

## ADDRESSING FINANCIAL CHALLENGES IN SPECIAL NEEDS FAMILIES: THE IMPORTANCE OF EARLY PLANNING AND TRUSTS

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### ABSTRACT

**Concomitant with the increasing use of financial care plans has been an increasing awareness of the need for early planning to prevent long-term financial burdens and financial toxicity. Caregivers can benefit from information on support and resources to help them navigate the challenges that arise following a special needs' diagnosis. Imbuing key information into the financial care plan will help caregivers mitigate the ongoing financial burden and also deal with the financial impact of care needs.**

**Keywords: Financial distress, Cost, Financial Plan, Resources**

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### INTRODUCTION

Families of children with special needs often face complex issues and unique challenges when it comes to financial planning. Financial Planning for a family with special needs goes beyond planning for a parent's retirement or children's education or general well-being care. It requires deeper planning for long-term costly medical care, financial security, future care, and living arrangements even after the caregiver has passed away.

Studies have shown that the cascade of economic burden of special needs starts at diagnosis and leads to medical debt, financial declines, and appreciable out-of-pocket expenses (copayments and cost of transportation to travel with the special needs).

Financial burden can occur due to loss of productivity, missed days from work, time off from work, and caregivers being made more vulnerable to out-of-pocket expenses due to unemployment and depletion of financial assets, as a result of caring for the recipients. Financial care planning reveals addresses these expected direct and indirect costs, and follow-up care costs, and provides resources to manage and minimise said costs.

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For these families of children with special needs, a sensible financial strategy for the future, though more complicated than for other families, is most critical, in particular for persons with low income or low financial literacy. The goal is to harmonise the financial and life strategy to allow the child with special needs to maintain a sense of security, dignity, and autonomy.

Caregivers who report caregiving-related financial problems or high costs are more likely to avoid planning. Financial distress due to financial obligations, debt, and diminished wealth may interfere with the ability of caregivers to cope with caregiving, further compounding the problem, leading to poorer health-related quality of life and health outcomes for both them and the care recipients. To address the financial needs of the caregivers and recipients, there is a need for early financial planning and resource considerations.

Fully supported by the Ministry of Social and Family Development, a Special Needs Trust allows caregivers to set up a trust account for their special needs dependent. The fund will be used to support the beneficiary's specific needs, including special therapies and interventions, educational programmes (if dependent is a child), caregivers, equipment, and so on. The trust can be funded with cash and liquid assets that arrived in the form of insurance nominations, etc.

The trust funds will be disbursed to care for the special needs beneficiaries according to the wishes of the settlor (the caregiver who sets up the trust). Unlike other trusts, the Special Needs Trust can be funded with cash and liquid assets. Life insurance is also a good way to fund the trust. A Special Needs Trust is protected from creditors and litigation.

A Letter of Intent will help manage the intention of caregiver's wishes for a child's future care and living arrangements. This letter can also detail characteristics of the child, including preferences for everything from food to environment.

Funding a special needs trust has frustrated many caregivers as the amount of money they perceive would be needed within a special needs trust is unattainable. An effective life insurance or a term plan that provides payouts after death that can be transferred to the trust may be an option.

Due to advances in medicine and the development of early interventions, many with special needs see their lives prolonged, living beyond early adulthood. Increasingly, more of these individuals are opting to live in family homes rather than institutions. With these developments, caregivers now confront the challenge of ensuring stable care and financial resources for their dependents and themselves.

Financial planning can give families peace of mind not only for the special needs beneficiary but also for other members of the family. A comprehensive strategy ensures that most needs, if not all, are met and fulfilled by caregivers knowing that they have taken steps to provide for their special needs dependent's long-term care. This can reduce stress and anxiety and allow families to focus on providing the best possible care for their loved ones. It also ensures that the other heirs are provided for.

Embedding information into future planning on how to reduce or avoid financial toxicity presents an opportunity to address a highly prevalent caregiver need. Using future care planning as a vehicle for providing information on financial resources could help disseminate information on the need for financial planning and reduce financial distress for special needs families.

## CONCLUSION

Families of children with special needs face complex challenges in financial planning, which extend beyond typical considerations. The economic burden of special needs begins early, leading to medical debt and substantial out-of-pocket expenses. Caregivers often experience financial distress due to lost productivity and depleted assets. Early financial planning and establishing a Special Needs Trust are crucial in addressing these challenges.

The trust allows caregivers to support their dependent's specific needs and ensure their security and autonomy. Financial planning benefits both the special needs beneficiary and the entire family by reducing stress and providing peace of mind. A Letter of Intent further outlines the caregiver's wishes, while options like life insurance can help fund the trust. Incorporating financial planning into future care planning reduces distress and promotes better outcomes for special needs families.

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## LEARNING POINTS

- **Financial planning for families with special needs requires deeper considerations beyond traditional retirement or education planning. It takes into account the beneficiary's long-term care, mostly medical expenses, future living arrangements, and financial security, even after the caregiver's passing.**
  - **The economic burden of special needs starts at diagnosis, leading to medical debt, financial decline, and significant out-of-pocket expenses. Caregivers may face unemployment and depletion of financial assets, resulting in financial distress and poorer health-related quality of life for both the caregiver and the care recipients.**
  - **The Special Needs Trusts Company ("SNTC"), supported by the Ministry of Family and Social Development, provides affordable trust service for caregivers to set up trust accounts to support the specific needs of their dependent. An SNTC trust account can be funded with cash, liquid assets, or life insurance. A Letter of Intent can also be helpful in managing the child's future care and living arrangements, detailing parental wishes and preferences.**
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