Looking out for the SPECIAL CHILD

If you have a child with special needs, estate planning becomes a crucial aspect of your financial planning strategy as you will have to ensure that he is well provided for for the rest of his life. JEEVA ARULAMPALAM finds out what you should be looking at.

Kamal aims to provide Safuan, 18, with a passive income

Unit trust consultant Mohd Kamal Mohd Doon considers his 18-year-old autistic son Mohd Safuan a gift from God, one who has been entrusted to him and his family for safekeeping.

However, like many other parents of children with special needs, Kamal has a lot to contend with. Not only does he have to deal with the challenges of raising a child with a disability, he also faces the additional financial strain that comes with trying to equip his child with the necessary skills to lead a normal life.

Most parents tend to focus on their child's present needs and development, but it is important that they also think of their child's future well-being, particularly in the event that both parents predecease the child. This is more so if the child has special needs. Depending on the severity of their child's disability, parents need to consider the right course of action for the care of their child when they are no longer around to look after him. They need to decide who will look after the child, ensure that there are sufficient funds to support him for his lifetime and that he will not be cheated of his inheritance.

Planning

Estate planning helps ensure the continuity of caring for the special needs child, says K P Thum, CEO of Lion Wealth Advisors Sdn Bhd, a licensed investment adviser. This means making sure there is enough funding until the death of the person with special needs, because he will probably be unable to earn a decent income or save for his financial requirements.

There are several considerations when planning one's estate for such a child. First, you need to assess the child's medical condition to determine if he will get better or deteriorate with time, says Carol Yip, CEO of Abacus Advisory Sdn Bhd, which specialises in coaching individuals on money matters. If the child requires special medical care in time to come, you will need to allocate extra funds in your estate planning.

"Parents could also budget in case there are other treatments made available in future that will improve the child's condition," says Joshua Lim, CEO of BHLB Trustee Bhd.

Other medical costs to consider include medical equipment and medication.

Also bear in mind that no insurance coverage for children with special needs is available. Parents will have to bear the medical costs should the child fall ill, says Yip, a financial coach.

Lawyer Azlina Hashim relates her difficulties with obtaining insurance coverage for her son Imran. "My husband bought an insurance policy for my son when he was born, but when we later discovered that he had Down's Syndrome, the company refused to provide further coverage and terminated the policy by refunding our paid premiums."

Also consider the life expectancy of the child. Parents are advised to overestimate rather than underestimate their child's life expectancy, to ensure that there will be adequate funding for the child's lifetime, says Lim.

Next, consider if you will be sending the child to a special school.

"If you can afford it, also look at providing funding for speech therapy and educational courses that can help the child," says Lim. Azlina sends Imran, 8, for additional education classes at a Kumon learning centre to equip him with the learning tools for his later years.

In planning for their child's future funding, parents should calculate their child's average monthly living expenses for the future years. Remember to include factors like rising inflation and the investment rate for the duration of the child's life.

"Keep track of your family's daily expenses — your groceries, everyday needs and also the special needs of your child. This will help you to project forward," says Yip, adding that parents should also look at ways to trim expenses to help keep living costs low.

Parents shuld also get their overall financial situation sorted out, and look at areas like housing loans or credit card debt, says Azhar Iskandar Hew, general manager of Rockwills Trustee Bhd. "Otherwise, debt will eat away at your assets, leaving your child with no money at the end of the day."

Yip recommends that parents know their present asset count so that they can decide on how the assets will be distributed to their child. Also, she notes, if

Thum has purchased a life insurance policy on himself for the benefit of Ying Cheang, 18

parents intend to leave behind a house for their child, they should consider the fact that property prices are dependent on market cycles.

In order to maintain the child's quality of life, parents should also consider other aspects like social, religious, leisure and advocacy, says Thum. These needs, which come in material and non-material forms, can enhance the child's lifestyle.

Tools

When it comes to estate planning, most trustees offer similar advice to parents of children with special needs — make sure you write a will, set up a testamentary trust within the will and start an insurance trust for your child.

A will is crucial when you have special needs children, as it allows you to leave a bigger legacy to the child in need. Otherwise, the estate will be distributed according to the Distribution Act 1958, which gives your children equal shares of your estate (for non-Muslims).

Creating a testamentary trust in your will allows you to distribute your assets over a specific period of time, as the beneficiary may not have the necessary skill to handle a lump-sum inheritance. You can leave a set of instructions as to how and when the assets are to be distributed. For example, you can instruct that 20% of your estate be distributed when the beneficiary is 18, the next 20% at age 20, 20% of the balance at age 22 and so forth, writes author Saw Leong Aun in his book *Guide to Planning Your Will Effectively*.

However, Rockwills' Azhar says that when drawing up a will, place only part of your estate to the child in a testamentary trust. This is because it takes time (months, sometimes years) for the assets in the will to be distributed upon the parents' demise.

This is where an insurance trust comes in. The advantage of an insurance trust over a bequest made in a will is that the insurance trust is distributed immediately and is not subjected to the estate administration process, says Ong Eu Jin, COO of OSK Trustees Bhd. Thus, the funds can be used immediately to finance the child's needs upon the parents' demise.

An insurance trust can either be a statutory trust that arises under Section 166 of the Insurance Act 1996, or a living trust. The subject matter of both types of trust is an insurance policy, or monies payable under that policy, writes Ong in his book *Your Guide to Trusts in Financial Planning*.

"Middle-income parents will find it easier to set up an insurance trust because they pay small amounts of premium annually for an insurance policy to obtain a large sum assured at a later stage," explains Rockwills' Azhar.

However, as insurance companies don't cover children with special needs, trustees advise parents to take life insurance coverage for themselves to ensure that there is some monetary payment for the child once they are no longer around.

For example, Lion Wealth's Thum has purchased a life insurance policy on himself, with the payout to be made to his autistic son's trust. This ensures that 18-year-old Ying Cheang will be well provided for in the event of his father's demise.

Another plus point of an insurance trust is that it is protected against creditors.

When setting up a trust, it is important that you choose the right trustee, as this person or entity will be managing the assets in the trust over the long term. "You don't want it to be mismanaged because this will be your child's financial lifeline," says OSK's Ong.

Most trustees recommend appointing a corporate trustee to oversee the child's trust.

"With a trust corporation, there will be no interruptions in terms of payment from the trust to the child, and you eliminate the chances of someone absconding with or misappropriating the funds for the child," adds Ong.

Yip suggests speaking to a lawyer experienced in setting up trusts, because the trust needs to be structured in a manner that does not deprive the child of future welfare benefits provided by the Social Welfare Department. Children with special needs registered with the department are entitled to benefits like exemption from fees for specific medical treatment and waiver of import duty and sales tax on special equipment. They are also eligible for tax benefits of up to RM5,000.

Aside from using these estate-planning tools to provide financial security for your child, parents also need to save regularly to ensure there is something to leave behind for their child, says BHLB's Lim.

"I've tried allocating some money or provide some sort of financial nest egg for Safuan but I had my own financial crisis to overcome. Therefore, I'm sticking to a savings account for him," says Kamal, who has tried his hand at several businesses to provide passive income that can be inherited by his son. ■

Appointing a guardian/carer

WHEN drawing up a will and creating a testamentary trust or setting up an insurance trust, parents have to consider that a child with special needs may not be able to make financial decisions. Therefore, parents can appoint a guardian in both instances to undertake this responsibility.

It is often recommended that the trustee and guardian be two separate individuals. Most couples will appoint their surviving spouse as the legal guardian of the child, but you also need to have a successor guardian in case both parents predecease the child.

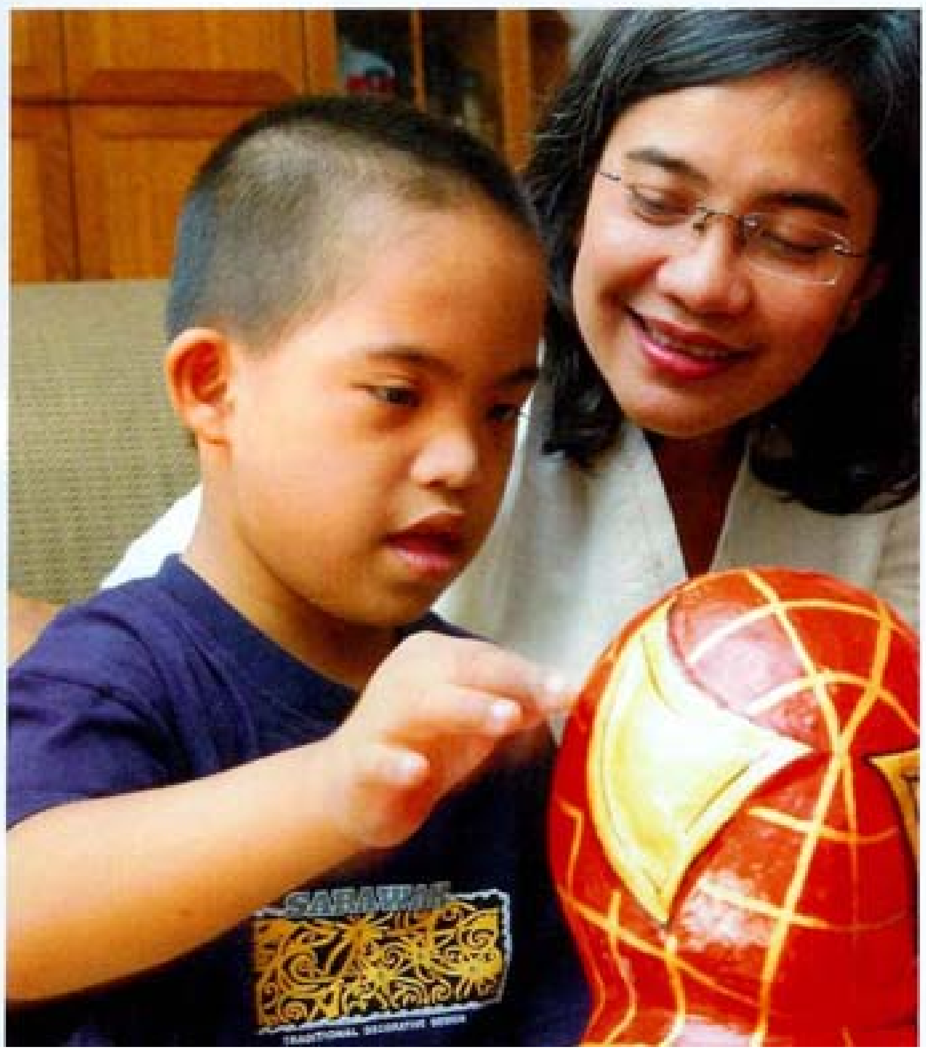
You need to carefully consider your choice of guardian, says K P Thum, CEO of Lion Wealth Advisors Sdn Bhd. "As the guardian is usually the person looking after the child, it is best that you ask the person if he is willing to be a guardian first."

When planning the financial needs of the child, parents must also take into consideration the guardian or carer's needs. "To care for a person with special needs requires great patience and it sometimes can be very stressful. Therefore, fulfilling the needs of the carer is important to ensure the continuity of caring," says Thum.

He adds that parents should write a "letter of special instructions" denoting the special and unique characteristics, needs, likes, dislikes, emotions, social activities and daily routine of the person with special needs — to the guardian or carer who would then be able to provide the same level of care and "service".

Although family support is pivotal in caring for a child with special needs, Thum says parents can't rely solely on their other children to take care of the disabled child's needs.

Kamal agrees that siblings should not be burdened with such a request, as they too have their own lives to lead and may not be able to financially support their disabled sibling.



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