

Enhancing the Financial Security of Persons with Special Needs

Parents Workgroup Report

October 2006

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15 October 2006

Minister Dr Vivian Balakrishnan
Minister for Ministry of Community Development, Youth and Sports

Dear Minister,

**Parent Workgroup Report on
Enhancing the Financial Security of Persons with Special Needs**

In mid-July 2006, you appointed us as a Parent Workgroup to gather views, analyse and recommend initiatives to enhance the financial security of persons with special needs in Singapore.

Within the short project duration of 2 months, we have spoken to close to 100 parents and consulted several experts in the field. We now present you with our report.

We do not pretend to be financial experts holding all the answers. However, we do believe that the attached report reflects the major concerns of families with special-needs children on an issue that if not addressed proactively, is a potential time bomb.

We hope our findings and recommendations will serve as a starting point for Government and interested and competent citizens to further hone the necessary strategies and action plans toward a more hopeful future for the persons with special needs in our country.

All of the Workgroup members are parents except for one. As parents of children with special needs and on behalf of other similar families, we thank you for taking the initiative to make this Study possible. We are deeply grateful for the opportunity to be of service to the persons with special needs in Singapore and to our nation.

Sincerely,

Denise Phua, Chairperson
On Behalf of Members of the Parent Workgroup
to Enhance the Financial Security of Persons with Special Needs

MEMBERS OF THE PARENTS WORKGROUP

S/N	Name of parent	Profession	Child's Special Need
1.	Ms Denise Phua (Chairperson)	President, Autism Resource Centre (ARC)	Autism
2.	Ms Loh Wai Mooi	Lawyer	Autism
3.	Mr Nick Lim	Distributor	Physical Disability
4.	Mr Ong Chin Wah	IT Professional	Down Syndrome
5.	Ms Florence Lim	Director, Covenant Family Service Centre	Intellectual disability
6.	Mr Alban Kang	Lawyer	Dyspraxia
7.	Mr Bertie Cheng	Represented on various Companies' Boards	Speech-impaired
8.	Mr Lee Chak Meng	Professional Engineer	Intellectual disability
9.	Mr Conrad Campos*	Lawyer	Has been assisting MCYS on the Trust Scheme

* not a parent of a special needs child

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EXECUTIVE SUMMARY

On 19 July 2006, the Ministry of Community Development, Youth and Sports (MCYS) announced the formation of a Parents' Workgroup to gather and analyse the view of parents on enhancing the financial security of their child with special needs; and to recommend initiatives to enhance the financial security of persons with special needs. The Workgroup was expected to submit their recommendations to MCYS in September 2006 for consideration. This paper is our report of the key findings and recommendations to the Minister of MCYS, Dr Vivian Balakrishnan.

Over the project duration of 2 months, the Workgroup spoke to 74 parents with special-needs children across different special-needs groups and family income strata. We also administered 93 written surveys to these parents and other parents who did not take part in the face-to-face focus group discussions. In addition, we consulted various individuals with financial planning backgrounds.

In this Executive Summary, we present the Key Findings and Key Recommendations for Government consideration.

Summary of Key Findings

Finding 1: There is an alarmingly low level of awareness and application of financial planning and discipline amongst respondents. The high degree of concerns expressed does not commensurate with the generally low level of knowledge and action to address the expressed concerns.

Finding 2: Many persons born with special needs are not covered for basic health insurance coverage due to the exclusion of persons with congenital and/or pre-existing medical conditions. Other non-disabled citizens do not have this problem.

Finding 3: Many families do not have basic protection coverage to ensure there are some financial resources for the special-needs child especially upon early demise of the parents. Many parents do not even plan for sufficient funds for their own retirements. Hence, the need for parents to undertake further savings and investment to enhance their special-needs child's financial security.

Finding 4: There is no one-size-fits-all solution in addressing the need for financial security of persons with special needs. There is a need for a matrix of solutions that cover at least 2 dimensions – the severity of the special-needs and hence the functional ability of the child; and the financial background of the family with the special-needs child.

Finding 5: Families who have the ability to save for the future of their special-needs children articulated some common desired features of potential financial schemes. These include the desire to protect the capital sum; reasonable growth of savings; lower administration fees and safeguard by a government or government-linked organisation.

Finding 6: The social service scene being fragmented with many different agencies and welfare organisations pursuing their own plans, **there is no one effective umbrella body in Singapore to whom families with special-needs children can consult on enhancing their future financial security.**

Finding 7: There is little access to a proficient non-profit agency which can help average-income families to further save and provide for their special-needs children. Many middle-income families are asset-rich even if they may be cash-poor. The need for a trusted body to help them save, grow and later transmit their assets to their children with special needs.

Finding 8: Majority of families deemed that jobs were the most preferred form of financial security as it would generate a steady stream of income.

Finding 9: Parents' concerns for their children with special needs extend beyond financial issues. Many are concerned with the employment prospects, and lack of caregiving options for their adult-children with special needs

Summary of Key Recommendations

In response to the above findings, the Workgroup proceeded to conduct some desk-research on the current social security schemes in Singapore. We also consulted with several individuals in the financial planning and banking sector. We understand that we are not financial experts capable of drawing up detailed financial schemes within the project's short duration. Nonetheless, we feel it important to propose the following broad recommendations for immediate follow-up in order that the current situation does not get worse.

Key Recommendation 1: In recognition of the low level of awareness and knowledge toward financial planning, we recommend that the Government considers the provision of **Free Financial Planning and Legal Education** to all families with special-needs children.

Key Recommendation 2: We also propose that the Government reviews and re-designs the current basic health schemes such as the MediShield and ElderShield or other new schemes so that persons with special needs would be able to enjoy the same level of benefits as non-disabled persons. This is in recognition that many persons with special needs are not able to purchase health insurance due to exclusion clauses.

Key Recommendation 3: Efforts should be made to educate parents on the merits of taking up **Basic Financial Protection especially upon their early demise.** We propose that financial assistance be extended to lower-income families to help them acquire basic protection.

Key Recommendation 4: In addition to basic protection, the Workgroup recommends that the CPF be utilised as a savings mechanism for their child with special needs.

Parents or other family members should be encouraged to contribute toward the special-needs person's CPF account through Tax Relief. Donors can be encouraged by Tax Exemptions to contribute to CPF accounts of special-needs persons of their choice. Government can also consider topping up the said CPF accounts through Progress Packages in good economic-performing years. As the CPF was not designed with persons with special needs in mind, the Government could consider modifying it to make it more attractive for persons with special needs.

Key Recommendation 5: In addition to the CPF as a savings mechanism, **a non-profit special needs trust** could also be established as another mechanism for families to pool resources to further help themselves.

Key Recommendation 6: There is general apprehension over the lack of follow-up to the issues raised on the financial security of persons with special needs. Therefore, **a one-stop umbrella body focusing on financial security issues of persons with special needs** should be established.

Key Recommendation 7: Throughout the consultations, **pertinent issues pertaining to employment and the lack of caregiving options were raised.** The Workgroup would like the respective sub-committees of the recently appointed Enabling Masterplan Steering Committee to analyse and address these pressing concerns.

A Time Bomb and Challenge

Although the group started with a simple objective to gather views and suggest initiatives to enhance the financial security of persons with special needs, we learnt that the issue is more serious than it was earlier presented. Unless addressed proactively, it is a potential time bomb creating worry and anxieties amongst the families affected. .

As reported in the October 2006 AXA survey of 10,000 Singaporeans, most people do not have sufficient to retire and a 'worrying disconnect with reality' was observed. This problem is further compounded in families with special-needs children and more so in

lower- and average-income families with children of more severe disabilities. If parents have insufficient for themselves, it is almost certain that there will be even less for their special-needs children.

Even parents of higher-functioning children with hopes that employment is the key financial security solution are not confident that the preferred solution of employment is possible unless more effective preparation to hone their children's employability skills takes place.

The Workgroup therefore urges the Government to proactively address this issue of lack of preparedness for the financial security of persons with special needs in Singapore. We hope that the Government (with involvement from the people sector) will take the lead in following up on the key recommendations surfaced in this Report and design and implement a matrix of solutions for the said population before it is too late.

CHAPTER 1: METHODOLOGY

Introduction

1. The Parents' Workgroup on Enhancing the Financial Security of Persons with Special Needs was constituted in July 2006 with the following terms of reference:
 - i. Gather and analyse the views of parents on how to enhance the financial security of their special-needs children
 - ii. Recommend new initiatives to enhance the financial security of children with special needs

Process

2. A series of nine focus groups were conducted with a cross representative sample of parents across different income levels and children with differing special needs. During these sessions, parent respondents were asked about their views on the following issues:
 - Parents' biggest concerns for their children with special needs when they are no more around to watch over them;
 - What they are doing now to address the concerns;
 - Understanding of how much is required for basic expenditure if employment is not available;
 - Ideas to ensure financial security of their children with special needs; and
 - Preferred persons as child's guardians after parents' death.
3. During the focus group sessions, the participants were also asked to complete a written survey comprising 13 questions. These questions were designed to complement the focus group discussions. The survey was also distributed to parents who did not manage to attend the focus group discussion.

Instrumentation

4. Based on the research objectives, in consultation with MCYS, a facilitator's guide was designed by the workgroup for use during each of the focus groups (see Annex A). A simple written survey was also designed to extract demographic information and quantitative data from the participants on their views toward financial security of their child with special needs (Annex B). The survey was intended to reflect the concerns of the sample cohort and its results have not been validated against the general population.

Group Composition

5. The composition of the nine focus groups was as follows:

- Parents of children with Autism Spectrum Disorder (ASD) (<50th Income Percentile¹)
- Parents of children with ASD (>50th Income Percentile)
- Parents of Adults with ASD
- Parents of children in Christian Outreach for the Handicapped
- Parents of children with Intellectual Disability (ID) (<50th Income Percentile)
- Parents of children with ID (>50th Income Percentile)
- Parents of Adults with ID
- Parents of children with Physical Disability (PD) / Visual Impairment (VI) (<50th Income Percentile)
- Parents of children with PD / VI (>50th Income Percentile)

In total, 74 parents attended the nine focus group discussions.

6. The written survey drew responses from 93 individuals across the different income levels and special needs groups. Of these, 58 responses were from participants who took part in the focus group discussions. This was a response rate of up to 80%. Table 1 below depicts the income strata of all respondents to the written survey.

¹ Families who belong to the > 50th percentile group implied those with a per capita income of > \$1,000. Families belong to the < 50th percentile group had a per capita income of < \$1,000. Per capita income is derived from the Total household income / Total no. of persons in the household.

Table 1

Income Strata²	n	%
< 50th percentile	56	60
> 50 th percentile	37	40

7. In addition, the Workgroup also consulted individuals with financial planning backgrounds, including, Mr Stanley Jeremiah, ex-NTUC Income GM, Mr Leong Sze Hian, President of the Financial Advisors Society and other insurance and financial sector professionals.

Recruitment of Parent Respondents

8. The recruitment of parent respondents was done through the Voluntary Welfare Organisations (VWOs). Names of parents who were interested to attend the focus group discussions were surfaced to the secretariat, who invited them to the relevant sessions through a phone invitation.

Period of Feedback and Analysis

9. The focus group discussions were conducted from 3 Aug 2006 to 17 Aug 2006. Eight of these Sessions were conducted at the Telok Ayer Hong Lim Green Community Centre between 6-8 p.m., and one was conducted at the Christian Outreach for the Handicapped.

Limitations

10. The findings from qualitative research methods like focus group discussions are not meant to be statistically tested. These discussions are held to surface common themes and to obtain a deeper understanding of relevant issues that are more difficult to obtain in quantitative surveys, through probing or follow-up questions. It should also be noted that the views expressed during such discussions are strictly the participants' personal opinions and may or may not represent the population they belong to.

² The Income strata of parents are derived from the per capita household income of parents. That is the total household income / total number of household members. This information is either provided by the VWO, or drawn from responses to question 5 & 7 of the questionnaire.

CHAPTER 2: VIEWS OF PARENTS ON ENHANCING THE FINANCIAL SECURITY OF THEIR CHILD WITH SPECIAL NEEDS

“I think there should be a law to say that I can put my daughter to sleep after I die. I really don’t see who can look after my daughter. This is the only way I can think.”

“ I pray to God that .. if you can do anything better for him, let him go. If continue his life, if cannot do anything more, please take him away. Because I’ve done everything for him..”

1. Although not all parents are as pessimistic as the ones quoted above, there was a general mood of anxiety and at times helplessness when asked about their biggest concerns for their child with special needs after they are no longer able to take care of them.

2. This chapter seeks to provide a synopsis of the Key Views expressed by parents in the areas of their overall concerns; their understanding of the financial needs of their child with special needs; their preparedness; and their current methods and suggestions to improve the future financial security of their child especially upon the demise of the parents.

Overall Concerns Expressed by Parents

3. The overall concerns of parent respondents can be categorised into 2 main areas namely – Financial and Caregiving arrangements when they are no longer around to look out for their special-needs children.

Financial Concerns

4 Across the income strata, **parents generally did not know how much their child with special needs would require** after they have passed on. Despite attempts to save, they were uncertain if their savings would be sufficient to last their child’s lifetime after

they have passed on. The cost of medical treatment when their special-needs children are older and parents are no longer around, is also a concern raised.

“Money is the basic necessity”

“... we ... put aside money, but how much?”

“What if what we put in is not enough? Can we have some form of insurance that will come in and top up the difference if we die earlier?”

“I’m willing to contribute but what if it is not enough?”

“My first concern even when I am still around is financial security for his medical especially for hospitalization and critical illness as I am unable to find any insurance willing to provide coverage”

5. Concerns appear more serious amongst the lower-income families. **Parents from the lower income strata responded that their more pressing needs were meeting day-to-day expenses.** Although these parents recognise the importance of enhancing the financial security of their child with special needs, many of them do not make plans for their child’s financial future as they are still struggling with their own and current financial needs.

“My husband is earning \$1,600/- per month. We have 5 children. We tried to save abit but everytime the children fall sick, all the savings is gone again.”

“...living on a day-to-day expenditure...no one is thinking about after death...worried about now.”

“... take one step at a time...”

6. Respondents who are able to save expressed their **need for a “trusted organisation” to safeguard the monies they would be putting aside for their child with special needs.** They hoped that upon their demise, this organisation would administer the monies to their child with special needs. The monies should be disbursed regularly, ideally over the lifetime of their child. . Parents believed that their child’s care needs should not discontinue upon their demise and can be overseen by the same

organisation. In this respect, many expressed their faith in the present Government to be this “trusted organisation”.

“...Although he may have the money, there must be someone or an organisation to manage this fund to meet his needs, such as disbursements for his accommodation, subsistence, training, medical etc. I feel strongly that it is best to be entrusted to an organisation, which is secure and trustworthy and overseen by Government Body and at least until my son’s demise.”

“Who’s going to help manage all that money? ... can that person be trusted?”

“I can leave aside money... who’s going to look after and make sure the sum of money is used for my child?”

“We are willing to work towards saving for the child, but we need a trusted organisation”

Caregiving Concerns

7. Parents were asked who would look after their child with special needs when they are no longer able to do so or when they have passed on. Many parents interviewed felt that their child would not be able to manage their own day-to-day needs, much less financial matters. There was a **need for a caregiver** to continue to provide care for their child with special needs.

“Who will be taking care of her when we are gone?”

“No one looks after my child. And he can’t take care of himself”

“Will the child be able to practise their learned skills from school?”

“Who will be the assigned caregiver and whether the assigned caregiver can be trusted to fulfil his/her responsibility in taking care of the child?”

“Will there be any form of housing arrangement for the child?”

“Where I can leave him to live out his years in a suitable environment.”

“My son is very low functioning... has to be cared for 24 hours... no speech... has to be supervised... Who is going to take physical care of him? ”

“Who will look after him? Don’t want to burden my other kids and their spouses.”

“... my daughter is fairly independent... but... weak in money matters... may get cheated...”

“His ability to be independent & secure a job.”

“Legal issues ..Iskander, teenager with intellectual disability was jailed for molest”

“Expression of child’s sexual needs expressed in inappropriate form”

“... a Home for children with autism... make them feel at home...”

“His well-being, his future, what job he’s going to do... society to understand him”

“... accepted in a society... happy in his future life... can work independently...”

8. Many parents expressed hope that **the siblings of the special-needs child would be able to take over the care of their brother or sister.**

“All my assets will go to my younger son... he will take care of his brother (with special needs...”

“... the siblings will take care of him.”

9. Although the parents were keen to have family members continue to care for their child with special needs, they were aware that other family members could choose not to do so and view the latter as a “burden”. There were some who expressed concerns that when siblings of the child with special needs eventually marry and have families of their own, their families may not be as accepting of a relative with special needs. Some also recognised the fact that the siblings may not be available in Singapore to care for their special-needs child because of travel demands of jobs or emigration.

“... Who is going to take ... care of him? I have a daughter and younger son... not practical to think of him and her taking care... will destroy their lives...”

“Now the brother can look after, but they will have a family of their own. We don’t know if his wife will accept a child with special needs.”

11. Parents wanted **options apart from relying on their family members in supporting the care of their child**. Those with only one child or whose children are all disabled expressed the urgency of the need for adult residential care for their special-needs children. Specifically, there was request for the building of residential facilities e.g. homes.

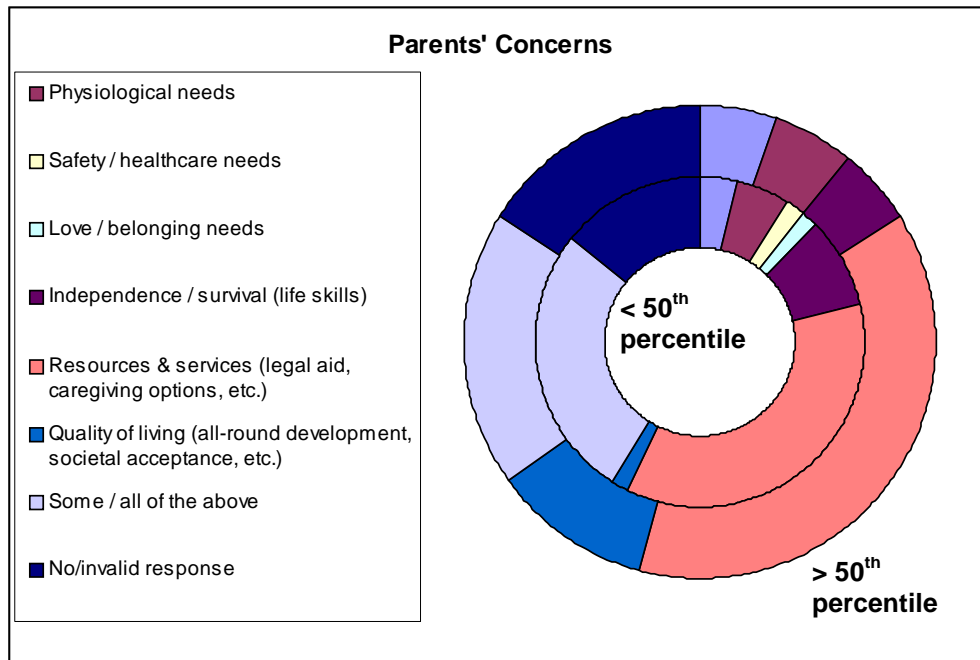
12. Some parents were also keen to ensure that **the standard of care (i.e. quality of life)** that their child is receiving now would not deteriorate after they pass on. They do not want their child to merely exist and leading a life without any purposeful engagement.

“I would like to have someone decide on his basic well being and quality of life. He should be continued to be trained as his living skills will deteriorate. Due to his severe disability, he is not capable to be engaged in any vocation. However I still hope that with his continued training and the re-designing of job tasks, he could be deployed in some simple job functions...production of products or services... making his life interesting and realistic.”

13. Parents, whose children are higher functioning, were anxious and eager that their child would be able to find sustainable employment to support himself/herself.

14. Figure 1 below depicts the categories of concerns raised by parents in the 2 different income groups. As expected, more lower-income families are concerned with their child’s basic physiological needs like daily living whilst higher-income parents are concerned with the quality of living and societal acceptance of their children when they are no longer around.

Figure 1



Parents' Understanding of Financial Needs and Level of Preparedness

15. Parents' responses to the question on what they were currently doing to address their wide array of concerns revealed that **they generally had not given much thought or taken much action to address the concerns articulated.** This is observed of parents from all income strata.

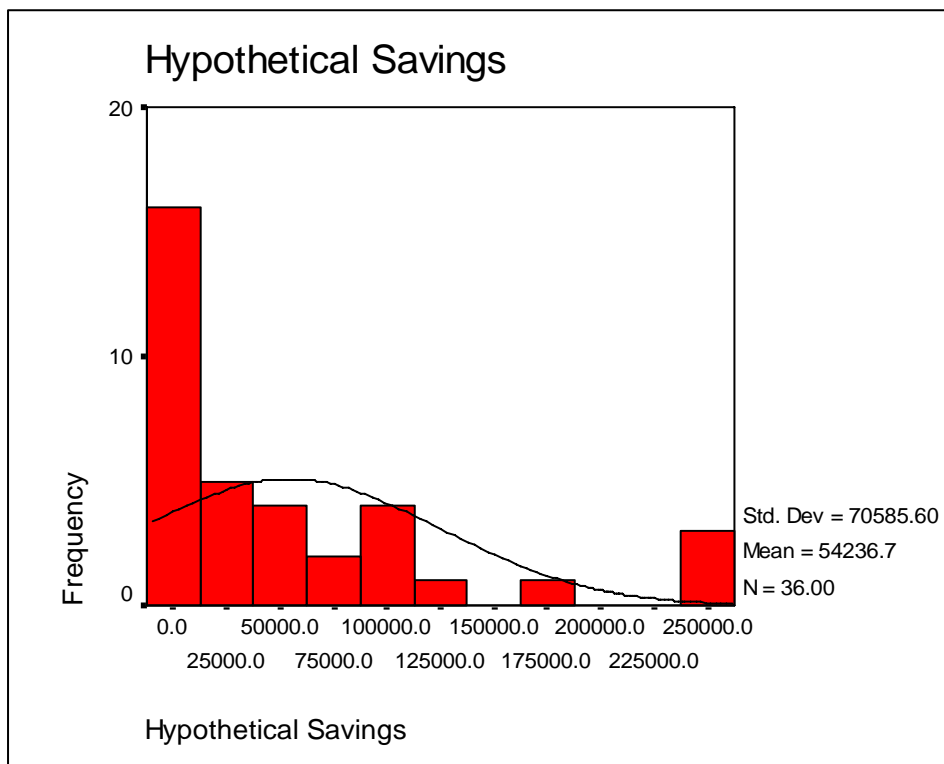
16. In the first instance, many respondents were not able to share readily on **how much they thought their special-needs child would require for their monthly expenditure on basic needs.**

“... can't say how much... need to go back and think...about this.”

17. Amongst those who responded at the focus group discussions, participants from the lower income strata tended to cite lower amounts on their child with special needs' monthly expenses on basic needs than those from the higher income strata. This may be indicative of the different lifestyles and expectations of the two income groups.

18. Less than 50% of focus group participants responded to the survey question on **how much in total they were prepared to set aside for their child** to ensure that their child would be financially secure after they had passed on. Out of those who responded, half indicated a range of savings from \$0-\$25,000, an amount that is unlikely to be sufficient. Figure 2 below depicts the responses from the participants of the focus group discussions:

Figure 2



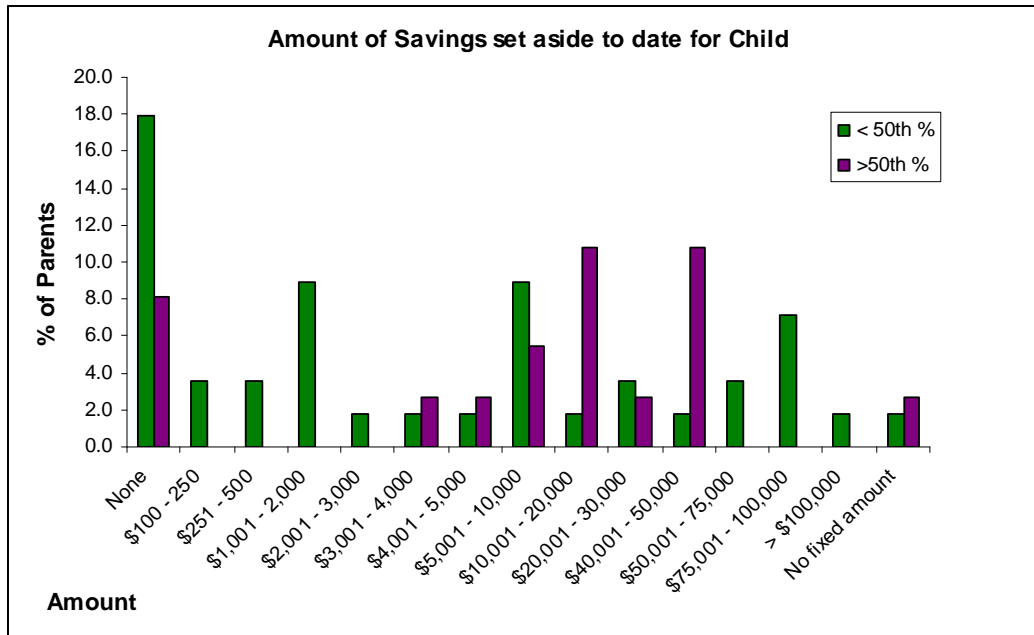
19. Parents of children with special needs also appeared to be **unfamiliar with financial tools** available to enhance financial security. Although there were a couple of parents who had already executed Wills, most were not familiar with the topic of financial planning and its associate tools. There is little mention of whether their own retirement and health needs are considered. There is little evidence that parents had any knowledge of legal matters relating to legal guardianship, trusteeship or custodian of funds. Replies generally centred on the following themes:

- Inability to purchase life or medical insurance for their child with special needs;
- Purchasing insurance on their own lives, with child as beneficiary
- Imparting essential life skills to child / training child’s siblings to take over care
- Selling away / downgrading / their flats to set aside monies for their child
- Leave their CPF savings to their child

State of Preparedness

20. When parents were asked the actual amounts they have put aside to date, 60% of them responded to this question in the written survey (see Figure 3 below). As expected, many in the lower income group had either not put anything aside or had put aside amounts likely to be insufficient for their child’s future needs.

Figure 3



“I think it is too early to talk about this. If you ask parents who are 50-55, they can answer better.. We are in our 40s, we need more time”

“I do have some savings... how to ensure it will last his lifetime?”

“... tried to get insurance in his name... no company... accept him.”

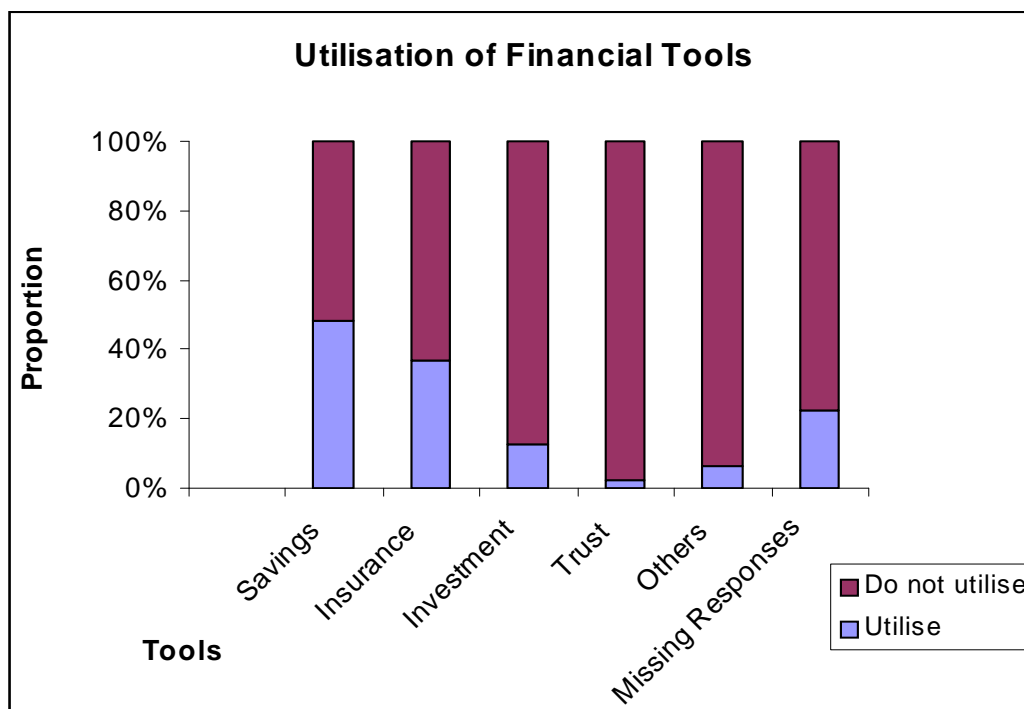
“sell off my 3-room flat... my other daughters help him oversee the money...”

“Insurance is a good way. I bought the insurance for my child at birth. Perhaps a good way is for parents to buy insurance, and then when the parents pass on, the money can be channelled to the child.”

“Where to get the money? If... have the money, how to manage funds, what... schemes to make money grow?”

21. Amongst those who are more prepared, **most put aside their monies in the common form of savings or insurance**, Figure 4 below indicates the parents’ responses when asked about the nature of their savings vehicle.

Figure 4



Parents’ Suggestions to Enhance Future Financial Security

22. **Earning a regular stream of income through employment as a source of financial security is the most preferred solution** expressed by the parents. However, there are some parents for whom the reality is that their child would not be able to gain

employment due to the low functional ability of their child. Hence, employment may not be an option to the more severely disabled persons with special needs.

“Hopefully... can learn some simple life skills to support herself in future...”

23. The following were some of the suggestions parents raised to provide employment to their child with special needs:

- Start a cooperative to employ persons with special needs
- Set up an organisation to train vocational skills
- Start a “salvation army” for persons with special needs so that they could sell “donated items”
- Identifying “cottage industries” for persons with special needs
- Have sheltered workshops for persons with autism

“...Government should give some monetary help to those who do well in studies...after they grow up, the government can employ them”

24. Other suggestions raised (other than employment) to improve the future financial security of the special-needs child include the following:

- Insurance including term coverage for protection and medical protection
- Trust Scheme
- Utilising parents’ CPF Savings
- Sale of Parents’ Home
- Reverse Mortgage of Parents’ Home

“One way is to open a savings account, and every month, the parent can put \$200... government can match dollar-for-dollar...”

*“Government dollar match for parent’s contribution for the child e.g. baby bonus
“... buy... condominium, when we’re not around, ... can rent it out and the renting fees to pay him”*

“I have heard about trust funds which means that I entrust money with a company which invest the money and which disburse the amount required for the financial needs according to care plan set up by me for my son. However I understand that it needs at least \$1 million”

25. In deliberating on the features of a financial scheme in which parents are willing to participate, several desired features were highlighted by the respondents:

- Protection of capital sum
- Reasonable growth of savings
- Minimum fund management and other administration costs
- Staggered release of monies eg annuity rather than a lump-sum disbursement
- Role of government or government-linked organisation is key to ensure maximum safeguard

“Will there be a scheme where more money can be topped up?”

“... good to have an umbrella organisation to manage and have a sight over these funds”

“We are willing to work towards saving for the child, but we need a trusted organization.”

“...Although he may have the money, there must be someone or an organisation to manage this fund to meet his needs, such as disbursements for his accommodation, subsistence, training, medical etc. I feel strongly that it is best to be entrusted to an organisation, which is secure and trustworthy and overseen by Government Body and at least until my son’s demise.”

26. It can be concluded that there is no one-size-fits-all solution. Suggestions offered varied according to the following:

- Severity of the special need of the child;
- Family Income and ability to put aside funds for the future;
- Knowledge of the parents in financial planning and management

CHAPTER 3: KEY ISSUES AND RECOMMENDATIONS

Key Issue One:

Low level of Awareness & Application of Financial Planning & Discipline

Recommendation:

Make available free access to Financial Planning Education

1. The Workgroup found an alarmingly low level of awareness and application of financial planning and discipline amongst most respondents. Many parents have little knowledge of national schemes such as the Dependant's Protection Scheme, MediShield and ElderShield currently under the CPF. Many parents have also not heard of term life insurance, a cheaper form of basic protection especially in the event of early demise of parents. Several parents have indicated that they wished to insure their child's life, a measure that is not advisable by financial planners.

2. To address the low levels of financial awareness and knowledge, we recommend that **free financial planning education be made accessible** to all families with special-needs children. This must be provided by Independent Consultants who are not linked to any financial products or who may be in a position to directly or indirectly promote the products.

3. A core education package could be drawn up and approved by a panel comprising professionals and parent representatives. This package should provide roadmaps that are relevant to families of different income groups; education and language backgrounds; and with children of varying degrees of severity of special needs. The following information is to be part of this package:

- Money management and
- Legal guardianship and/or trusteeship issues

We are pleased to advise that the National University of Singapore Pro Bono Society's legal faculty undergraduate members and lecturer(s) have offered to contribute toward this initiative.

4. Care should be taken to ensure the effective dissemination of the information so that it reaches the target audience it is intended to reach. Such information should be made available at VWOs, the Disability Information and Referral Centre, Schools and Community Centres, all of which are common interface points with families of children with special needs.

Key Issue Two:

Need for Basic Health Benefits Coverage for Persons with Special Needs

Recommendation:

Make available Basic Health Benefits for Persons with Special Needs

5. We are concerned that the current national healthcare insurance schemes such as the MediShield and ElderShield, exclude persons with special needs because they do not cover congenital and/or pre-existing illnesses. Another limitation of these health schemes is that they only provide benefits up to a specified age. As a result, many persons born with special needs do not enjoy (regardless of whether they are able to pay for it) national health insurance coverage unlike non-disabled citizens.

6. We propose that the Government conducts a study to review and implement an appropriate Health Scheme that will allow persons with special needs to enjoy at minimum, the same level of health benefits as non-disabled citizens. In particular, we request that the conditions of non-coverage of congenital and pre-existing and age limit ceiling for health benefits be re-examined in order not to exclude special-needs persons at the onset.

7. In order to assist families with lower incomes, we propose that the Government considers subsidizing the costs which may come in the form of premiums of health insurance for those families that fall within the bottom 50th percentile. For all other families, the Government could contemplate the possibility of allowing them to deduct the premiums for health insurance (should insurance be the solution) from the CPF accounts of either parents or the child with special needs.

Key Issue Three:

Need for Suite of Basic Financial Protection upon Parents' Demise

Recommendation:

**Facilitate Suite of Basic Financial Protection
of Persons with Special Needs**

8. We note that many parents are not aware of need to have Basic Protection i.e., some financial provision for their dependents especially upon early demise of the parents. We recognize that the Dependant's Protection Scheme (DPS) is one such Basic Protection coverage that families ought to have, The current DPS is a term insurance scheme with coverage of up to 60 years old, with a maximum Sum Assured of \$46,000. It an opt-out scheme with premiums ranging from \$36 to \$260, depending on age.- Low-income families may not have been included in it due to lack of funds. We feel that without basic coverage, the bulk of the children's financial future is largely left to chance and this will no doubt add to the stress and panic which parents may experience in the later stages of their lives.

9. We would like to encourage families to put in place Basic Protection for the financial security of their child with special needs. The Government should consider designing and implementing Basic Protection Schemes that parents could take up on their own lives.

10. One possible way would be to expand the coverage of the CPF DPS scheme by (among others) a waiver of the cessation of coverage at age 60. The Government could also assist families who wish to purchase additional coverage (e.g. Decreasing Term Life insurance or under the same DPS scheme) by subsidising the premiums or underwriting the payment of premiums for the lower income families. To encourage parents in the higher-income group to similarly increase their basic protection, premiums can be allowed to be deducted from their CPF accounts.

Key Issue Four:

Need for Safe and Basic Savings and Investment Avenues

Recommendation:

**Modify CPF Mechanism to Encourage Savings
by and for Persons with Special Needs**

11. Many parents may not have sufficient retirement funds for themselves and will need to be encouraged to save and invest to enhance their child's financial security. The Workgroup also notes parents' persistent calls for safe and accepted government-linked avenue for savings and investment.

12. In the light of the need for a safe and basic savings and investments avenue for parents, we recommend using the generally trusted CPF mechanism to encourage savings and investment. We encourage as a basic first step, all parents to open a CPF account for their child with special needs and make voluntary contributions into the account. We recommend that tax relief be granted for these voluntary contributions. We also recommend that these voluntary contributions receive an interest return similar to that of Medisave and the Special Account in the CPF. As at today, contributions to the Ordinary account enjoy an interest rate of 2.5%, whilst those to Medisave and Special Accounts will receive an interest return of 4%.

13. We would like these CPF accounts established for special-needs persons to be identified so that other than parents, donors or the Government could assist to top-up these accounts to the prevailing voluntary contribution limit³. Government may also top-up these accounts through Progress Package payments during years of good economic performances. Donors may be encouraged to top-up especially to special-needs persons of their choice by receiving tax-exemptions for their donations.

³ The prevailing voluntary contribution limit for 2006 is \$25, 245.

14. For those persons with special needs who managed to find employment, the Government could offer them a greater incentive to their accounts, akin to Workfare.

15. The Workgroup agrees that the minimum sum requirement should also be applied to the said CPF accounts as well given that the monies are intended to be disbursed over the life span of the special-needs persons after their parents had passed on. The current CPF Scheme provides for the withdrawal of the minimum sum over 7 years for a person with 'disability'. Many persons with special needs may outlive the specified 7 years. We hence suggest that the rules on withdrawal and early withdrawal be fine-tuned to meet the needs of the special-needs persons especially if the demise of the parents occurs before the official withdrawal age of the CPF holder.

Key Issue Five:

***Need for Additional Savings and Investment Avenue
for Average and Above-Average-Income Families
to Further Help Themselves***

Recommendation:

Set Up Non-Profit Special Needs Trust for voluntary parent participation

16. The Workgroup notes that average and above-average income families who want to save more for their child with special needs do not have access to a non-profit agency who understands special needs. Many of these families may be asset-rich but cash-poor. Parents would like a trusted agency to allow them to pool savings for growth and/or to transfer assets for their special-needs child upon their parents' demise. This agency can also ensure that the monies they saved are distributed according to Care Plans they desire for their children upon their demises.

17. We recommend the establishment of a National Non-Profit Special Needs Trust for families to pool resources to further help themselves. This may be more relevant for families from the average to above-average income families as an additional tool to the modified CPF mechanism proposed earlier. The features of this Trust should include:

- Protection of capital sum
- Reasonable growth of fund
- Reasonable administrative fees
- Managed by a board comprising reliable and respectable members approved by Government who will dictate Investment Policy for growth of funds

18. We recognize that such a Trust has no precedence in Singapore, and we strongly urge that the establishment of the Trust learns from the best practices of overseas models. We have looked at overseas models and noted that developed countries such as the United States of America have more sophisticated and tested knowledge-base on tools such as a Trust for Special-Needs Persons. We note that a Trust Company would need to

be formed in order for the Trust scheme to be implemented. We suggest that the role of the Trust Company be undertaken by a focused and professionally-manned one-stop body which will look into the various aspects of the financial security of persons with special needs. The formation of the one-stop body is detailed in our Recommendation Six.

Key Issue Six:

Need for One-Stop Body Focusing on Financial Security Issues of Persons with Special Needs

Recommendation:

Set Up an Effective One-Stop Body Focusing on *Financial Security Issues of Persons with Special Needs*

19. We have observed that parents in general fear the dilution and lack of follow-up of the critical issues that they have raised to us. We share these concerns. There were parents who indicated their desire to see a professionally-equipped One-Stop body established, so that one can obtain advice and services from this body to secure the future of their adult-child with special needs.

20. We strongly support parents' desire to see the establishment of a one-stop body to ensure focus and continuity. We propose that an Independent Quasi-Government Body be set up. This 'body' should be led by a Government-Appointed Board of Directors and Executive team, which will undertake the promotion of all matters relating to the financial security of persons with special needs. Parents also expressed the view that the body must be a "trusted organisation" and the Government was preferred over VWOs.

21. We propose that this one-stop body play a 'System Integrator' role linking a suite of the following services:

- Financial Investment Schemes
- Financial Education and Planning
- Legal Education and Advice
- Advocacy
- Case Management Services if family has no other members
- Trustee Services (Custodian of Funds and Supervision of Use/Distribution of Funds in accordance to Parents' Care Plans where applicable)
- Special Needs Trust Participation (see Key Recommendation 5)

Key Issue Seven:

Insufficient Efforts to Maximise Employment of Persons with Special Needs

Recommendation:

**Analyse and Address Root Causes for Low-Employment Rates
of Persons with Special Needs**

22. Our consultations with parents revealed that employment remains their most preferred source of financial income for their child with special needs. We believe that current efforts to maximise the employment of persons with special needs require review and improvement. In particular, we note that present efforts are primarily ad hoc individual VWO-driven efforts without any overall blueprint or synergy. Many of these efforts are not scalable and may not be widely known, especially to the non-English-speaking families or those currently beyond 18 years old and out of the formal school system.

23. We strongly encourage that more be done to encourage the employment of persons with special needs. Research should be undertaken to analyse the employment and turnover patterns of persons with special needs. We feel that the possible root causes of poor upstream employment preparation and negative perceptions and reluctance of potential employers ought to be studied and addressed.

24. Overall, there appears to be a lack of an on-going Multi-Tiered Employment Support framework and schemes to support sustainable employment of special-needs persons with different degrees of severity. The Government could formalise and fund Multi-Tier Supported Employment Schemes for major disability groups.

25. We had received feedback that the present Workmen's Compensation scheme had unfortunately been deterrent to the employment of special-needs persons because potential employers were unable to obtain from insurers Workmen's Compensation

insurance coverage for special-needs person whom they were willing to employ. We propose that the Government look into and address this issue.

Key Issue Eight:

Lack of Caregiving Options for Adults with Special Needs

Recommendation:

Make available free access to Financial Planning Education

26. We would like to point out the Workgroup had not attempted to address one of the biggest concerns that parents had raised i.e., the lack of caregiving options for adults with special needs. We note that this would go beyond the scope of the terms of reference of our Workgroup. However, we strongly share parents' concerns that the lack of caregiving options is a significant service gap and undoubtedly, has a big impact on parents' ability to develop and subsequently implement care plans for their child with special needs upon their demise.

27. We would like for Professor Tan Ser Kiat's Sub-Committee in Enabling Master Plan to study and recommend steps to address the concerns raised by parents on this subject. We encourage the Government and the said Sub-Committee to refer to best practices of other developed countries with more relevant experience and also to previous recommendations submitted such as the proposal for an "Attendant Care Foundation" by Mr Ron Chandran-Dudley, President of the Disabled People's Association.

**FOCUS GROUP DISCUSSIONS ON ENHANCING FINANCIAL SECURITY FOR
PERSONS WITH SPECIAL NEEDS**

Introduction

Good evening.

First of all, I want to thank you for your time in coming here to participate in this focus group session. We understand you are busy with work, as well as caring for your child who may need more care than most children.

We know that it is not easy bringing up a child with special needs/ caring for a family member with special needs. We are parents of children with special needs too. For many of us here, I am sure we are concerned as to who will care for our child with special needs after we are no longer around to do so.

I'm (Name) and this is (Name). We are members of the Parents Workgroup On Enhancing Financial Security For Persons With Special Needs. This Workgroup is chaired by Ms Denise Phua.

The Ministry of Community Development, Youth and Sports formed this workgroup as it wants to hear first hand, the concerns of parents on enhancing the financial security of their child with special needs. The feedback from our discussion will be invaluable as it will assist my workgroup in coming up with some recommendations to the Minister.

We would like to hear from you. At the same time, we would also try our best to keep the discussion to within 2 hours. Hence we would like to apologise in advance, if we have to stop you at times.

I would like to assure you that any information that is shared in this discussion will be kept strictly confidential. We will not tag any person's name to his/ her opinions. Your views are certainly important to us. However, as we will be talking to many other families from various backgrounds, we will only be able to show the Ministry the broad findings and the more pressing concerns. Hence, not all suggestions may be incorporated.

At any time during the discussion, please feel free to let me know if you are not clear or need more information on any terms or meanings that are discussed.

Moderator Guide

| Prompters

SECTION 1:**VIEWS ON PLANNING FOR FINANCIAL SECURITY OF CHILD WITH SPECIAL NEEDS****第一项：****为特殊儿童提供长远保障计划的看法**

- What are your biggest concerns for your child when you are no more around to watch over him?
- 当您已不在世后，您最为您孩子担忧的会是什么？
- What are you doing now to address these concerns?
- 您有为了这些担忧做了任何打算吗？

E.g. insurance policies, savings plan, Wills, Trusts, etc.

例如：保险，储蓄计划，遗嘱，信托计划，等等。

SECTION 2:**UNDERSTANDING FINANCIAL NEEDS OF CHILDREN WITH SPECIAL NEEDS****第二项：****了解特殊儿童的照料与经济需求**

- If he/she is not able to hold a job, how much do you think will be needed each month for the basic expenditure?
- 若您的孩子不能打工，您认为他每个月在生活必须的开支会是多少呢？

Basic needs may include: 3 meals, accommodation, enrolment in Day Activity Centres, Regular visits to doctors, Residential Home, etc.

必需的开支可包括：三餐，日间活动中心费用，定期的医药费用，残障人士局住所的费用，等等。

SECTION 3:

IDEAS ON ENHANCING FINANCIAL SECURITY OF PERSONS WITH SPECIAL NEEDS

第三项：

对于增进特殊人士长远经济保障的其他提议

- What do you think are some ways to ensure your child is financially secure in the future?
- 您认为有什么方法能够增进您孩子的长远经济保障？
- Can you share some financial schemes that might help to ensure your child is financially secure?
- 您能否和我们分享任何能够增进您孩子经济保障的计划吗？

SECTION 4:

APPOINTMENT OF GUARDIAN FOR CHILD WITH SPECIAL NEEDS

第四项：

委任特殊孩子的监护人

- Who would you prefer to appoint as your child's guardian of your child after you are gone?
- 当您已不在世后，您会希望委任谁当您孩子的监护人呢？

Spouse, siblings, other relatives, or Government

伴侣，兄弟姐妹，亲戚，或政府

We have come to an end of our discussion. I sincerely want to thank all of you for coming to participate in this discussion. I know that it may not be easy to discuss openly about your disabled child, especially what will happen after his/her primary carers have passed on. The information that you have provided is extremely valuable. We will be submitting the broad findings and recommendations from all the discussions to the Ministry so that it can inform them in future policy-making. Again, we will not put in any individual details or names to the findings.

Thank you once again for your participation. We greatly appreciate your help.

**SHORT SURVEY ON ENHANCING THE FINANCIAL SECURITY OF
PERSONS WITH SPECIAL NEEDS**

增进特殊儿童经济保障的小型调查

Thank you for showing your interest to participate in this short survey. All information gathered from this survey will be kept strictly confidential.

谢谢您对这个小型调查的兴趣。您的答案将会保密。

1.	What is the age of your child / children with special needs? 请问您特殊孩子今年几岁？																
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				Years old					Years old					Years old			
2.	What is your child's special need? 请问您孩子的残疾是什么？																
	<table border="1"> <tr> <td> <input type="checkbox"/> Intellectual disability 智障 <input type="checkbox"/> Autism spectrum disorder 自闭症 <input type="checkbox"/> Physical disability 体障 <input type="checkbox"/> Hearing impairment 听障 </td> <td> <input type="checkbox"/> Visual impairment 视障 <input type="checkbox"/> Multiple disabilities, please state: 集和型, 请例: (_____) </td> </tr> </table>	<input type="checkbox"/> Intellectual disability 智障 <input type="checkbox"/> Autism spectrum disorder 自闭症 <input type="checkbox"/> Physical disability 体障 <input type="checkbox"/> Hearing impairment 听障	<input type="checkbox"/> Visual impairment 视障 <input type="checkbox"/> Multiple disabilities, please state: 集和型, 请例: (_____)														
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3.	Which voluntary welfare organisation(s) is/are your child(ren) receiving service from right now ? 您孩子现在正向哪个自愿福利团体索取服务呢？																
4.	What is the total number of persons staying in the same household as you (excluding your domestic helper)? 请问您家中总共有几个成员 (不包括佣人) ？	()															

5.	What is the total number of persons in the household who are working? 请问您家中总共有几个成员目前就业？	()
6.	What is the total number of children you have (including your special needs child / children)? 包括您的特殊孩子，您总共有几个孩子？	()
7.	What is the range of your total gross monthly household income? 请问您每个月的家庭收入有多少？	
	<input type="checkbox"/> Below \$1,000 <input type="checkbox"/> \$1,000 – 1,999 <input type="checkbox"/> \$2,000 – 2,999 <input type="checkbox"/> \$3,000 – 3,999 <input type="checkbox"/> \$4,000 – 4,999 <input type="checkbox"/> \$5,000 – 5,999	<input type="checkbox"/> \$6,000 – 6,999 <input type="checkbox"/> \$7,000 – 7,999 <input type="checkbox"/> \$8,000 – 8,999 <input type="checkbox"/> \$9,000 – 9,999 <input type="checkbox"/> \$10,000 and above
<p>The questions below may be sensitive to some. Please accept our apologies for having to pose them to you. These questions are important to give us a have better understanding on how we can help special needs children much better, and we would appreciate your responses to them.</p> <p>若以下的问题或许会令你感到敏感，我们在此请你原谅。然而这些问题能够让我们更加了解特殊儿童的需要。希望你能协助回答。</p>		
8.	When I am no longer able to support my special needs child (e.g. I am too old or pass on), my biggest concern for my child is 若我再也无法照顾我的特殊孩子（例如：我已老了或已过世），我最为我孩子担心的是	
9.	Where possible, I am prepared to set aside \$_____ per month in the form of saving for the next _____ years so that my child is financially secure when I am no longer around (e.g. old or pass away).	

	<p>若能够的话，我预备在接下来的_____年内，每个月为我特殊孩子储蓄\$_____，以确保在我不在世时，他的经济有保障。</p>	
10.	<p>To date, I have set aside as savings \$_____ for my child for after I am too old or have passed on.</p> <p>至今，我已为我孩子将来的经济保障储蓄了\$_____</p>	
11.	<p>In which forms did you set aside the savings in? (you may tick more than one):</p> <p>请问您用了那些方法为您孩子纯钱？（您能够选多过一个）：</p> <p><input type="checkbox"/> Savings 储蓄</p> <p><input type="checkbox"/> Insurance 保险</p> <p><input type="checkbox"/> Investment 投资</p> <p><input type="checkbox"/> Trust 信托计划</p> <p><input type="checkbox"/> Others, pls specify: 其他，请例： _____</p>	
12.	<p>What other forms of assets have you considered setting apart for your child with special needs when you have passed on? (you may tick more than one)</p> <p>当您过世后，请问您还打算过为您孩子留下什么资产？（您能够选多过一个）</p> <p><input type="checkbox"/> HDB flat 政府组屋</p> <p><input type="checkbox"/> Private house 私人房子</p> <p><input type="checkbox"/> Shares / Investment 股票/投资</p> <p><input type="checkbox"/> Others, pls specify: 其他，请例： _____</p>	
13.	<p>Additional Comments on this topic:</p> <p>针对以上的课题，您还有什么看法：</p>	

Thank You
谢谢