help to lessen what is often considered one of the largest problems to care coordination and written care plans-- time constraints (Sox, 2011).

Community Activities

As discussed earlier, the inability that people with TBI often have to effectively use new information as a result of their injuries tends to result in concrete thinking, inability to appropriately apply rules, and trouble distinguishing relevant from irrelevant information (Lundy-Ekman, 2007). This creates a challenge as to providing education and information that will help these individuals when faced with having to do things like navigating the healthcare system, scheduling appointments, and remembering which healthcare service is located where. Other cognitive factors, such as decreased motivation and positive outlook due to the subsequent depression following a TBI, also offer another hurdle in providing care and needed services. Other common effects often caused by TBI include difficulties in problem solving, initiating activities, or understanding the underlying meaning of activities (Pedretti, 2006).

Turner, Ownsworth, Cornwell, and Fleming (2009) discovered that a large contributing factor to this post-injury depression was due to differences in desired vs. actual participation in the community. This subsequently experienced depression is much different from the depression experienced after many other serious injuries and can often be reactive. They found that while still in the hospital, individuals often had much higher

expectations for themselves upon discharge than they could actually accomplish when they re-integrated back into their community. If so, this might imply that getting the individuals with TBI to get out of their homes more often and participate in different programs, like self-management and/or care coordination training, would help them to keep up with their expectations of participation that they made while still in the hospital. According to Hassett et al. (2009), participation in an outpatient exercise program for individuals with TBI produced better adherence, was safer to implement, achieved more goals, and was a more motivating environment for the individuals, when compared to a home-based exercise program. Although this study focused on physical exercise, some of the same findings may result when looking at someone's ability to coordinate care. This study hypothesized that the friendly and supportive social environment associated with the exercise clinic led to many of the improvements, including increased motivation, over those who conducted the same exercise program in their homes.

In a different study, Goverover et al. (2007) found that there was a positive correlation between improving self-awareness and IADL performance, which includes care coordination, seen in individuals with acquired brain injuries. This was done by having participants perform activities that they had done frequently in the past, but rate how they thought that they would do before actually performing the activity, and then yet again post-activity. Self-awareness is usually very dismal after a TBI or ABI, and usually returns gradually. But the use of this type of self-awareness intervention could prove to be very relevant and useful to health care providers of any setting.

In a separate review, Teasell et al. (2005) focused on epidemiology and long-term outcomes following acquired brain injury. Among the conclusions, it was confirmed that there is also a strong positive correlation between the severity of a brain injury and the individual's subsequent productivity in their community. Bombardier et al. (2009) found that basic OT interventions of improving function after a TBI also have a significant impact on decreasing the individual's depressive symptoms. This information helps to support the above premise that having an outpatient program (such as a support group) helps to improve the motivation and overall mood of someone who has had a brain injury.

In contrast, Bell et al. (2005) found that scheduled telephone counseling and education improved individuals with brain injuries' functional status and quality of well being, when compared with usual outpatient care. This is a much more cost effective and convenient treatment for both the client and health care provider, and should be looked into further. One other study by Ponsford et al. (2006) also found evidence to show that this type of in-home treatment may also be more cost effective while working with people who have had a brain injury. They found that the costs associated with outpatient, center based treatment was higher overall because of factors such as treatment session costs, travel costs, and costs of attendant care. This is crucial to keep in thought when taking into consideration the financial burden that having a disabling injury, like a brain injury, can have on a person and their family. Even if the effects are not as distinct and fast paced, some individuals and their families may prefer to have a more financially

stable and affordable type of intervention, rather than one that will plunge them further into debt.

Methods

Literature Search

The electronic databases Medline with Pub med, UWM library search engine, CINAHL, EBSCOHOST, Google Scholar and Evidence Map were used to find research articles that related to the topics surrounding care coordination for individuals with TBI and/or ABI. Some common search terms included: "care coordination", "brain injury", "written care plan", and "self-management". After findings several articles, additional articles of interest were identified through citations and references of those initially read. This information was helpful both for the acquisition of background knowledge related to care coordination, as well as to development of the CASCAM as well.

Survey Development

The CASCAM has been slowly refined over several years of work and prior research in the area of care coordination for people with disabilities. The initial questionnaire was developed by Dr. Mark Johnston in 2006 as part of a Research Growth Initiative (RGI) at UW-Milwaukee, and has then been restructured over the past six years to address various issues and populations. This original questionnaire was inspired

following an informal review of similar surveys, such as the PAM, AHPPPAL, PACIC, CPCQ, TCARE, and CPM. In addition, two research projects and one master's thesis helped to evolve this initial questionnaire into what is today the CASCAM (Satariano, 2009; Jannsen, 2009; Gaikwad, 2009). Out of these, Gaikwad's (2009) thesis--on care coordination for children with disabilities--provided the main background and foundation for the CASCAM, as the two topics were most relevant and similar to one another. The CASCAM had various limitations and problems which were addressed in the initial draft (Appendix A).

The initial questionnaire developed several years ago was 37 (adult version) or 49 (children version) pages long, which provided a large limitation to data collection. In response, Gaikwad (2009) shortened the survey to 18-20 pages, while still retaining the most important items. This version also allowed the participants to skip certain sections if they regarded the sections as not being relevant to their situation. Later on, Kathy, a research assistant, began this current research project in the fall of 2010, before leaving in the winter of 2010. Upon her departure, a new research assistant, Brian, was brought on to work with Dr. Johnston on the development of the CASCAM. Kathy and Dr. Johnston had worked to convert the questionnaire from what was used during Gaikwad's (2009) research, into the initial questionnaire that was used to create the CASCAM (see Appendix A), in order to be suitable for people with TBI and/or ABI as well as their SSO. This original questionnaire was later revised through re-wording and adding items based on the suggestions made by early participants, as well as Dr. Johnston. Feedback from participants was crucial to these revisions, and after doing so, these same

individuals were asked to complete the new items for the revised, operational survey which was used for the current research (Appendix B). The years of work put into these various surveys have allowed the surveys to be used as screening tools, the results of which help to indicate areas requiring further investigation (Gaikwad, 2009).

When formatting a questionnaire, Taylor-Powell and Marshall (1998) offer several guidelines, many of which have been incorporated into the CASCAM. For example, a questionnaire should begin with a short introduction, including the survey's purpose, and then begin with several easy questions. The entire questionnaire should have a natural flow, to achieve a logical progression of topics. In accordance with this, it is important that numbered responses have the same meanings throughout the questionnaire consistently (for example, 1= No and 2=Yes the whole time, for example). Another important principle which they emphasize is that "Questions and answers are easiest to read if they flow vertically. By placing answer choices under questions (rather than side by side), the respondent moves easily down the page" (Taylor-Powell & Marshall, 1998, p. 12). Throughout the development of the CASCAM, several formatting changes such as these have taken place in order to make the questionnaire easy to follow, understand, and complete (see Appendix B).

Taylor-Powell and Marshall (1998) describe four different types of information that can be identified through questionnaires: knowledge, beliefs/attitudes/opinions, behavior, and attributes. Each one of these types of information can provide essential data that may be able to solve any number of questions or hypotheses. The CASCAM has been made to incorporate all of these types of information, with specific knowledge being

focused on to a greater extent than others. Participants' attributes are of a high importance in many medical and health studies, and this holds true to this study and the CASCAM. But information regarding PWD and SSO beliefs, attitudes, opinions, and behaviors are of a particular concern in the CASCAM. It is this information which is able to identify strengths and limitations of current or past care coordination practices, and then to improve upon those previously used.

In general, questions regarding knowledge, behaviors and attributes are considered easier to write than those focusing on attitudes (Taylor-Powell & Marshall, 1998). This is because, as these same authors write, "Questions concerning attitudes tend to be more difficult to write given the complexity underlying most attitudes" (p. 3). This information, as well as the behaviors underlying CASCAM questions, serves as the basis for possibly answering some major questions regarding care and service coordination for people with brain injuries.

The CASCAM survey collects quantitative data, although there are miniscule qualitative elements. However, it should be noted that the CASCAM is not considered a mixed-methods design instrument. These elements include the use of open-ended questions and being open to additional comments and any other participant perceptions and/or reactions throughout the interview. Major sections of the CASCAM include:

- Background: Both general, as well as health background of the PWD. This section involves both open-ended questions, as well as quantitative, multiple choice items. The items in this section of the operational questionnaire that was used

(Appendix B) include items A1 through A21. This section is useful for understanding to what degree the PWD coordinates their health/rehabilitation and independent living services, who (if anyone) assists them in these tasks, and allows for a clinical/personal history of the PWD.

- <u>Care Coordination Activities for Health and Rehabilitative Needs:</u> This section uses a likert scale in several items to determine how often (0 being never and 5 being several times a day) the participant performs certain care coordination activities involved with health and rehabilitative needs, in order to collect quantitative information. There are additional questions in this section which use both open-ended questions and multiple choice items in order to gain a further understanding of efforts and difficulties that the participant has experienced, if they have ever used preventative health services, and to determine if the PWD has a trained professional whom they trust who can help them with any health/rehabilitative issues. The items in this section of the operational questionnaire that was used (Appendix B) include items B1 through B26.

- <u>Care Coordination Activities for Independent Living Needs:</u> This section uses a likert scale in several items to determine how often (0 being never and 5 being several times a day) the participant performs certain care coordination activities involved with independent living needs, in order to collect quantitative

information. There are additional questions in this section which use both open-ended questions and multiple choice items. These items serve the purpose of allowing for a further understanding of efforts and difficulties that the participant has experienced, and in determining if the PWD has a trained professional whom they trust who can help them with any independent living issues. The items in this section of the operational questionnaire that was used (Appendix B) include items C1 through C20.

- Questions about Both Health and Independent Living Needs: These questions are mostly open-ended, but also include several multiple choice items, that ask about health/rehabilitative needs and independent living needs together. These include items BC1 through BC8 in the operational questionnaire which was used (Appendix B). It is important to note here that although this section is organized in a separate heading from the others here (for organizational purposes), it is not considered one of the five main sections of the CASCAM because it is a combination of information belonging to the previous two sections.

- Written Care Plan: This section uses a likert scale in one item to determine how often (0 being never and 5 being several times a day), if ever, the PWD uses their written care plan (if they have received one at all). There are also multiple choice items in this section, which aim to determine what care needs any received written

care plans have covered. The items in this section of the operational questionnaire that was used (Appendix B) include items D1 through D4.

- Productive Community Activities: This section uses open-ended questions and multiple choice items to determine what activities the PWD enjoys, has difficulties with, or wants to pursue in the future, among other things. The items in this section of the operational questionnaire that was used (Appendix B) include items E1 through E21.

- Opinion Questions: Although not officially numbered in the CASCAM, these questions are designed to allow the participants an opportunity to give their thoughts on the questionnaire itself. The questions ask what improvements, if any, could be made, as well as what the participant thinks should be added or taken out of the questionnaire. These questions are the basis for survey development between the operational questionnaire that was used (Appendix B) and the final questionnaire that resulted after research concluded (available from authors).

The open ended questions used throughout the survey allow the participants to express their own thoughts and give specific details regarding the various areas involved with the coordination of their care, or the care of their close friend/relative.

Procedures

Community living people with TBI or other ABI, as well as the SSO of anyone with such a diagnosis, were recruited in person from multiple brain injury support group meetings throughout the greater Milwaukee metropolitan area, by email from the Brain Injury Association (BIA) of Wisconsin, and over the phone with friends and/or family members of people who had already participated. These support groups were found from both the recommendation of the BIA, or through internet searches for various centers and organizations in the Milwaukee metropolitan community. The research team had spoke with staff members at several Milwaukee area hospitals about putting up recruiting flyers at their facilities, but these negotiations proved to be unsuccessful. In addition, participants had to be at least 18 years of age or older.

Participants gave their consent to be involved in the study following the University of Wisconsin Milwaukee's Institutional Review Board (IRB) approval. The IRB approved this study as being of minimum risk, which is consistent with a protocol number of 08.043. It is also worth noting that no personal information was linked with any given responses and that the privacy of participants was regarded as being very important. No participants' names and/or actual initials were used in this paper and will not be used in any other future publications without a written approval by the participant beforehand. All information, both quantitative, as well as demographic, was saved in encrypted computer files (Microsoft Word, Microsoft Excel, and SPSS files) on a password protected computer in locked rooms. In addition, all physical information tying to any of the participants was also locked in a cabinet within locked rooms. Participants

were told that their participation and involvement in the study was entirely voluntary and that they were free to refuse to answer any questions for any reason or withdraw from the study at any time. In addition, all archiving and preservation of data, as well as data retention, was done in accordance with UW-Milwaukee policies and procedures.

Prior to partaking in the study, participants were provided with a letter that explained the workings of the research project, who was involved, and what the goals were (see Appendix C). Risks of participating were minimal, and there were no costs for participating, other than the respondent's time. Benefits of participating in this research included possible satisfaction in being a contributing member to research designed to improve the system of care, possibly learning educational or functionally relevant and beneficial information, as well as a $10 gift card.

Upon completion of the operational (Appendix B) CASCAM questionnaire, participants were recruited for several months. Initially, 50 participants were recruited, with 13 withdrawing over time. Subsequently, a total of 37 interviews were completed (23 in the PWD version; 14 in the SSO version). Individuals were initially asked what type of media they would prefer to have the questionnaire delivered to them through, as well as which dates and/or times they thought would work best for an interview to be conducted. Most interviews were conducted over the phone, but other strategies (email, in person, online Qualtrics: can be found at https://milwaukee.qualtrics.com/SE/? SID=SV_55D6NKkX6w98Ls0, physical mail) were also used in order to provide convenience for the participants. Interviews via the telephone took on average 30-40 minutes to complete, whereas interviews conducted in person took on average 45-50

minutes to complete. Before interviewing (or filling out the questionnaire through other means), the participants were encouraged to "think out loud", and comment on what they thought of the specific questions. This type of interviewing, commonly known as cognitive interviewing, was used in order to obtain honest and constructive responses and suggestions regarding survey items from participants. This participatory process allows for the researchers to either change these certain questions under scrutiny, or at least consider changing them. In order to ensure understanding by participants to accomplish this type of interviewing, questions were asked slowly and clearly.

No matter the method used, follow up interviews were available in order to clarify any responses or ask the participants any new CASCAM survey items. During interviews, participants were asked several times if they believed any questions were confusing, worded poorly, or were not relevant to the topic of care coordination for people with brain injury. If so, participants were then asked how they would suggest changing the items, as well as if any additional items should be added, or if any items should be deleted from the survey entirely. These suggestions and responses to specific questions are presented in table 2 below.

Table *2*

Participant Suggestions Regarding the Questionnaire in Entirety and Specific Items

Question	Participant Response/Suggestion
A13.) Do you have a chronic or serious health condition?	Does this cover secondary diagnoses, or completely separate diagnoses?
A15.) Do you have more than one condition?	Does this cover secondary diagnoses, or completely separate diagnoses?
B3.) Asking questions to providers (from "Care Coordination Activities for Medical and Rehabilitative Needs" frequency grid)	"Regarding what?"
B11.) Arranging for transportation. (from "Care Coordination Activities for Medical and Rehabilitative Needs" frequency grid)	"Can be read two ways"
B12.) Obtaining and transporting equipment or supplies. (from "Care Coordination Activities for Medical and Rehabilitative Needs" frequency grid)	Elaborate meaning more
B16.) Think of the efforts you have made to manage and coordinate needed, high quality health care and services. How successful have these efforts been?	"Hard question to answer"
B18.) Has getting access to high quality, needed services been a problem?	Specify about these more. Is it just medical services or more?
C1.) Searching for the care or services you need in your community. (from "Coordination Activities for Independent Living Needs" frequency grid)	"Confused from the wording" "Term 'searching' may be unclear"
C2.) Trying to get access to needed services (e.g. dealing with administrative and eligibility staff). This includes trying to insure continued access to the services you need. (from "Coordination Activities for Independent Living Needs" frequency grid)	"Confused from the wording"
C6.) Coordinating housing-related issues (from "Coordination Activities for Independent Living Needs" frequency grid)	"Should give examples"
C7.) Maintaining the household (may include cleaning, meal preparation, lawn care, etc). (from "Coordination Activities for Independent Living Needs" frequency grid)	"This item seems very similar to the last item"
C13.) Think of the efforts that you have made to obtain the care and services you need to live independently in the community. How successful have these efforts been?	"Question doesn't have much value"
BC3.) Which of the above activities requires the most effort for you?	"This question seems to cover what was already identified in the last question" (Referring to the previous question, BC1, "Considering both health and independent living needs, were any of the care coordination

	activities above stressful to you? If yes, which items are most stressful?")
Are any of the preceding questions confusing? Please write in comments or suggestions where there is space.	"Some questions are worded strangely"
Does anything need to be added? Please comment.	"Caregiver's concerns for the future" "Be sure to stay away from technical medical terms" "The questionnaire does not get at the emotion of things" Does the PWD care about the various issues (wellness, care plan)? Is it important to them?" "Information on day programs" "Does the PWD like/trust their current care provider(s)?" "Add some questions about relationships"

Questions and Hypotheses

This study aimed to develop a questionnaire and to evaluate its clarity, acceptability, and content validity. In addition, this research attempted to collect an exploratory description of care coordination and management experienced by people with brain injuries and by their family members in the community. Because of the exploratory nature of this research, there are several a priori expectations that were tested, which increased the statistical power of the tests, but there were also significant findings which came to light during analysis of those expectations.

It is important to first provide an overview of the participant population. To do so, important aspects of the participants must be described, including: patient demographics, limiting diagnostic conditions, commonly described care coordination activities, and a particular focus on describing the major burdens and problems participants reported.

The first research question addressed is which care and service coordination and management activities are most (or least) time consuming. It is hypothesized that

explaining one's needs would be a highly burdensome and time consuming activity, as evident by the "several times per day" option being the median.

The second question of this study is how do certain care coordination activities correlate with one another in terms of frequency. It is expected that there is a high positive correlation between participants listening to/learning from service providers, and participants asking questions to providers (as was seen in Gaikwad, 2009).

The last question is what are the gaps or needs faced by people with brain injury when coordinating care and services. Rather than test a hypothesis, this study's aim is to summarize and organize participants' answers into themes and trends.

Lastly this study looks at if the CASCAM questionnaire successfully addresses issues related to care and service coordination which apply directly to people with brain injury and their SSO. This is of extreme importance because this question may validate and clarify whether the CASCAM must go through further development or not.

After analyzing these questions, several findings which also contribute to the understanding of the care gaps which individuals with brain injury and their SSO experience are analyzed. Because of the relatively small sample, most information is exploratory and found through post-hoc analyses. These potential findings are added to the previously described information.

Data Analysis

All data were transcribed into the Statistical Package for the Social Sciences (SPSS) 17.0 analytic program. Once organized and coded, various analyses were run for each question and hypothesis. Quantitative data analysis included several internal consistency tests through the use of SPSS, which are described below in further detail for each of the four research questions.

Descriptive items were reported by running descriptive frequencies through SPSS to calculate percentages, means, ranges, upper/lower limits, medians and standard deviations for various items. The goal of this was to show what the sample population looks like, what their care coordination activities are, and to find additional interesting information.

The first question, focusing on which care coordination and management activities are most (or least) time consuming, was addressed using SPSS. The Kolmogorov-Smirnov and Mann-Whitney U tests were used to test the differences between groups and obtain medians. A Kolmogorov-Smirnov test, commonly referred to as a K-S test, is used as a means to test whether a sample comes from a continuous distribution. This test is appropriate for unequal samples, with no more than two groups. These nonparametric statistics are appropriate due to the relatively small sample sizes used, in addition to subsequent lack of normality and homogeneity assumed (Portney & Watkins, 2009). While running these analyses, the hypothesis used was that explaining needs is a highly burdensome and time consuming activity, as evident by the "several times per day" option being the median.

The next question, how do items describing frequency of care coordination activities correlate with one another, also was determined using SPSS. Spearman rank correlation coefficient values were calculated, in addition to an examination of internal-consistency (cronbachs alpha) between care coordination activities during medical/rehabilitation needs, as well as independent living needs. Benefits of using the Spearman rho include those previously listed for nonparametric tests. Since the data used is ordinal in nature, a Spearman rho must be used when determining inter correlations (Portney & Watkins, 2009). A two tailed test was used, as a directional relationship was not to be expected in all cases. The hypothesis used during this calculation was that there is a high positive correlation between participants listening to/learning from service providers, and participants asking questions to providers.

Third, it was asked what the specific gaps and needs are that people with brain injury in the community experience when coordinating care and services. This was addressed through observing and describing the participants' open-ended answers and categorizing them into evident themes and trends. The analysis of this followed a phenomenological approach, which implements a description of the meaning of lived experiences by several individuals regarding a concept or phenomenon (Creswell, 1998).

In following this approach, researchers attempt to identify the central underlying meaning of the individual's experience of both outward appearance and inner consciousness, from memory, meaning, and image. Creswell (1998) also writes that phenomenological data analysis "proceeds through the methodology of reduction, the analysis of specific statements and themes, and a search for all possible meanings. The

researcher also sets aside all judgments, bracketing his or her experiences and relying on intuition, imagination, and universal structures to obtain a picture of the experience" (p. 53).

Themes were developed based off of common phrases used by participants, as well as deciphering the underlying premise of each statement. In addition, another Occupational Therapy graduate student was asked to look over the participants' statements and categorize them into themes and trends as well, allowing for a kappa analysis of rater agreement to be conducted on the grouping and categorizing of those statements. Statements were categorized twice overall: once by the author of this text, and once by the additional Occupational Therapy graduate student. During instances in which the two Occupational Therapy graduate students did not agree in their choice of quotation allotment, an OT professor acted as an arbitrator for categorization. Kappa was calculated both before and after arbitrator involvement in this process.

In order to determine whether the CASCAM questionnaire successfully addresses issues related to care coordination and management that apply to people with brain injury and their SSO, a largely subjective process was used. Analysis was based on participant reports about questions and experiences with questions that they found confusing or thought should have been rephrased or explained differently. Many of the participants followed the instructions to "think out loud"- the standard procedure in cognitive interviewing (as described earlier). From these responses, we learned how participants understood the questions and how they might need to be rephrased, as well as if any

questions should be added or deleted. Rephrasing needs were directly addressed in the

questions on the respondents' opinions of the questionnaire at the end.

Results

Demographic Results

In total 37 participants completed the CASCAM, with 23 belonging to the PWD group

and 14 belonging to the SSO group. There were nearly twice as many men as women in the PWD

group (15 men, 8 women), and in contrast, there were almost twice as many females as males in

the SSO group (5 men, 9 women). It is also important to note that not every PWD reported

having a caregiver and/or SSO. Furthermore, people who sustained a brain injury ranged in

their time post injury from one and 45 years, with a mean post-injury length of 10.6 years. Table

3 below presents the self-described races of the participants.

Table *3*

Participant Self-identification of Race

RACE	PERCENT (n)
White/ Caucasian	91.9% (34)
African American	0% (0)
Hispanic	5.4% (2)
Asian	2.7% (1)
Other. Please specify	0% (0)

The majority of the participants making up this study described themselves as being Caucasian, with a small percentage also describing themselves as of Hispanic and Asian descent. The makeup of participant age was much more varying, with the mean age of individuals being 46.2, with a range of 59 years (SD= 15).

Out of these actual people with brain injury who filled out the survey themselves, as well as the people with brain injury that the SSO was referencing to while taking the survey, 87.5% were diagnosed with a TBI, with the remainder being described with having an "Other ABI". The majority of these other acquired brain injuries occurred due to a brain aneurysm, with a lesser amount occurring due to drug overdose. In addition, a total of 67.6% of participants noted that their injury (or the injury of the PWD whom they are a SSO to) was caused from a car accident or other similar traumatic event.

However, the brain injuries are not the only conditions that many of the participants have been diagnosed with. The secondary diagnoses described by the participants include: depression, epilepsy, musculoskeletal injuries, post-traumatic stress disorder, post-concussive syndrome, anxiety disorders, alcoholism, sleep disorders, and severe headaches. In addition, some of the other conditions that the participants were diagnosed with include: bipolar disorder, attention deficit disorder, bronchitis, cataracts, obesity, asthma, arthritis, and hepatitis C.

Care Coordination Activities

Tables 6 through 9 represent the total frequency for all care coordination activities reported by all participants. From these total responses, medians for all activities were

calculated. A value of 0 indicates that the participant has "Never" partaken in the particular activity; 1 indicates that the participant performs the activity "At least once per year"; 2 indicates "At least once per month"; 3 indicates "At least once per week"; 4 indicates "At least once per day"; and 5 indicates "Several times per day".

Several interesting frequencies are evident in tables 6 through 9, particularly when comparing between PWD and SSO groups. The SSO group reported a higher frequency rate when "Searching for Medical/Rehabilitation Services" (SMRS) and "Searching for Independent Living Services" (SILS) than those in the PWD group. This can also be seen for the items of attempting to access medical/rehabilitation services (TGAMRS) and independent living services (TGAILS). Other activity frequencies of particular note in which the SSO reported higher performance include "Managing Paid Attendants/Caregivers" (MPAC); "Locating Social Supports or Activities" (LSSA); Reading and Learning about Care Needs" (RLCN); and "Checking to Make Sure that thing Happen as Planned and on Schedule" (CTHPS). In contrast, it can be seen that the PWD group reported a higher frequency of "Scheduling Appointments and Services" (SAS).

Table *4*

List of Medical and Rehabilitation Abbreviations

Care Coordination Activities	Abbreviation
Arranging for transportation	AFT
Asking questions to providers	AQP
Checking to make sure that things happen as planned and on schedule	CTHPS
Explaining needs to others	ENO
Listening to and learning from service providers	LLSP
Making requests or demands	MRD
Monitoring the quality of services received	MQSR
Obtaining and transporting equipment or supplies	OTES
Reading and learning about care needs	RLCN
Scheduling appointments and services	SAS
Searching for medical/rehabilitation services	SMRS
Trying to get access to medical/rehabilitation services	TGAMRS

Table 5

List of Independent Living Abbreviations

Care Coordination Activities	Abbreviation
Coordinating housing-related issues	CHRI
Dealing with personal finances	DPF
Locating social supports or activities	LSSA
Maintaining the household	MH
Managing paid attendants/caregivers	MPAC
Managing unpaid attendants/caregivers	MUAC
Searching for independent living services	SILS
Shopping for personal needs	SPN
Trying to get access to independent living services	TGAILS

Table *6*

Total PWD Responses for Medical/ Rehabilitation Care Coordination Activities

Activities	Never	At least once per year	At least once per month	At least once per week	At least once per day	Several times per day	Median
SMRS	8	4	8	1	2	0	1
TGAMRS	3	8	5	7	0	0	2
AQP	3	8	5	7	0	0	2
ENO	3	4	5	6	4	1	2
MRD	8	2	6	4	2	1	2
LLSP	4	3	7	9	0	0	2
RLCN	7	3	7	1	4	1	2
SAS	4	3	6	10	0	0	2
CTHPS	9	1	2	3	7	1	2
MQSR	9	4	3	6	1	0	1
AFT	13	1	2	4	3	0	0
OTES	18	1	4	0	0	0	0

Table *7*

Total PWD Responses for Independent Living Care Coordination Activities

Activities	Never	At least once per year	At least once per month	At least once per week	At least once per day	Several times per day	Median
SILS	17	1	2	1	2	0	0
TGAILS	15	4	3	0	1	0	0
MPAC	20	0	1	1	1	0	0
MUAC	16	0	2	0	3	2	0
DPF	2	2	5	5	8	1	3
CHRI	6	0	5	4	5	3	3
MH	0	1	0	4	14	4	4
SPN	0	0	4	13	5	1	3
LLSA	2	2	10	7	1	1	2

Table *8*

Total SSO Responses for Medical/ Rehabilitation Care Coordination Activities

Activities	Never	At least once per year	At least once per month	At least once per week	At least once per day	Several times per day	Median
SMRS	3	3	5	1	2	0	2
TGAMRS	5	2	3	2	2	0	1.5
AQP	3	3	6	1	1	0	2
ENO	2	0	4	5	3	0	3
MRD	6	1	4	2	1	0	1.5
LLSP	2	0	9	1	2	0	2
RLCN	1	1	6	3	1	2	2
SAS	3	1	6	3	1	0	2
CTHPS	2	1	5	4	2	0	2
MQSR	5	1	3	3	2	0	2
AFT	8	0	1	4	1	0	0
OTES	7	0	3	2	1	1	1

Table *9*

Total SSO Responses for Independent Living Care Coordination Activities

Activities	Never	At least once per year	At least once per month	At least once per week	At least once per day	Several times per day	Median
SILS	6	4	1	1	2	0	1
TGAILS	7	3	1	1	2	0	.5
MPAC	9	0	0	3	1	1	0
MUAC	9	0	2	0	3	0	0
DPF	2	2	0	7	1	2	3
CHRI	5	0	1	5	1	2	3
MH	4	1	2	2	2	3	2.5
SPN	2	3	1	7	0	1	3
LLSA	2	3	3	5	0	1	2

Question 1: Time Consumption of Care Coordination Activities

All CASCAM care coordination activities for medical/rehabilitative needs and independent living needs were compared across PWD and SSO groups using Kolmogorov-Smirnov and Mann-Whitney U tests. In terms of medical and rehabilitative care coordination activities (from those listed in Table 4), no significant differences were seen between groups with any of the activities after running the K-S test. In terms of independent living care coordination activities, "Maintaining the Household" was the only activity found (from those listed in Table 5) to have a significant difference ($p\leq$ 0.05) between the two groups, with the PWD reporting increased rates. The Mann-Whitney U test found no significant differences between any of the care coordination activities. The hypothesis that explaining ones' needs to others would have a median option of "several times per day", was rejected both between groups ("At least once per week") and within groups (PWD: "At least once per month"; SSO: "At least once per week").

Question 2: Care Coordination Activity Frequencies

The overall degree to which the care coordination activities together form a homogenous group or scale (using classically test theory assumptions) was examined using cronbach's alpha. Alpha was as follows (not listed in tables): PWD medical/rehabilitation needs (α=0.826); PWD independent living needs (α= 0.774); SSO medical/rehabilitation needs (α= 0.945); SSO independent living needs (α= 0.883). Item-

total statistics for cronbach's alpha if an item was deleted were also calculated for these themes, with items from PWD medical/rehabilitation needs ranging between .774 and .827; PWD independent living needs ranging from .658 to .767; SSO medical/rehabilitation needs ranging from .935 to .948; and SSO independent living needs ranging from .852 to .878.

The inter relatedness of care coordination activities was explored in terms of inter correlations. These results are depicted in Tables 10 through 13, with Tables 4 and 5 explaining abbreviations used. All significant correlations have been noted with between one ($p \leq 0.05$), two ($p \leq 0.01$ level), or three ($p \leq 0.001$) asterisks. Following completion of the Spearman rho, there were many inter correlations found significant at the 0.05, 0.01, and 0.001 levels. Table 10 shows 19 significant inter correlations, with Table 11 having 11, Table 12 with 38, and Table 13 with 6. When interpreting these correlations, 0.00 to .25 is considered to have little to no relationship; .25 to .50 fair relationship; .50 to .75 moderate to good relationship; and above .75 is considered a good to excellent relationship (Portney & Watkins, 2009). In addition, these authors write that "these values should not be used as strict cutoff points" (p. 525). As such, it can be seen through tables 8 through 11 that there were 49 inter correlations between 0.00 and .25, 79 between .25 and .50, 57 between .50 and .75, and 19 larger than .75.

Regarding the hypothesis that "Listening to and learning from providers" and "Asking questions to providers" would show a high positive correlation, there was a significant correlation found within the PWD sample (r= .413; $p \leq 0.05$), but not in the SSO sample (r= .421).

Several noteworthy inter correlations from each table are described below:

Correlations among Medical/Rehabilitation Care Coordination Activities by PWD

The items with the highest inter correlation among those on Table 10 are "Trying to get access to medical/rehabilitation services" (TGAMRS) and "Asking questions to providers" (AQP) (r= .796; p≤ 0.001). This indicates that the two have a good relationship and that when a PWD attempts to access medical/rehabilitation services, they also tend to ask questions to providers. A possible explanation is that when attempting to get access to needed services, asking questions to providers regarding topics such as "Am I eligible for these services?", "Will I benefit from these services?", and "What is preventing me from gaining access to these services?" enable the individual to gain greater insight into both the services themselves, as well as what they need to do, from the provider's standpoint, in order to gain access to these services.

Also of significant and high correlation are "Explaining needs to others" (ENO) and "Making requests or demands" (MRD) (r= .784; p≤ 0.001). The actions of explaining one's needs to others and of making requests or demands are highly associated. When explaining to someone what services and/or assistance one needs, one must commonly also request for assistance if it is not offered initially.

"Explaining needs to others" (ENO) and "Making requests or demands" (MRD) to others did not, however, correlate strongly with either "Searching for medical/ rehabilitation services" (SMRS) or "Trying to get access to medical/rehabilitation services" (TGAMRS), with r values of between .217 and .363, without reaching

statistical significance in any of the four combinations. Explaining needs and making requests are clearly distinct from searching for or attempting to gain access to services. This suggests that PWD from this study commonly have taken a passive role while attempting to search for and gain access to services, likely having someone else act as their advocate, if at all.

Correlations among Medical/Rehabilitation Care Coordination Activities by SSO

The highest of the inter correlations in Table 12, "Arranging for transportation" (AFT) and "Obtaining and transporting equipment or supplies" (OTES) (r= .887; p≤ 0.001) indicates that a PWD who requires medical equipment or supplies often also arranges for transportation.

Furthermore, there was a high correlation between "Making requests or demands" (MRD) and "Arranging for transportation" (AFT) (r= .878; p≤ 0.001), as well as "Making requests or demands" (MRD) and "Obtaining and transporting equipment or supplies" (OTES) (r= .772; p≤ 0.001). This indicates that when someone is arranging for transportation and/or obtaining and transporting their equipment/supplies, they must often make requests or demands related to details such as specific times and locations, as well as specific details related to equipment/supplies and their need for them, respectively.

Interestingly, only one item significantly correlated with "Asking questions to providers" (AQP), which was "Searching for medical/rehabilitation services" (SMRS) (r= .602; p≤ 0.05). It seems that in this sample, SSOs tended to ask questions to providers more frequently when they were searching for services for the PWD.

In contrast to the high inter correlation found in Table 10 between "Trying to get access to medical/rehabilitation services" (TGAMRS) and "Asking questions to providers" (AQP), these same items correlate to a much less extent (r= .497), as well as not meeting statistical significance. This indicates that once medical/rehabilitative services have been identified, it has been primarily the PWD asking questions to providers regarding access.

Another high correlation from Table 10, between "Explaining needs to others" (ENO) and "Making requests or demands" (MRD), was also much less correlated between SSO (r= .445) and did not meet statistical significance. This suggests that the close friends and/or family members of the PWD generally do not wish to attempt to explain the individual's needs and request or demand things for them because they themselves are unaware of exactly how the PWD feels and what they are experiencing. However, when these items (ENO and MRD) are correlated with 'Searching for medical/rehabilitation services' (SMRS) and "Trying to get access to medical/rehabilitation services" (TGAMRS), inter correlations become much higher (r ranging from .562 to .837), in addition to all becoming statistically significant, which was not mirrored in the PWD sample. Of these, ENO and SMRS correlated the highest (r= .837; p≤ 0.001). As a result, this shows that the SSO tends to explain the needs and make requests and demands on behalf of the PWD when necessary, such as when attempting to search for and gain access to needed medical services.

Correlations among Independent Living Care Coordination Activities by PWD

Items with the highest correlation in Table 11 include "Managing paid attendants/caregivers" (MPAC) and "Searching for independent living services" (SILS) (r= .723; p≤ 0.001). This suggests that high levels of effort at managing attendant care probably involve searching for independent living services, or that search for services is a large part of managing attendant care.

Correlations among Independent Living Care Coordination Activities by SSO

It can be seen in Table 13 that "Managing paid attendants/caregivers" (MPAC) and "Searching for independent living services" (SILS) inter correlate insignificantly with a moderate relationship (r= .522). Compared to this same item correlation in Table 11, SSOs search for independent living services for the PWD to a lesser extent when there is a paid attendant or caregiver. This suggests that when an individual begins to receive services from a paid attendant or caregiver, their SSO may believe that further functional recovery is limited and that care giving services will be appropriate for the remainder of the individual's life. Thus, searching for additional services is no longer necessary.

An additional reasoning behind this may be that the PWD does not have a good relationship with their caregiver and thus wishes to search for a new one to provide services. This is consistent with correlations between "Managing unpaid attendants/caregivers" (MUAC) and SILS, as well as MUAC and "Trying to get access to independent living services" (TGAILS), being lower than those of the MPAC

counterpart. Both PWD and SSO attempt to search for and access independent living services to a lesser extent if they have an unpaid caregiver (often a close friend, family member, or the SSO themselves), likely because they maintain a more desirable relationship with these individuals than a paid caregiver (often a stranger initially hired through an agency).

Table 10

Spearman Correlations of Medical/Rehabilitation Care Coordination Activities by PWD

Activities	SMRS	TGAMRS	AQP	ENO	MRD	LLSP	RLCN	SAS	CTHPS	MQSR	AFT	OTES
SMRS	1.000											
TGAMRS	.603**	1.000										
AQP	.619**	**.796***	1.000									
ENO	.363	.228	.248	1.000								
MRD	.356	.217	.268	**.784***	1.000							
LLSP	.432*	.306	.413*	.267	.275	1.000						
RLCN	.317	.375	.517*	-.051	-.073	.110	1.000					
SAS	.222	.427*	.585**	.365	.381	.400	.229	1.000				
CTHPS	.186	.613**	.587**	.174	.006	.216	.242	.312	1.000			
MQSR	.284	.508*	**.686***	.238	.196	.352	.465*	.485*	**.764***	1.000		
AFT	.106	.111	.123	.500*	.469*	.069	-.181	.078	-.030	-.071	1.000	
OTES	.269	.096	.143	.274	.361	.079	.081	-.015	.122	.266	.514*	1.000

*** r<0.001

** r<0.05

* r<0.05

Table *11*

Spearman Correlations of Independent Living Care Coordination Activities by PWD

Activities	SILS	TGAILS	MPAC	MUAC	DPF	CHRI	MH	SPN	LSSA
SILS	1.000								
TGAILS	**.625***	1.000							
MPAC	**.723***	.578**	1.000						
MUAC	.311	.458*	.583**	1.000					
DPF	.506*	.112	.370	-.142	1.000				
CHRI	.536**	.368	.280	.026	**.648***	1.000			
MH	.057	.300	.250	.406	.278	.299	1.000		
SPN	**.672***	.339	.395	-.008	.596**	.566**	.213	1.000	
LSSA	.338	.148	.148	-.105	.355	.262	.223	.338	1.000

*** r<0.001

** r<0.05

* r<0.05

Table *12*

Spearman Correlations of Medical/Rehabilitation Care Coordination Activities by SSO

Activities	SMRS	TGAMRS	AQP	ENO	MRD	LLSP	RLCN	SAS	CTHPS	MQSR	AFT	OTES
SMRS	1.000											
TGAMRS	.679**	1.000										
AQP	.602*	.497	1.000									
ENO	**.837***	.588*	.433	1.000								
MRD	.562*	.656*	.381	.445	1.000							
LLSP	.601*	.593*	.421	.480	.673**	1.000						
RLCN	.250	.428	.119	.422	.370	.588*	1.000					
SAS	.556*	.662**	.451	.558*	.501	**.775***	**.780***	1.000				
CTHPS	.445	.504	.331	.569*	.656*	**.803***	**.780***	**.877***	1.000			
MQSR	.515	.637*	.298	.554*	**.794***	**.770***	.683**	**.764***	**.869***	1.000		
AFT	.465	.542*	.240	.397	**.878***	**.699***	.248	.447	.633*	**.784***	1.000	
OTES	.395	.650*	.182	.501	**.772***	.631*	.458	.577*	.702**	**.868***	**.887***	1.000

*** r<0.001

** r<0.05

* r<0.05

Table *13*

Spearman Correlations of Independent Living Care Coordination Activities by SSO

Activities	SILS	TGAILS	MPAC	MUAC	DPF	CHRI	MH	SPN	LSSA
SILS	1.000								
TGAILS	**.857***	1.000							
MPAC	.522	.573*	1.000						
MUAC	.259	.377	.148	1.000					
DPF	.475	.497	.000	.685**	1.000				
CHRI	.488	.442	.502	.430	.378	1.000			
MH	.350	.572*	.523	.393	.384	.585*	1.000		
SPN	.448	.358	.363	.485	.637*	.379	.466	1.000	
LSSA	.187	.347	.125	.440	.545*	.464	.605*	.138	1.000

*** r<0.001

** r<0.05

* r<0.0

Question 3: Themes of Reported Care Gaps

Several themes were identified from participants' reports of gaps in care and services that they have experienced. Table 14 lists these themes, the number of participant statements included in the specific groups, and examples of statements from each group. In total, seven themes were identified. These themes are: Access to Needed Services; Lack of Communication and/or Collaboration Between Providers; Lack of Knowledge and/or Personalized Care and Service from Providers; Lack of State Government, Insurance or Financial Support; Poor Patient-Provider Relationship & Communication; Receiving the Wrong Services; and Other. The theme "Receiving the Wrong Services" also holds statements related to poor quality of care. The total percentage of agreement between raters was 65.5%. The initial Kappa was .522, and .541 after arbitrator reorganization of non agreed upon statement categorization.

Table *14*

Summary of Themes Identified from Reported Problems with Tallies of Number of Responses Categorized to Each

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Access to Needed Services: 20

"Discontinuation of services after I moved to another state."

"I go to 6 different doctors in 4 separate cities."

Lack of Communication and/or Collaboration Between Providers: 4

"They were going to set up inpatient rehabilitation at [name of hospital] but that never happened. I had to get services for her in Illinois. If I didn't know what to do she would have never recovered. There's no one who really helps."

"My mom spends a lot of time trying to obtain information [from providers]."

Lack of Knowledge and/or Personalized Care and Service from Providers: 10

"Trying to ask around for local support groups- not many providers know about local community events/information."

"Without my constant advocacy, my son's needs probably wouldn't be met."

Lack of State Government, Insurance or Financial Support: 7

"We didn't have enough money to pay for services because of all the expenses and co-pays."

"Lack of medical coverage for things that I need."

Poor Patient-Provider Relationship & Communication: 5

"Seems like people we talk to don't want to share resources."

"No one to give needed information to. We were not given options or written instructions"

Receiving the Wrong Services: 5

"Having three years of physical therapy, where occupational therapy should have been done instead for those three years."

"Getting surgeries done that haven't worked."

Other: 4

"I was having to advocate for myself. After that didn't work, I was forced to allow my ex-wife to be my care manager."

"Day programs again- my client worked at a coffee shop for people with disabilities. But her attitude didn't fit the place."

Additional Findings

An additional intention of this study was to determine whether the CASCAM questionnaire successfully addresses issues related to care and service coordination which apply directly to people with brain injury and their SSO. Table 15 shows new and adjusted CASCAM items in response to participant responses and suggestions related to the CASCAM's original items or lack of necessary items from the participant's point of view. The resultant version of the CASCAM incorporating these new items can be found is available from authors.

Table *15*

New Questionnaire Items in Response to PWD and SSO Participant's Responses

Original Question	Participant Response/Suggestion	New Question
A13.) Do you have a chronic or serious health condition?	Does this cover secondary diagnoses, or completely separate diagnoses?	A14.) Do you have a chronic or serious health condition (both primary and/or secondary diagnoses)?
A15.) Do you have more than one condition?	Does this cover secondary diagnoses, or completely separate diagnoses?	A16.) Do you have more than one condition (both primary and secondary diagnoses)?
B3.) Asking questions to providers (from "Care Coordination Activities for Medical and Rehabilitative Needs" frequency grid)	"Regarding what?"	B3.) Asking questions to providers regarding your medical and/or rehabilitative needs
B11.) Arranging for transportation. (from "Care Coordination Activities for Medical and Rehabilitative Needs" frequency grid)	"Can be read two ways"	B11.) Arranging for transportation (through physical and/or social acts)
B12.) Obtaining and transporting equipment or supplies. (from "Care Coordination Activities for Medical and Rehabilitative Needs" frequency grid)	Elaborate meaning more	B12.) Obtaining and transporting equipment or supplies required for your health and/or medical needs
B16.) Think of the efforts you have made to manage and coordinate needed, high quality health care and services. How successful have these efforts been?	"Hard question to answer"	B16.) How successful have your past efforts been in trying to manage and coordinate required health services?
B18.) Has getting access to high quality, needed services been a problem?	"Specify about these more. Is it just medical services or more?"	B18.) Has getting access to high quality rehabilitation and medical services been a problem?
C1.) Searching for the care or services you need	"Confused from the wording"	C1.) Searching for the care or services in the

in your community. (from "Coordination Activities for Independent Living Needs" frequency grid)	"Term 'searching' may be unclear"	community that are needed for you to live independently
C2.) Trying to get access to needed services (e.g. dealing with administrative and eligibility staff). This includes trying to insure continued access to the services you need. (from "Coordination Activities for Independent Living Needs" frequency grid)	"Confused from the wording"	C2.) Trying to be accepted to receive needed independent living services (e.g. dealing with administrative and eligibility staff). This includes trying to insure continued access to the services you need.
C6.) Coordinating housing-related issues (from "Coordination Activities for Independent Living Needs" frequency grid)	"Should give examples"	C6.) Coordinating housing-related issues (may include trying to buy/sell property, interacting with landlord/tenants, etc.)
C7.) Maintaining the household (may include cleaning, meal preparation, lawn care, etc). (from "Coordination Activities for Independent Living Needs" frequency grid)	"This item seems very similar to the last item"	Was not changed at all because by clarifying previous question (C6), C7 should now seem dissimilar to it.
C13.) Think of the efforts that you have made to obtain the care and services you need to live independently in the community. How successful have these efforts been?	"Question doesn't have much value"	C13.) How successful have your past efforts been in trying to manage and coordinate required independent living services?
BC3.) Which of the above activities requires the most effort for you?	"This question seems to cover what was already identified in the last question" (Referring to the previous question, BC1, "Considering both health and independent living needs, were any of the care coordination activities above stressful to you? If yes, which items are most stressful?")	BC3.) Of the above activities, which requires the most effort and work for you?

Are any of the preceding questions confusing? Please write in comments or suggestions where there is space.	"Some questions are worded strangely"	
Does anything need to be added? Please comment.	"Caregiver's concerns for the future" "Be sure to stay away from technical medical terms" "The questionnaire does not get at the emotion of things" "Does the PWD care about the various issues (wellness, care plan)? Is it important to them?" "Information on day programs" "Does the PWD like/trust their current care providers?" "Add some questions about relationships"	A13.) What is your current marital status? B22.) If you have a question about your medical/rehabilitative needs, is there a knowledgeable professional or other person with special training that you <u>trust</u> and can easily go to for advice? BC1.) Considering both health and independent living needs, were any of the care coordination activities above stressful to you and have caused you a burden? BC2.) If YES, which items are most stressful and worrisome? BC6.) Living with a brain injury or other chronic condition is a lifelong process. When you experience a change in your condition or other change in your life, is there a professional person you can consistently <u>trust</u> and consult if you are having problems? D5.) If you do not currently have a written care plan, do you think one may be helpful? D6.) How important do you think a written care plan

		is to be able to receive high quality services?
		E21.) How important do you think a wellness program is to receiving high quality services?
		E23.) What feelings did you have during your <u>individual</u> (by yourself) past experiences with coordinating and managing medical and rehabilitation needs?
		E24.) What feelings did you have during your past experiences with coordinating and managing medical and rehabilitative needs with others (with medical staff and/or SSO)?
		E25.) What feelings did you have during your <u>individual</u> (by yourself) past experiences with coordinating and managing instrumental living needs?
		E26.) What feelings did you have during your past experiences with coordinating and managing instrumental living needs with others (with medical staff and/or SSO)?

Care Plan

Without a care plan, there is no identifiable system of care, as it is not possible to evaluate whether care is received in the sequence and the type needed. As such, participants were asked whether they, or the PWD, had ever received any type of written care plan from service providers in the past. According to the participants, only 40.9% of individuals ever received a written care plan after sustaining their brain injury. In fact, after asking the participants if they had ever received one, as well as describing what one is, many of the participants reported that they were unaware of what a written care plan is.

When both the PWD and SSO participants were asked if there was a trained professional whom they trust and can go to if they are experiencing medical/rehabilitation problems, 83.8% said yes. Specifically, they reported being able to go to: Primary care physician (25.8%); Neurologist (19.4%); Close friend/relative who is a health care professional (19.4%); Support group facilitator (12.9%); Other or unsure (22.5%).

When both the PWD and SSO participants were asked if there was a trained professional whom they trust and can go to if they are experiencing independent living problems, over half (63.9%) said yes. Specifically, they reported being able to go to the following: Close friend/relative who is a health care professional (39.1%); Primary care physician (17.4%); Support group facilitator (17.4%); Other or unsure (26.1%).

Discussion

Demographic Results

After interpreting the medians, frequencies and distributions from tables 4 through 7, several significant findings surfaced. Many distributions were exponentially and negatively skewed, with several also containing bimodal characteristics. Bimodal distributions typically suggest that there are two different groups performing the measureable activity. In this case, these activities of care coordination appear to not apply to a lot of people, but to those who do need to perform such activities, it is extremely important. The medians and distributions for the following frequencies of care coordination activities were much lower than expected across both groups: "Searching for Medical/Rehabilitation Services" (SMRS- PWD: 1; SSO: 2), "Trying to get Access to Medical/Rehabilitation Services" (TGAMRS- PWD: 2; SSO: 1.5), "Searching for Independent Living Services" (SILS- PWD: 0; SSO: 1), "Trying to get Access to Independent Living Services" (TGAILS-PWD: 0; SSO: .5), and "Making Requests or Demands" (MRD- PWD: 2; SSO: 1.5).

Consistent with the medians and distributions displayed, these same items also presented with lower frequencies than previously expected. That is, participants in both groups engaged in searching and attempted to get access for both medical/rehabilitative and independent living services, as well as making request or demands, infrequently if ever. For these individuals, living in the community now long term post injury (and likely no longer receiving services regularly, if at all), it is likely the case that they have been unable to receive high quality needed services because they (as well as their SSO) have

either not sought out any such services, or learned not to do so. In addition to this, participants also have been advocating for services by making requests or demands rarely, if at all in some cases.

Other frequencies of particular interest in which groups differed included: "Reading and Learning about Care Needs" (RLCN); "Scheduling Appointments and Services" (SAS); "Checking to Make Sure that things Happen as Planned and on Schedule" (CTHPS); "Managing Paid Attendants/Caregivers" (MPAC); and "Locating Social Supports or Activities" (LSSA). It is likely that the PWD perform scheduling of services more often because they are directly and consistently in contact with the individuals providing the PWD with services, making scheduling convenient. However, after initially scheduling the appointments, this data suggests that the SSO then takes over to ensure that the appointments are followed through with and happening as planned. It appears that those in the SSO group wish to learn more about their close friend/family member, whether it be simply to understand their situation more in depth, or to attempt to identify new services, including social supports or activities, which the PWD could begin participating in. It is also interesting that the SSO group manages the paid caregivers more often than the PWD group. One might assume that a paid caregiver is often times managed by their client, with the exception to a very low functioning individual.

The several negative exponential distributions suggest that over time an individual with a brain injury may begin to search for services, attempt to access services, as well as advocate for services, less frequently than they may have shortly after their injury. However, this study does not provide data directly on this. It can be assumed these most

likely diminished in frequency over the months and years post injury, reaching the low and skewed frequencies documented in this study. It has been shown through many past studies that services are most intense shortly after the injury.

Unlike most injuries, depression in the PWD has recurrently been reported to increase over time after a brain injury, which could also cause the individual to no longer desire services or no longer have the motivation to search for, contact, and advocate for such services (Bombardier et al., 2009). Conversely, an individual may also become accepting of his/her injury and subsequent disability, deciding that services are no longer necessary.

Systems of care are usually short term, and gradually diminish over time. As such, the PWD has likely established a pattern of care or non-care over time. As such, it is then perhaps more likely that these frequencies could be the result of people no longer having to perform these activities of care coordination as much as in the past, but these issues will eventually come up. When they do, it is of extreme importance that the PWD and/or SSO perform the care coordination activities.

Question 1: Time Consumption of Care Coordination Activities

The relatively small sample size used in this study caused wide confidence intervals (plus and minus 9%), affecting the ability to identify further significant differences. The non-significant findings indicate that a SSO performs care coordination activities if the PWD cannot or does not perform them. This is a prime example then of

co-occupation, described earlier, in which both the PWD and their SSO share the role as an advocate and coordinator of services. As such, it is important to focus time, effort, and attention to both the PWD and their SSO equally.

Question 2: Care Coordination Activity Frequencies

Results indicated that the items used to characterize frequencies of medical/rehabilitation and independent living care coordination activities among PWD and SSO have a high internal consistency overall (cronbachs alpha= .774-.945). These findings were somewhat unexpected, as it was expected that because care coordination is multidimensional, internal consistency would be limited overall. An explanation of the result is that as people have different levels of need that give rise to different general frequencies of care coordination activity. Another possible explanation is that individuals may have perceptual biases (i.e the halo effect), that affect responses to the activity questions. Also, it may be that different systems provide different general levels of coordination and access. Although the explanation is unclear, the internal consistency found strongly supports that it is possible to provide a summary measure of care coordination activities. With a larger sample size, it may in the future be possible to perform factor analyses or item-response theory (IRT) analysis. This would permit combining of items for shortening of the CASCAM.

Question 3: Themes of Reported Care Gaps

The moderate kappas for the categorization can be explained. While categorizing these statements into themes, it was found that many of the statements could be placed into more than one category. That is, the statements are not mutually exclusive. Nonetheless, we decided to place each statement into just one theme for the sake of simplicity. This lowered the percentage of agreement between raters, but the themes identified still reflect respondent experiences.

The "Access to Needed Services" theme contains by far the largest number of statements (20). Many participants reported being unable to access needed services due to geographic and/or economic conditions. Appropriate services (or those that are covered by their insurance) may often be located at too far of a distance from the home of the PWD.

Revised and Added Items

Participants generally had positive feedback towards the CASCAM, reporting that it covered all areas of care coordination that they have experienced. However, several participants provided positive feedback related to how to change specific items, as well as the addition of new items to encompass other areas of care coordination that they found important. Readers may recall that draft items were revised and new items were added (Table 15) in the first phase of the research, which asked respondents about the content validity of items and involved cognitive interviewing.   The final revised questionnaire is available from authors.   In total, 13 items were adjusted based on participants'

comments on the items and 12 other items were added to the CASCAM. As a result, the

newest version of the CASCAM now maintains appropriate content validity.

Care Plan

The frequent (59.9% without) lack of a care plan, or in some cases lack of

knowledge of, what a care plan is, is significant because without a care plan, no

professional knows whether the PWD is receiving needed services and there is no

standard by which quality or coordination of care can be gauged. The PWD and/or SSO

surely are not part of the care team, and a team cannot coordinate unless there is a shared

plan. Without explicit knowledge of major care needs and connections, the likelihood of

major gaps in care surely increases.

Additional Findings

More respondents reported having a trained professional they trust and can go to

if they experience medical needs (83.8%) compared to independent living needs (63.9%).

The responses to the question about who would be contacted were also of significance.

For medical needs, the modal response was the individual's PCP, whereas the modal

response for independent living needs was a close friend or relative who is a health care

professional. Although described as a professional, it is uncertain whether participants'

friend/relatives have been educated and trained in issues related to independent living and

related services. A PWD may prefer to approach someone with whom they have a prior

relationship, or professionals trained in the relevant issues maybe unavailable. A possible

implication is the need for increased education and training of SSO, PWD, and others in independent living needs and services upon or after discharge.

Throughout the data collection phase of this study, we discovered that many of the participants became confused with several terms common to health care and care coordination, most specifically care coordination itself. Despite explanations of the essence of care coordination, many participants tended to think that "care" referred to self-management, such as taking medications routinely. Subsequently, we decided to call it "coordination of services" in the majority of patient interactions in order to clarify our topic and lessen confusion. Other terms that commonly needed to be clarified to participants were independent living services and written care plan.

We also observed during the data collection phase that, when contacting a PWD and their SSO, many individuals chose to have the person who does the majority of the care coordination to be the one to participate in the study. Had we insisted on speaking with both PWD and SSO, we would have increased respondent burden. We believe that the non-responding members of the PWD-SSO pair engaged in much less care coordination, but there could be exceptions. This observation leads to the thought that many health care providers focus on speaking only to a PWD (whether the SSO is there or not) during appointments and virtual or face to face conversations. However, for instances in which the PWD does not perform the majority of coordinating their own care, we believe that it is of importance then to focus discussions to the SSO in terminology that they understand. This is also vital to avoid isolating the PWD and to avoid excluding them in decisions.

Limitations

The main limitation of this study is the small sample size, comprised of a convenience sample. Participants were in the chronic phase of recovery, often several years after their injury had occurred. These factors resulted in a non-representative sample.

Future Research

It is recommended that the findings from this study be validated through use with a larger sample. If doing so, it is suggested that future work allow multiple categorizations of participant comments for greater detail. Findings could also be tested on a sample of people with brain injury more acutely after their injuries, to track changes over time, sampling both the PWD and SSO if both are involved. This could also involve the addressing of issues in the medical and independent living care plan, including whether these critical plans even exist.

Ideally, we would also develop an intervention to help the person and SSO to coordinate care, otherwise intervene to enhance coordination and continuity of needed care. One such intervention could be a care coordination training program to train a PWD and/or SSO how to effectively conduct care coordination, much like therapeutic interventions for other IADLs.

Further examination in the future could also be conducted regarding the relationship between a PWD and their SSO, depending on the type of SSO (parent, spouse, sibling, close friend, etc). Depending on the length in which an individual is experiencing a disability, sometimes only a temporary SSO is required, which would also alter the relationship between the two. Overtime, the relationship is then thought to be affected by the number of sentinel or warning events which take place, subsequently either strengthening or breaking down the PWD and SSO relationship.

Conclusion

Care coordination often presents as more of an observed problem than a specific construct. A collection of multiple attributes can be combined into what is known as coordinated care. As such, the process of coordinating the multitude of care and services occurring in someone's life can become confusing and overwhelming. This, coupled with the fact that brain injuries are unique to the point where no two are pathologically alike, make the capturing of all needed information onto a single questionnaire difficult.

In order to match this variability, we have developed a measure to gain a general understanding of care gaps in one's life following brain injury, in addition to collecting an exploratory description of care coordination with this population. During which, we were able to ratify the CASCAM on its clarity, acceptability, and content validity. It contains both general and somewhat precise questions, in quantitative multiple choice

and open-ended style, as a means to fully understand that which an individual with a brain injury and any of their supportive significant others must go through on a daily basis as a result of gaps to needed health services.

Quantitative findings related to internal consistency suggest that it is possible to provide a summary measure of care coordination activities. Future work with the CASCAM may include shortening the length through the use of IRT analysis, as well as the development of a care coordination intervention for clinical use. By doing so, people who have sustained brain injuries and their close friends and family members will again be able to go about their daily lives without the stress, confusion, and sometimes even detrimental health effects that result from care gaps.

References

Accreditation Council for Occupational Therapy (ACOTE) Standards and Interpretive Guidelines. (2010, December).

American Academy of Pediatrics, Committee on Children with Disabilities. 2002. Medical home initiatives for children with special needs project advisory committee. *Pediatrics, 110,* 184-186.

American Academy of Pediatrics, Committee on Children with Disabilities. 2005. Care coordination in the medical home: Integrating Health and related systems of care for children with special needs. *Pediatrics, 113*, 1973-1983.

Bell, K. R., Temkin, N. R., Esselman, P. C., Doctor, J. N., Bombardier, C. H., Fraser, R. T., & Hoffman, J. M. (2005, May). The effect of a scheduled telephone intervention on outcome after moderate to severe traumatic brain injury: A randomized trial. *Arch Phys Med Rehabili*, *86*, 851-855.

Ben-Yishay, Y., & Diller, L. (1993). Cognitive remediation in traumatic brain injury: update and issues. *Archives of physical medicine and rehabilitation*, *74*(2), 204-213.

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002, November). Patient self-management of chronic disease in primary care. *JAMA*, *288*(19), 2469-2475.

Bombardier, C. H., Bell, K. R., Temkin, N. R., Fann, J. R., Hoffman, J., & Dikmen, S. (2009). The efficacy of a scheduled telephone intervention for ameliorating depressive symptoms during the first year after traumatic brain injury. *J Head Trauma Rehabil*, *24*(4), 230-238.

Bushnik, T., Hanks, R.A., Kreutzer, J., & Rosenthal, M. (2003). Etiology of traumatic brain injury: Characterization of differential outcomes up to 1 year postinjury. *Arch. Phys. Med Rehabili,* 84, 255-262.

Cicerone, K. D., Dahlberg, C., Malec, J. F., Langenbahn, D. M., Felicetti, T., Kneipp, S., & Ellmo, W. (2005, August). Evidence-based cognitive rehabilitation: Updated review of the literature from 1998 through 2002. *Archive of Physical Medicine and Rehabilitation*, *86*, 1681-1689.

Cicerone, K. D., Mott, T., Azulay, J., & Friel, J. C. (2004). Community integration and satisfaction with functioning after intensive cognitive rehabilitation for traumatic brain injury. *Arch Phys Med Rehabili*, *85*, 943-950.

Cifu, D. X., Kreutzer, J. S., Marwitz, J.H., Rosenthal, M., Englander, J., & High, W. (1996). Functional outcomes of older adults with traumatic brain injury: A prospective, multicenter analysis. *Arch. Phys. Med Rehabili,* 77, 883-888.

Coleman, E. A., Smith, J. D., Frank, J. C., Eilertsen, T. B., Thiare, J. N., & Kramer, A. M. (2002, June). Development and testing of a measure designed to assess the quality of care transitions. *International Journal of Integrated Care*, *2*(1), 1-9.

Creswell, J. W. (1998). *Qualitative Inquiry and Research Design* (pp. 51-55). London, United Kingdom: SAGE Publications Ltd.

Dellefield, M. (2006, February). Interdisciplinary care planning and the written care plan in nursing homes: A critical review. *Gerontologist*, *46*(1), 128-133.

Eriksson, G., Kottorp, A., Borg, J., & Tham, K. (2009). Relationship between occupational gaps in everyday life, depressive mood and life satisfaction after acquired brain injury. *J Rehabil Med*, *41*, 187-194.

Fleming, J., Tooth, L., Hassell, M., & Chan, W. (1999). Prediction of community integration and vocational outcome 2-5 years after traumatic brain injury rehabilitation in Australia. *Brain Injury*, *13*(6), 417-431.

Fowles, J. B., Terry, P., Xi, M., Hibbard, J., Bloom, C. T., & Harvey, L. (2009). Measuring self management of patients and employees health: Further validation of the patient activation measure based on its relation to employee characteristics. *Patient Education and Counseling*, *77*, 116-122.

Gaikwad, N. R. (2009). *Care coordination and management by parents of children with special needs: Developing a survey measure* (Master's thesis). December, 2009, 1-34.

Glasgow, R., Wagner, E., Schaefer, J., Mahoney, L., Reid, R., Greene, S. (2005). Development and validation of the patient assessment of chronic illness care (PACIC). *Medical Care, 43* (5), 436-444.

Geriatric assessment and chronic care coordination act of 2007, S. 1340, 110th Cong. (2007).

Goranson, T. E., Graves, R. E., Allison, D., & La Frenieres, R. (2003, September). Community integration following multidisciplinary rehabilitation for traumatic brain injury. *Brain Injury*, *17*(9), 759-774.

Goverover, Y., Johnston, M. V., Toglia, J., & DeLuca, J. (2007, August). Treatment to improve self-awareness in persons with acquired brain injury. *Brain Injury*, *21*(9), 913-923.

Greenwald, B.D., Burnett, D.M., & Miller, M.A. (2003). Congenital and acquired brain injury. 1. Brain injury: epidemiology and pathophysiology. *Arch.Phys.Med Rehabili, 84,* S3-S7.

Gupta, V. B., O'Connor, K.G.,& Quezada-Gomez, C (2004). Care coordination services in pediatric practices. *Pediatrics, 113,* 1517-1521.

Hassett, L. M., Moseley, A. M., Tate, R. L., Harmer, A. R., Fairbairn, T. J., & Leung, J. (2009). Efficacy of a fitness centre-based exercise programme compared with a home-based exercise programme in traumatic brain injury: A randomized controlled trial. *J Head Trauma Rehabil*, *41*, 247-255.

Hibbard, J. H., Mahoney, E. R., Stockard, J., & Tusler, M. (2005, December). Development and testing of a short form of the patient activation measure. *Health Serv Res*, *40*(6), 1918-1930.

Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., & Ireland-Knight, L. (2002, March). Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. *J Head Trauma Rehabil*, *17*(2), 112-131.

Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tulser, M. (2004, August). Development of the patient activation measure (PAM): Conceptualization and measuring activation in patients and consumers. *Health Serv Res.*, *39*(4), 1005-1026.

Individualized health plan. (2011). In *www.Diabetes.org*. Retrieved August 13, 2011, from http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/written-care-plans/individualized-health-plan.html.

Janssen, J. L. (2009). *Enabling adults with disabilities to coordinate their own services and care: An exploration of professional views and activities* (Master's thesis). August. 2009.

Kim, H., & Colantonio, A. (2010, September). Effectiveness of rehabilitation in enhancing community integration after acute traumatic brain injury: A systematic review. *The American Journal of Occupational Therapy*, *64*(5), 709-719.

Kroll, T., & Neri, M. (2003). Experiences with care co-ordination among people with cerebral palsy, multiple sclerosis, or spinal cord injury. *Disability and Rehabilitation, 25*, 1106-   1114. Retrieved August 11, 2011, doi: 10.1080/0963828031000152002.

Levine, B., Robertson, I. H., Claire, L., Carter, G., Hong, J., Wilson, B. A., & Duncan, J. (2000). Rehabilitation of executive functioning: An experimental-clinical validation of goal management training. *Journal of the International Neuropsychological Society*, *6*, 299-312.

Linsmeier, J. A. (2008). *Self-efficacy to coordinate care among adults with disability: Developing a survey measure* (Master's thesis). December.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Bandura, A., Ritter, P., & Gonzalez, V. M. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitilization. *Medical Care*, *37*(1), 5-14.

Lundy-Ekman, L. (2007). *Neuroscience: Fundamentals for rehabilitation* (3rd ed., pp. 470-472). St. Louis, MO: Saunders Elsevier Inc.

Martelli, M. (2011). *Community based rehabilitation: Special issues* (PowerPoint slides). Retrieved from http//:villamartelli.com

Matlow, A. G., Wright, J. G., Zimmerman, B., Thomson, K., & Valente, M. (2006, April). How can the principles of complexity science be applied to improve the coordination of care for complex pediatric patients? *Qual Saf Health Care, 15*(2), 85-88.

McAllister, J. W., Presler, E., & Cooley, C. (2007, September). Practice-based care coordination: A medical home essential. *PEDIATRICS, 120*(3), 723-733.

McDonald, K.M., Sundaram, V., Bravata, D. M., Lewis, R., Lin, N., Kraft, S., McKinnon, M., Paguntalan, H., Owens, D.K. (2007). Care Coordination. Vol 7 of: Shojania, K. G., McDonald, K.M., Wachter, R.M., Owens, D.K., editors. Closing the quality gap: A critical analysis of quality improvement strategies. Technical Review 9 (Prepared by the Stanford University-UCSF Evidence-based Practice Center under contract 290-02-0017). AHRQ Publication No. 04(07)-0051-1. Rockville, MD: Agency for Healthcare Research and Quality.

McDonald, S., & Togher, L. (1999). *Communication disorders following traumatic brain injury* (, pp. 235-236). East Sussex, England: Psychology Press.

McGuiness, C., & Sibthorpe, B. (2003). Development and initial validation of a measure of coordination of health care. *International Journal for Quality in Health Care, 15* (4), 309-318.

Montana Department of Public Health & Human Services. (2011). *Home and community based services: Plan of care: Development* (809th ed., Vol. 1, p. 1). Helena, MT: Montana DPHHS.

Montgomery, R. J., Rowe, J. M., & Jacobs, J. (2010). *Tailored Caregiver Assessment and Referral: TCARE User Manual* (3rd ed., pp. 5-66). Milwaukee, WI: University of Wisconsin-Milwaukee Research Foundation.

Murdoch, B.E. & Theodoros, D. G. (2001). Introduction: Epidemiology, neuropathophysiology, and medical aspects of traumatic brain injury. *Traumatic brain injury: associated speech, language and swallowing disorders*, 1-23.

Occupational therapy practice framework: Domain and process. (2008, November). *American Journal of Occupational Therapy, 62*, 625-683.

Ownsworth, T. L., & McFarland, K. (1999). Memory remediation in long-term acquired brain injury: Two approaches in diary training. *Brain Injury, 13*(8), 605-626.

Palsbo, S. E., Diao, G., Palsbo, G. A., Tang, L., Rosenberg, W. F., & Mastal, M. F. (2010, September). Case-mix adjustment and enabled reporting of the health care experiences of adults with disabilities. *Archive of Physical Medicine and Rehabilitation*, *91*(9), 1339-1346.

Palsbo, S. E., & Mastal, M. F. (2011). Assessment of health plans and providers by people with activity limitations. Hamilton, NJ: Center for Health Care Strategies, Inc.

Pedretti. (2006). *Pedretti's occupational therapy: Practice skills for physical dysfunction* (6th ed., pp. 839-870). St. Louis, MO: Mosby Elsevier.

Pennings, J.L., Bachulis, B.L., Simons, C.T., & Slazinski, T. (1993). Survival after severe brain injury in the aged. *Arch surg.*, 128, 787-793.

Ponsford, J., Harrington, H., Olver, J., & Roper, M. (2006). Evaluation of a community-based model of rehabilitation following traumatic brain injury. *Neuropsychological Rehabilitation*, *16*(3), 315-328.

Portney, L. G., & Watkins, M. P. (2009). *Foundations of clinical research: Applications to practice* (3rdrd ed., pp. 503-532). Upper Saddle River, NJ: Pearson.

Powell, J. H., Beckers, K., & Greenwood, R. J. (1998, October). Measuring progress and outcome in community rehabilitation after brain injury with a new assessment instrument--the BICRO-39 scales. *Arch Phys Med Rehabili*, *79*(10), 1213-1225.

Powell, J., Heslin, J., & Greenwood, R. (2002). Community based rehabilitation after severe traumatic brain injury: A randomised controlled trial. *Journal of neurology, neurosurgery & psychiatry with practical neurology*, *72*, 193-202.

Rogers, J. C., & Holm, M. B. (1994). Assessment of self-care. In B. R. Bonder & M. B. Wagner (Eds.), *Functional performance in older adults* (pp. 181–202). Philadelphia: F. A. Davis.

Satariano, K. A. (2009). *Enabling parents to coordinate care of their child: Occupational interventions and roles* (Master's project). July. 2009.

Sherer, M., Bergloff, P., Levin, E., High, W., Oden, K., & Nick, T. (1998). Impaired awareness and employment outcome after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *13*, 52-61.

Sohlberg, M. M., McLaughlin, K. A., Pavese, A., Heidrich, A., & Posner, M. I. (2000). Evaluation of attention process training and brain injury education in persons with acquired brain injury. *Journal of Clinical and Experimental Neuropsychology*, *22*(5), 656-676.

Sox, H. F. (2011). Care plans- How to get it right. In *www.Nursetogether.com*. Retrieved August 13, 2011, from http://www.nursetogether.com/Career/Career-Article/itemId/2569/Care-Plans-How-to-get-it-Right.aspx.

Stuss, D. T., Binns, M. A., Carruth, F. G., Levine, B., Brandys, C. E., Moulton, R. J., & Snow, W. G. (1999, April). The acute period of recovery from traumatic brain injury: posttraumatic amnesia or posttraumatic confusional state? *Journal of Neurosurgery*, *90*(4), 635-643.

Taylor-Powell, E., & Marshall, M. G. (1998). *Questionnaire design: Asking questions with a purpose* (pp. 2-12). Madison, WI: University of Wisconsin-Extension.

Teasell, R., Cullen, N., & Bayley, M. (2005). Epidemiology and long-term outcomes following acquired brain injury. *Ontario Neurotrauma Foundation*, 1-14.

Thurman, D. J., Alverson, C., Dunn, K.A, Guerrero, J., & Sniezek, J.E. (1999). Traumatic brain injury in the United States: A public health perspective. *J Head Trauma Rehabili,* 14, 602-615.

Turner, B., Ownsworth, T., Cornwell, P., & Fleming, J. (2009, September). Reengagement in meaningful occupations during the transition from hospital to home for people with acquired brain injury and their family caregivers. *The American Journal of Occupational Therapy*, *63*(5), 609-619.

Vanderploeg, R. D., Crowell, T. A., & Curtiss, G. (2001). Verbal learning and memory deficits in traumatic brain Injury: encoding, consolidation, and retrieval. *Journal of Clinical and Experimental Neuropsychology*, *23*(2), 185-195.

Wagner, A. K. (2001). Functional prognosis in traumatic brain injury. *Physical Medicine and Rehabilitation*, 15, 245- 265.

Appendix A: Original Survey

Care Coordination and Management Questionnaire for Adults with Disability DRAFT

Background Questions

Would you say that your health services and care is managed and coordinated::

　　1.___ Entirely by yourself (no help from others)

　　2.___ Mostly by yourself (a little help from others, such as a family member or significant other)

　　3.___ Jointly with another (both of you work closely and both do a lot of the work in managing and coordinating care)

　　4.___　Mostly by another person or persons.

　　5___　Entirely by others.

Who is the primary person responsible for managing the health services?

　　1.___ Person him/herself

　　2. ___ Male spouse/significant other

　　3.___　Female spouse/significant other

　　4. .___　Mother

　　5.___ Father

　　6.___ Grandfather

　　7.___ Grandmother

　　8.___ Other relative.

　　9.___ Other person, non-relative.

SPECIFY NAME AND RELATIONSHP:: _____

Who is the secondary person involved in coordinating the person's care?

     0.___ Noone – no secondary person helps with coordinating care

    1.___ Person him/herself

    2. ___ Male spouse/significant other

    3.___ Female spouse/significant other

    4.___ Mother

    5.___ Father

    6.___ Grandfather

    7.___ Grandmother

    8.___ Other relative.

    9.___ Other person, non-relative.

SPECIFY NAME AND RELATIONSHIP::   _____

Race/ethnicity (check all that apply)

    __ White/Caucasian   __ Af. American

    __ Hispanic   __ Asian

    __ Other:

_____

Your occupation and employment status

__ Employed (for pay, part-time)

__ Homemaker   __ Retired

__ Disabled   __ Other Specify...

Your Health Needs Background questions

Do you have a chronic or serious health condition? If yes, what is it? Do you have more than one condition?

      0.__ No

      1.__ Yes, one

      2__ Yes, several

Diagnostic Conditions. (Name or list).

      1. _____

      2. _____

      3. _____

Does one of these disable you or limit you in your everyday activities?

      0.__ No

      1.__ Yes

      Which one? _____

What would you say is your main diagnosis or disabling condition?

_____

Code:

      1. TBI

      2. Other ABI

      3. Other traumatic injury or accident

4. Other disabling injury not due to accident.

Did you have a traumatic injury such as an auto accident or other event that injured you?

0. ___ No

1.___ Yes

IF YES: How many years ago? ___

IF TBI: How long were you in coma or unconscious? _____

99 = NA, no TBI

How old are you?   ____ yrs   ____ months

Administrative Services

ADMINISTRATIVE SERVICES INCLUDE FINANCIAL AND PAYMENT SERVICES. THESE SERVICE PROVIDERS ARE PERSONS WHO APPROVE ELIGIBILITY FOR SERVICES AND EQUIPMENT, AND OTHER BUREAUCRATS. THEY MAY WORK FOR THE GOVERNMENT OR FOR A PRIVATE ORGANIZATION.

Who deals with these administrative services for the person?

1.__ Person with injury or disability alone

2.__ Person with injury/disability and another person

3.__ Another person (e.g. family, close friend)

Identifying Phases of Care Organizing

SOMETIMES CARE NEEDS CHANGE RAPIDLY— FOR INSTANCE, AFTER AN EMERGENCY EVENT OR HOSPITALIZATION—WHILE AT OTHER TIMES THEY SETTLE DOWN INTO A SMOOTH ROUTINE.

In the last year, have you experienced many changes in care -- or has the last year been relatively routine?

    1.__ Routine

    2.__ Moderately or rapidly changing.

IF CHANGING (2): What accounts for the changes (e.g. continuing problem, hospitalization, change in health status, change in situation or environment, relocation etc).

Would you say that you (and your family) have experienced problems with care coordination and management in the last year?

    0.__ No

    1.__Slight problems

    2.__ Substantial problems

Please comment:

_____

IF YOUR CARE WAS IN THE ROUTINE PHASE IN THE LAST YEAR: Was there a period in the past when you put much more effort into managing and coordinating care (for instance, the care needs were changing)?

    0.__ No

    1.__ Yes

IF YES: Specify period:_____

Comment: _____

Was this also a time when you were developing new relationships to doctors or other service providers?

      0.__ No

      1.__ Yes

WAS THERE A PERIOD IN THE PAST DURING WHICH THERE WERE PROBLEMS AND CHALLENGES WITH CARE AND SERVICE COORDINATION.

Period:

      1.__ Last 12 months

      2.__ Previous year.

QUESTIONS IN THE FOLLOWING SECTIONS REFER TO THE TIME PERIOD STATED ABOVE:

Do you have an assigned clinical case manager or care coordinator? (The person might be a special point of contact, arranges care, explains care needs, and rules, and so on).

      0.__ No

      1.__ Uncertain

      2.__ Yes

IF yes:

What does she/he do? (Provides support, schedule appointments, help communicate with specialists, provide information to schools etc)

_____

How often do you contact her/him?

      _____ (approximate number, per month or per year. 0 = no).

Does he/she come out to your house to help insure that s/he understand your needs?

     0.___ No

     1.__ Yes

Comment: _____

Overview of Care

We would now like to ask you about various activities you may or may not have done to coordinate and manage your health care needs and services. Please specify if you did none, some, or a lot of the following activities.

Grid A1:

Activities	None	Some	A lot
Asking questions to the providers	0.__	1.__	2.__
Explaining your needs	0.__	1.__	2.__
Making requests (or demands)	0.__	1.__	2.__
Listening to and learning from service providers	0.__	1.__	2.__
Learning, reading, and studying about your needs	0.__	1.__	2.__
Searching for community resources	0.__	1.__	2.__
Scheduling appointments and services	0.__	1.__	2.__
Planning ahead	0.__	1.__	2.__
Checking to make sure that things happen as planned and on schedule	0.__	1.__	2.__
Monitoring or checking the quality of services provided	0.__	1.__	2.__

Transportation	0.__	1.__	2.__
Getting and transporting equipment or supplies	0.__	1.__	2.__
Obtaining information or documents and transporting them between services providers	0.__	1.__	2.__
Training and supervising others about your needs (e.g. attendants)	0.__	1.__	2.__
Dealing with various administrative and eligibility staff.	0.__	1.__	2.__
Other care coordination and management activities. Specify: _____	0.__	1.__	2.__

Please tell us the time and effort you take per week to manage and coordinate the above mentioned activities. Where 0 = Absolute no effort and 10 = Extreme effort

How much effort did you put into these activities?

```
|--------|--------|-------|--------|-------|--------|--------|-------|-------|--------|
0        1        2       3        4       5       6 7      8       9        10
Absolutely          Considerable effort                      Extreme Effort
no effort
```
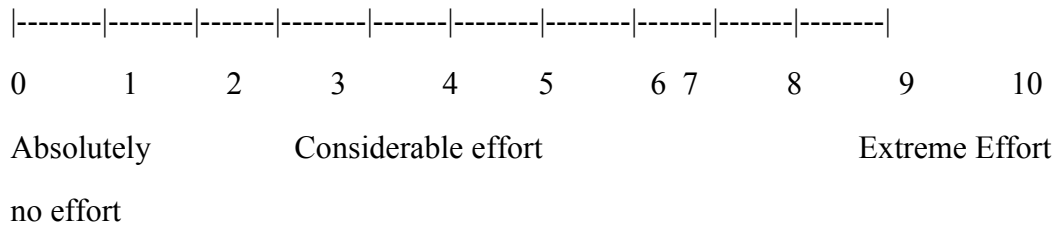
About how many hours per week do you engage in these activities?

Estimate: _____ hrs/wk

Written Care Plan

CARE PLAN IS A DOCUMENT OUTLINING THE TASKS AND RESPONSIBILITIES OF ALL THOSE INVOLVED IN CARING FOR A PERSON. IT IS A SUMMARY OR A LIST OF MAJOR CARE AND SERVICE NEEDS. FOR EXAMPLE, A HOME CARE PLAN OR A HOME EXERCISE PLAN.

Has any professional provided you with a written care plan?

    0.__ No

    1.__ Yes

IF YES, What types of care needs does it cover? Please check off.

    __ Health/Medical and nursing care

    __ Rehabilitative therapy services

    __ Routine personal care such as feeding, grooming, and so on.

    __Educational service needs

    __Social needs

    __Other.   Please specify:

_____

Did you use the written plan of care?

    0.__ Not at all.

    1__ Somewhat (e.g. when learning)

    2.__ A lot

If you have a question about your medical/rehabilitative needs, is there a knowledgeable professional or other person with special training that you trust and can easily go to?

_____

Same question about independent living needs:

_____

Health and Medical Services

THIS SECTION DEALS WITH HEALTH AND MEDICAL CARE AND SERVICES, INCLUDING SERVICES FROM DOCTORS, NURSES, PHARMACISTS, AND OTHERS.

Have you been hospitalized in the last year? IF NO, RECORD 0. IF YES, How many times?

    Number of admissions   _____

    About how many days in total?   _____

Doctors and clinic visits (other than hospitalization)

Do you have a primary care doctor (physician)?

    0.__ No

    1.__ Yes

Are there unmet service needs in this area?

    0.__ No

    1.__ Yes

Please Comment:

_____

How often did you see your primary doctor?

_____ (approximately, per month)

Optional comment (e.g. on type of doctor)

_____

How many other specialists or doctors did you see?   (As an outpatient; exclude doctors seen in a hospital or institution)

_____

About how often did you see these doctors?

_____ (approximately, per month)

Is there one particular clinic or doctor's office that you usually go to if you are sick or you need advice about your health?

0.__ No

1.__ Yes

2.__ More than one place

9.__ Don't know/Not sure

Optional comment (e.g. where?)

_____

How would you rate the overall quality of health care services received? Please rate as Excellent, Very good, Good, Fair, or Poor (or Not applicable)

Grid A2:

	5	4	3	2	1	9
Primary Doctor	E	VG	G	F	P	N/A
Specialists	E	VG	G	F	P	N/A
Nursing staff	E	VG	G	F	P	N/A
Others like Pharmacists	E	VG	G	F	P	N/A
Please comment if you have NOT rated the quality as "Excellent":						

How would you rate the overall quality of communication and relationship with each of the following?   Please rate as Excellent, Very good, Good, Fair, or Poor (or Not applicable)

Grid A3:

	5	4	3	2	1	9
Primary Doctor	E	VG	G	F	P	N/A
Specialists	E	VG	G	F	P	N/A
Nursing staff	E	VG	G	F	P	N/A
Others like Pharmacists	E	VG	G	F	P	N/A
Please comment if you have NOT rated the quality as "Excellent":						

Assistive Devices, Medical Equipment, and Home Modifications

THIS SECTION DEALS WITH MEDICAL EQUIPMENT (ITEMS THAT HELP WITH PHYSICAL OR HEALTH PROBLEMS SUCH AS G-TUBES, MONITORS, VENTILATOR, SPLINTS), ASSISTIVE DEVICES (SUCH AS WHEELCHAIRS, GRAB STICKS, SPECIAL COMMUNICATION DEVICES), AND HOME MODIFICATIONS (SUCH AS A RAMP, A GRAB BAR, MODIFIED ROOM) THAT WOULD HELP SOMEONE WITH HEALTH CARE NEEDS.

Have you received any assistive devices, medical equipment or home modifications?

0.__ No

1.__ Yes

Are there unmet service needs in this area? (Unmet needs are those needs which you needed but didn't get)

     0.__ No

     1.__ Yes

Please explain why

_____

_____

What type of medical equipment/assistive device/home modifications do you use? IF NONE, WRITE "NONE" OR "0" AND THEN SKIP TO REHABILITATIVE THERAPIES SECTION

_____

_____

How would you rate the overall quality of these services you have received? Please rate as Excellent, Very good, Good, Fair, Poor or Not applicable

Grid A4:

	5	4	3	2	1	9
Assistive device	E	VG	G	F	P	N/A
Medical Equipment	E	VG	G	F	P	N/A
Home Modification	E	VG	G	F	P	N/A
Please comment if you have NOT rated the quality as "Excellent":						

How would you rate the overall quality of communication and relationship with each of the following?   Please rate as Excellent, Very good, Good, Fair, or Poor, or Not applicable

Grid A5:

	5	4	3	2	1	9
Assistive device provider	E	VG	G	F	P	N/A
Equipment provider	E	VG	G	F	P	N/A
Home modification service provider	E	VG	G	F	P	N/A
Please comment if you have NOT rated the quality as "Excellent":						

Rehabilitative Therapies, such as Physical therapy, Occupational Therapy, or Speech Therapy

THIS SECTION DEALS WITH REHABILITATIVE THERAPIES, INCLUDING PHYSICAL THERAPY, OCCUPATIONAL THERAPY, SPEECH-LANGUAGE THERAPY, PSYCHOLOGISTS, AND OTHER NON-DRUG THERAPIES THAT HELP TO IMPROVE YOUR FUNCTION OR INDEPENDENCE.

Do you receive rehabilitative therapies such as PT, OT, SLP, or other non-drug therapies to improve your function or independence?

0.__ No

1.__ Yes

Are there unmet service needs in this area?

0.__ No

1.__ Yes

Please explain
why:_____

I<small>F NO, SKIP TO THE NEXT SECTION ON</small> "<small>ATTENDANT CARE</small>"

What types of rehabilitative therapies have you received?

_____

_____

How would you rate the general quality of rehabilitative services received? Please rate as
Excellent, Very good, Good, Fair, Poor or Not applicable

Grid A6:

	5	4	3	2	1	9
Physical therapist	E	VG	G	F	P	N/A
Occupational therapist	E	VG	G	F	P	N/A
Speech therapist	E	VG	G	F	P	N/A
Others Specify Who:	E	VG	G	F	P	N/A

Please comment if you have NOT rated the quality as "Excellent":

How would you rate the overall quality of communication and relationship with each of the following? Please rate as Excellent, Very good, Good, Fair, Poor or Not applicable

Grid A7:

	5	4	3	2	1	9
Physical therapist	E	VG	G	F	P	N/A
Occupational therapist	E	VG	G	F	P	N/A
Speech therapist	E	VG	G	F	P	N/A
Others P N/A Specify Who:		E	VG	G	F	
Please comment if you have NOT rated the quality as "Excellent":						

Attendants, Sitters, and Household Help

THIS SECTION ASKS ABOUT THE PEOPLE WHO HELP YOU (PERSON WITH DISABILITY) WITH YOUR BASIC SELF-CARE AND MOBILITY AT HOME, FOR INSTANCE, EATING, DRESSING, BATHING, AND GETTING IN AND OUT THE HOUSE AS WELL AS HOUSEHOLD HELP NEEDED FOR YOU TO LIVE INDEPENDENTLY OVER THE LONG TERM.

Do you receive help with basic Activities of Daily Living and mobility around the house?

    0.___ No

    1. __ Yes

Are there unmet service needs in this area?

    0.__ No

    1.__ Yes

Please Explain why:

_____

_____

Do you employ paid help?

    0) _____ No

    1) _____ Yes

IF NO, PLEASE SKIP TO THE NEXT SECTION ON "TRANSPORTATION"

How often do you have paid help over, to care of you and your needs?

Total: _____ hours per week

How would you rate the general quality of each of the following? Please rate as Excellent, Very good, Good, Fair, or Poor, or Not applicable

Grid A8:

	5	4	3	2	1	9
Paid attendant	E	VG	G	F	P	N/A
Unpaid attendant	E	VG	G	F	P	N/A
Others	E	VG	G	F	P	N/A
Specify Who:						
Please comment if you have NOT rated the quality as "Excellent						

How would you rate the overall quality of communication and relationship with each of the following? Please rate as Excellent, Very good, Good, Fair, or Poor, or Not applicable

Grid A9:

	5	4	3	2	1	9
Paid attendant	E	VG	G	F	P	N/A
Unpaid attendant	E	VG	G	F	P	N/A

Others	E	VG	G	F	P	N/A
Specify Who						
Please comment if you have NOT rated the quality as "Excellent":						

Transportation to and from sites in the community

THIS SECTION DEALS WITH THE PROBLEMS IN WAYS THAT YOU TRANSPORT YOURSELF TO AND FROM SITES IN THE COMMUNITY, SUCH AS DOCTOR OFFICES, SCHOOLS, WORK PLACE, SHOPPING, SOCIAL OUTINGS, AND SO ON.

How do you usually get around in the community? Do you use a:

___ Bus/public transport

___ Own Automobile

___ Others Auto-unpaid

Are there unmet service needs in this area?

0.__ No

1.__ Yes

Please explain why:

_____

_____

Does this transportation allow you to visit all the places you would like to?

1. __Some

2. __Most

3. __All of the places

How would you rate the overall quality of your transportation services?   Please rate the general quality as Excellent, Very good, Good, Fair, or Poor or Not applicable

Grid A10:

	5	4	3	2	1
Transportation services	E	VG	G	F	P
Please comment if you have NOT rated the quality as "Excellent:					

IF YOU REGULARLY USE EXTERNAL PAID TRANSPORTATION SERVICES THAT DEPEND ON ANOTHER PERSON:

How would you rate the overall quality of communication and relationship with the transportation provider? Please rate as Excellent, Very good, Good, Fair, or Poor, or Not applicable.

Grid A11:

	5	4	3	2	1	9
Transportation services	E	VG	G	F	P	N/A
Please comment if you have NOT rated the quality as "Excellent":						

Do you go to school/college?

    0.__ No

    1.__ Yes

If Yes, What level?

_____

Are there unmet service needs in this area?

    0.__ No

    1.__ Yes

Please Explain why:

_____

_____

Do you receive or need special education services through the school?

    0.__ No

    1.__ Yes

If Yes, What kind of services?

_____

IF NO, PLEASE SKIP TO NEXT SECTION ON "*OTHER SERVICES*"

How would you rate the overall quality of educational services received? Please rate as Excellent, Very good, Good, Fair, or Poor or Not applicable

Grid A12:

	5	4	3	2	1	9
School Services	E	VG	G	F	P	N/A
Special education services	E	VG	G	F	P	N/A
Other (e.g. private tutor).	E	VG	G	F	P	N/A
Specify who:						
Please comment if you have NOT rated the quality as "Excellent":						

How would you rate the overall quality of communication and relationship with each of the following services received? Please rate as Excellent, Very good, Good, Fair, Poor/ Not applicable.

Grid A13:

	5	4	3	2	1	9
School Services	E	VG	G	F	P	N/A
Special education services	E	VG	G	F	P	N/A
Other (e.g. private tutor).	E	VG	G	F	P	N/A
Specify who:						
Please comment if you have NOT rated the quality as "Excellent":						

Are you involved with agencies, organization, or people who provide social, recreational, or play opportunities?   What are they? Check all that apply.

_____ Recreation therapy

_____ Recreation program, (e.g. Y-program, city recreation program)

_____ Private individual friends

_____ Other. Specify:

_____

Are there unmet service needs in this area?

    0.__ No

    1.__ Yes

Please explain why:

_____

_____

How would you rate the overall quality of social services received? Please rate as Excellent, Very good, Good, Fair, or Poor /Not applicable

Grid A14:

	5	4	3	2	1	9
Recreation therapy	E	VG	G	F	P	N/A
Recreation program	E	VG	G	F	P	N/A
Private individual friends	E	VG	G	F	P	N/A
Other. Specify:						
Please comment if you have NOT rated the quality as "Excellent":						

How would you rate the overall quality of communication and relationship with social service providers? Please rate as Excellent, Very good, Good, Fair, Poor/ Not applicable

Grid A15:

	5	4	3	2	1	9
Recreation therapy	E	VG	G	F	P	N/A
Recreation program	E	VG	G	F	P	N/A
Private individual friends	E	VG	G	F	P	N/A
Other. Specify						
Please comment if you have NOT rated the quality as "Excellent":						

Please describe any other important special services that you need or that you have tried to obtain; for example, dental care, better economic support for the family, more or better food, better or safer housing.

_____

_____

Summary

WE WOULD NOW LIKE TO TALK ABOUT THE IMPORTANT PROBLEMS THAT YOU HAVE EXPERIENCED REGARDING CARE AND SERVICES.

Please check off the service in which you faced the most serious problems

_____ Health care services

_____ Medical equipment, assistive device/ home modifications

_____ Therapies

_____ Paid/unpaid attendant care

_____ School/University services

_____ Services for transportation

_____ Other important services

Please describe the most serious problems in this service your received or needed to receive

_____

_____

Please describe the problem in terms of categories below. Check ALL THAT APPLIES

___Coordinating and managing the services

___Quality of the services you received

___Unmet needs

___ Access problem

___Other specify _____

Did the problem affect your health or functioning in anyway?

0___No

1___Yes, actually affected my health or function

IF YES, Please describe the consequence:

_____

How serious was the problem?

|---------|---------|--------|-------- |------- |-------- |--------|-------- |-------- |--------|

  0   1   2   3   4   5   6   7   8   9   10

No problem   Mild   Moderate   As

                                              serious as a

                                    problem can be
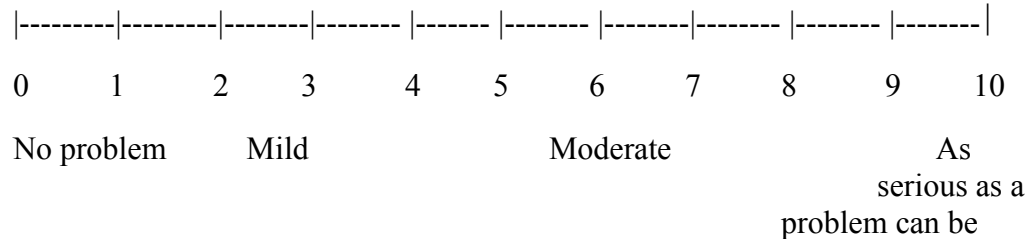
Please rate the seriousness of the problem on the 10 point scale, where 0 = No problem, 1= very slight tiny problem and 10 = the most serious problem you can imagine

Do you think that the service care provider could or should have done something to help with the problem?

      0.__ Probably Not

      1.__ Probably Yes

If probably yes, what?

_____

Do you think that you or your family could have done something to help with the problem?

      0.__ Probably Not

      1.__ Probably Yes

If probably yes, what?

_____

IN THE FOLLOWING SECTION WE WOULD LIKE TO KNOW ABOUT THE 2ND MOST IMPORTANT PROBLEM IN THE SERVICES RECEIVED. THIS SECTION IS OPTIONAL.

Is there any 2nd most important problem in the services you received?

0.__ No

1.__ Yes

Please describe the serious problems this service you received or needed to receive

_____

_____

Please Comment on the overall questionnaire:

_____

PLEASE TELL US IF THE QUESTIONS IN THE QUESTIONNAIRE WERE:

0. UNCLEAR___

1. 1. CLEAR___

COMMENT: _____

_____

PLEASE TELL US IF THE RESPONSES OF THE QUESTIONS WERE

    0. NOT DETAILED ENOUGH__

    1. TOO DETAILED__

COMMENT: _____

PLEASE LET US KNOW: WHAT DID YOU THINK OF THE QUESTIONNAIRE AS A WHOLE?

_____

_____

THANK YOU FOR YOUR TIME!! KNOWLEDGE OF YOUR EXPERIENCES WILL GREATLY HELP OUR WORK TO IMPROVE THE SYSTEM OF CARE.

Appendix B: CASCAM Operational Version

Care and Service Coordination and Management (CASCAM) Questionnaire for People with Disabilities: Person with Disability Version

This questionnaire is about care coordination and management. Care coordination involves communicating with a variety of individuals who provide you with services you need. The purpose of the questionnaire is to identify what people with a disability do to manage and coordinate their own services and care -- and to understand the difficulties they face. . PLEASE NOTE ON THIS QUESTIONNAIRE "PWD" STANDS FOR PERSON WITH A DISABILITY.

Background Questions:

A1.)   Are you a person with disability --- or are you a person who is involved in helping to coordinate services for a person with disability (PWD)?

0.___ No. IF NO, TRY TO REACH PWD OR PERSON WHO HELPS COORDINATE CARE.

1.___Yes, PWD.   USE THIS VERSION OF THE QUESTIONNAIRE.

2.___Yes, other who helps to coordinate.   SWITCH TO FAMILY/SIGNIFICANT OTHER VERSION OF   THIS QUESTIONNAIRE.

A2.)   Would you say that your health services and care is managed and coordinated:

1.___ Entirely by yourself (PWD) (no help from others)

2.___ Mostly by yourself (a little help from others, such as a family member or significant other)

3.___ Jointly with another (both of you work closely and both do a lot of the work in managing and coordinating care)

4.___ Mostly by another person or persons. IF 4, ASK TO CONTACT THE OTHER PERSON TO INTERVIEW HIM/HER TOO.

5___ Entirely by others.   IF 5, STOP. INTERVIEW FAMILY/SIGNIFICANT OTHER

A3.)　Who would you say is the primary person who manages and coordinates various health care services for you? PUT A 1 BESIDE THEIR RELATIONSHIP BELOW.

A4.)　Who would you say is also very highly involved (but not the main person)? Put a 2 beside that person's relationship below.

___ Person him/herself

___ Male spouse/significant other

___ Female spouse/significant other

___ Mother

___ Father

___ Grandfather

___ Grandmother

___ Other relative.

___ Other person, non-relative.

A5.)　IF ADDITIONAL PERSONS ARE HIGHLY INVOLVED, PLACE A 3 BESIDE THEIR RELATIONSHIP ABOVE. SPECIFY NAME AND RELATIONSHIP:

_____

People with a disabling condition often need special services to manage their independent living needs in addition to health and medical care. For instance, they might need paid attendant care, unpaid attendant care or supervision, special equipment or, if the PWD cannot drive, community mobility services such as a taxi or van with a lift.

A6.)　Are different people involved in managing and coordinating these independent living services compared to those who coordinate the health and medical care?

0.___No

1.___Yes

A7.)　IF YES, who else is involved?

A8.) Are you more involved – or less involved – in managing and coordinating your own independent living needs services compared with involvement in managing health and medical care?

0.___less involved

1.___about the same

2.___more involved

A9.) Would you say your independent living needs and services are managed and coordinated:

1.___ Entirely or almost entirely by you (no help from others).

2.___ Mostly by the you (a little help from others, such as a family member or significant other)

3.___ Jointly with another (both the PWD and significant other work closely and both do a lot of the work in managing and coordinating care)

4.___ Mostly by another person or persons. IF 4, ASK TO CONTACT THE OTHER PERSON TO INTERVIEW HIM/HER TOO.

5___ Entirely by others. IF 5, STOP. INTERVIEW FAMILY/SIGNIFICANT OTHER.

A10.) Your gender?

0.___Male

1.____Female

2.___Other

A11.) How old are you? _____

A12.) Race/ethnicity (check all that apply)

__ White/Caucasian   __ African American

__ Hispanic   __ Asian

__ Other _____

Health Needs: Background Questions

A13.) Do you have a chronic or serious health condition?

0.__No

1.__Yes

A14.) IF YES, what is it? _____

A15.) Do you have more than one condition?

0.__ No

1.__ Yes, one

2.__ Yes, several

A16.) Diagnostic Conditions. (Name or list).

1. _____

2. _____

3. _____

A17.) Does one of these disable you or limit you in your everyday activities?

    0.__ No

    1.__ Yes

A18.) Which one? _____

A19.) What would you say is your main diagnosis or disabling condition?

    1.__TBI

    2. __Other ABI

    3.__Other traumatic injury or accident

    4.__Other disabling injury not due to accident

A20.) Did your injury result from an auto accident or other event that injured you?

    0.__No

    1.__Yes

A21.) IF YES, how many years ago? _____

Care Coordination Activities for Medical & Rehabilitative Needs:

Please specify below how frequently you do each of the listed activities. In answering these questions, please include all of the time you spent towards the activity including preparatory activities (such as getting telephone numbers, rehearsing what to say, or assembling information) as well as following up.

Grid B1:

Activities	Never	At least once per year	At least once per month	At least once per week	At least once per day	Several times per day
B1.) Searching for the care or services you need (e.g. affordable medical and rehabilitative services in your community).	0.__	1.__	2.__	3.__	4.__	5.__
B2.) Trying to get access to needed services (e.g. dealing with administrative and eligibility staff). This includes trying to insure continued access to the services you need.	0.__	1.__	2.__	3.__	4.__	5.__
B3.) Asking questions to providers	0.__	1.__	2.__	3.__	4.__	5.__
B4.) Explaining your needs to others	0.__	1.__	2.__	3.__	4.__	5.__
B5.) Making requests (or demands)	0.__	1.__	2.__	3.__	4.__	5.__
B6.) Listening to and learning from service providers	0.__	1.__	2.__	3.__	4.__	5.__

B7.) Reading and learning about your care needs	0.__	1.__	2.__	3.__	4.__	5.__
B8.) Scheduling appointments and services	0.__	1.__	2.__	3.__	4.__	5.__
B9.) Checking to make sure that things happen as planned and on schedule	0.__	1.__	2.__	3.__	4.__	5.__
B10.) Monitoring the quality of services you receive	0.__	1.__	2.__	3.__	4.__	5.__
B11.) Arranging for transportation	0.__	1.__	2.__	3.__	4.__	5.__
B12.) Obtaining and transporting equipment or supplies	0.__	1.__	2.__	3.__	4.__	5.__

B13.) Is there anything else you do to coordinate your medical and rehabilitative needs that are not in the list above?

    0.___No

    1.___Yes

B14.) IF YES, please describe

_____

B15.) How often do you do these additional activities?

Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

B16.) Think of the efforts that you have made to manage and coordinate needed, high quality health care and services. How successful have these efforts been?

Not usually successful	Somewhat successful	Generally successful/very successful
0.___	1. ___	2. ___

B17.) Please tell us about efforts/activities that you have made that have not led to success in getting high quality, needed care and services.

_____

_____

B18.) Has getting access to high quality, needed services been a problem?

    0.___No

    1. ___Somewhat/slight problem

    2.___Yes, definite or major problem

B19.) IF YES, What are the problems or barriers you've experienced?

_____

B20.) Do you need additional services to help with your medical and rehabilitative needs?

0.___No

1.___Yes

B21.) IF YES, What additional services are needed?

_____

B22.) If you have a question about your medical/rehabilitative needs, is there a knowledgeable professional or other person with special training that you trust and can easily go to for advice?

0.__ No

1.__Yes

B23.) IF YES, please specify

_____

B24.) Preventative health services include a variety of services to prevent future health problems, to help one to plan how to manage their health in the long run, and to keep current or past health problems from occurring again. How often have you used preventative health services in the last year?

Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

B25.) How often have you had discussions with your doctor about preventative health needs and services in the last year?

	Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
	0.__	1 __	2.__	3.__	4.__	5.___

B26.) Do you think that you need or would benefit from preventive health services, that is, services to prevent future health problems, to plan how to manage future health problems, or to keep current health problems from occurring again?

0.__No

1.__Might benefit

2.__Would benefit

Your Opinion about the Preceding Items:

Are any of the preceding questions confusing?   Please write in comments or suggestions where there is space.

0.__ No

1.__Yes

How important do you think the questions are to people with disabilities, particularly people with brain injury? Tell us whether any of the questions are not important or only slightly or rarely important to coordinating and managing the services and care they need.

_____

Does anything need to be added?   Please comment

_____

Coordination Activities for Independent Living Needs:

Care coordination and management also deals with managing the care and services you need to live independently. How often do you do the activities below?

Grid B2:

Activities	Never	At least once per year	At least once per month	At least once per week	At least once per day	Several times per day
C1.) Searching for the care or services you need in your community	0.__	1.__	2.__	3.__	4.__	5.__
C2.) Trying to get access to needed services (e.g. dealing with administrative and eligibility staff). This includes trying to insure continued access to the services you need.	0.__	1.__	2.__	3.__	4.__	5.__
C3.) Managing paid attendants/caregivers	0.__	1.__	2.__	3.__	4.__	5.__
C4.) Managing unpaid attendants/caregivers	0.__	1.__	2.__	3.__	4.__	5.__
C5.) Dealing with personal finances	0.__	1.__	2.__	3.__	4.__	5.__
C6.) Coordinating housing-related	0.__	1.__	2.__	3.__	4.__	5.__

issues					
C7.) Maintaining the household (may include cleaning, meal preparation, lawn care, etc.)	0.__	1.__	2.__	3.__	4.__	5.__
C8.) Shopping for personal needs	0.__	1.__	2.__	3.__	4.__	5.__
C9.) Locating social supports or activities	0.__	1.__	2.__	3.__	4.__	5.__

C10.) Is there anything else you do to coordinate your independent living needs that is not in the list above?

0.___No

1.___Yes

C11.) IF YES, please describe:

_____

C12.) How often do you do these activities?

Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

C13.) Think of the efforts that you have made to obtain the care and services you need to live independently in the community.   How successful have these efforts been?

Not usually successful	Somewhat successful	Generally successful/very successful
0.___	1. ___	2. ___

C14.) Please tell us about efforts/activities that you have made that have not led to success in getting high quality, needed care and services.

_____

_____

C15.) Has getting access to high quality, needed independent living services been a problem?

0.___No

1. ___Somewhat/slight problem

2.___Yes, definite or major problem

C16.) If YES, What are the problems or barriers you've experienced?

_____

C17.) Do you need additional services to help with your independent living needs?

0.___No

1.___Yes

C18.) IF YES, What additional services are needed?

_____

C19.) If you have questions about your independent living needs or services, is there a knowledgeable professional or other person with special training that you can easily go to for advice?

    0.__ No

    1.__Yes

C20.) Please specify or comment:_____

Questions about Both Health and Independent Living Needs:

BC1.) Considering both health and independent living needs, were any of the care coordination activities above stressful to you?

    0.___No

    1.___Yes

BC2.) IF YES, which items are most stressful?

_____

_____

BC3.) Which of the above activities requires the most effort for you?

_____

BC4.) Considering both medical and independent living care coordination and management activities, what would help you with the problems you've experienced?

_____

BC5.) What are the most important unmet service needs for yourself or your family members? Please consider both health/medical and independent living needs when answering this question.

_____

BC6.) Living with a brain injury or other chronic condition is a lifelong process. When you experience a change in your condition or other change in your life, is there a professional person you can consistently consult if you are having problems?

    0.___No

    1.___Yes

BC7.) IF YES, who?

_____

BC8.) IF NO, would you find this type of person useful?

    0.___No

    1.___ Not sure

    2.___Yes

Written Care Plan:

A care plan is a document outlining the tasks and responsibilities of all those involved in caring for a person.   It is a summary or a list of major care and service needs and who is responsible for doing them. For example, it may be called a home care plan. Sometimes it includes a home exercise plan.

D1.) Has any professional provided you with a written care plan?

    0.__ No

    1.__ Yes

D2.)   IF YES, What types of care needs does it cover? Please check off all that apply.

__Health/Medical and nursing care

__Rehabilitative therapy services

__Routine personal care such as feeding, grooming, and so on

__Educational service needs

__Social needs

__Other - Please specify:

_____

D3.)   Did you use the written plan of care? How often?

No/ Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

D4.)   Is there a section in your care plan that addresses future health problems or independent living problems?

0.__No

1.__Yes

Productive Community Activities:

We would like to ask you about your participation in community activities. (NOTE: NO NEED TO ASK IF FAMILY HAVE ALREADY TOLD US.)

E1.)   Do you have a job? (Paid).

0.___No

1.___Yes

E2.) IF YES, do you work part-time or full-time?

  1.___Part-time

  2.____Full-time

E3.) IF YES, what do you do?

_____

E4.) Do you go to school?

  0.___No

  1.___Yes

E5.) IF YES, do you attend part-time or full-time?

  1.___Part-time

  2.___Full-time

E6.) IF YES, What are you studying? _____

E7.) Do you care for a child?

  0.___No

  1.___Yes

E8.) IF YES: Are you the main care-giver?

  0.___No

  1.___Yes

E9.) Are there other productive community activities you engage in?

  0.___No

  1.___Yes

E10.) IF YES, please describe _____

_____

E11.) Of the above community activities, which one is most important to you?

_____

_____

E12.) Is there anything that threatens your ability to do the above activity?

_____

_____

E13.) What could help to improve your ability to continue to do the above activity?

_____

_____

E14.) Are there any community activities you would very much like to do more of?

0.___No

1.___Yes

E15.) IF YES, What are they?

_____

E16.) What are the barriers that prevent you from doing more of these community activities?

_____

E17.) Do you think you could benefit from additional services to help you to participate more in the community or to contribute more to society?

0.___No

1.___Yes

E18.)   IF YES, What kind of additional services?

_____

Wellness Questions:

Wellness programs go beyond treatment of disease or sickness.   They aim to enhance the overall health of people -- physically, mentally, emotionally, and socially.   In addition, they work with individuals to help them achieve a healthy lifestyle and to feel good every day.   (This may be done by helping a person to exercise more, to maintain a healthy diet, to quit smoking, to drink less, to lessen fears or anxieties, or in many other ways that help people to have long-term quality of life.)

E19.)   Have you ever participated in a wellness program?   IF YES: How often?

No/ Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

E20.)   Do you think that you might benefit from a discussion of whether a wellness program would be helpful to you? How much?

0.__No

1.__Might benefit

2.__Would benefit

Your Opinion about the Preceding Items:

Are any of the preceding questions confusing?   Please write in comments or suggestions where there is space.

0.__ No

1.__Yes

How important do you think the questions are to people with disabilities, particularly people with brain injury?   Tell us whether any of the questions are not important or only slightly or rarely important to coordinating and managing the services and care they need.

_____

_____

Does anything need to be added?   Please comment.

_____

E21.)   Would you consider yourself to expert or at least highly experienced in dealing with the system of care and services for people with TBI or other disabilities in your community?

0.__ No

1.__ Yes

Comment by interviewer or interviewee:

_____

Can we call again if we find that we have left something important out or need to clarify something later?

_____

THANK YOU !

Care and Service Coordination and Management (CASCAM) Questionnaire for People with Disabilities: Family/Significant Other Version

This questionnaire is about care coordination and management. Care coordination involves communicating with a variety of individuals who provide services to a person with a disability (PWD). The purpose of the questionnaire is to identify what people with a disability and/or a family member/significant other *do* to manage and coordinate services and care and to understand important problems. We also want to learn what might be done to help improve care coordination. PLEASE NOTE THAT IN THIS QUESTIONNAIRE "PWD" STANDS FOR PERSON WITH A DISABILITY AND "SO" FOR SIGNIFICANT OTHER.

Background Questions:

A1.) Are you a person with disability --- or are you a person who is involved in helping to coordinate services for a person with disability (PWD)?

0.___No. IF NO, TRY TO REACH PWD OR PERSON WHO HELPS COORDINATE CARE.

1.___Yes, PWD. USE THIS VERSION OF THE QUESTIONNAIRE.

2.___Yes, Family member/Significant other.

A2.) Would the PWD say that the health services and care of the PWD is managed and coordinated:

1.___ Entirely by PWD (no help from others)

2.___ Mostly by PWD (a little help from others, such as a family member or significant other)

3.___ Jointly with another (both of you work closely and both do a lot of the work in managing and coordinating care)

4.___ Mostly by another person or persons. IF 4, ASK TO CONTACT THE OTHER PERSON TO INTERVIEW HIM/HER TOO.

5___ Entirely by others. IF 5, STOP. INTERVIEW FAMILY/SIGNIFICANT OTHER

A3.) Who would the PWD say is the primary person who manages and coordinates various health care services for them? PUT A 1 BESIDE THEIR RELATIONSHIP BELOW.

A4.) Who would the PWD say is also very highly involved (but not the main person)? Put a 2 beside that person's relationship below.

___ Person him/herself

___ Male spouse/significant other

___ Female spouse/significant other

___ Mother

___ Father

___ Grandfather

___ Grandmother

___ Other relative.

___ Other person, non-relative.

A5.) IF ADDITIONAL PERSONS ARE HIGHLY INVOLVED, PLACE A 3 BESIDE THEIR RELATIONSHIP ABOVE AND SPECIFY NAME AND RELATIONSHIP:

_____

People with a disabling condition often need special services to manage their independent living needs in addition to health and medical care. For instance, they might need paid attendant care, unpaid attendant care or supervision, special equipment or, if the PWD cannot drive, community mobility services such as a taxi or van with a lift.

A6.) Are different people involved in managing and coordinating these independent living services compared to those who coordinate the health and medical care?

0.___No

1.___Yes

A7.)   IF YES, who else is involved?

_____

A8.)   Is the PWD more involved – or less involved – in managing and coordinating his/her own independent living needs services compared with involvement in managing health and medical care?

0.___less involved

1.___about the same

2.___more involved

A9.)   Would you say that the independent living needs and services for the PWD are managed and coordinated:

1.___ Entirely or almost entirely by the PWD (no help from others).

2.___ Mostly by the PWD (a little help from others, such as a family member or significant other)

3.___ Jointly with another (both the PWD and significant other work closely and both do a lot of the work in managing and coordinating care)

4.___ Mostly by another person or persons. IF 4, ASK TO CONTACT THE OTHER PERSON TO INTERVIEW HIM/HER TOO.

5___ Entirely by others. IF 5, STOP. INTERVIEW FAMILY/SIGNIFICANT OTHER.

A10.) What is your gender?

0.___Male

1.____Female

2.___Other

A11.) How old is the PWD? _____

A12.) Race/ethnicity (check all that apply)

   __ White/Caucasian   __ African American

   __ Hispanic   __ Asian

   __ Other _____

PWD Health Needs: Background Questions

A13.)   Does the PWD have a chronic or serious health condition?

   0.__No

   1.__Yes

A14.) IF YES, what is it? _____

A15.) Does the PWD have more than one condition?

   0.__ No

   1.__ Yes, one

   2.__ Yes, several

A16.) Diagnostic Conditions. (Name or list).

   1.) _____

   2.) _____

   3.) _____

A17.) Does one of these disable the PWD or limit him/her in his/her everyday activities?

0.__ No

1.__ Yes

A18.) Which one? _____

A19.) What would the PWD say is his/her main diagnosis or disabling condition?

1.__TBI

2.__Other ABI

3. __Other traumatic injury or accident

4.__Other disabling injury not due to accident

A20.) Did the PWD have a traumatic injury such as an auto accident or other event that injured them?

0.__No

1.__Yes

A21.) IF YES, how many years ago? _____

Care Coordination Activities for Medical & Rehabilitative Needs:

Please tell us how often you do each of the activities below for the PWD. Check off the answer that *best* describes how frequently you do each of them. In answering these questions, please include all of the time you spent towards the activity including preparatory activities (such as getting telephone numbers, rehearsing what to say, or assembling information) as well as following up.

Grid C1:

Activities	Never	At least once per year	At least once per month	About once per week	At least once each day	Several times a day
B1.) Searching for the care or services the PWD needs (e.g. affordable medical and rehabilitative services in his/her community).	0.__	1.__	2.__	3.__	4.__	5.__
B2.) Trying to get access to needed services (e.g. dealing with administrative and eligibility staff). This includes trying to insure continued access to the services the PWD need.	0.__	1.__	2.__	3.__	4.__	5.__
B3.) Asking questions to providers	0.__	1.__	2.__	3.__	4.__	5.__
B4.) Explaining his/her needs	0.__	1.__	2.__	3.__	4.__	5.__
B5.) Making requests (or demands)	0.__	1.__	2.__	3.__	4.__	5.__
B6.) Listening to and learning from service providers	0.__	1.__	2.__	3.__	4.__	5.__

B7.) Reading and learning about his/her care needs	0.__	1.__	2.__	3.__	4.__	5.__
B8.) Scheduling appointments and services	0.__	1.__	2.__	3.__	4.__	5.__
B9.) Checking to make sure that things happen as planned and on schedule	0.__	1.__	2.__	3.__	4.__	5.__
B10.) Monitoring the quality of services the PWD receives	0.__	1.__	2.__	3.__	4.__	5.__
B11.) Arranging for transportation	0.__	1.__	2.__	3.__	4.__	5.__
B12.) Obtaining and transporting equipment or supplies	0.__	1.__	2.__	3.__	4.__	5.__

B13.) Is there anything else you do to coordinate his/her medical and rehabilitative needs that are not in the list above?

0.___No

1.___Yes

B14.) IF YES, please describe

_____

B15.) How often do you do these additional activities?

Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

B16.) Think of the efforts that you have made to obtain, manage, and coordinate needed, high quality health care and services for the PWD. How successful have these efforts been?

Not usually successful	Somewhat successful	Generally successful/very successful
0.___	1. ___	2. ___

B17.) Please tell us about efforts/activities that you have made that have not led to success in getting high quality, needed care and services.

_____

_____

B18.) Has getting access to high quality, needed health care and services been a problem?

0.___No

1.___Somewhat/slight problem

2.___Yes, definite or major problem

B19.) If YES, what are the barriers you and the PWD have experienced?

_____

B20.) Does the PWD need additional services to help with his/her medical and rehabilitative needs?

0.___No

1.___Yes

B21.) IF YES, What additional services are needed?

_____

B22.) If you have questions about the person's health or rehabilitative needs, is there a knowledgeable professional or other person with special training that you or the PWD trust and can easily go to for advice?

0.__ No

1.__Yes

B23.) IF YES, please specify

_____

B24.) Preventive health services include a variety of services to prevent future health problems, to help one to plan how to manage their health in the long run, and to keep current or past health problems from occurring again. How often has the PWD used preventative health services in the last year?

Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

B25.) How often has the PWD had discussions with his/her doctor about preventative health needs and services in the last year?

Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

B26.) Do you think that the PWD needs or would benefit from preventive health services, that is, services to prevent future health problems, to plan how to manage future health problems, or to keep current health problems from occurring again?

0.__No

1.__Might benefit

2.__Would benefit

Your Opinion about the Preceding Items:

Are any of the preceding questions confusing?   Please write in comments or suggestions where there is space.

0.__ No

1.__Yes

How important do you think the questions are to people with disabilities, particularly people with brain injury?   Tell us whether any of the questions are not important or only slightly or rarely important to coordinating and managing the services and care they need.

_____

Does anything need to be added?   Please comment.

_____

Coordination Activities for Independent Living Needs:

Care coordination and management also deals with managing the care and services the PWD need to live independently. How often do you do the activities below for the PWD?

Grid C2:

Activities	Never	At least once per year	At least once per month	At least once per week	At least once per day	Several times a day
C1.) Searching for the care or services the PWD needs in his/her community	0.__	1.__	2.__	3.__	4.__	5.__
C2.) Trying to get access to needed services (e.g. dealing with administrative and eligibility staff). This includes trying to insure continued access to the services the PWD need.	0.__	1.__	2.__	3.__	4.__	5.__
C3.) Managing paid attendants/caregivers	0.__	1.__	2.__	3.__	4.__	5.__
C4.) Managing unpaid attendants/caregivers	0.__	1.__	2.__	3.__	4.__	5.__
C5.) Dealing with personal finances	0.__	1.__	2.__	3.__	4.__	5.__
C6.) Coordinating housing-related	0.__	1.__	2.__	3.__	4.__	5.__

issues						
C7.) Maintaining the household (may include cleaning, meal preparation, lawn care, etc.)	0.__	1.__	2.__	3.__	4.__	5.__
C8.) Shopping for personal needs	0.__	1.__	2.__	3.__	4.__	5.__
C9.) Locating social supports or activities	0.__	1.__	2.__	3.__	4.__	5.__

C10.) Is there anything else you do to coordinate his/her independent living needs that is not in the list above?

    0.___No

    1.___Yes

C11.) IF YES, please describe?

    _____

C12.) How often do you do these activities?

Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

C13.) Think of the efforts that you have made for the PWD to obtain, manage, and coordinate needed, high quality care and services for independent living. How successful have these efforts been?

Not usually successful   Somewhat successful   Generally successful/very successful

0._____   1. _____   2. _____

C14.) Please tell us about efforts/activities that you have made that have not led to success in getting high quality, needed care and services for independent living.

_____

_____

C15.) Has getting access to high quality, needed independent living services been a problem?

0.___No

1.___Somewhat/slight problem

2.___Yes, definite or major problem

C16.) If YES, What are the barriers you've experienced?

_____

C17.) Does the PWD need additional services to help with his/her independent living needs?

0.___No

1.___Yes

C18.) IF YES, What additional services are needed?

_____

C19.) If you have questions about the person's independent living needs or services, is there a knowledgeable professional or other person with special training that you can easily go to for advice?

0.__ No

1.__Yes

C20.) Please specify or comment:_____

Questions about Both Health and Independent Living Needs:

BC1.) Considering both medical and independent living needs, were any of the care coordination activities above stressful to you?

    0.___No

    1.___Yes

BC2.) IF YES, which items are most stressful?

_____

BC3.) Which one of the above activities requires the most effort for you?

_____

BC4.) Considering both medical and independent living care coordination and management activities, what would help the PWD with the problems you've experienced?

_____

BC5.) What are the most important unmet service needs for the PWD and their family? Please consider both health/medical and independent living needs when answering this question.

_____

BC6.) Living with a brain injury or other chronic condition is a lifelong process. When the PWD experiences a change in his/her condition or other change in his/her life, is there a professional person whom the PWD can consistently consult if he/she is having problems?

0.___No

1.___Yes

BC7.) IF YES, who?

_____

BC8.) IF NO, would the PWD find this type of person useful?

0.___No

1.___ Not sure

2.___Yes

Written Care Plan:

 A care plan is a document outlining the tasks and responsibilities of all those involved in caring for a person.   It is a summary or a list of major care and service needs and who is responsible for doing them. For example, it may be called a home care plan. Sometimes it includes a home exercise plan.

D1.)   Has any professional provided the PWD with a written care plan?

0.__ No

1.__ Yes

D2.)   IF YES, What types of care needs does it cover? Please check off all that apply.

__Health/Medical and nursing care

__Rehabilitative therapy services

__Routine personal care such as feeding, grooming, and so on

__Educational service needs

__Social needs

__Other - Please specify

_____

D3.) Does the PWD use the written plan of care? How often?

No/Never	At least once per year	At least once per month	At least once per week	At least once per day	4 or more times each day
0.__	1 __	2.__	3.__	4.__	5.___

D4.) Is there a section in the PWD's care plan that addresses any future health problems or independent living problems?

0.__No

1.__Yes

Productive Community Activities:

We would like to ask about the person's participation in community activities:

E1.) Does the PWD have a job? (Paid).

0.___No

1.___Yes

E2.) IF YES, does he/she work part-time or full-time?

1.___Part-time

2.____Full-time

E3.) IF YES, what does the PWD do?

_____

E4.) Does the PWD go to school?

0.___No

1.___Yes

E5.) IF YES, does the PWD attend part-time or full-time?

1.___Part-time

2.___Full-time

E6.)   IF YES, What is the PWD studying? _____

E7.)   Does the PWD care for a child?

 0.___No

1.___Yes

E8.)   IF YES: Is the PWD the main care-giver?

0.___No

1.___Yes

E9.)   Are there other productive community activities the PWD engages in?

0.___No

1.___Yes

E10.) IF YES, please describe _____

_____

E11.) Of the above community activities, which one is most important to the PWD?

_____

_____

E12.) Of the above community activities, which one is most important to you?

_____

E13.) Is there anything that threatens his/her ability to do the above activity?

_____

_____

E14.) What could help to improve his/her ability to continue to do the above activity?

_____

_____

E15.) Are there any community activities the PWD would very much like to do more of?

    0.___No

    1.___Yes

E16.) IF YES, What are they?

_____

E17.) What are the barriers that prevent the PWD from doing more of these community activities?

_____

E18.) Do you think the PWD would benefit from additional services to help him/her to participate more in the community or to contribute more to society?

    0.___No

    1.___Yes

E19.) IF YES, What kind of additional services?

_____

Wellness Questions:

Wellness programs go beyond treatment of disease or sickness. They aim to enhance the overall health of people -- physically, mentally, emotionally, and socially. In addition, they work with individuals to help them achieve a healthy lifestyle and to feel good every day. (This may be done by helping a person to exercise more, to maintain a healthy diet, to quit smoking, to drink less, to lessen fears or anxieties, or in many other ways that help people to have long-term quality of life.)

E20.) Has the PWD ever participated in a wellness program? IF YES: How often?

	At least	At least	At least	At least once per day	4 or more
No/ Never	once per year	once per month	once per week		times each day
0.__	1 __	2.__	3.__	4.__	5.___

E21.) Do you think that the PWD might benefit from a discussion of whether a wellness program would be helpful to him/her?   How much?

0.__No

1.__Might benefit

2.__Would benefit

Your Opinion about the Preceding Items:

Are any of the preceding questions confusing?   Please write in comments or suggestions where there is space.

0.__ No

1.__Yes

How important do you think the questions are to people with disabilities, particularly people with brain injury?   Tell us whether any of the questions are not important or only slightly or rarely important to coordinating and managing the services and care they need.

_____

_____

Does anything need to be added?   Please comment.

_____

E22.) Would you consider yourself to expert or at least highly experienced in dealing with the system of care and services for people with TBI or other disabilities in your community?

0.__ No

1.__ Yes

Comment by interviewer or interviewee:

_____

Can we call again if we find that we have left something important out or need to clarify something later?

_____

THANK YOU!

Appendix C: Recruitment Letter

Request for Participants in a Research Study on Care and Service Coordination for People with Brain Injury in the Community

Hello!

We are doing a research study on quality and coordination of care for community-living people with disability, particularly people with TBI and any of their family members or significant others who are involved in their care and services. If you have had a brain injury of any type, or if you are involved in managing the care of such a person – and if service needs are not simple – you are probably eligible to participate.

Could you help us by answering our questionnaire on coordination and management of care and services? You can complete the questionnaire by telephone interview, in person, through email, or we can send it to you, at your convenience. But in either case we would like to talk with you to ask your opinion about the questionnaire and any needed improvements. Each participant will receive a $10 gift or debit card as an honorarium.

 If you are willing to participate or interested in receiving more information, please contact:

Brian P. Johnson (no relation), Graduate Student.

Mark V. Johnston, Ph.D., Professor, College of Health Sciences, University of Wisconsin – Milwaukee.

Sincerely yours,

Mark V. Johnston, PhD, Principal Investigator
Professor, Department of Occupational Science and Technology
University of Wisconsin-Milwaukee

PS: This study has been approved by the Institutional Review Board of the University of Wisconsin-Milwaukee.