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RESEARCH ARTICLES

Life Care Planning: Multidisciplinary Collaboration for Children With Disabilities

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Life care planning for children with disabilities or special needs is most effective when developed through multidisciplinary collaboration. Families receive a comprehensive and coordinated plan that addresses financial, medical, developmental, and psychosocial needs by integrating expertise from life care planners, attorneys, special education teachers, and professionals in healthcare, rehabilitation, and social services. This collaborative, person-centered approach ensures the life care plan is a dynamic, evidence-based resource that guides care provision with life expectancy-based costs and aligns with a special needs trust and educational frameworks. This article focuses on the roles of the life care planner, attorney, and special education teacher in the development of special needs trusts and life care plans.

For children with disabilities or special needs, life care planning is most effective when approached through multidisciplinary collaboration, for example, between a life care planner, an attorney, and a special education teacher, in addition to treating providers, counselors, and economic advisors. Families can benefit from a comprehensive and coordinated plan that addresses the child's medical, developmental, psychosocial, and financial needs by bringing together professionals from healthcare, education, rehabilitation, social services, and legal fields. This collaborative approach increases the likelihood that care is not only holistic and person-centered, but also adaptive to the needs of these children as they grow older. This article focuses on the roles of and considerations for the life care planner, attorney, and special education teacher in creating a life care plan and special needs trust.

Life Care Planning for a Child with Disabilities

According to the National Center for Education Statistics (2024), in 2022–23, 7.5 million American students ages 3–21 yrs, or approximately 15 percent of public-school students, received special education and/or related services under the Individuals with Disabilities Education Act (IDEA). These statistics highlight the critical importance of coordinated life care planning, which addresses the diverse and evolving educational, legal, medical, social, financial, and legal needs of children with disabilities as they age. Disabilities can significantly impact the child and their family, caregivers, educators, and health care team. Early assessment and intervention are key to maximizing independence and long-term health. An individualized life care plan, which evaluates the cost of services over the child's lifetime, is invaluable for addressing their unique needs as they age and with input from the child's family, teachers, and caregivers, when available. Consideration may also be given for milestones such as transitions out of school-based programs, which typically occur at age 21.

Life Care Planning Considerations

The 4th edition of the Standards of Practice for Life Care Planners (International Association of Rehabilitation Professionals [IARP], 2022), developed by the International Academy of Life Care Planners (IALCP), serve as the cornerstone for ethical and evidence-based life care planning practice. These standards are important when planning for children with disabilities, whose needs evolve as they age and often require coordination between multiple professional disciplines and medical specialties. Planning needs may address such things as developmental delays, physical disabilities, genetic syndromes, traumatic brain injuries, and behavior modification and socialization. Additionally, if the individual cannot live independently or drive, living needs such as assisted living or long-term care and transportation needs such as a specialized vehicle or transportation services should be evaluated and included in the plan as needed. Children with special healthcare needs have or are at an increased risk for chronic physical, developmental, behavioral, and/or emotional conditions (Health Resources & Services Administration (HRSA), 2025). The life care plan can serve as a guide for additional healthcare or educational services to address chronic needs.

Standards of Performance

The Standards of Practice for Life Care Planners include Standards of Performance and Standards of Practice (IARP, 2022). Standards of Performance delineate the performance competencies, knowledge, and qualifications required to practice as a life care planner. Consistent with Standard 3 (IARP, 2022, p. 10), the life care planner has the skills and knowledge to address health care needs in the life care plan. Consistent with Standard 3, preparation of a pediatric life care plan requires knowledge that is unique to children with disabilities or special needs. These standards delineate core competencies that every life care planner must demonstrate, including the ability to assess, synthesize, and project future care needs based on evidence-based practices.

The Standards of Performance provide a structured framework that ensures consistency, ethical integrity, and clinical accuracy when developing life care plans. In alignment with Standard 3, the life care planner preparing a pediatric life care plan must possess specialized knowledge of pediatric health care systems, developmental changes, and the unique challenges faced by children with disabilities or special needs. This includes understanding the interplay between medical, educational, therapeutic, and psychosocial fields and integrating this knowledge into a cohesive, individualized plan.

Standards of Practice

Life Care Planning Standards of Practice “describe the authoritative process” which a life care planner should follow (IARP, 2022, p. 11). In addition, the standards outline how the profession of life care planning is carried out, with practice competencies serving as a mechanism for life care planners to demonstrate compliance with the standards Consistent with Standard 12 (IARP, 2022, pp. 13–14), the life care planner seeks collaboration from other qualified professionals, such as special education teachers, for inclusion of items and services in the life care plan. In accordance with Standard 12 (IARP, 2022, p. 13), the life care planner actively seeks collaboration with other qualified professionals to ensure the plan is both comprehensive and individualized. This is particularly vital when planning for children with disabilities or special needs, where educational, developmental, and therapeutic considerations intersect. Collaboration with special education teachers, for example, allows the life care planner to incorporate services such as individualized education program (IEP) supports, assistive technology, and behavioral interventions essential to the child’s academic and social development.

Standard 10 (IARP, 2022, p. 12) states, “the life care planner analyzes data using a consistent, valid, and reliable process.” In alignment with Standard 10 when preparing a pediatric life care plan, the life care planner should have knowledge of pediatric growth and development, pediatric immunization schedules, age-appropriate assistive technology for communication, age-appropriate and safe recreational activities, resources for social work services and counseling, and an understanding of what therapies and services are provided at home, in a clinic, or at school. Assessing development and identifying atypical development relative to peers is important for children with disabilities, enabling the identification and addressing of cognitive, motor, and behavioral needs. For additional information about pediatric care management and life care planning, the reader is referred to Bagnell and Moberg-Wolff (2024) in *Life Care Planning and Case Management Across the Lifespan* (Rutherford-Owen et al., 2024).

The life care planner is responsible for understanding human growth and development and analyzing comprehensive data to determine future care need recommendations as the child ages, as well as the long-term impact of aging on disability and function. Including both medical and educationally necessary therapies in a life care plan is essential to accurately reflect the full scope of the individual’s needs in both settings. Life care planners should understand the distinction and focus of medical and school-based therapies. Generally, school-based therapy focuses on academic function and performance related to the curriculum or learning objectives. While medical-based therapy is usually more intensive and focuses on social and home needs and objectives. This competency of data analysis is especially critical when planning for children with disabilities, as their needs evolve across developmental stages and may change as they reach adulthood. For more information on special needs care planning, the reader is referred to Rubin (2024) in *Life Care Planning and Case Management Across the Lifespan* (Rutherford-Owen et al., 2024).

Legal and Financial Considerations

Third-Party Special Needs Trust

A third-party special needs trust (SNT) is an essential estate planning tool for parents and caregivers of children with disabilities. Unlike a first-party special needs trust, third-party SNTs are funded with assets that do not belong to the child, typically from parents, grandparents, or other relatives. These trusts are designed to financially supplement, not replace, public benefits. Typically, these trusts are created in the parent's revocable living trust and upon their death transfers assets earmarked for the child directly to the SNT. This ensures the child's eligibility for needs-based government assistance is not jeopardized (Social Security Administration, 2025).

The trust can specify how funds should be used to enhance the child's quality of life, such as for medical expenses or therapy not covered elsewhere, adaptive equipment, educational opportunities, travel including paying for a companion, recreation expenses, and transportation. The trust prohibits disbursements that could be considered "countable resources" for public benefit purposes. Each state has its own requirements for SNTs, so precise, state-specific language is critical to avoid inadvertently disqualifying the child from state benefits, such as Medicaid. For more in-depth reading on special education law and special needs life care planning, the reader is referred to Rubin (2024) in *Life Care Planning and Case Management Across the Lifespan* (Rutherford-Owen et al., 2024).

Letters of Intent

A letter of intent (LOI) is a significant tool that serves as a comprehensive guide for future guardians, trustees, or caregivers. Although the LOI does not carry legal authority, it offers critical insights into a child's daily needs, routines, and preferences. The primary purpose of an LOI is to help future decision-makers step into the caregiver's role with minimal disruption to the child's life. It may include information about a child's daily schedule, dietary preferences, behavior management, religious beliefs, social environment, and the child's likes and dislikes (Special Needs Alliance, 2013). For children with disabilities, this level of detail can be invaluable in preserving consistency, stability, and dignity.

An LOI should be updated regularly to reflect continuing changes in the child's abilities, support needs, and available resources. Because it is not legally binding, it can be maintained in a flexible format such as a handwritten letter, binder, or digital document. Although the LOI cannot compel a caregiver to act, it provides invaluable guidance to assist the caregiver in the implementation of the child's broader life care plan.

Supported Decision-Making Agreements

Supported decision-making (SDM) agreements are a recent legal alternative to guardianship in which individuals with disabilities retain the right to make their own life choices with the assistance of trusted supporters. The purpose of an SDM agreement is to maximize autonomy while still ensuring that the individual receives help in understanding options, weighing consequences, and communicating decisions (Martinis, 2015).

As of 2025, over 20 states had enacted legislation recognizing SDM agreements (National Resource Center for Supported Decision-Making, 2025). These laws vary in scope but generally allow an adult with disabilities, who has sufficient mental capacity to understand and enter into such an agreement, to designate one or more supporters to assist in specific areas such as healthcare, financial matters, education, or housing.

In the context of life care planning, SDM agreements represent an increasingly valuable tool for helping a child with disabilities transition into adulthood. While life care planning has evolved over more than four decades without relying on this mechanism, SDM agreements introduce a modern framework that formalizes how trusted individuals can assist with important decisions. This approach is particularly significant in the legal and financial arenas, where strict confidentiality, conflict-of-interest rules, and concerns about undue influence or coercion often limit professionals from engaging directly with anyone other than the principal. By clarifying roles, permissions, and expectations, SDM agreements provide attorneys, financial institutions, and other advisors, a clear ethical path to collaborate with designated supporters while ensuring that the individual with disabilities retains control and autonomy. Because these agreements can be modified or revoked as circumstances change, they remain a flexible and adaptive element of long-term planning.

Educational Considerations

Medical Versus School-Based Therapy Services

A child with special needs may require an array of therapy services, such as physical therapy, occupational therapy, and/or speech-language pathology services. Medically-based services generally require a provider's order and focus on rehabilitation to a prior level of functioning or achieving a goal that will improve health and decrease future medical services. In comparison, school-based therapies and services focus on the child's ability to perform and progress in an educational setting. To learn more, the reader is referred to Eagan-Johnson and Lockovich (2024) in *Life Care Planning and Case Management Across the Lifespan* (Rutherford-Owen et al., 2024). The primary goal of therapy services under a medical model is to address overall daily functioning and quality of life in various environments, including home, community, and school. For example, teaching the child how to dress independently with adaptive aids. A school-based therapy model focuses on access and participation in the school environment, such as obtaining and learning how to use an adaptive communication device in the classroom.

Navigating the Complex System of Accessing Services

Children with special needs present a variety of needs in the areas of communication ability, physical impairments (including vision and hearing), cognitive delays, psychological challenges, and self-care skills. In the school setting, the student's Individualized Education Program (IEP) seeks to meet these needs so that students can access and progress in the general education curriculum. A student's IEP ends with the separation from the school system, which occurs when a child graduates with a regular diploma or when they turn 22 (whichever comes first). Transition services are available to students through the school system from age 18-22 with services designed to move the student from school to post-school activities such as continuing education and vocational training. Students and their families may not have an Assessment/Support Plan in place for the home setting. School personnel may inform parents about the resources available to them but depending on the level of care parents are providing, they may not be able to spend time researching and filling out long complicated forms (Agrawal, 2025).

Meeting the Needs of Families

Depending on the level of needs that a child has, a parent may have trouble maintaining employment. States differ on the amount of support given to parents, including whether they can be paid to care for their child, get paid respite care, or get necessary outside therapies. A life care planner can play an important role in identifying resources available from local, state, or national programs, and incorporate such resources into the life care plan. A well-designed life care plan is necessary to ensure the wishes of the parents are followed if they are unable to provide the support needed for any reason.

Conclusion

A life care plan that incorporates input from multiple professionals is a valuable resource tool guiding not only the individual with disabilities or special needs but also their families, caregivers, and healthcare providers. The life care plan functions as a dynamic, evidence-based tool that not only guides the provision of services for individuals with disabilities or special needs but also integrates seamlessly with special needs trusts and educational frameworks. In situations where the life care plan is being used for trust planning purposes, not litigation, it is a living document that may be periodically reviewed and updated to reflect the evolving healthcare, developmental, and financial needs of the individual across their lifespan.

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