

## **Life Care Plan for Youth with Disabilities**

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The goal of this paper is to provide an overview of the life care planning process for youth with chronic disabilities. The unique features of pediatric-onset disabilities that impact life care planning, especially developmental issues throughout the lifespan, will be highlighted.

A life care plan for a child with a chronic disability must be individualized and comprehensive, accounting for all domains of an individual's life across the lifespan.

These domains include psychosocial, environmental, familial, cultural, and medical factors as well as personal preferences. Understanding the natural history of the specific disability assists in identifying future needs, including allocation of resources for the development of secondary health conditions and the effect of aging as well as the potential for employment and independent living.

## **Developmental issues**

Life care plans must account for the unique developmental aspects of youth with a chronic disability. From birth through young adulthood, enormous changes occur continuously in all domains of an individual's life including physical, physiological, psychosocial, and cognitive. For example, the size of equipment such as a wheelchair or urinary catheter changes with growth. Cognitive and physical abilities to manage different aspects of their care also evolve as youth age. For example, neurogenic bladder management progresses to self-catheterization between 5 to 7 years of age because of their readiness to learn and complete these tasks independently.

Long-term outcomes such as independent living and employment are significantly related to cognitive functioning and psychosocial issues in individuals with disabilities. For instance, youth with profound cognitive deficits will be dependent upon others throughout their lifespan for all aspects of their care, ranging from custodial and financial to management of complex medical conditions such as tracheostomy and ventilator care. Nonetheless, for the vast majority of youth with disabilities independent living and employment should be a goal and expectation. Therefore, the life care plan must incorporate interventions that maximize these goals. Certain developmental stages are characterized by significant psychosocial and cognitive changes such that additional interventions including physical and occupational therapy, psychological treatment, and vocational counseling, should be considered to maximize independence and successful

progression through these transitional times. Developmental stages are typically categorized as infancy and early childhood (0 to 5 years), early school-aged children (6 to 12 years of age), adolescence (13 to 17 years of age), and emerging adulthood (18 to 25 years of age). As an example, during emerging adulthood, normative milestones include education, employment, independent living, financial independence, and adaptive psychosocial functioning and fulfilling social functioning.

### **Secondary Health Conditions**

A life care plan takes into account secondary health conditions that frequently affect individuals with a specific disability and the consequent need for preventative measures or treatment including medications, rehabilitation, bracing, surgery, or hospitalization. For example, youth with a spinal cord injury (SCI) or spina bifida (SB) are susceptible to a variety of complications due to neurologic deficits including pressure ulcers because of sensory loss or urinary tract infections and urinary stones because of neurogenic bladder. In addition, the surgical management of the neurogenic bladder in youth with SCI or SB may include procedures such as the Mitrofanoff procedure or a bladder augmentation. As a result of muscle weakness, muscle imbalance, and spasticity, youth with SCI, SB and cerebral palsy (CP) are at risk of developing scoliosis or hip dislocation. Individuals with mobility impairment (such as SCI, SB, CP, and osteogenesis imperfecta) are at risk of overuse syndromes including upper extremity pain and degenerative joint disease.

## Components of a life care plan

Life care plans are grouped in standardized categories with a frequency and duration of need and a related cost for each item (see Table).

*Medical evaluations*

*Medical care – routine*

*Medical care, surgical or aggressive treatment*

*Non-physician/therapeutic evaluations*

*Therapeutic modalities*

Youth with a wide variety of disabilities such as SCI, SB, and CP benefit from receiving care from an transdisciplinary team including physical, occupational, speech and recreation therapists, social workers, psychologists, nurses, dieticians, orthotists, and physicians specialists such as pediatric orthopaedic surgeons, orthopaedic spine surgeons, neurosurgeons, neurologists, physiatrists or urologists. Therefore, life care plans generally have separate categories for evaluations and treatments, which are further separated into non-physician and physician services. For physician services, routine care is distinct from “surgical or aggressive treatment,” which includes invasive procedures, surgery, and hospitalizations. The frequency of non-physician and physician services depends upon a variety of factors including the age of the individual, specific diagnosis, stability of the chronic condition and associated secondary health conditions, and developmental periods. In general, more frequent non-physician and physician encounters are needed for younger

children when they are experiencing dramatic physical, physiologic, and cognitive changes related to development. Moreover, they are more likely needed as individuals experience premature aging with degenerative changes (such as overuse syndrome) or cardiovascular and metabolic disorders (such as hypertension and diabetes) as well as greater assistance with everyday activities (such as self-care activities).

For children who are susceptible to neurogenic scoliosis, such as those with SCI, increased surveillance is needed during the pubertal growth spurt. Because adolescence is commonly associated with significant psychosocial turmoil, increased clinical services may be indicated in order to avoid the development of secondary health conditions. For example, the relatively adherent school-aged child may become less adherent during adolescence with pressure relieves resulting in pressure ulcers. Moreover, adolescents with disabilities may benefit from psychological treatment to address the emotional and social demands in the context of life with a disability during this developmental period.

When youth with disabilities are in school, they may receive physical, occupational, and speech therapy to support their educational program as defined in their Individualized Education Program (IEP). In addition, youth with disabilities should receive supplemental physical and/or occupational therapy whenever they receive new or replacement equipment such as wheelchairs, orthotics, or splints. The frequency, duration, and specifics of the

therapy vary for these situations. A youth receiving a new orthoses, such as a reciprocating gait orthosis (RGO) for the first time, may require 2 to 3 weeks of intensive physical therapy followed by 1 to 2 sessions of physical therapy per week for 3 to 6 months. In contrast, a child receiving a replacement of an orthotic or an upper extremity splint may simply need one additional session of physical therapy or occupational therapy, respectively.

Youth who undergo a surgical procedure to enhance their function, such as upper extremity reconstruction, a Mitrofanoff procedure or lower extremity orthopaedic surgery, frequently benefit from additional therapy postoperatively. Although the purpose of these procedures are to enhance function, youth may experience a decrease in their functional abilities postoperatively and require additional rehabilitative services to regain their prior level of function and then to improve on their prior functional level.

### *Diagnostic testing*

The type of diagnostic testing depends upon the specific disability and associated secondary health conditions. For youth with a neurogenic bladder (such as SCI or SB), annual renal ultrasounds are indicated with urodynamics performed whenever there are significant changes in bladder functioning. For those at risk of neurogenic scoliosis and hip dislocation (such as SCI, SB, or CP), spine and pelvic radiographs should be performed

every 6 months prior to skeletal maturity. Because of the high incidence of osteoporosis and vitamin D deficiency in youth with mobility disorders, routine DXA scans and 25-hydroxy vitamin D levels should be obtained. Lastly, because of the high incidence of obesity and metabolic syndrome in individuals with mobility disorders, comprehensive chemistry and lipid panels should also be routinely obtained. For youth who have cognitive issues, educational testing should be performed by the school system. Additional neuropsychological testing may be indicated for youth with more severe or complex cognitive deficits.

#### *Drugs and vaccines*

This section should include medications that the youth with a disability is currently taking and potentially others that they will more likely than not need in the future. Since most youth with disabilities will receive routine vaccinations that are recommended for all children, only those “non-routine” vaccines or related substances should be included in the life care plan, such as additional doses of pneumococcal vaccine.

#### *Wheelchairs and accessories*

Mobility significantly affects all aspects of an individual's life from infancy throughout adulthood and therefore must be addressed in a life care plan. Mobility should be viewed in a comprehensive manner and include crawling, ambulation, standing, and various forms of transportation such as motor vehicles and public transportation. As individuals progress through childhood, adolescence, and adulthood, the forms of mobility used will vary and depend upon the needs of the individual as well as their size and cognitive abilities. The needs of a child in elementary school may be met by orthotics for walking or a wheelchair; whereas, the needs for an employed young adult may necessitate a wheelchair and access to private or public transportation. In addition, it should be obvious that the size and configuration of a wheelchair will vary for a 7 year old compared to someone in their late 20s. Another important aspect of mobility for individuals of any age is being independent. Children with average cognition should be able to propel a wheelchair in an independent manner by 12 to 18 months of age; this also applies to children who are physically unable to propel a manual wheelchair but could independently operate a power wheelchair. Because of aging and the risk of overuse syndromes, preservation of upper extremity function may warrant transition to powered mobility as the individual ages; however, there are no established guidelines to indicate when this switch would occur.

### *Orthotics/prosthetics*

The frequency of replacing orthotics, splints, and prosthetics in youth with disabilities is dependent on their age and usage pattern so that replacement frequency could be as frequent as every six months to two years in children who are growing and have daily use.

### *Equipment and supplies*

Equipment and supplies encompasses a wide variety of items such as those required for catheterization (catheters, gloves, wipes and lubricant), bowel program (gloves, lubricant, wipes), incontinent supplies (incontinence briefs and chuxs), abdominal binders, graduated elastic stockings, respiratory equipment (ventilator and ventilator associated supplies, mechanical insufflator/exsufflator), and blood pressure machine. This section should also include aids for independent functioning, which may include bathroom equipment such as hand-held showerheads, shower/commode chairs, long-handled mirrors, reachers, suppository inserters, freestanding or ceiling lifts, and assistive technology devices.

### *Architectural, home furnishings and accessories*

For youth with mobility impairments, architectural modifications (e.g., ramps, door widening, accessible bathrooms and kitchens) or acquisition of an accessible home may be required during childhood. In addition, architectural modifications or acquisition of an accessible home may be needed 1 to 2 additional times in the future as they become adults

and acquire their own home and then eventually further needs associated with aging. Home furnishings and accessories could include hospital beds, ramps, or exercise mat tables.

### *Home or facility care*

Home or facility care is frequently the most expensive component of a life care plan. The amount and type of care required is dependent upon a variety of factors, including the need for specialized services such as ventilator care, catheterization, bowel program, and tube feedings, and state regulations regarding licensure for the various specialized services. The role of family members (usually parents) as care-providers needs to be defined. Parents typically provide the majority of care for their infants and toddlers; however, if their infant or toddler has a disability, obtaining daycare or even routine babysitting may be more challenging or unavailable. This is particularly true if the child requires specialized services because of ventilator dependency or requires bladder catheterization or tube feedings. Depending upon the youth's needs and state laws, a home-health aid or a personal care attendant may also be utilized. An important aspect of home or facility care for youth with disabilities is to promote their autonomy and independence in all of their daily activities. Additionally, the youth's parents would greatly benefit from respite care provided on a regular basis.

Children and adolescents will generally receive nursing, therapy, and related services during school hours as it relates to their educational needs. Youth who are ventilator-dependent or require specialized services throughout the day may need 24 hours a day/ 7 days a week skilled nursing care. When an adolescent goes away to college, the type and amount of care required is dependent upon the degree of functional impairment. Because of the importance that a college-aged individual become as independent as possible, they need to assume the responsibility for this care, which may include the hiring, training, and supervision of personal care attendants.

### *Transportation*

At all ages, individuals with disabilities should have access to appropriate motor vehicles including access (such as wheelchair lifts) and restraints (including wheelchair tie downs and personal restraint devices). State laws dictate the need for proper child safety restraints and generally include rear facing infant and toddler seats for those 2 years of age and younger, forward facing car seats and boosters for older children and those less than 4 feet 9 inches in height, and three-point restraints thereafter for individuals with adequate head and trunk support. Youth with poor head and trunk control or youth who are ventilator-dependent require special restraint systems prescribed by properly trained professionals.

Adolescents of driving age should undergo a comprehensive adapted driver's evaluation to determine their capability to drive given their physical and cognitive abilities and to identify appropriate adaptations. Those adolescents capable of driving should undergo adapted driving training with a qualified instructor. Adolescents who use manual wheelchairs will benefit from physical and occupational therapy for transfer training and storage of the wheelchair. Adolescents with tetraplegia who use power wheelchairs will require an adapted van with a wheelchair lift and automatic wheelchair locking system.

#### *Vocational/educational*

Employment rates for youth with disabilities are substantially below those for the general population. Because employment is related to better overall health and higher quality of life, the life care plan should include sufficient resources to ensure there is the opportunity to maximize educational and vocational attainment. Thus vocational counseling should be directed not only at finding post injury employment, but also for employment retention and to maximize employment outcomes. A vocational rehabilitation counselor who has experience in evaluating children and adolescents without prior work experience should perform an evaluation and provide counseling.

#### *Recreation/leisure time*

This category would include equipment that facilitates fitness such as a hand-propelled

bicycle, recreation-specific wheelchair (e.g. basketball, rugby, or track), or functional electrical stimulation (FES)-cycles. For those youth who would benefit from aquatic therapy or swimming, a membership to a fitness facility with a handicap accessible pool would be appropriate.

## Conclusion

The development of the life care plan is the process of identifying lifetime needs and associated costs related to the underlying health condition. For children with disabilities, the life care plan must take into account the dynamic impact of development throughout the individual's life from birth to childhood, adolescence to emerging adulthood, adulthood, and finally, the aging adult.

## Suggested Reading

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Table: Components of a life care plan

Medical Evaluations

Medical care – routine

Medical care, surgical or aggressive treatment

Diagnostic testing (labs, X-rays)

Non-physician therapeutic evaluations

Therapeutic modalities

Drugs and vaccines

Wheelchairs and accessories

Orthotics/prosthetics

Equipment and supplies

Architectural, home furnishings and accessories

Home care/facility care

Transportation

Vocational/educational

Recreation/leisure