

CONCEPT NOTE

SRI ARUNODAYAM'S "SPECIAL MOM" AWARD

I. PURPOSE

The problem and the need

Parents of Mentally Retarded (MR) children (whether biological or adopted) are never really prepared for what lies ahead in the journey with their children. MR children have absolutely no ability to self-regulate, experience major mood shifts, sometimes demonstrate extremely angry outbursts, and may appear to have very disruptive tendencies. They need regular appointments with their therapists, doctors, special educators and other caregivers' – much more than normal children.

Because MR children are unable to express themselves except in rather primitive ways, it is difficult even for their own parents to truly understand them. And thus, the cumulative negative effects on parents make them inevitably end up resenting their child at some point in time as the stress and frustrations continue to mount daily. Parents need positive reinforcement to keep chugging along, but they don't get that reinforcement if their children don't respond. This leads to a sort of crisis of faith and parents often wonder if their efforts are making a difference at all. Their moods also suffer in a major way because the daily home environment is so demanding.

- **Elgar and Colleagues (2004) found that being the mother of a child with mental illness or MR is associated with high levels of distress and depression.*
- **Barkley and Colleagues (1992) found that mothers of such children were two to three times more likely to be depressed than mothers of healthy children.*

This research should come as no surprise.

When Sri Arunodayam spoke to mothers of MR children we found most of them to be exhausted, frustrated or depressed. When working mothers come home to MR children - there's even more work to do! The truth is that MR children are more draining than other children, leaving their parents too tired to figure out where to go to get their own emotional needs met.

Another huge complicating factor for parents of MR children is that the special needs of their children rarely get met by the end of childhood - meaning that many of these children have trouble managing into their adult life—and this continues to impact the parents.

- **A study by Fingerman (2010) investigated the effect on parents' well-being of having a grown child who has experienced significant life problems (e.g., trouble with the law, a*

substance abuse problem, etc.) and found that having even one grown child with a significant life problem had a negative impact on the parents' mental health.

Undoubtedly, these are the negative effects on parents caring for MR children, but there are positives too. Yet, few are equipped to see those because of the continuous stress that they experience.

Sri Arunodayam believes that it is time to recognize and encourage primary caregivers – the mothers of special children - to come out into the open and share both negative and positive thoughts and feelings. Only by embracing the negatives along with the positives will there be a true opportunity for them and their MR children to grow in a holistic manner.

How our program tries to address some of these needs

In our country we see two types of extremes - on the one hand, we see too much pressure in our culture to pretend that parenting is a pleasure (even parenting MR children!); and on the other hand, we see parents completely abdicating their responsibilities towards their MR children by totally abandoning them or handing them over to institutions to take care of without any further involvement on their part.

It's time to start a social and cultural change, right where we are!

Sri Arunodayam wants to be the channel of change that (1) spreads awareness, (2) brings hope (to both MR children and their parents), and (3) provides recognition for deserving mothers who tirelessly strive to cope with MR children day-after-day.

Indeed, the time has come to recognize and honor such mothers - especially those who have been left to fend for themselves and their children. Such mothers truly deserve care and recognition because they often have to delay the gratification of their own most basic needs just because their children need it more!

II. PROGRAM DESCRIPTION

Creator and Owner of the Program

Sri Arunodayam Charitable Trust, based at:
Plot No: 35, Sivananda Nagar, Kolathur, Chennai - 600 099 (TN), India

Program Title

Sri Arunodayam's Special Mom Award

Transformative Nature of the Program

Sri Arunodayam will be celebrating its 15th year of service in February 2017.

As an authority on MR and a certified Government partner in the rehabilitation of abandoned MR children in Chennai, Sri Arunodayam has accumulated extensive research and experience in this field. For a society to be educated and sufficiently transformed there

is a critical need for sustained awareness and advocacy programs of this nature. Therefore, Sri Arunodayam is widening its broader “societal transformation” program through advocacy programs such as the one proposed in this document.

This particular Award focuses on the immediate caregiver – specifically the mother.

Program Activities

- ¹Identify mothers with MR children (either through direct application or nomination)
- A ²Selection Committee will review all applications and shortlist 15 finalists
- A ³Verification Authority will verify and authenticate the short-listed candidates
- 15 deserving candidates will be honored each year on Mother’s Day (which falls approximately between May 10 - May 14)
- Each year’s 15 finalists will be given the Award which consists of (1) a *Certificate of Excellence in Parenting*, (2) a cash award of *INR 15,000 each*, and (3) a *Special Lifetime Pass* that entitles them to ⁴support services from Sri Arunodayam Charitable Trust.

Who benefits?

In broader terms – society at large! Such advocacy impacts:

- The direct beneficiaries - MR children and their parents
- Siblings of MR children (*To educate, catch them young!*)
- Educators, educational institutions, education authorities
- Governments and the concerned local governing bodies
- Medical and research environments
- Constitutional lawmakers, judicial and redressal systems, law & order enforcement departments
- Other organizations in similar advocacy fields

Program Launch Date

December 1, 2016

Program (1st Event) Culmination Date

Mother’s Day, May 14, 2017

III. OBJECTIVES

What does Sri Arunodayam hope to achieve?

There are several objectives we hope to achieve. These are:

- To celebrate the wonders of motherhood – especially the joy of bringing special children into the world and what this teaches parents, families, and societies

- To teach society that mothers of special children need to be respected and honored just like other mothers
- To give hope to mothers of special children that there is a good future ahead for their children
- By such events, bring about a transformative cultural change in society
- Through advocacy, bring about the much needed change in our governing and legal systems
- To create a special support group/forum for moms of special children, which will help them gain and provide learning experiences to one another, and share and gain from the group's experiences and best practices to find strength in their situations.
- To empower mothers of special children to learn and evolve into child advocates in society.

IV. METHODOLOGY

a) How the project will be carried out

1. ¹Identify mothers with MR children (either through direct application or nomination)

- **Channels**
 - Website campaigns (with facility for direct submission via the website)
 - Social media campaigns
 - Direct mailer campaigns (to existing/potential donor base, peer organizations, networking platforms)
 - Print media campaigns (non-paid)
 - FM radio
 - Television?
- **Input required**
 - Submission Form, supporting materials, relevant requested proofs

2. ²Selection Committee to review all applications and shortlist 15 finalists

- **Choosing the Selection Committee:**
 - The Selection Committee to be chosen from among reputed professionals and organizations in relevant fields – medical care, MR/Autism/Down Syndrome research, special education, members from the Indian Association of Physiotherapists, Chennai, Government bodies – e.g. ChildLine, Law enforcement, CWC
 - Not to exceed 5 members - excluding Sri Arunodayam's Founder and 2 Senior Members
- **Committee Functions:**

Convene to review all applications and choose the finalists after the due diligence process; Work with the Verification Authority to close the loop in finalizing the 15 finalists each year.

3. ³Verification Authority will verify and authenticate the short-listed candidates:

- **Choosing the Verification Authority:**
The Verification authority will comprise 1 independent legal member from Sri Arunodayam's Legal Department and a group of trained volunteers for on-the-ground research
- **Authority Functions:**
 - Conduct investigative checks on 18 finalists through personal interviews with the mothers and narrow down to the final 15 finalists.
 - Talk to family members, neighbors, school authorities, and associated contacts so as to develop a complete and impartial view of each finalist.
 - Provide impartial feedback and certify the veracity of the finalists to the Selection Committee, helping them close the loop and decide on the 15 finalists each year.

4. ⁴Support services to finalists

- On or before the day of the Award, mothers, their special child, and one other person (family of friend) will be provided free transportation and accommodation to attend the event.
- The special moms will be given a 'day out' to enjoy themselves through various activities, sponsored by Sri Arunodayam. This may include a spa session, or a stress relief massage session, or a tour to tourist sites in Chennai city, etc. The activities will be finalized closer to the date of the event.
- While the mothers are attending the event activities, their special children will be taken care of by Sri Arunodayam. This gives the mothers a stress-free time to enjoy themselves.
- Each year's 15 finalists will be given access to regular training programs and materials to help them learn more and advance in their caregiving abilities.
- Understanding the anxiety of parents concerning the future of their special children on their demise, Sri Arunodayam offers the option to finalists to appoint Sri Arunodayam as the custodian and official guardian of their special children. Sri Arunodayam will network with peer organizations to enable a safe haven for their children on the parent's demise.
- Establish a network or support system for finalists to collaborate, learn, share and also leverage Sri Arunodayam's services and support to develop into a sisterhood of special moms who can enjoy hope for themselves, their children and families, and other affected families in society through association.

b) Anticipated Timeline

The first event will happen on 14 May 2017 and will continue to be hosted annually on Mother's Day. Each year's learnings and Best Practices will be integrated back into the main strategy, so that the program evolves into a benchmark program in its category.

- **Finalizing the Selection Committee and the Verification Authority:**
On or before 1 January 2017
- **Commencing channel campaign activities:**
December 1, 2016
- **Campaign run period:**
1 December 2016 to 28 Feb, 2017
- **Finalists Announced:**
10 April, 2017
- **Award Event Date:**
May 14, 2017
- **Project Fundraising:**
To commence with immediate effect

V. PROGRAM BUDGET

(TOTAL = INR 6,00,000)

- Prize money for 15 finalists (x INR 15,000) = INR 2,25,000
- Special Gift Hampers for finalists and their children
- Award venue hire cost
- Dinner for 400 people including the finalists and their families (400 x INR 500 = INR 2,00,000)
- Equipment hire costs - Audio-visual /sound system; photography
- Website campaign development costs (pre- and post-award campaign themes/banners, event pages, data capture form development & feedback integration, etc.)
- Channel costs (associated costs for advertising and publicity before, during and after the event, printing costs, etc.)
- Admin costs (function hosting, finalists' travel, hotel stay, event day activities, and all related costs for the day)

Study References:

- *Elgar FJ, McGrath PJ, Waschbusch DA, Stewart AH, Curtis LJ. Mutual influences on maternal depression and child adjustment problems. *Clinical Psychology Review*. 2004; 24 (4):441–459.
- *Barkley RA, Anastopoulos AD, Guevremont DC, Fletcher KE. Adolescents with attention deficit hyperactivity disorder: Mother-adolescent interactions, family beliefs and conflicts, and maternal psychopathology. *Journal of Abnormal Child Psychology*. 1992; 20(3):263–288.
- *American Psychological Association (2010, August 15). Parents' mental health more likely to suffer when a grown child struggles. *ScienceDaily*. Retrieved October 3, 2013, from http://www.sciencedaily.com~ " target="_blank">http://www.sciencedaily.com~ /releases/2010/08/100812161926.htm