

The Winston Churchill Memorial Trust of Australia

Report by Susan Davis – 2002/1 Churchill Fellow

The Northern Districts Education Centre Churchill
Fellowship

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Signed

Dated

Susan Davis

Acknowledgments

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Executive Summary

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Project Description: To study, evaluate, and develop teaching skills in the Son-Rise program for children with Autism Spectrum Disorder and other disabilities.

Fellowship Highlights:

- Attending courses at the Autism Treatment Centre of America, and the Option Institute and Fellowship.
- Meeting a large number of families who were running Son-Rise programs, and observing and participating in six of these programs. The children were of varying diagnoses, ages and levels of severity of disability. The families represented a wide range of cultures, socioeconomic background, and training in the Son-Rise program.
- Meetings with other professionals (teachers, occupational therapists etc) who are trying to integrate Son-Rise philosophies into traditional educational settings.
- Discussions with parents and professionals regarding their experiences of other programs, such as Auditory Integration Training, ABA, biomedical interventions, etc.

Conclusions:

- The Son-Rise program is a highly effective, loving and gentle approach to teaching children with autism. It has great potential to assist children with autism to form positive, trusting relationships with the people in their environment.
- The attitude and teaching style inherent in the Son-Rise programs results in improved emotional well-being, which leads to less aggression and self-injurious behaviours, and increased potential for learning.
- Professionals and organisations providing services to children with autism and their families can be more effective and meet the needs of more families if they are open to, and knowledgeable about, alternatives for children with autism (e.g. auditory integration training, biomedical interventions, Son-Rise etc).
- Children with ASD and their families vary greatly, therefore a range of educational options is needed to meet their individual needs.

Fellowship Program

May 20-24, 2002: 'Maximum Impact' course at the Option Institute. Advanced training for parents and professionals involved in Son-Rise programs. Included interviews and discussions with many parents and professionals. Sheffield, Massachusetts.

May 25-June 2, 2002: Visit to a family implementing a part-time Son-Rise program for their high-functioning five year old (diagnosed PDD-NOS). Included observations both in the Son-Rise program and at school. New York State.

June 3-7, 2002: 'Empowering Yourself' at the Option Institute. A course teaching the attitudinal concepts and dialogue process that form the basis of the Son-Rise program. This week included meeting parents and professionals involved in Son-Rise programs on a variety of levels. Sheffield, Massachusetts.

June 8-24, 2002: Visit to a family with two children with special needs (aged five and seven, diagnosed with autism and PDD-NOS) in the early stages of implementing their Son-Rise program. Attended a Committee for Special Education meeting, and interviews with the media to recruit volunteers and begin fundraising. New York State.

June 25-28, 2002: Visit to a family utilising the Son-Rise attitude, but not running a playroom program, with a five year old girl diagnosed with mild mental retardation. Included a consultation with her occupational therapist. Boston, Massachusetts.

June 29 - July 5, 2002: Visit to a family running a very comprehensive Son-Rise program fully funded by the school district for their seven year old with pervasive developmental disorder. This visit included detailed discussions regarding biomedical interventions and auditory integration training. New Jersey.

July 5-10, 2002: Visit to a family with a three year old who has been diagnosed with autism, and a seventeen month old with delayed language, autistic tendencies, and other developmental concerns. Included a visit to a psychiatrist experienced in biomedical interventions for children with autism, as outlined in the DAN (Defeat Autism Now) Protocol. Pittsburgh, Pennsylvania.

July 11-14, 2002: Visit to a family with an eight year old with autism, and three other children, two of whom also show mild developmental concerns. Included a meeting with all of his current therapists, and a social meeting with the Simi Valley Child Development Centre (where many of the therapists involved with the three children are based). California.

Introduction

Autism Spectrum Disorder is a neurological disorder that impacts significantly on children's ability to communicate and interact with other people, process information about their environment, and function on a day-to-day level. The prevalence of autism in Australia appears to have increased significantly over the past ten to twenty years. Controversy exists as to whether this increase reflects a real change in the numbers of children with autism, or whether more flexible diagnostic criteria and increased awareness have resulted in children being diagnosed at higher rates. Whatever the reason, there is a huge, and increasing, demand for educational services for children with autism. Currently, services are struggling to meet this demand; in 1991, there were more children on the waiting list for Autism Association of N.S.W. schools and satellite classes than there were children currently enrolled.

When a child is diagnosed with Autism Spectrum Disorder, parents are generally told that autism is an incurable disorder whose cause is not clearly known and understood. In Australia at the present time, treatment for children with autism involves teaching the skills necessary for the child to participate in their community (e.g. shopping, using public transport, vocational skills), improving verbal language while using visual communication systems (e.g. PECS) and reducing inappropriate behaviours. The child's school education may also be supplemented by speech therapy, and, if necessary, physiotherapy and occupational therapy. These traditional approaches work well for many children, and many parents have reported satisfaction with services offered by the Autism Association and/or their child's local school. However, given that children with ASD all have individual needs and learning style, and their families vary greatly as well, it is clear that a range of educational options is necessary. The Son-Rise program is one of these options. It offers parents the opportunity to become extensively involved in their child's education, to build a loving relationship with their child, and to teach their child in a setting specifically and carefully designed to facilitate this process. This report will analyse and explain the Son-Rise program and then examine how the Son-Rise program can complement our existing services for children with autism.

The Son-Rise Program:

1. The history of the Son-Rise Program

The Son-Rise program began in the 1970's, when the Kaufman family's son, Raun, was diagnosed as severely autistic, labelled ineducable, and assessed as having an under thirty IQ. After researching existing educational and therapeutic approaches and finding them unsatisfactory, the Kaufmans developed their own home-based program. Their primary focus was not to train Raun in basic skills and socially acceptable behaviours, but to reach out and make a connection with him. The Kaufman's worked with Raun for three and a half years, eventually transforming him from a severely autistic toddler to a highly intelligent, sociable child who showed no traces of his former condition (Kaufman, 1994).

My visit to America included the opportunity of being taught in classes led by Raun - he is a truly exceptional and gifted teacher, whose social and verbal skills are unquestionable.

Following their success with Raun, the Kaufman's were flooded with requests for help, which resulted in the establishment of the Option Institute and Fellowship in 1983. Since then, the Kaufman's have been teaching the Son-Rise program and philosophy to parents and professionals. The following points reflect some of the aspects of the Son-Rise program that make it so unique and successful.

2. Distraction free environment

The Son-Rise playroom is designed to reduce distractions. The walls and floor are a light, unpatterned colour, and fluorescent light (with its high frequency flicker) is avoided. The windows are covered in rough plexiglass, or plastic that blurs the outside view while still letting light in. There are no siblings, pets, television or other distractions. Without these distractions to turn to, the child is more likely to turn their attention towards the child facilitator, and then be able to maintain this focus.

Just as the playroom is distraction-free for the child, so it is for the child facilitator.

There is no telephone to answer, dishes to wash, lunch time bells, or other adults to talk to. The playroom is also designed to minimise safety concerns, with padded floors and unbreakable windows. These factors combine to free the parent or teacher to focus their entire attention on the child, which allows teachers and parents to notice subtle cues. For example, the child may respond more to voices spoken in a certain pitch, or show interest in a toy with a very quick, sideways glance. By enabling child facilitators to observe these subtle cues, the distraction-free environment contributes to the effectiveness of the teaching within the playroom, as well as the ability of the child to stay on-task.

3. Joining

One of the key characteristics of autism is the repetition of certain behaviours, such as hand flapping, lining objects up, spinning or repeating one particular sentence over and over again. These behaviours, which are frequently called self-stimulating behaviours (or 'stims'), are known as 'isms' in the Son-Rise program.

The Son-Rise Program maintains that isms are comforting and important to the child. These repetitive behaviours are possibly curative in nature, and may have a purpose that we are unable to see (Autism Treatment Centre of America, 2001). Given this view of self-stimulating behaviour, Son-Rise facilitators don't try to forcibly stop children from isming. Instead, they join children in their repetitive behaviour and use the ism as an

opportunity to create a bond between the facilitator and the child. As competent social beings, we know that part of making friends and forming a bond with someone is showing an interest in the things they like to do. This principle can be extended to children with autism - we join them in their world and take part in their games as we ask them to take part in our world. The impact of joining can be very powerful; several parents spoke of the expression on their child's face when they first looked up and saw somebody else joining them in their favourite activity.

The technique of joining has also been supported by research from the Touch Research Institute at the University of Miami School of Medicine. They found that "an adults imitations of the behaviours of children with autism led to increased social behaviour in children the children in the imitation group spent a greater proportion of time showing distal social behaviours toward the adult including (1)looking; (2)vocalizing; (3)smiling; and (4)engaging in reciprocal play." (Autism 2001, Sept:5(3): 317-23).

4. Attitude

Imagine you were to walk into a class to learn the Japanese language and culture. The teacher begins your class by stating that you have a very limited ability to learn and succeed in her class. However, since her language and culture are clearly far superior to yours, you still have to try and learn it. This attitude would not motivate and inspire many people, yet it is an attitude that children with autism are faced with in their homes and schools every day of their lives.

The attitude inherent in the Son-Rise program is markedly different, and according to the Son-Rise staff, is what makes the Son-Rise program so unique and so successful. Son-Rise children are surrounded by a loving, accepting and non-judgmental attitude, and the child facilitators do not have expectations or limitations regarding the child's prognosis and learning ability. By joining children in their repetitive behaviours and following the child's interests, Son-Rise parents and child facilitators aim to show their child that they are loved and accepted no matter what they are capable of learning. This respect and deep caring becomes a key motivational factor in the Son-Rise program (Autism Treatment Centre of America, 2001).

5. The Three E's - Energy, Excitement and Enthusiasm

Motivation is a key issue for children with autism - they often seem uninterested in learning what we have to offer, and far more interested in pursuing their self-stimulating behaviours, or 'isms.' Traditional programs have addressed this problem by introducing token economies, food reinforcers, or a structured system of rewards that are often not clearly related to the task (e.g. Complete this exercise and you may have ten minutes to spin objects). Son-Rise uses what they have termed the 'three E's;' energy, excitement and enthusiasm, to motivate children to join us in our world. These three E's can be seen when a casual observer looks in through the playroom observation window; the child facilitator might be jumping up and down to cheer a child who has just spoken a word more clearly, or participating whole-heartedly in a game of hunting tigers (and yes, children with autism can play imaginative games, particularly when their teachers are as creative as Son-Rise facilitators are). By presenting an environment that is energetic, exciting and filled with enthusiasm, children are more motivated to interact and learn.

6. Interaction

Currently in Australia, the majority of special education services use objectives to

determine their teaching content (e.g. For John to consistently use a spoon, without any assistance, to eat his yoghurt at lunchtime). The Son-Rise program also identifies goals for the child to work towards, but the acquisition of these skills is not considered to be the most important part of the program. Instead, the focus is on interacting with the child, and motivating them to want to interact with us. To achieve this, the Son-Rise program emphasises moving with children (Kaufman, 1981). In traditional educational settings, children with autism are constantly moved against. The structure of the classroom timetable and the expectations of teachers and parents leads to an environment where the words 'no' and 'stop' may be used more than any other. The playroom allows child facilitators to enjoy being with the child, and minimises behaviour management problems.

7. Flexibility and the effective use of time

In a traditional classroom setting, the timetabling of the day determines and limits the teaching opportunities. Scheduled recess and lunch times, circle time, assembly and other students whose behaviours may need to take priority at times result in missed teaching opportunities. Many teachers I have met mentioned the frustration of almost reaching a child only to be interrupted at a crucial moment. Another common frustration reported by parents and special education teachers was the significant amount of wasted time, due to situations that are inevitable when children with special needs are taught in small groups in a classroom setting.

What strikes me about the Son-Rise program is that there is almost no wasted time; children aren't left standing, waiting in a line while the teacher organises the rest of the class. The curriculum is individualised so children don't spend time working on tasks that are too easy or too difficult, or not relevant to them. The one to one ratio allows complete flexibility to adapt teaching goals and learning experiences.

8. Sound Educational Practices

The Son-Rise program is known for its innovative ideas and practices, such as joining a child in repetitive behaviours, and adopting a loving, accepting and non-judgemental attitude. What is not so frequently discussed is that in addition to their unique techniques, Son-Rise also utilises many of the time-tested, well-known teaching techniques that are known to be effective, such as;

1. Task Analysis, i.e. breaking down complex tasks into their smallest components and teaching them one step at a time.
2. Reinforcing desired behaviours, or a slight move towards a desired behaviour.
3. Keeping detailed, accountable records of the child's progress.
4. Providing extensive support and training for child facilitators.
5. Developing an individualised program that is meaningful and relevant to each child.
6. One to one child to adult ratios.

The combination of these sound educational practices and the more unique Son-Rise techniques combine to make an educational program that is highly effective. Samahria Kaufman comments that when professionals and government representatives have observed a Son-Rise program, their concerns about the educational validity of the program dissipates (Kaufman, 1989). Many parents also reported reluctance and resistance towards Son-Rise by their school district until teachers and other professionals came to view the program. Once they had seen the child being worked with in the playroom, they realised that the Son-Rise program is educationally sound. One mother

reported that:

“The school really resisted us pulling James out of school and doing Son-Rise at home. Their perception was that a Son-Rise program consisted of sitting around loving a child, and hoping that would be enough to miraculously cure him. Once they saw James in the playroom, smiling and laughing, and trying so hard to say “I want swing” clearly, they changed their minds. Said they’d never seen James look so happy and relaxed, and they’d never been able to motivate him at school like he is in the playroom”.

Evaluation of the Son-Rise Program

My experience with the Son-Rise Program prior to this Churchill Fellowship had raised some questions, such as how the program impacted on parents and siblings, how far the children progressed, and how Son-Rise children differed from children with ASD in more traditional educational settings. These issues are dealt with below:

1. What impact does the Son-Rise program have on the family?

The Son-Rise program is very intensive and time-consuming, and as it is a home-based, parent-directed program, the impact on families is considerable.

Although all of the Son-Rise families I visited were busy, and many were struggling to maintain the Son-Rise program and other areas of their lives, the stress levels in these families were surprisingly low. Most parents reported that since beginning the Son-Rise program they felt more enthused and less despairing regarding their child’s future. Many stated that emotionally, they were coping far better with running a Son-Rise program than they had when their child was receiving more traditional educational services, and were therefore more productive and effective within their child’s program.

Most parents felt that their reduced stress level and more positive attitude was directly attributable to the teaching they received at the Autism Treatment Centre and the Option Institute. All Son-Rise courses focus on the attitude of the parents, as well as teaching skills such as time management, and addressing relationship problems between parents. The positive attitude of Son-Rise parents is a testament to the effectiveness of the teaching style and high standards at the Autism Treatment Centre of America.

One family I visited in America had their program fully funded; the school district paid for aides to work in the playroom, and for outreach support services from the Autism Treatment Center. The total cost was significantly less than the cost of educating the child in a school setting, for a program that is far more effective, according to both his parents and former school teachers and therapists.

2. What impact does the Son-Rise program have on siblings of children with disabilities?

Siblings of children with disabilities face a particular set of challenges, including lack of time and money because their sister or brother demands so much of both, restricted family holiday and outing options, and the need to take care of a sibling that demands more maturity than their chronological age suggests. The Son-Rise program does not

miraculously remove these problems, but many parents reported that their children had become closer since beginning the Son-Rise program. Children with siblings in Son-Rise programs, like children with siblings receiving traditional special education services, still had to accept that their brother or sister received more time and attention than they did. However, Son-Rise siblings had the following benefits;

1. They regularly witnessed their parents interacting with their sibling in a loving, fun way.
2. Parents who have been exposed to the Son-Rise program and other teachings of the Option Institute were able to use these skills (e.g. the Dialogue Process) to improve their parenting skills with all of their children.
3. Son-Rise siblings can actively participate in their brother or sister's educational program, giving them a greater feeling of involvement and control.
4. Techniques such as joining, and the safety-focused design of the playroom can allow and teach children how to play with their sibling with special needs.
5. The Son-Rise program gives siblings the skills and opportunities to form a relationship with their brother or sister, which makes the difficult parts of living with a sibling with autism easier to accept. One mother reported:

“She still gets cranky with him at times, but it’s easier now. Before Son-Rise, he wouldn’t look at her, or anyone. He never seemed to know he had a sister. So it was hard to explain that she should be loving and kind to her little brother. Now, he looks up and smiles and coos when she walks in the room. He approaches her to be tickled and squeezed, or for help to open his drink bottle. So it’s easier, if he makes funny sounds when her friends are visiting, or if he breaks something of hers. They seem more like ordinary brothers and sisters now. They still fight, but who doesn’t?”

3. How do the educational and behavioural outcomes of children in Son-Rise programs compare to children in more traditional programs?

Studies comparing the progress of children in Son-Rise programs to other programs have not been carried out, and my visit to America was not extensive enough to allow for a definitive comparison. The following is a series of impressions gleaned from families, professionals, and staff at the Autism Treatment Center.

- The development of self-help, language, academic and social skills varied greatly, from moderate to almost miraculous gains. Many children had developed skills and language that parents had been told would never be attainable.
- All children displayed significant progress in eye-contact, emotional well-being, and willingness to interact with others, areas that are often considered the most difficult to see progress in.
- No children had become more aggressive, self-injurious or withdrawn, which is significant as any intensive intervention programs can result in an increase in undesirable behaviours.
- Children were able to easily and naturally transfer the skills learned in the playroom into their everyday lives.
- Many of the children showed far more flexibility and spontaneity than is generally expected from children with ASD.
- Son-Rise children appeared more imaginative than traditional views of children with autism indicate. I was regularly surprised at the children's ability to participate in, and initiate imaginative play episodes, with their toys, their siblings,

and their child facilitator.

Son-Rise children did not become spoiled, or develop behavioural problems as a result of lack of discipline or guidance. In contrast, the behaviour of the children I met reflected the love and respect that was shown to them.

4. How does the emotional well-being of children in Son-Rise programs compare with children in more traditional educational settings?

Children with autism frequently display behaviours that indicate emotional difficulties, such as self-injurious behaviours, aggression and severe tantrums. What was noticeable about children in Son-Rise programs was the absence or reduction in these behaviours. In comparison with their peers in more traditional educational settings, Son-Rise children displayed a basic sense of trust in their environment and the people around them. They seemed to know that their needs would be met and that their fears and sensory defensiveness would be respected. This increased emotional healthiness is probably a result of the loving and accepting attitude and safe, predictable environment that is inherent in the Son-Rise program. This provides opportunities for greater growth and learning than is possible when children are stressed and anxious. Families also reported that the improvement in emotional well-being led to improved relationships with family and friends, less tantrums, aggression and self-injurious behaviours, and an increased willingness to accept change and interruptions.

Conclusions

The Son-Rise program is a highly effective, non-invasive and inspiring approach to teaching children with autism. Of all the programs I have seen, the Son-Rise program has the greatest potential to assist a child to build loving and meaningful relationships with their parents, siblings and teachers. These relationships pave the way for greater learning in social, communication, self-help and academic skills.

Incorporating tenets of the Son-Rise program into existing educational services.

Children who were in full-time Son-Rise programs behaved somewhat differently from the typical child with Autism Spectrum Disorder. Son-Rise children appeared to be less aggressive and self-injurious, had fewer tantrums, interacted more closely and lovingly with their family and friends, generalised a learned skill from one context to another and played creatively and imaginatively. This suggests that some of the difficulties faced by children with autism are related to the teaching techniques and style frequently used with children with autism, rather than the disorder itself. For example, traditional literature suggests that children with autism are structured and rigid in their behaviour and patterns of thought, yet the school system that they are taught in is also structured and rigid in its behavioural expectations, timetabling and language. The Son-Rise program is able to provide an environment that is spontaneous and flexible, and this results in children who are able to cope with, enjoy and benefit from spontaneity and flexibility. From my time spent in both traditional classroom settings and Son-Rise playrooms, I believe that it would be worthwhile to examine the possibility of incorporating some of the Son-Rise techniques into existing educational services. Joining a child in their repetitive behaviours, developing a child-centred curriculum, and acknowledging parents as the child's best expert all have the potential to improve the quality of education available for children with Autism Spectrum Disorder.

Providing more educational options and choices for parents of children with Autism Spectrum Disorder

There are many different approaches to teaching children with autism, ranging from visual communication systems, to very structured, behaviourist-based programs (e.g. ABA) to biomedical interventions. One thing that all these different programs have in common is that children will progress at very different rates, and it is generally difficult to predict which children will progress the furthest in any program. Given that professionals are unable to tell parents accurately and decisively if their program will work for the child involved, it seems that parents should be given more choice regarding the program their child is enrolled in. When a child is diagnosed, parents are referred to the Autism Association, and/or to therapists and early intervention services. These services all use quite similar approaches, and generally the parent is not given much information or choice about the educational service that will be offered to the child. Even when the child's current program is not working effectively professionals don't generally suggest alternatives. One Son-Rise father reported his frustration at this situation:

“I can remember sitting in this woman's office for Tim's yearly review. She sat there and told us that Tim hadn't learnt much in his first two years of school (which we already knew), then went on to say that for the next eleven years we should continue with the same setting, techniques and teaching approach, even though nobody really expected much progress!!

When we asked about some of the alternative approaches we'd been researching, she told us not to waste our time and money. But she wanted us to continue with a program that had already been proven not to work. What was worse, she recommended that this be the only education or treatment that he receive".

These parents, and many others, reported that it would have helped a great deal if professionals had been more knowledgeable and open-minded about alternatives.

Financial and practical assistance

The Son-Rise program is based on the concept that parents are a child's best expert, resource and advocate, and when given the tools, can show a passion and dedication to helping their child that outstrips any professionals. The parents that I visited in America, and those that I work with in Australia, are certainly a testament to what parents can achieve. Currently, Australian parents who wish to pursue an intensive home-based program such as Son-Rise have only one option; home schooling, which offers very little practical help, and no financial assistance. While these families are managing to run their child's program with varying degrees of success, financial assistance could dramatically increase their effectiveness.

Recommendations

1. Continue working intensively with the three children in the Goulburn District who are in Son-Rise programs, and assist other families who are interested in Son-Rise.
2. Seek funding for my position as a teacher supporting children in home-based programs who have special needs. Currently, parents are paying my wages, which is a considerable financial strain.
3. Speak to schools and professional groups who are interested in learning more about the Son-Rise program, and incorporating aspects of it (e.g. joining, employing a non-judgmental attitude) in their existing program.
4. Speak to parents via parent support groups and school committees regarding the different options that are open to them (e.g. Son-Rise, biomedical interventions, auditory integration training).
5. Research the feasibility of establishing a school, or unit within an existing school, that caters to families who do not believe that the current educational system can meet their child's needs, but who would prefer for their child to be educated in a school, rather than at home. Families that I have spoken to about this in the Goulburn District have stated that they want an education for their children that:
 - 5.1 Focuses on a child-centred curriculum.
 - 5.2 Acknowledges parents as a child's best resource and most knowledgeable expert.
 - 5.3 Provides support for parents so that they have the tools to become an integral part of their child's educational program.
 - 5.4 Utilises extensive parent involvement in order to provide as much one-to-one time as possible.
 - 5.5 Acknowledges that learning to interact with other people, and being motivated to do so, is one of the biggest challenges for children with ASD. Learning these skills has a great impact on the child's, and his or her family's quality of life.
 - 5.6 Provides a learning environment in which the child feels safe, accepted and loved. Parents have expressed that they would prefer that their child's emotional well-being be prioritised over the acquisition of skills.
6. The Son-Rise program is a home-based program, and it is difficult to imagine how it could be incorporated into our existing school structure. However, some aspects of the program could be used to improve the educational services available to children with autism. These possibilities include using the Son-Rise technique of joining a child in their exclusive, repetitive behaviours, developing a more child-centred curriculum, changing our attitude towards children with autism.
7. Professionals working with families with children with ASD need to be well-informed and open-minded regarding alternative approaches so that they can knowledgeably discuss these options with parents.

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