Journal of Life Care Planning, Vol. 16, No. 1, (23-27)
Printed in U.S.A. All rights reserved

Life Care Planning for Children With Acquired Brain Injuries

Susan Riddick Grisham, RN, BA, CCM, CLCP
Sharon Grandinette, MSEd., CBIST
Richard P. Bonfiglio, MD

A version of this article was previously published in Brain Injury Professional (2017) 13(4), but submitted for peer review before being published in the Journal of Life Care Planning.

Introduction

According to the Centers for Disease Control and Prevention, traumatic brain injury (TBI) is the leading cause of death and disability in children and adolescents in the United States. More than 60,000 children per year sustain a TBI sufficiently severe to require hospitalization, while many others go unreported. The most common causes of pediatric traumatic brain injury are motor vehicle collisions, falls, sports injuries, and physical abuse. Children also experience non-traumatic acquired brain injuries every year due to stroke, brain tumor, infection, post-surgical complications, etc. This article will focus on children who acquire brain injuries (ABI) from both traumatic and non-traumatic causes.

For more than three decades, life care plans (LCP) have been used to document the future needs of children with chronic disabling conditions. The development of a well-conceived LCP for children suffering from the effects of a brain injury requires a unique perspective that does not pertain to long-term planning for adults. The life care planner must focus on future growth and development and project the child's needs into adulthood and across the lifespan. In this complex endeavor, the skilled and experienced life care planning professional must have an understanding of the prognosis and available medical and rehabilitative treatments, as well as the resources available to the child and family to allow for access to education and transition to adult years.

Medical Foundations in Pediatric Brain Injury Life Care Plans

The extent of ongoing symptoms, impairments, functional limitations, and sequelae following ABI varies widely depending on the age of the child at the time of injury, the nature and extent of the trauma, pre-existing conditions, and associated injuries. The extent of TBI and its future implications can be understood by a thorough review of the available medical records.

A common medical tool for evaluating the child's initial level of cognitive functioning is the Glasgow Coma Scale. The scale runs from 3 to 15 with lower scores indicating a profound brain injury and higher scores generally indicative of a better outcome. Review of diagnostic testing including brain CT scans, MRI's, PET scans, EEG's, and cerebrovascular studies can provide an understanding of the underlying structures that have been injured. Neuropsychological testing provides delineation of the ongoing cognitive and linguistic impairments.

Further delineation of functional capabilities is provided by Functional Independence Measurement for Children (WeeFIM©) as utilized in most rehabilitation facilities. The WEEFIM measures the relative independence of patients in 18 areas with regards to mobility and daily activities including eating, grooming, dressing, bladder and bowel management, bathing, transfers, ambulation, and cognition including comprehension, expression, social interaction, problem- solving, and memory. Scoring reflects the child's independence from completely dependent to completing independent in each category.

Physician and other professional recommendations include future medical and rehabilitative care needs including all anticipated future medical visits, surgical procedures, therapies, adaptive and medical equipment, assistive technology, daily and medical supplies, medications, and hospital care. Life care plans should cover all applicable needs resulting from the injury. There should also be consideration of the child's daily care needs. A nurse, either RN or LPN, is needed for children with severe brain injuries who have skilled care needs including monitoring of vital signs, respiratory evaluation and management, tracheostomy and gastrostomy tube management, tone, and spasticity management, contracture prevention, pressure ulcer prevention, and medication provision. For children severely injured, especially those in a persistent vegetative or minimally conscious state, 24 hours per day nursing care is likely needed. For children with mild traumatic brain injuries, supervision by a family member, certified nursing assistant (CNA), or attendant may be sufficient according to the child's presentation. The state's Nurse Practice Act may also guide the level of care required (Table 1.)

Table 1: Typical Skilled Care Needs

- Monitoring vital signs and acute medical conditions such as seizures
- Medication provision
- Pressure ulcer prevention and management
- Tone management and contracture prevention
- Bladder management program including suprapubic, intermittent catheterization or other bladder diversion

programs
- Gastrostomy or GJ tube feedings and maintenance
- Bowel program and prevention of constipation
- Respiratory care including tracheostomy tube and ventilator management

There may be a variety of living environments to be considered for children with significant impairments following ABI. If there is sufficient family support, a home environment is preferred. Not only does this provide a greater quality of life, but the risk of infection with organisms with multiple antibiotic resistances is usually much less at home with dedicated staff than long-term care facilities such as nursing homes or group homes. Single-level home settings with a barrier-free design may be best. Stairs are usually a challenge when providing care for children with mobility impairments and present a safety barrier. There also needs to be sufficient space for equipment, therapies and care/treatment/nursing staff. A ceiling mounted lift device between the child's bed and the tub or shower greatly facilitates daily care. Children with severe brain injuries usually need to be transported in a van with a wheelchair lift or rails. Adapted safety carseats or lockdown systems for wheelchairs are often needed.

Ongoing motoric, cognitive, linguistic, and psychological issues may impede the educational process for a child with ABI. The child may need an Individualized Education Program (IEP) or other services to facilitate the educational process. Developing skills leading to employment may also be impeded. An ongoing rehabilitation process including physical, occupational, speech, and recreational evaluations and therapies; neuropsychological evaluations, psychological services; and vocational testing and counseling can facilitate eventual employment. A job coach may also be needed during initial employment to identify areas of concern and provide guidance.

Transitioning to adulthood frequently involves the identification of options for long-term living. For many families, this process can be overwhelming. Many are unaware to the long waiting lists for placement into group homes or other supported living environments. Across the country there are a variety of long term living environments including supported and supervised living such as group homes or congregate living. Some programs include day programming or supported employment opportunities. Funding streams for placement can be confusing.

School Services and the Important Role They Can Play in Rehabilitation and Education

In the data from the National Pediatric Trauma Registry found that many children discharged from acute hospitalization with one to three impairments are sent home, while those with four or more impairments may be sent to a rehabilitation facility (Di Scala and Savage, 2003). However, due to poor funding, limited rehabilitation facilities for children, and the distances to them, most families take their children home, and back to school. As a result, schools have become the "rehabilitation centers" for children with brain injuries. Schools can offer varied levels of supports to students with ABI when medical evidence is verified, based on assessed need. For students who are experiencing mild deficits, interventions and accommodations can be provided in general education classrooms via a Student Study Team, or a more formal Section 504 Accommodation plan. Accommodations can include rest breaks, shortened assignments, visual aids or cue cards, and extended time on tests and assignments, to name a few. Since Section 504 is an anti-discrimination, civil rights statue, general education teachers must allow and support these accommodations in their classrooms.

Students with brain injuries associated with more significant impact to their functioning may require special education services. The Individuals with Disabilities Education Act (IDEA) is the federal law that mandates specialized supports and services for students with disabilities. Under that law, there are 13 eligibility categories under which children with identified disabilities birth to age 22 can be served based on assessment findings, including but not limited to: Intellectual Disability, Orthopedic Impairment, Specific Learning Disability, and Emotional Disturbance. There are two categories that specifically apply to children who acquire a brain injury. Brain injuries caused by non-traumatic events (stroke, brain tumor, etc.), would most likely meet criteria under the category of Other Health Impaired (OHI), defined as (the list is not exhaustive):

> ...having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—
> (a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and
> (b) adversely affects a child's educational performance.
> IDEA-97: 20 U.S.C. 1401(3); 1401(30))

Until 1991, children with Traumatic Brain Injury (TBI) were placed in one of the other categories that most closely resembled their presenting deficits. That year, however, TBI was added to the list of special education eligibility categories under which a student could be served. The educational definition of TBI is:

> …an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The

> term applies to open or closed head injuries resulting in impairments in one or more areas such as cognition; language; memory; attention; reasoning, abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.
>
> 34 Code of Federal Regulations 300.7 (c)(12)
>
> Discussion section of the Federal Register (Vol. 57, No. 189, p. 44842, Tuesday, September 29, 1992) it is stated:
>
> "The definition of traumatic brain injury does include an acquired injury to the brain caused by the external physical force of near-drowning."

Parents, teachers, physicians, and rehabilitation professionals can refer children to their public school for a multidisciplinary assessment to determine eligibility under one of 13 categories. Under a section of the IDEA called CHILD FIND, it is a school district's responsibility to locate and assess any child suspected of having a disability. If an evaluation determines a student is eligible, an array of services can be offered, as children are entitled to FAPE (Free Appropriate Public Education) at no cost to the parents. Di Scala & Savage's findings also found that due to limited knowledge about brain injury in the educational community and poor communication between the medical community and schools at the time of discharge, less than 2% of children ages 0-19 with TBI were referred for special education services. Unfortunately, 13 years later, this still holds true. Traumatic brain injury is the most misidentified and under-identified disabling condition, compared with all other special education eligibility categories, due to a lack of adequate teacher and school psychologist training.

Appropriate assessment will determine a child's present functioning levels. Information is presented to the parents at an IEP meeting by the educational evaluation team and goals are written into this legal document to address all areas of suspected disability. Since goals drive placement and services, the IEP team determines whether the child will be provided service in the general education classroom (push-in model), or pulled out for individual or small group intervention in a Learning Center/resource room (pull-out model). Students with more significant needs may receive specialized academic instruction in special education classrooms for part or all of their day. Once a placement is determined, the IEP team should meet frequently to address the often rapid changes that students with ABI experience, especially initially, and adjust goals and classroom placement accordingly.

In addition to goals and placement, the IEP must outline needed accommodations and/or modifications as well as additional supports and "related services" students might require in order to receive educational benefit. "Related services includes transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education..." [IDEA, 1997, section 300.24(a)]. It is important to note that related services are provided in order for the student to benefit from their education, and therefore, goals developed and services provided must be educationally relevant, meaning that they must address skills that are impacting learning and education.

Related Services can include, but are not limited to:

- Language and speech
- Audiology
- Interpreting services
- Occupational and physical therapy
- Psychological services
- Counseling, including rehabilitation counseling
- Orientation and mobility services for students with visual impairments
- School health and school nurse services
- Social work services in the schools
- Parent counseling and training
- Medical services for diagnostic or evaluation purposes only, early identification and assessment of disabilities in children
- Recreation, including recreation therapy

This list is not exhaustive, and some states may offer additional services to students. However, even if a service is not listed, it is to be provided by the school if found necessary for the child to benefit from his/her education. For example, neuro optometric deficits are common after ABI, and developmental optometry or vision therapy may be provided by the school as a related service.

Keeping the Family Intact and Healthy

Every parent looks forward to their child conquering major developmental milestones. Households around the world have boxes of old videos and photographs documenting the child's first steps, first words, first day of kindergarten, learning to ride a bicycle, learning to drive and high school and college graduation. While toddlers and preschoolers need constant supervision, school age children become gradually ready for more independence as they travel through teen years to eventually arrive at the transition to young adult.

Many families involving a child with a ABI will never get to such milestones. Their lives often continue to be focused on daily tasks such as medication administration and helping their child with basic functions such as dressing, grooming and feeding. There are often multiple doctor visits, school meetings and therapy sessions that can consume their days. In their dual role of parent and extended caregiver, they have to monitor, advocate and communicate on behalf of their loved one; their child.

In many instances, instead of looking forward to a time when their child will develop skills that perpetuate greater independence and less parental supervision, they look to the future with heightened anxiety about who will replace them when they are no longer able to care for their child. Caregiver burnout is a constant concern and should be adequately addressed in the life care plan by the inclusion of support services in the home. Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude -- from positive and caring to negative and unconcerned. Burnout can occur when caregivers do not get the help they need, or if they try to do more than they are able -- either physically or financially. Caregivers who are "burned out" may experience fatigue, stress, anxiety, and depression (Web MD, 2016). The AARP Public Policy Institute & National Alliance for Caregiving (2015) research reveals that 38% of caregivers report high emotional stress from the demands of caregiving.

The inclusion of respite care and other home supports in the life care plan can play a major role in keeping the family unit intact and healthy. The Council on Accreditation (2017) states that respite care reduces caregiver stress, promotes the well-being and safety of care recipients, and contributes to stable families. No two family units are alike, and there is no simple formula for life care planners to rely on when addressing home care supports. The planner considers the unique needs of each child and family.

Building Blocks of Foundation in Life Care Plans for Children with ABI

Webster defines foundation as "an underlying base or support." In life care planning it is important to create the necessary foundation to support the opinions outlined in the LCP. For a LCP to be useful in clinical or legal setting, it must have a medically appropriate foundation (Figure 1.).

Life care planners do not work in isolation, but depend upon the skills and knowledge of other professionals to collaboratively determine the immediate and future needs of children with brain injuries. Although it is common for life care planners to consult with a child's current treatment providers, there are times when additional experts such as a physician, therapist or psychologist are also utilized to identify specialized needs. These treatment providers and experts help to provide the medical or psychological projections in the life care plan.

Observations made during a family interview can be especially helpful in developing life care plan opinions. Issues of home accessibility and equipment use are noted. Family dynamics including family stressors and caregiver supports can be incorporated into the foundation for the need for future respite services and family counseling. Using the medical records, the planner can identify diagnoses, pre-existing or co-morbid conditions, response to treatment, achievement of functional outcomes and medical complications with related treatments. This information can be useful in supporting items in the Life Care Plan. For example, if the planner notes that a neuropsychologist who evaluated the child with TBI made several recommendations for behavioral therapy, the planner can in part rely on those recommendations to support the need for behavioral therapy in the life care plan.

Medical bills are frequently reviewed and relied upon in the development of the life care plan opinions. They can be particularly helpful in providing historical documentation of the frequency of disability-related complications and the associated treatment costs. In the child with an TBI, one might see complications such as repeat VP- shunt infections or the re-hospitalization for treatment of a seizure disorder. Again, the historical documentation of these complications and the related treatment costs can in part serve as the foundation for their inclusion in the life care plan. School records including the IEP can provide a basis for opinions regarding what may or may not be included in the school setting. Documentation in the school records can also provide insight into the child's educational achievements.

Conclusion

A life care plan for a child following ABI requires an explicit medical foundation to delineate medically necessary and appropriate daily, medical, and rehabilitative care. The plan should anticipate future medical issues and complications and provide the recommendation to prevent or timely deal with these secondary medical issues.

Creating a reliable life care plan requires a foundation that draws from the experience and education of a life care planner who works collaboratively with treatment providers and other allied health experts. This can result in a plan that accurately forecasts future lifetime needs of the child. The life care plan can then serve as a roadmap for the family to utilize as they oversee their child's medical care, as well as decisions about family supports and future living arrangements.

References

AARP Public Policy Institute & National Alliance for Caregiving (2015). *Caregiving in the U.S.-AARP Report 2015*. NAC and AARP Public Policy Institute. Retrieved from http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf

Council on Accreditation. (2017). Respite care. Council on Accreditation. Retrieved from coanet.org/standard/pa-rc/purpose.pdf

DiScala, C., & Savage, R.C. (2003) Epidemiology of children with TBI requiring hospitalization. *Brain Injury Source, 6*(3), 8-13.

Government Publishing Office. (2017). Electronic Code of Federal Regulations. Government Publishing Office. Retrieved from: http://www.ecfr.gov/cgi-bin/text-idx?tpl=/ecfrbrowse/Title34/34tab_02.tpl

U.S. Department of Education. (1997). Individuals with Disability Education Act Amendments of 1997 [IDEA]. U.S. Department of Education. Retrieved from http://www2.ed.gov/policy/speced/reg/regulations.html

Web MD. (2016). Recognizing caregiver burnout. *Web MD*. Retrieved from http://www.webmd.com/women/caregiver-recognizing-burnout#1

Whiting, C.G. (2015). New study identifies challenges for family caregivers, Caregiving solutions needed. PRWeb. Retrieved from http://www.prweb.com/releases/2015/06/prweb12765231.htm