

The Son-Rise Program (including information on LEA funding)

By Karenza Cassidy, Eddie's mum (22 September 2008)

Eddie developed at the normal rate, with speech, eye contact, interactions etc., until he reached 14 months of age, at which point he started to regress, gradually losing speech, eye contact and any interaction at all.

He had an uncontrollable fever and an obvious reaction to the MMR vaccination. By the time he was two years old, he had no vocabulary. He also suffered with recurring tonsillitis so I took him to the doctor, who assured me that it was very common that Eddie wasn't talking and that it was probably because he had a sore throat! So he was put on yet another course of antibiotics and I was advised to relax.

As an experienced mum of two children already, I asked to be put on the waiting list for a developmental check. They tested his hearing first and suggested he wasn't talking because he was deaf, but I explained that he could hear crisp and chocolate wrappers from the other side of the house! Finally at the age of two years three months his test results in Hong Kong showed signs of autistic features. More tests followed over the next few years as he continued to regress, then at the age of five, he was diagnosed with autism again in the UK.

Like a lot of parents of children affected by ASD I felt lost. I was sure that there was a good reason as to why this was happening to our family, but I couldn't make any sense of it. The worst part was knowing that Eddie was physically perfect, in fact, he was a very beautiful child, but knowing that he might never connect in a meaningful way with me or his brothers and sister was very tough.

After the diagnosis there was nothing in terms of support from the professionals. It's a matter of researching and reading and taking the initiative yourself, which is hard work when you're still trying to come to terms with the whole thing. Eddie's father was in denial for sometime after the diagnosis, not believing that his son was autistic, so I felt very alone. A couple of months after the diagnosis given in Hong Kong, when Eddie was just over two, Henry, my eldest son, who was five at the time told me that he felt like his "brother had died". This was probably my lowest point.

Initially, I decided to home-school Eddie. Realising that he was a strong visual learner, I set up a workstation with visual aids and we played at encouraging him to look and talk. This seemed to work very well, but a major upset was just around the corner and one that would affect all our lives dramatically. We were living in Hong Kong at the time as my husband was working in an international school. I discovered that he was having an affair and it was this which eventually led to me moving back to the UK with all four children. The demands of looking after my family alone were huge so I immediately began looking for educational provisions to meet Eddie's needs, as I thought it was impossible to teach him myself at home as well as caring for the other three children.

Eddie was placed in a specialist unit for autistic children in Clase Primary Swansea and this is when his behavior seemed to worsen. He began waking up three to four times every night, head banging everything and attacking his siblings. His eye contact and speech disappeared yet again and he had to be escorted to school every day in a taxi. One morning he locked the escort and the taxi driver out of the cab.

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The final straw came when one day when I visited his teacher to discuss strategies. From her approach and attitude, it was quite clear that she did not know how to deal with a very challenged child and this started me on my quest to find a solution.

Some of the other mothers of autistic children I kept in touch with had been mentioning they'd seen an American guy being interviewed about his organisation in the States and had been very impressed with what he had to say and so I decided to look into it further. I kept looking at his website and one day ordered a free information book. When it arrived, I read it through and was excited at some of the ideas to try at home. So I tried them and realised that they were simple but effective.

I then called up for a free 25-minute consultation with the Autism Treatment Center of America (who co-ordinate the Son-Rise Program) and was very impressed at their understanding and attitude to autism. It was totally different from the usual "what a tragedy" or "just accept it and get on with your life" approaches. I booked to take part in their initial Start-Up training in London in January 2005. The week's training course enables you to effectively direct a full-time Son-Rise Program from your house, including playroom skills, training volunteers, strategies to deal with difficult issues, etc.

I was so confident on leaving that I was going to change the course of Eddie's life that I took him out of school immediately and just went for it! That was in February 2005. I had a team of 8-10 volunteers playing with Eddie one-to-one for 8-10 hours a day. It varies, but most of the volunteers did between 6-10 hours every week with Eddie.

I recruited the volunteers from our local university, college, and schools and asked for people who were open-minded, fun, and willing to commit to changing a little boy's life. I had already received the training on the Son-Rise Start-Up on how to equip them with the necessary skills to work in the therapy room with Eddie. I also booked for a Son-Rise Teacher to come and work with us in our home environment, to offer full support and check that we were on the right track. Son-Rise offers these Outreach Visits for two day periods, and they are incredibly useful to propel your program.

As with any home-therapy programme, there are obvious costs involved in training staff, paying for training programmes, the running of the programme, and so I approached the Local Education Authority with a proposal to divert the monies that were being spent on Eddie in school to our home-schooling. The Local Education Panel met two weeks later and agreed to the plan!! I also fund-raised privately to top up the funds; neighbours, local schools, and charities, stepped into raise funds and this was incredibly uplifting.

Eddie has responded beautifully to his Son-Rise Program. He sleeps through the night, he's toilet trained, he plays with us the majority of the time, he looks at us 6-8 times per minute and he's just getting the hang of talking! It is wonderful to see him interacting and playing with his brothers and sister and really trying to communicate with us.

The focus of the Son-Rise Program is the core communication skills: eye contact, interaction span, participation, and flexibility. Below you will find my Proposal to my Local Education. I am happy for anyone to use any of it to obtain funding for a home-based programme. It also gives a more detailed explanation of some of the Son-Rise methods.

It should come as no surprise that I'm totally biased towards the Son-Rise Program as it has quite literally changed our lives. We have turned around from being in a place of total desperation to

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having a positive to focus on in a personal time of grief and sadness. But mostly it has been a very effective vehicle in helping Eddie realise the beauty of being with and interacting with other people. We are selling Eddie the idea of communicating and we're having lots of fun in the process. I'm certain that Eddie would not have developed in the great way he has over the past three years without it.

Taking Eddie out of school was a big decision, but I think that one of the major factors for me was that I, as his parent and the person who knows him the most, would be in charge of all aspects of his development and growth. I should also mention that prior to this I had looked at other home therapy programs, but didn't feel comfortable with some of the ABA (Applied Behavioral Analysis) type programs.

It was very important to me to be deeply respectful of Eddie and move at a pace that he was comfortable with and this is what I believe is the key element to the Son-Rise Program. It has taken the guesswork out of educating him and I oversee all aspects of his progress, his self-help skills, his diet, his sleep patterns and perhaps his most challenging area—social development.

If I had to give some simple advice that sums this whole thing up it would be this: we as parents are the best equipped people to help our own children. No one loves our children as we do. Trust that you have the determination and conviction to be your child's best resource.

Presentation to Swansea LEA

Introduction: The aim of this presentation is to state the case for receiving LEA funding to run the Son-Rise programme (an Individual Educational Programme) at home for our son, Edward Cassidy, who suffers from ASD (Autistic Spectrum Disorder)

The presentation will contain the following sections:

1. Case Background
2. Rationale for undertaking the programme
3. Justification for receiving LEA funding
4. Summary
5. Appendix: Programme Details

1. Case Background

Edward Cassidy is the third of four children and was born in the UK in 1999 moving to Hong Kong when he was 6 months old. His development was quite normal until the age of about 14 months when it was noticed by his parents that he began to withdraw and lose the language that he had already acquired.

He began to exhibit self-stimulatory behaviour and indifference to communication and at the age of 2 years 3 months he was diagnosed as autistic. He started having sensory, speech, occupational and play therapies in order to assist his development and he was taught how to use PECS (Picture Card Exchange System).

Upon his return Edward's ASD was confirmed and he was targeted to receive appropriate educational

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provision by Swansea LEA. In September 2004 he started attending the special autistic unit at Clase Primary School.

Edward was recently removed from the special autistic unit at Clase Primary School and placed on the Son-Rise programme, a home-based specialised therapy programme for the treatment of autism.

Edward's mother, Karenza, attended a 50-hour training course to learn how to administer the initial stages of the programme and is the principal therapist.

Organisation behind the programme:

The Son-Rise programme is delivered by the Option Institute from their Headquarters in America and has been established for over 20 years. It was devised by a couple who had a severely autistic child themselves, but refused to accept the medical wisdom of the day: that there was nothing that could be done about his condition. Raun now shows no traces of autism; after three years of doing the programme he became totally integrated into mainstream schooling and he even went on to graduate from Brown University and now delivers lectures all over the world. The Option Institute is a registered charity in the US.

2. Rationale for Undertaking the Programme

A) Results: Having spent the last four years researching treatments for autism, Karenza concluded that the Son-Rise programme was the only approach that had actually delivered results and consistently 'cured' the individual's autistic features. She spoke to many parents of formerly autistic children who were so delighted with the progress of their children that they were now offering their own time to help train families new to the programme.

B) Empirical evidence of Edward while at school: Since attending full-time school over the last five months, Edward's self-stimulatory behaviour showed a marked increase and his sleep patterns became so erratic that he was disrupting the entire family's sleep. He also started biting his siblings and suffered from unpredictable mood swings. This has been attributed to the massive overload of sensory information he was getting from the time he left the house at 8:30 until his return at 3:40.

The unpredictability of the environments experienced by Edward was a crucial factor in his worsening behaviour: taxi to school with different drivers and different escorts, large open spaces, other children and teachers, and being physically manipulated around school in order to complete everyday tasks. All this resulted in Edward not being in control of his environment and he consequently began to exhibit more extreme repetitive behaviours.

C) Empirical evidence since embarking upon the Son-Rise programme: Even though it has only been running full-time for a month, the differences in his behaviour have been nothing short of miraculous. His eye contact has improved tremendously, his repetitive behaviours have reduced by 50%, his health is excellent, and his sleep patterns are getting back to normal.

3. Justification for LEA funding

A) Educational entitlement: The Son-Rise programme is an intensive, one to one, relationship-based therapy programme, designed to normalise a child's behaviour. Local Education Authorities cannot

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possibly hope to match this level of individualised educational provision. All children are entitled to an appropriate education and we have no doubt that the Son-Rise method will benefit Edward more than any other programme.

B) Funding entitlement: Even as an average student, Edward will have an amount of money allocated to him for his education annually. Since Edward has special needs, the money allocated to provide suitable education for him will be quite considerable. This money should still be spent on Edward's education, even if the LEA is not directly involved in its administration.

C) Long Term Plan: It is expected that the programme will last from 2-4 years, after which time Edward will no longer have special needs and will be able to join the mainstream schooling provision. This will save the LEA approximately eight years of payments at the special need level.

D) Family Commitment: Tom has returned from Hong Kong, leaving his business interests, in order to support the programme's delivery. He plans to work an average of three days per week, spending as much free time as possible in the playroom doing therapy with Edward. Karenza is the lead facilitator in the programme and is responsible for the details of the programme, including the training of all volunteer therapists.

E) Commitment to continuous training: The family is totally committed to investing in the training that the Option Institute provides. Karenza went on the initial training course in January and she has booked further intensive training sessions in October and December. In addition to these week-long courses, we have scheduled bi-weekly phone consultations for the next three months and have booked for a specialist to spend two days in the playroom with Edward doing hands-on training in June.

4. Summary

A) Our plan is to run the programme for more than 8 hrs/day, seven days per week for the next three years.

B) The programme has been very successful for children with ASD.

C) Edward is entitled to receive funding for an appropriate education.

Therefore we ask for Edward's allocated funding to be dedicated to the Son-Rise programme.

5. Appendix: Programme Details

Philosophy: The Son-Rise programme places parents as key teachers, therapists and directors of their own programs and utilises the home as the most nurturing environment in which to help their children. The Son-Rise programme suggests that respect and caring are key factors impacting on a child's motivation to learn, and from the beginning has made acceptance (of the child as they are) a meaningful part of every teaching process. Employing this attitude, through the programme we seek to create bonding and a safe environment first, and then apply sound, educational strategies to encourage the child's development.

Core principles: Joining in a child's repetitive behaviour and ritualistic behaviours supplies the key to unlocking the mystery of these behaviours and facilitates eye contact, social development and the

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inclusion of others in play.

Utilising a child's own motivation advances learning and builds the foundation for education and skill acquisition.

Teaching through interactive play results in effective and meaningful socialisation and communication.

Using energy, excitement and enthusiasm engages the child and inspires a continuous love of learning and interaction.

Employing a non-judgmental and optimistic attitude maximises the child's enjoyment, attention and desire throughout their Son-Rise Program.

Placing the parent as the child's most important lasting resource provides a consistent and compelling focus for training, education and inspiration.

Creating a safe, distraction-free work/play area facilitates the optimal environment for learning and growth.

Implementation of program: Child-led, parent-directed, home-based intensive program.

1. Child centred: We join, celebrate and build on what the child wants to do – doorway is through the child's motivation.

2. Parent directed: As parents we believe we are the expert on our child – and we have now been given the tools to run the programme ourselves. In addition to the extremely high motivation we have as parents we are also in total control of everything that Eddie experiences. We know what his diet is, how long he is doing therapy, who he is being exposed to, how he is responding to specific approaches. This takes the uncertainty out of the equation.

3. Approach (including number of hours): At the moment running programme for approximately 60 hours a week.

4. In order to run the programme we must have volunteers – we currently have 5 volunteers each offering at least 4 hrs per week contact with Eddie, either in 2 x 2hr sessions or 1 x 4hr slot.

5. All volunteers have agreed to do 4 hours a week.

6. Feedback/training for volunteers. Every session volunteers are observed for 20 minutes – note the techniques they are doing well and things that need to be changed or included. Will continue observing for up to 6 months until volunteers fully trained. Show example of observation form.

7. Set Programme goals and discuss in meeting – always reviewed.

8. Bi-weekly meeting - all volunteers meet to discuss evaluation forms. This includes topics for discussion and questions, the techniques that are most effective for Eddie, how child he is growing and changing, gathering baseline information, and creating programme goals. At the moment as we are at the start of programme we are using meeting more for training, discussing what motivates Eddie, how to deal with certain situations etc. Volunteers are given evaluation forms to fill in.

9. Playroom: A room with no distractions –has all his toys on shelves, a slide, trampoline, desk and chair, big mirror, windows frosted, CCTV camera, one way mirror in the door. Playroom is the YES room. Eddie has the control in the room. Toys on the shelves encourage him to ask for things. Also

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put his drink and snack on shelves. Join and play with him in the things he likes doing. We join in using YES as a way of getting him to bond with people—same interests bring a bond. Can initiate but only when he gives you eye contact or some sort of contact. No mechanical or electrical toys. We want to stack the odds in our favour for maximum communication opportunities.

10. Main aim is to improve his social skills, hence it is a relationship-based programme. Eye contact, interaction span, language, physical contact: essential to do these first. Once social skills are there, you can then concentration cognitive skills.

11. Praise him enthusiastically when he looks at you and you say, “You looked at my eyes” and point to your eyes. Works very well, eye contact is now prolonged and more frequent

Successes to date

1. Much more eye contact, especially during self-stimulating activities. Previously his self-stimulatory activities were totally exclusive. Responds to ‘look at my eyes’ commands approximately 95% of the time.

2. Has started saying a few words in context; ma (mummy) daddy, bu (butter), di (dinosaur), poo (Winnie the pooh)

3. Loves his playroom – drags you back in there

4. Will come and call Daddy by name to read books to him

5. Sleeping through the night

6. 95% toilet trained, out of nappies but sometimes gets surprised!

7. Started eating fruit & veg

8. Seems much more contented, less overload symptoms

9. Able to focus for longer periods with sustained eye contact

10. Looks at mother’s mouth when modelling words

11. He initiates interaction with mother and father to join him in activities such as reading and playing with toys

Fundraising Strategies

1. Need to raise approx £20k p.a. to run the programme for next 2-4years

2. Currently fundraising with various events

3. Monkey club, raffle, etc

4. Applied to UK charities that support the Son-Rise programme (Caudwell Charity, etc)