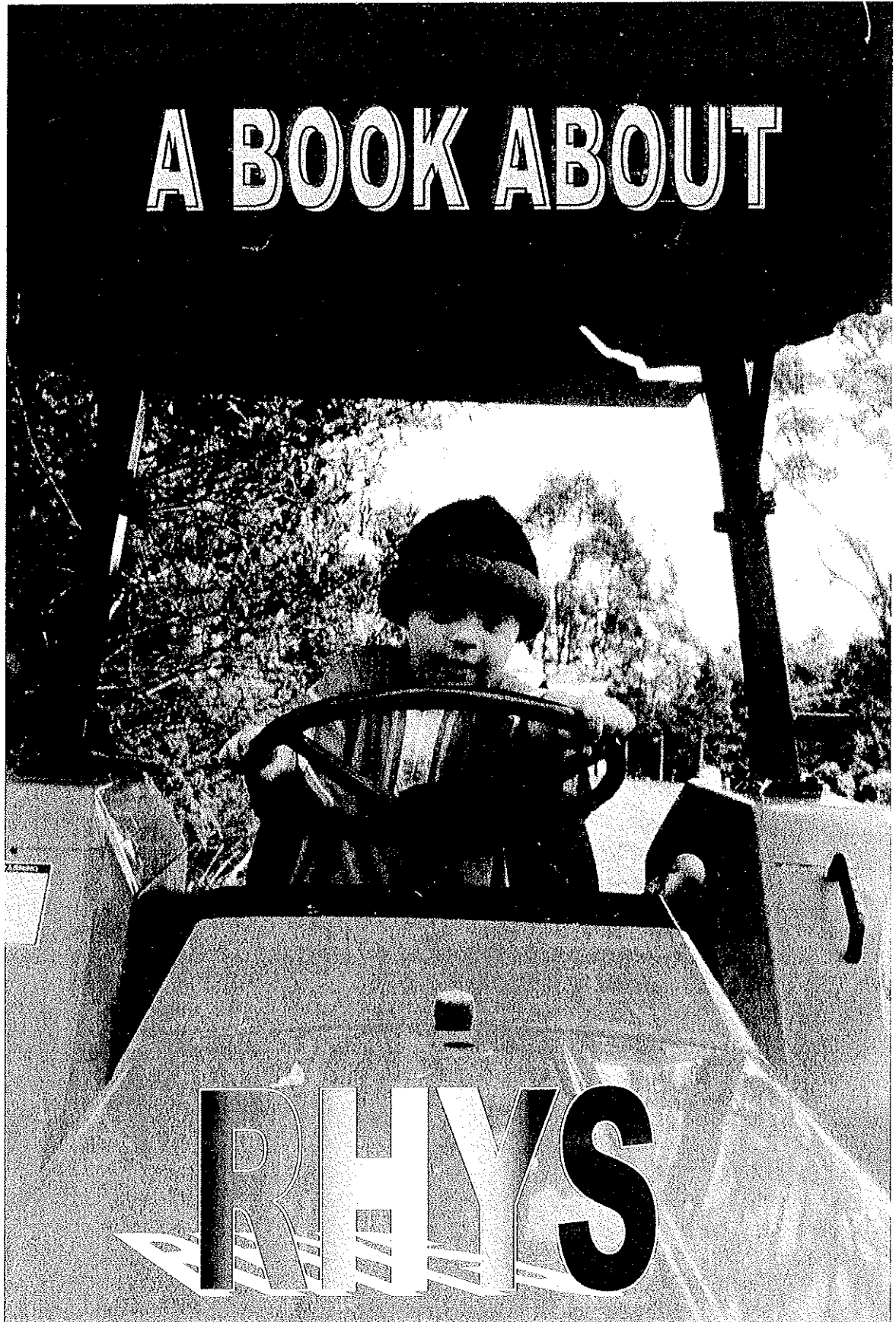


A BOOK ABOUT



Written and compiled by Susanne Walden

"For Rhys and Julius. Love goes in circles."

With many thanks for publishing to



contact@carersnsw.asn.au

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NSW/Australia 2004

The purpose of life

I believe that the purpose of life is to be happy.

From the moment of birth, every human being wants happiness and does not want suffering.

I believe that at every level of society - familial, tribal, national and international - the key to a happier and more successful world is the growth of compassion. We do not need to become religious, nor do we need to believe in an ideology. All that is necessary is for each of us to develop our good human qualities.

I try to treat whoever I meet as an old friend. This gives me a genuine feeling of happiness. It is the practice of compassion.

TENZIN GYATSO
THE FOURTEENTH
DALAI LAMA

"Compassion and the Individual",
Wisdom Publication, Boston 1991

Preface

Hi!

Our names are Robert and Susanne. We are the parents of two beautiful boys aged ten and five. One of our boys has a disability. We compiled this booklet in 2002 to help our son Rhys in the transition process at his local school. Primarily our intention was to help the teachers to get a feeling for the person Rhys is rather than knowing him for the disability or syndrome he has. We didn't want him to become his disability or his condition. Rhys *has* a disability. We would like him to be seen as a child first. A child, who has an older brother, loves his Mum and Dad (and the family dog!), really enjoys music, dancing and drama and according to his long term teacher from Early Intervention - has a great laugh!

Our desire seems to be just natural, doesn't it? But the sad reality is for our family and most other families who have a member with a disability, that a lot of people are not aware, lacking knowledge, are uncomfortable, fearful and inexperienced to realize this. People often still use a language, which is not only not appropriate but also disrespectful towards the child and his or her family. This can be in times cruel, hurtful or negative.

As families we also have to deal with the perception and the myth that people with disabilities are not able to learn. But the opposite is true. Fact and research show that people with disabilities are able to learn and achieve when well supported.

We had wonderful responses to our 'Book about Rhys'. Friends and family, who have been reading and looking at this book, were touched by its content and we were encouraged to share it with the wider community. It has developed into a resource book, an educational tool that can be used in Early Intervention Centres, preschools, schools and at home and wherever else you want to challenge attitudes:

- It creates awareness about discrimination via language use towards people with disabilities and their families
- It helps break down barriers towards people with disabilities, because they can be seen as human beings first and not as their handicaps, their limitations, their problems
- It helps and encourages other parents of children with a disability to choose an inclusive education and inclusive life for their child/children.

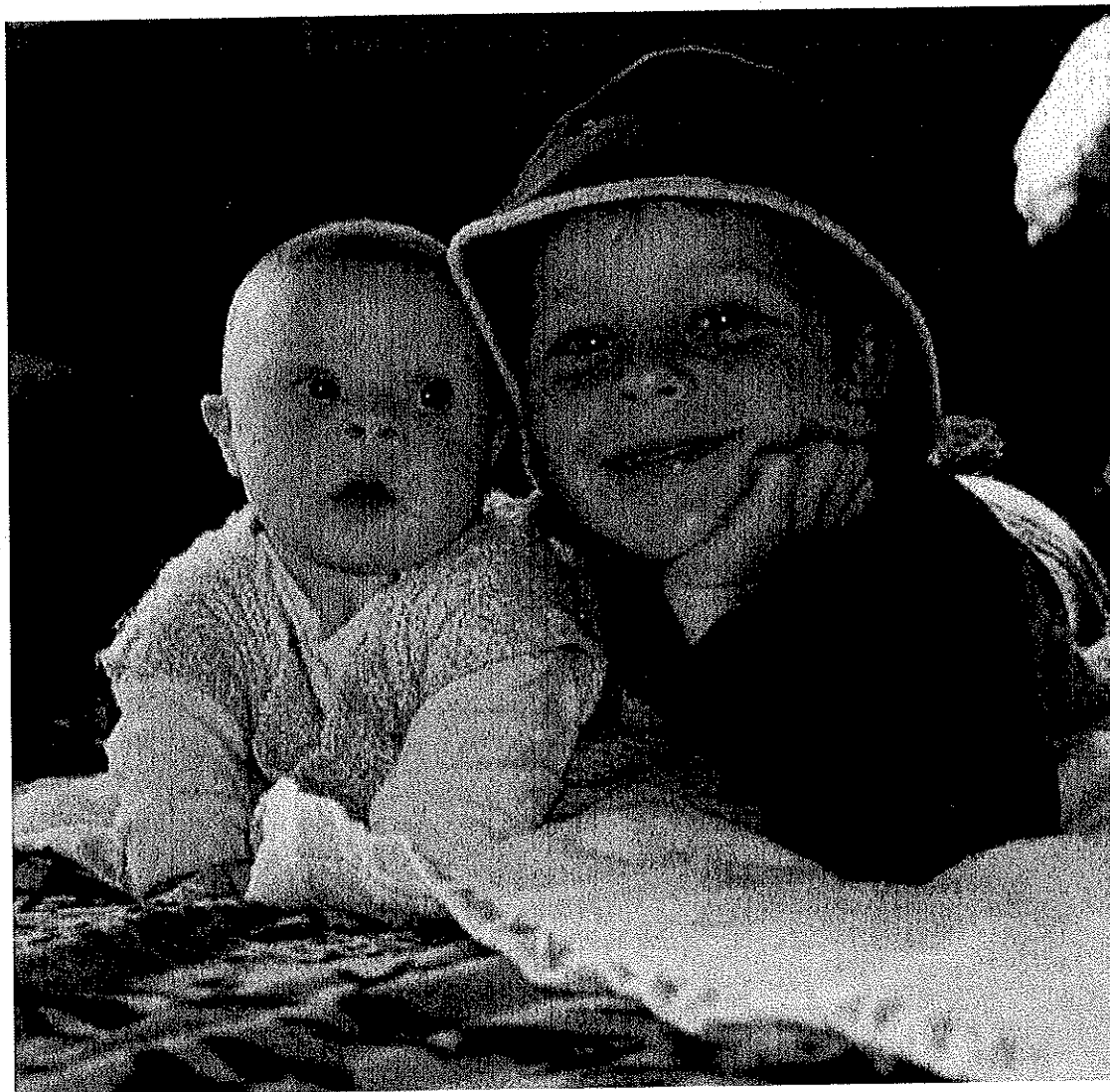
- It encourages them to have a vision for their family member with a disability
- It helps professionals in the area of disability to have the human aspects of their work in mind as well as the aspiration of the parents for their child and be considerate of it
 - The book can be used as a picture book to educate children as much as adults. It is a tool for parents and 'normal children' towards a better understanding about people, who look or behave differently. It stimulates their thinking and how they might behave to develop a more accommodating, caring and considerate attitude towards people with disability
 - It's a great resource for developing a vision for the wider community and where we as a society need to go. It may also help generate much needed compassion in this world

Rhys has successfully started school and obtained part time funding for a teachers aide. It is the same school his big brother Julius is attending. It is going to be a challenge for everybody involved. We can only succeed.

It will be a step towards social change!

Susanne Walden and Robert Goodlet
February 2003

When we dream alone it is just a dream.
When we dream together it becomes reality.



Your children are not your children
They are the sons and daughters
of Life's longing for itself.

They come through you
but are not from you.

And though they are with you
yet they belong not to you.

You may give them your love
but not your thoughts,

for they have their own thoughts.

You may house their bodies but not their
souls

for their souls dwell in the house of
tomorrow,

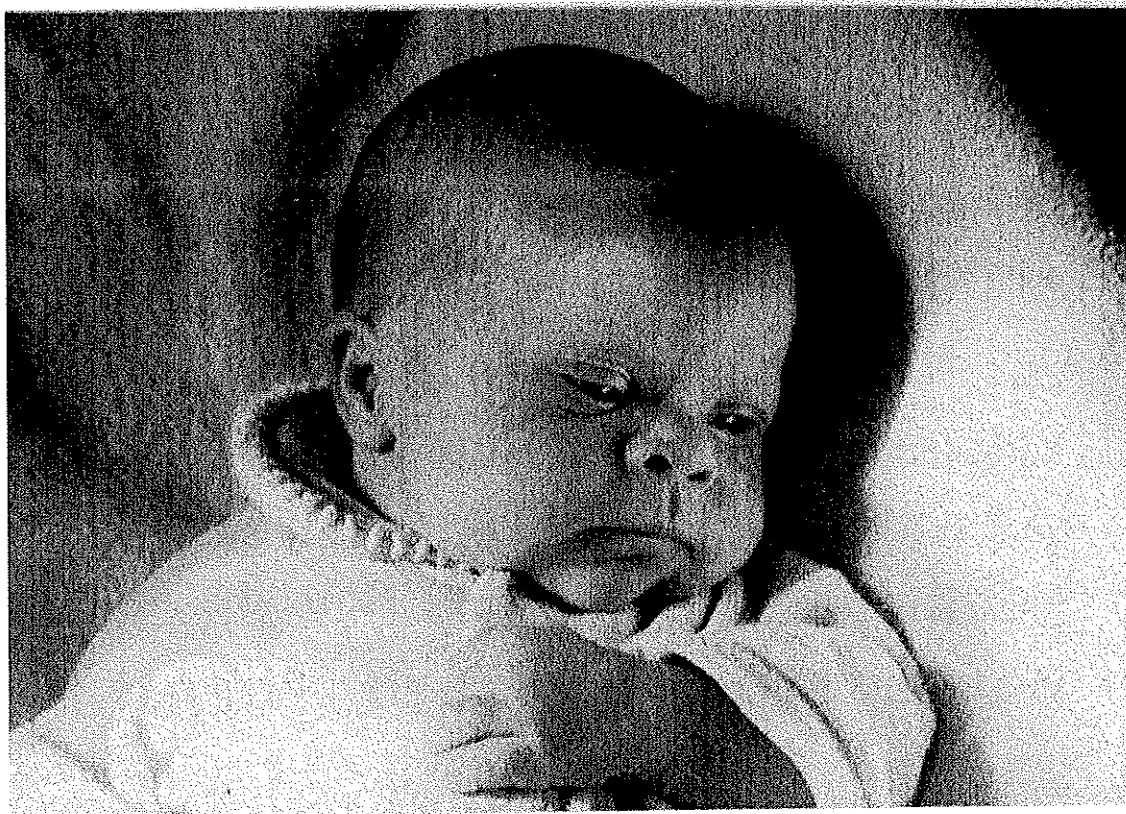
which you cannot visit, not even in your
dreams.

You may strive to be like them,

But you cannot make them like you.

For life goes not backwards
nor tarries with yesterday.

The Prophet
Kahlil Gibran



Hello - I'm RHYS
and I've just arrived on the planet.....

well, not just....

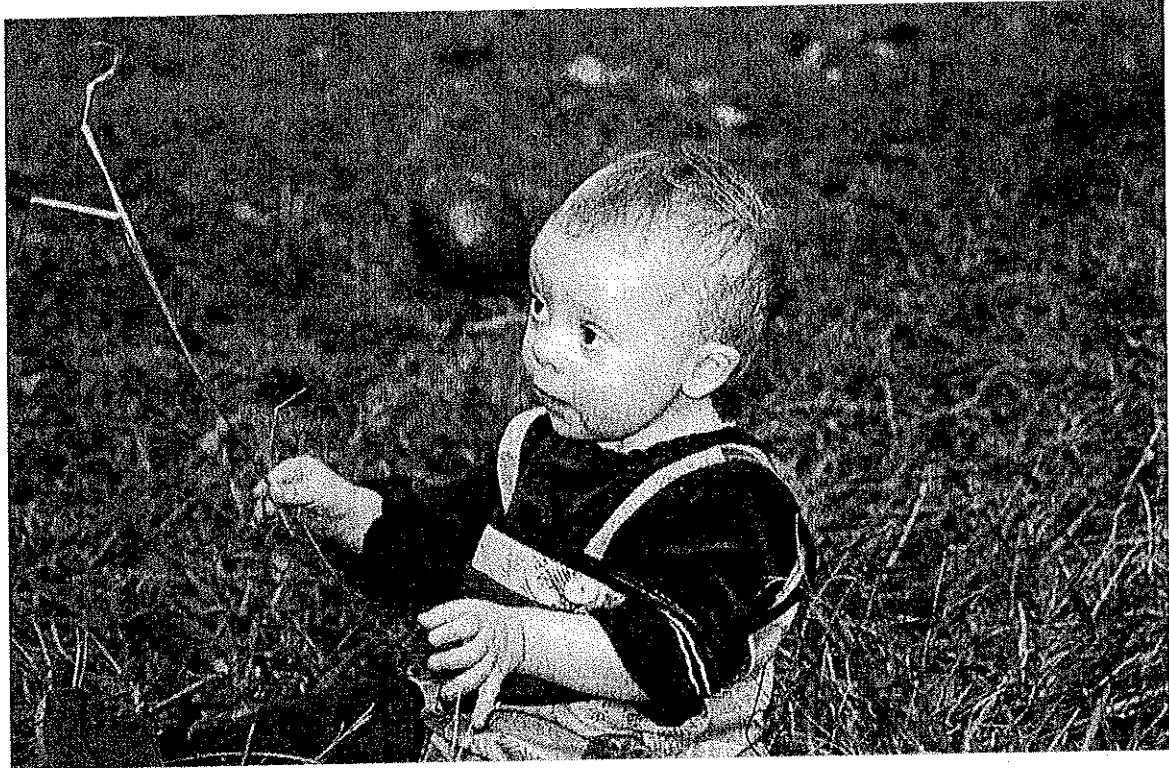
In fact it was the 28th March 1997 at 2:53 a.m. I weighed 3400 Grams and was 52 cm long.

I was born at home. My Dad caught me and my brother Julius cut the cord. But of course my Mum did the real work.

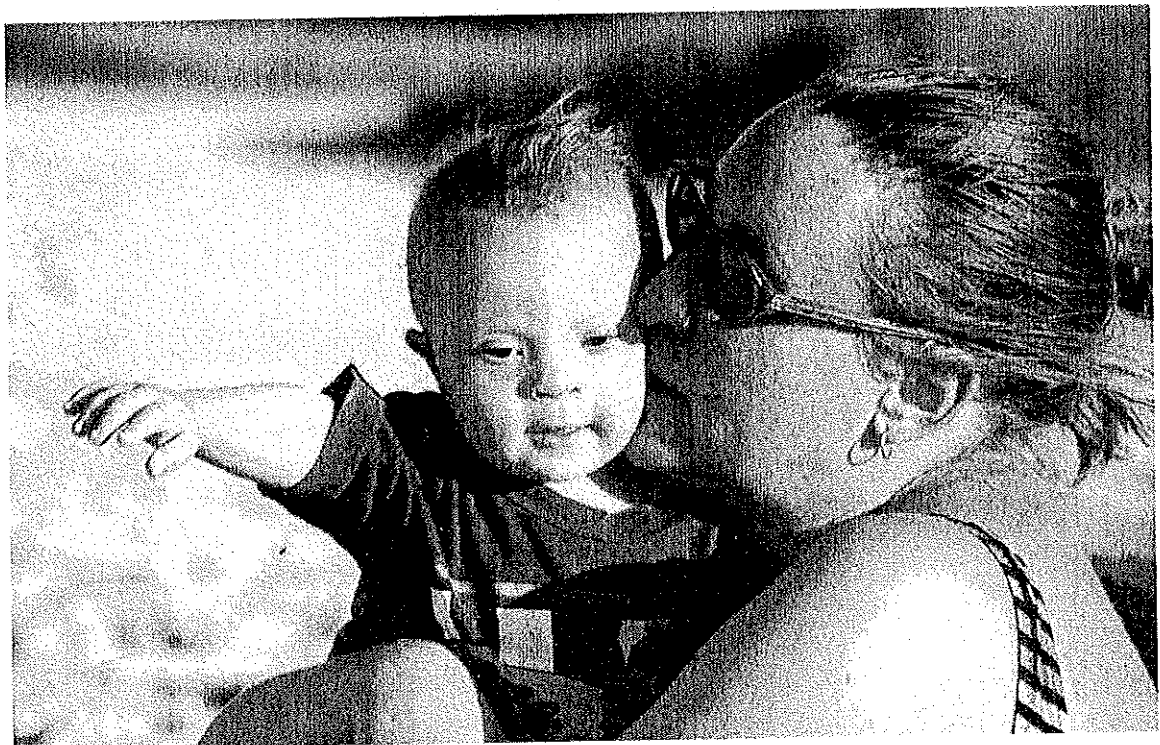
It's taken awhile to get around to this because mum and dad have taken so long to adjust to the fact that I was born with an extra chromosome.

I'm a baby with Downs - that's a syndrome, not a sentence. Otherwise I'm healthy and very happy.

I may not meet some expectations, but with your love and understanding I can reach my full potential.

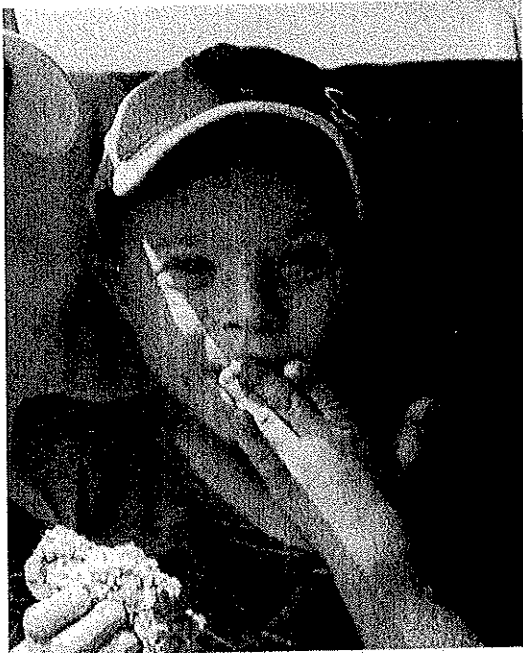


**WHO IS RHYS?
RHYS IS A MUCH LOVED AND VALUED
MEMBER OF OUR FAMILY**





OUR VISION FOR RHYS- The Family Dream



In Rhys' birth-announcement we let our families and friends know that our son was born with an extra chromosome and what that meant to us: Rhys has a syndrome and not a sentence.

"I may not meet some expectations, but with your love and understanding I can reach my full potential."

That statement was 5 years ago and it had the effect of an icebreaker. After all we were not going to abandon Rhys, because he wasn't the perfect baby we had longed for.

Like most parents we want our children to develop their full potential and live happy and fulfilled lives. We want the best for our children, even more so if one of them has a disability or special needs. You are not only living and coping with the disability or special needs; you also have to deal *constantly* with a lack of knowledge and understanding, as well as people's fear and prejudices towards the person with the disability and their families.

We want to change that.

Our vision is for Rhys to live a life as a valued member more or less independently in his community and contribute to that community to his ability. We want him to have the same choices and opportunities as other members of society have. We want him to be part of his local community and not segregated and isolated. Rhys is participating in the local community-life, making friends with people and being acknowledged as one of them, as a fellow human being - a person with an individual personality.

We wholeheartedly believe that this can be achieved by an inclusive education for Rhys:

- By attending the local school

- Being with his brother and the other kids from the neighbourhood
- Using the school bus to go to school
- Learning with a modified curriculum for his needs
- Making friends in the area where he lives

This participation in the local community makes him part of the general community and not isolated from it. The benefits of inclusive education are for everyone. Rhys, the other children, their parents and the teacher will all gain from it. The whole community will be enriched in terms of creating a community, which is based on

- Diversity
- Acceptance
- Living with difference
- Tolerance
- A better understanding of disability
- Compassion

The outcome is a safer, better, more caring and enjoyable place for all of us to live in.

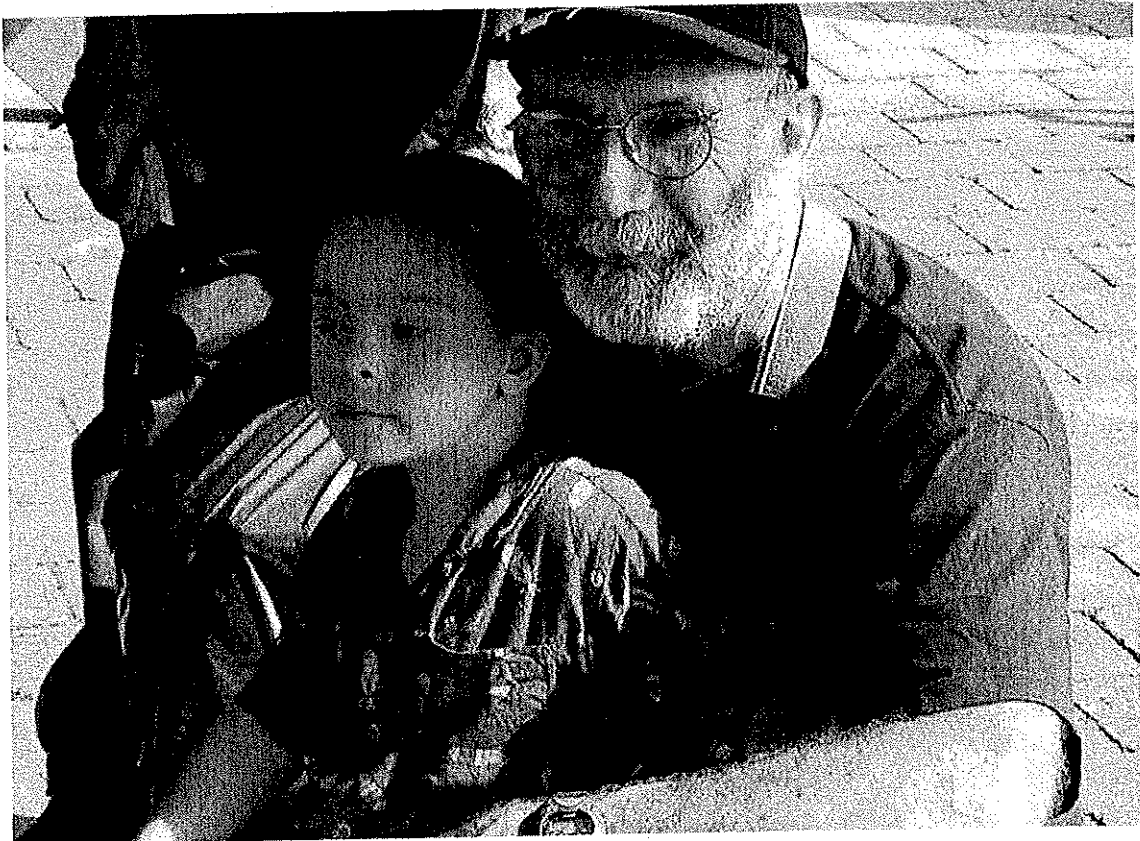
Our hope is that when Robert and I are no longer around, Rhys will be able to look after himself in a caring community. Inclusive education will help him to develop skills and abilities to do so.

Our worst nightmare is that the world develops more and more into a place, where hearts don't exist and only perfection counts. Rhys isn't welcome. He has no friends, no meaningful work, fills in time, lives segregated in an institution, is lonely and isolated and considered as a burden to society- Rather than being seen as the beautiful warm hearted person he is, with a wonderful sense of humour. Rhys' gifts of joyfulness, empathy, gentleness and unconditional love can make us all more appreciate how undervalued such qualities are in our society and how much we have need of them.

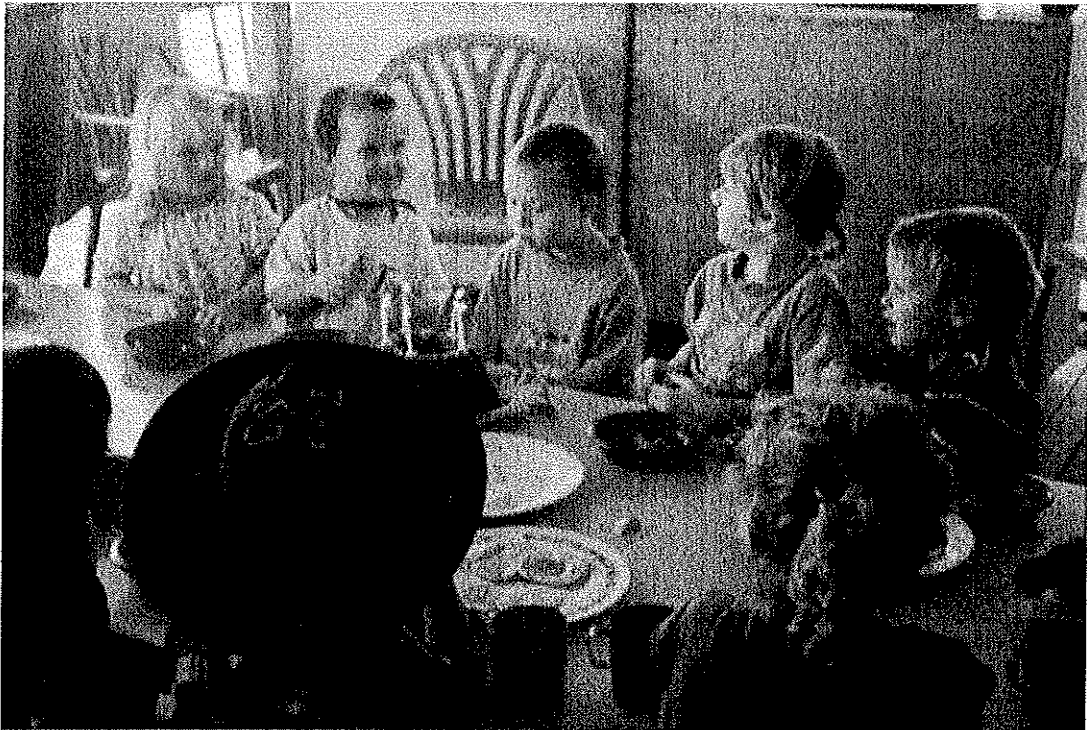
A last word: Should we measure the quality of our society in how much it cares for their weaker members e.g. people with disabilities, children, women, the elderly, the poor- or do we find the quality in the support of people who have strong resources and are too often already advantaged?

What do *you* think?

March 2002



What do we need?



Rhys will need good quality support workers- but he also needs friends, real friends, people, who are not paid to be with him. He needs a circle of friends, who will always be there for him.

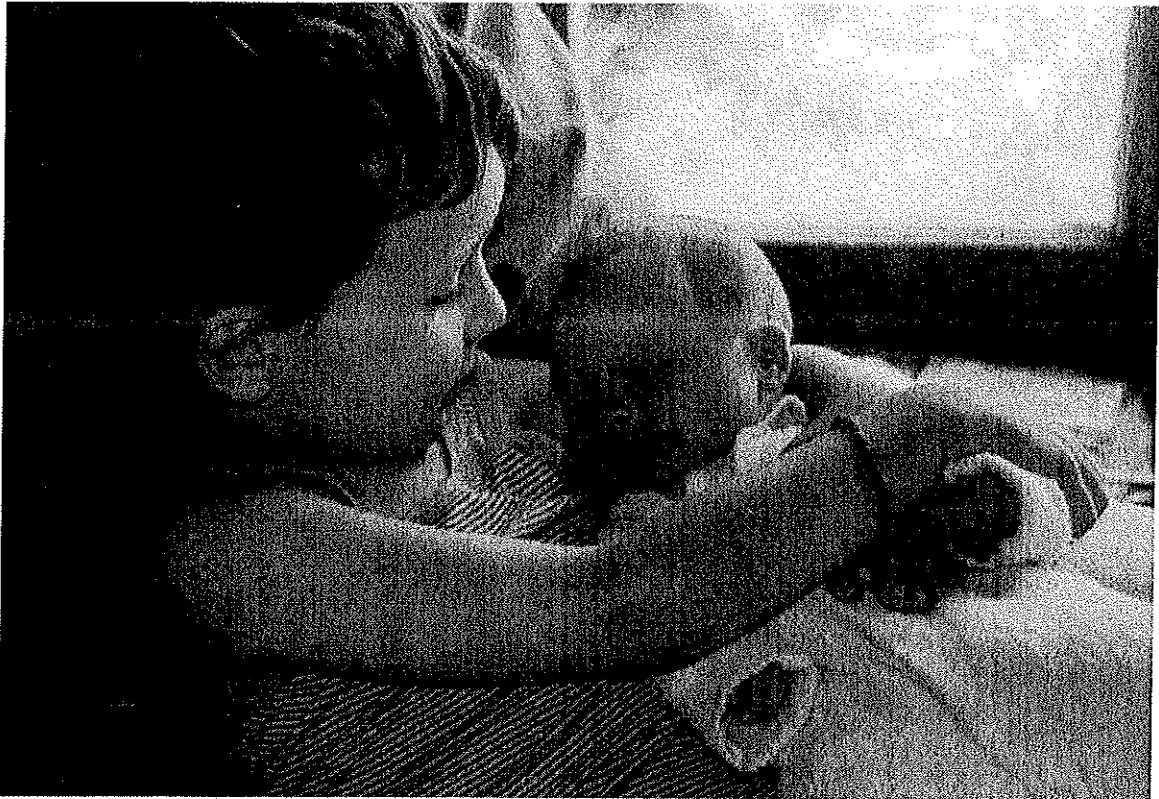
WHO IS RHYS?

Rhys is 5 years old and one of the most affectionate kids you could ever hope to meet. He is incredible warm and loving and not shy about letting his friends know, how much he likes them. He adores his big brother Julius, who is nine.

Julius was holding Rhys, when he was just minutes old. The bond between them is very strong. They love playing together. They enjoy ballgames, playing with cars and playing cubby houses. Like all siblings they have fights at times and get annoyed with each other, but this is generally short-lived.

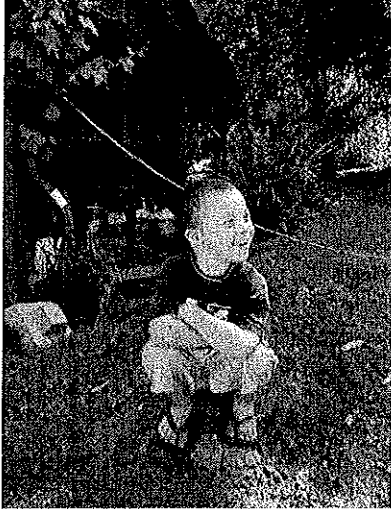
Being ignored, bored, not considered or not included can cause Rhys to get upset and frustrated. At these times he'll let his feelings be known.





RHYS is the name of welsh kings.
The meaning is "someone who
loves life and people".

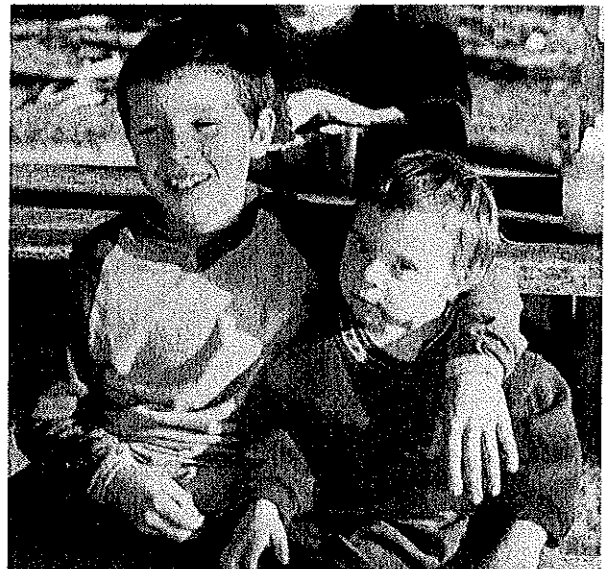
Rhys



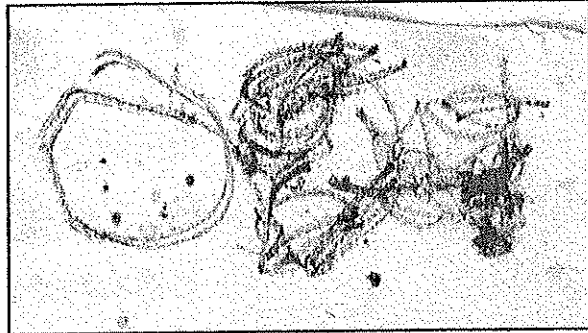
Rhys is my kind and loving little brother. He is good at sharing because he doesn't like anyone to be left out (except me!!). He can be annoying and naughty at times but mostly he isn't.

I think it's great that he goes to my school, where he can see all his friends. I couldn't imagine him going to a special school where I couldn't see him at school.

**Julius age 11
May 2004**

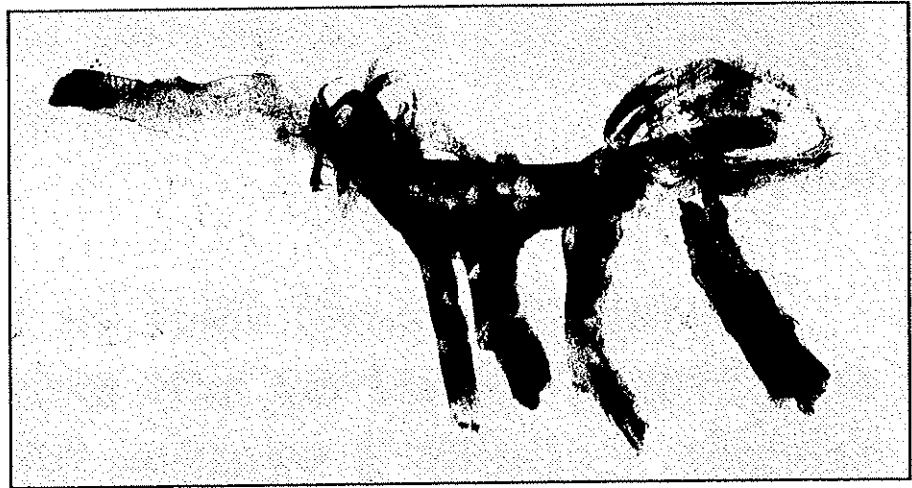


RHYS is very fond of animals

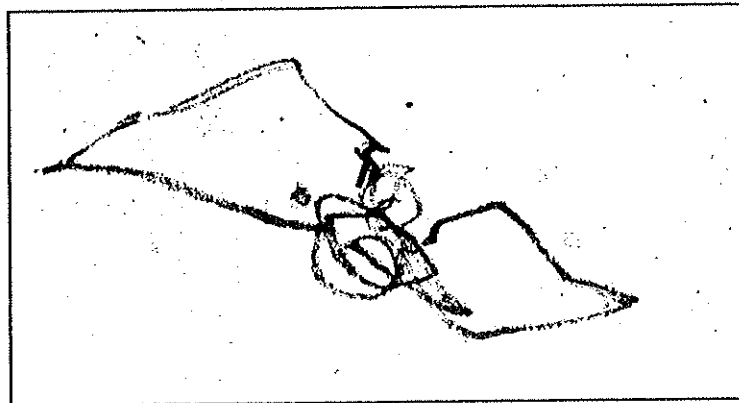


This is Frodo

This is a horse
10/2003



A picture of Lilly our cockatiel in 2003



He loves our dog "SPOOKY"

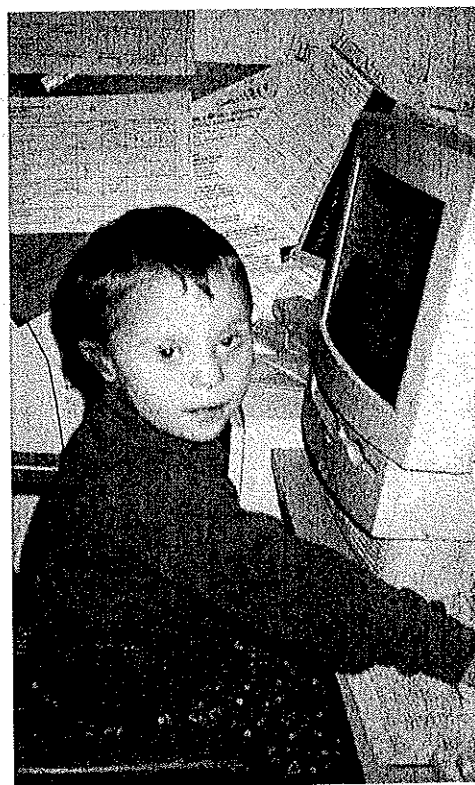


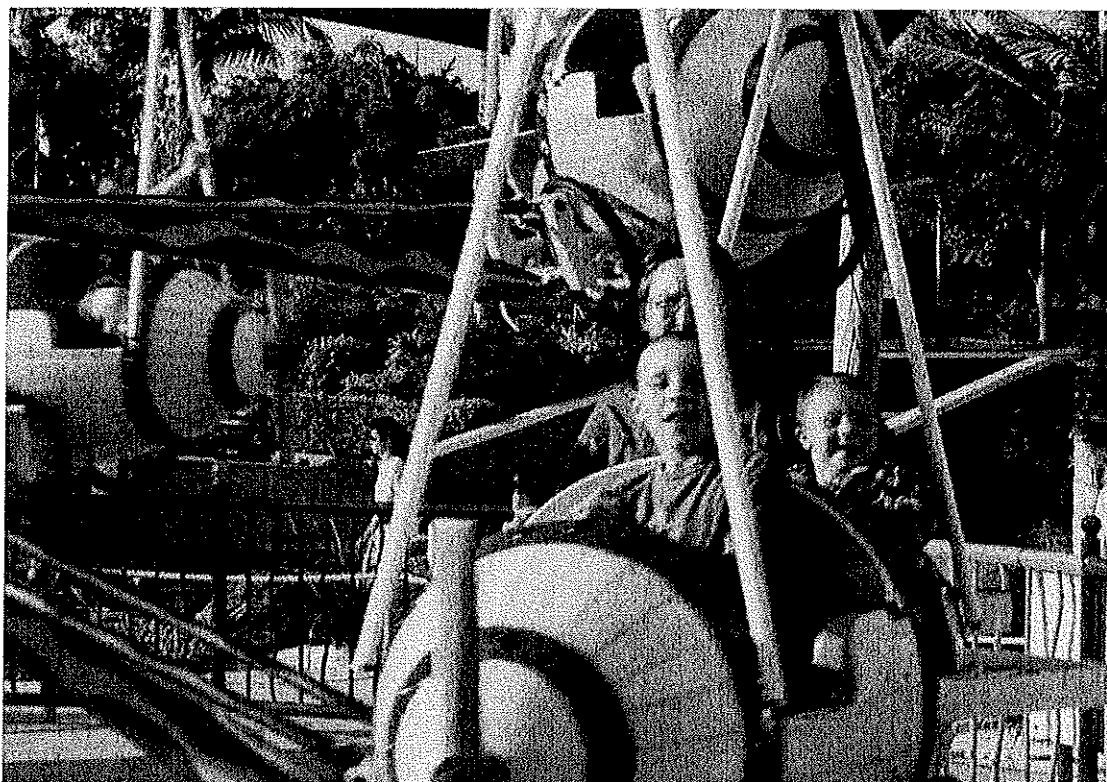
and little Jesse



Rhys likes tractors,
mowers, ride on's,
cars, trains,
bobcats,
bulldozers, trucks,
motorbikes

and computers





RHYS loves having fun



Books and music are Rhys' major passions. He loves making music with his harmonica and his guitar. Rhys likes acting, performing and dressing up. Dancing is one of his favourite activities.



This is a note from Rhys' dance teacher:

Bija Studio runs weekly classes in yoga and creative dance for children aged 2 to 12 years.


I find this form of "movement to music" a concept young children relate to and enjoy. It builds great confidence; good listening and co-ordination skills.

Rhys has been coming to my dance classes for the past two and a half years, since he was 2. He is a keen student and participates happily. Has a love for music and interacts very well with-in the group.

Joan Gutormsen
Bija Studio
CECIL ST, NIMBIN
66 21 3309.

pre-school swimsafe



certificate of performance



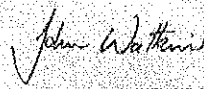
awarded to

Rhys Walden-Goodlet

by the
NSW Department of Sport and Recreation

WJ GILLOOLY
Director-General
NSW Sport and Recreation



THE HON. JOHN WATKINS MP
Minister for Sport and Recreation
Minister for Fair Trading

swimsafe skills record

<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Entry 1 Enter the water willingly with assistance. <input checked="" type="checkbox"/> Blow Bubbles Able to exhale in the water <input type="checkbox"/> Open Eyes Open eyes under the water, come up and blink <input checked="" type="checkbox"/> Prone Float 1 Float on tummy with assistance <input type="checkbox"/> Back Float 1 Float on back with assistance <input type="checkbox"/> Submerge Happy to go under the water independently (not forced) <input checked="" type="checkbox"/> Exit Able to get out of the pool without assistance <input checked="" type="checkbox"/> Entry 2 Enter the water independently (without assistance) <input type="checkbox"/> Disengage Able to disengage from parent and move independently (during a fun activity). <input type="checkbox"/> Prone Float 2 Float on tummy without assistance <input type="checkbox"/> Back Float 2 Float on back without assistance 	<ul style="list-style-type: none"> <input type="checkbox"/> Propulsion Able to move through water with assistance using legs and/or arms <input type="checkbox"/> Propulsion 2 Able to move through water without help using legs and/or arms <input type="checkbox"/> Enter/Back Float Enter the water and back float without help <input type="checkbox"/> Propel/Tread Change body position from propulsion to tread water without help <input type="checkbox"/> Propulsion/Breathe Move through the water for a distance of 4 metres using any movement, and able to take a breath. <div style="border: 1px solid black; padding: 5px; margin-top: 10px;"> <p>NOTE: With help/assistance generally refers to the support of the adult although may also include support with a flotation aid.</p> </div> <p>The Adult The following refers to the adult's participation in the program and is NOT a judgement of parenting skills;</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Encourage - Encourage and provide appropriate instruction to child. <input checked="" type="checkbox"/> Support - Provide correct support to assist the child. <input checked="" type="checkbox"/> Participation - Willing to participate in the activities during the lessons and demonstrate skills to the child.
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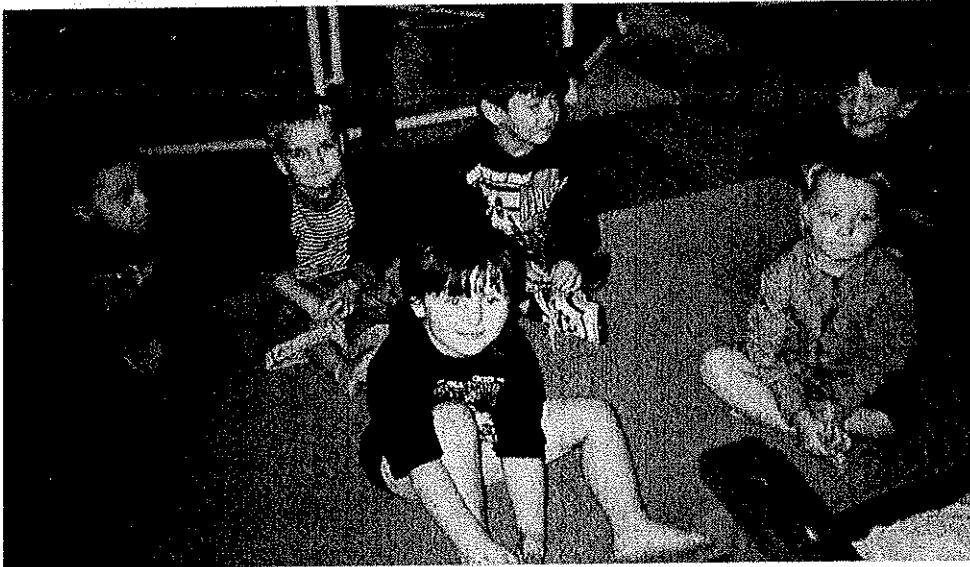
Instructor *Lisa Larsen* Date *25.11.99*

Comments *Keep smiling Rhys you will go a long way. Keep up the bubbles and the splashing you will swim soon.* ★



2002

Rhys enjoys going to the Cawongla-Playhouse /Preschool twice a week. He just loves it.



Hi

My name is Deborah Loadsman. I have been working with Rhys at our centre for almost three terms. Rhys is coping very well, he has settled into the routine although he needs some time and reminding during transition periods.

Socially Rhys has come ahead very quickly. He is now involved in group play and not relying on adult company.

Rhys is comfortable and happy here. He is accepted as part of the group.

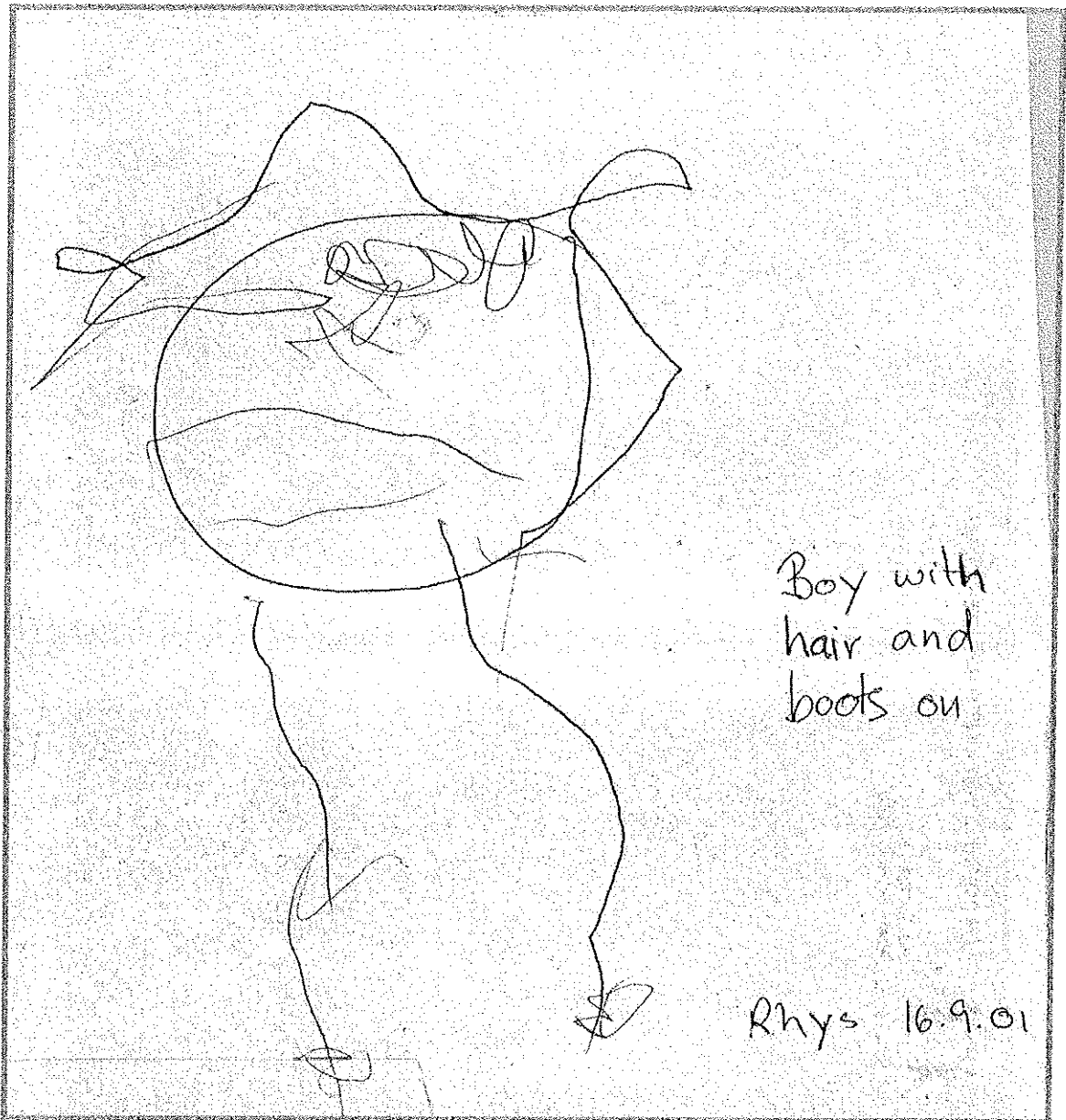
Rhys has increased his use of language and words are becoming clearer. We feel this is due to his increased social play.

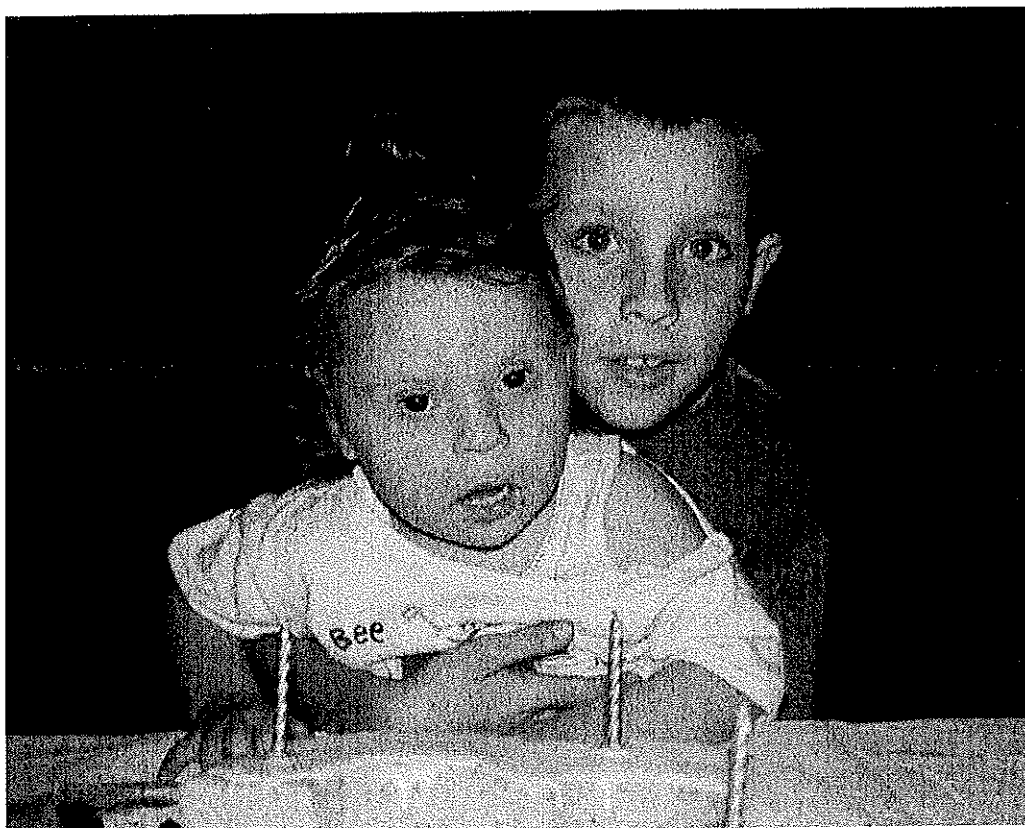
We are very comfortable with Rhys being in our care and see the benefits for his development in this environment in such a short time.

We all enjoy his company and love having him at our centre.

Deborah Loadsman

Rhys loves drawing, scribbling and writing.





Birthdays are favourite times for fun, food and friends







Tell me and I will forget



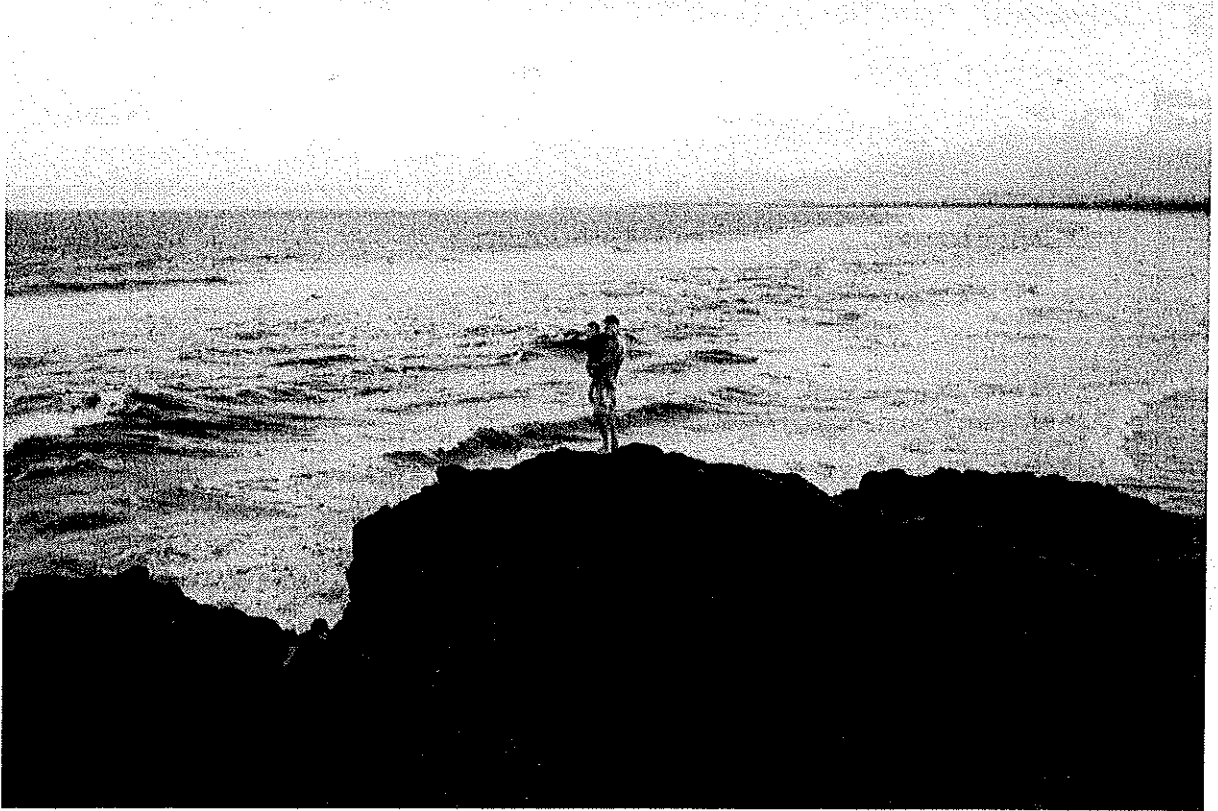
Show me and I might remember



Involve me and I will understand

CONFUCIUS





...we do not love
those we love
because they
are perfect.
Rather, they are
perfect because
they are loved...

Kids belong together!

Inclusive education is a worldwide movement. In NSW however, enormous pressure is still exerted by the education system on parents who try to exercise their legitimate choice of the regular class. Once they have overcome this, families still face huge struggles to get their children properly supported and educated. It is the system that is failing the children - not the children who are failing.

It is not a question of funding, but a question of how to adequately support a student in the regular classroom so that he/she can succeed.



An Ethic of Caring

Processes of deep social change require more than a shallow response. The fundamental purpose of education is a moral one - *to foster an ethic of caring*. Intellectual development is not the first priority of schooling.

Schools are multi-purpose institutions. Educational policies and methods must be consistent with an ethic of caring.

The Canadian Educator BRUCE UDITSKY

It is from countless acts of courage and beliefs that human history is shaped. Each time someone stands up for an ideal or acts to improve the lot of others or strikes out against injustice, he sends a tiny ripple of hope and crossing each other from a million different centres of energy, these ripples build a current that can seep down the mightiest wall of oppression and resistance.

ROBERT KENNEDY

This was our introductory letter to the Preschool:

Dear parent/caregiver!

Here comes a little note from parent to parent. As parents we are all more or less concerned about the wellbeing of our children - health wise, emotional, socially or our parenting skills. Even more so, I suppose, if our child/children have special needs. They will need more support than other children in the same situation will. These children encounter a lot of ignorance towards them, which is often based on a lack of experience and knowledge about people, who behave or look different.

It's easy to feel superior towards these "different people". And children do that too, if their parents model that or don't guide them through these important learning opportunities for better acceptance, tolerance as well as to learn to be compassionate towards other beings.

At this point of time Rhys' biggest problems are lack of language and not standing up for himself. A tendency to be excluded from everything people normally take for granted will follow him around like a shadow through out his whole life. As parents, we are aware and concerned about it. That's the reason, why we assembled a book about Rhys, to help him in the transition process to his local school. Beyond that we'd like to share our vision for Rhys with the wider community. In the coming weeks you are invited to access this book.

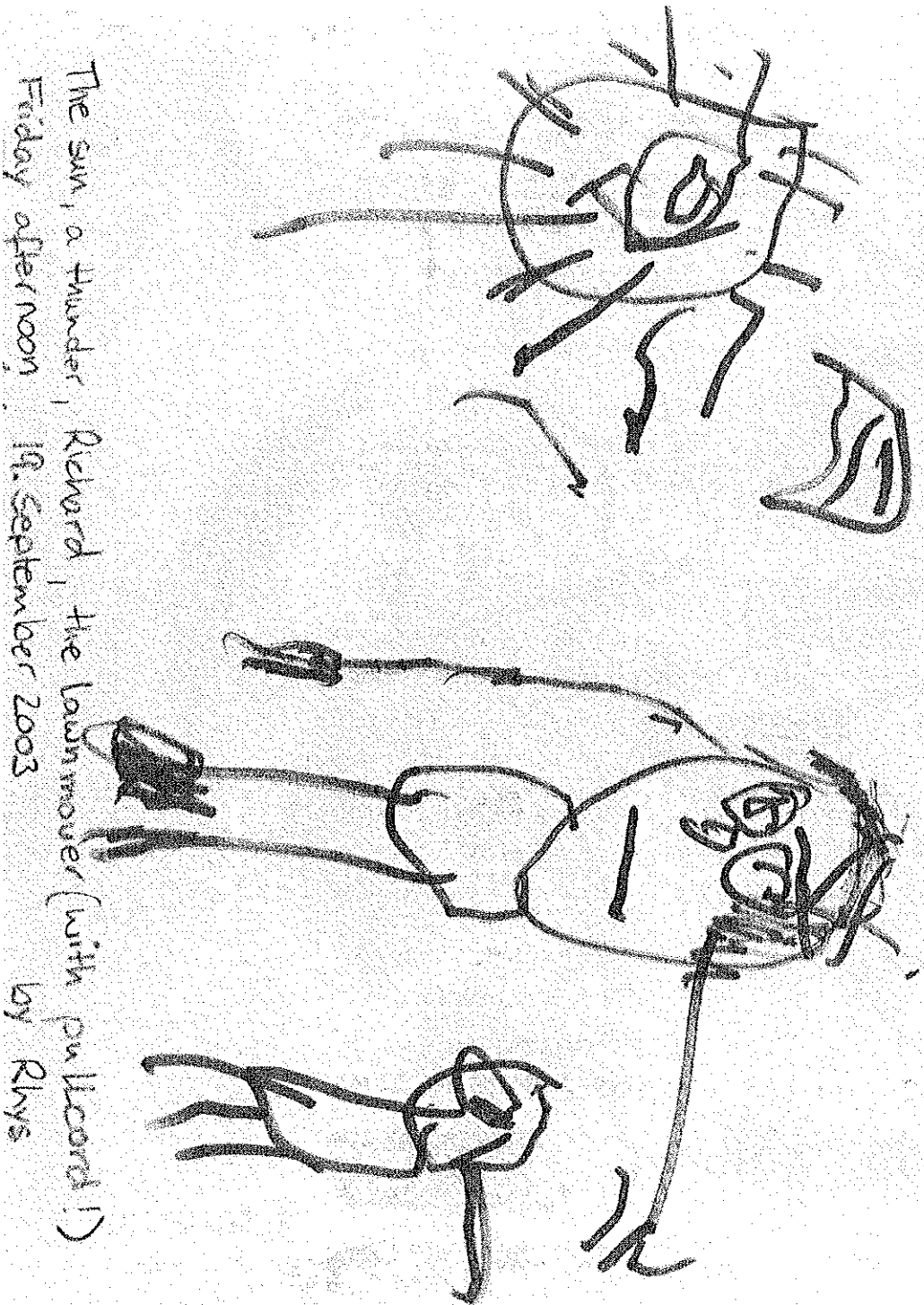
We would love some feedback and support for creating a better society for our children and their future!

Can you help us?

August 2002

This is my family:
Mum, Dad, Julius and ME with red hats and
Spooky. 9/2003





The sun, a thunder, Richard, the lawnmower (with pu lecord!)
Friday afternoon, 19. September 2003
by Rhys

Some of the responses we have had to Rhys' book:

"Rhys is very fortunate to have such a wonderful family. Great work. Love to you all."

"Your inspiration, integrity and love reach out beyond the bounds of your own child and support humanity with blessings "

"Reading the book put tears in my eyes"

"I'm very touched by it."

"This book is a very proactive piece of work."

"A very, very beautiful book. It touches me deeply."

"I loved all the photographs and especially the black and white one, where Julius holds the Baby. What a wonderful connection they have."

"A great documentation with beautiful pictures."

"You found the right words to express what a lot of us parents think and feel. Well done."

"Good work"

"I had to cry, let's hope that things can only get better than they have been in the past, so that people with an intellectual disability can have a better life"

"I just didn't know..."

"I have to make one of those for my child. I hope you don't mind..."

"I have one of those for my child, but I have to redo it. I just love the clarity of your vision statement"

"This inspires me to make a folder like that for my son's transition to High school."

"I'm very touched by your vision statement for Rhys"

"Just loved it."

"Others here that read it were very moved by the love that surrounds Rhys".

10 Things You Need To Know About People With Down Syndrome...

1. Most people with Down syndrome (DS) were born before their mothers were 35.
2. People with DS enjoy their lives when they are well supported - like all of us.
3. Down syndrome causes disability, it is not an illness. Some people with Down syndrome do have health problems and are entitled to the same quality health care as everyone else.
4. Learning starts young for everyone, including kids with DS, and doesn't stop. Most people with Down syndrome now learn to read, for example, and learn much more than we ever thought possible.
5. Children, teenagers, adults with DS all have feelings, thoughts, ideas, interests and dreams. They know what they want from life - friends, relationships, work, leisure and a measure of independence for a start. Most people with Down syndrome can live interesting, fulfilling independent adult lives with support.
6. You may have difficulty understanding the speech of a person with DS, though they are usually excellent communicators. Their understanding is usually better than their speech. Some have a lot to say!
7. Every one with DS has a different personality with different likes and dislikes, just like the rest of us.
8. You'll find people with DS working successfully, with varying degrees of support, in retail, offices, child care, hospitality and gardening to name but a few occupations.
9. In 1960 the life expectancy of an Australian with DS was ten years of age. Today people with DS live longer lives than ever before - most will live into their 50s and 60s. The oldest person with DS on record was 85 when she died in 1998.
10. People with Down syndrome have an extra chromosome (no. 21) but the regular 46 are there too. This means they are as alike and as different from each other as the rest of us. Although people with



DS may share some common facial features they look more like their families than others with DS.

Source: www.dsansw.org.au

Kids with special needs
will need our help
and our friendship -
but they *never* need our fear.

Our family found the following resources useful:

Books:

- **Hammeken, Peggy A:** Inclusion: 450 Strategies for Success. A practical guide for all educators who teach students with disabilities. Peytral Publication 1997
- **Kennish, Fae:** Developing Inclusive School Communities. Strategies for Parents. Community Resource Unit. Brisbane 1998
- **Kumin Libby:** Classroom Language Skills for Children with Down Syndrome. A guide for Parents and Teachers. Woodbine House 2001
- **Kumin Libby:** Early Communication Skills for Children with Down Syndrome. A Guide for Parents and Professionals. Woodbine House 2003
- **Oelwein Patricia I:** Teaching Reading to Children with Down Syndrome. A Guide for Parents and Teachers. Woodbine House 1995
- **Selikowitz Mark:** Down Syndrome. The Facts. Oxford University Press 1997
- **Stroeve Wendy:** One of the kids. Educating children with and without disabilities together, in the same classes and schools. Disability Council of NSW 1998
- **Tien, Barbara:** Effective Teaching Strategies for Successful Inclusion. A Focus on Down Syndrome. The PREP Program, Calgary, Alberta 1999

World Wide Web:

- **Canadian Down Syndrome Society:** 811 - 14 Street N.W., Calgary, Alberta T2N 2A4 : www.cdss.ca
- **Community Resource Unit,** Brisbane: www.cru.org.au
- **Disability Solutions.** Publication of THE ENOCH-GELBARD FOUNDATION: www.disabilitysolutions.org
- **Down Syndrome Association NSW,** Sydney: www.dsansw.org.au
- **Down Syndrome Society of South Australia Inc.** www.downssa.asn.au
- **Family-Advocacy,** Sydney: www.family-avocacy.com