

Children of Fire  
and  
Dorah Mokoena Charitable  
Trust

Schools' Guide



Issue 2 June 1999  
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## **1. Introduction to Children of Fire / The Dorah Mokoena Charitable Trust**

Dorah Mokoena turned four on Easter Sunday 1998. This little South African girl was severely burned in a squatter camp fire at the age of six months. She was turned away from three hospitals which were convinced that she would die.

Because of the severity of the fire and because of the delay in getting appropriate treatment, Dorah lost her nose, eyelids, lips, bone in her forehead and hands. She was separated from her mother for two years and spent most of that time entirely cot-bound. Nonetheless Dorah had several friends. One of these, Bronwen Jones, visited Dorah regularly with her young son Tristan and his friend Thobeka, to try to ensure that Dorah knew the pleasure of childhood friends.

In December 1997 the doctors charged with Dorah's well-being intended to remove her eyes, because they said she was blind. And because the dressings used to protect them were deemed too expensive. This decision - and the ability of caring individuals to overturn the decision and to save Dorah's eyesight, led to the formation of the Dorah Mokoena Charitable Trust in the United Kingdom and the Children of Fire Trust in South Africa. The two organisations assist each other to provide medical treatment and therapy for Dorah, training for her mother Margaret and other helpers; proactively try to prevent burn injuries through education of South African communities; and inform people how to seek the swiftest and best-possible medical treatment for children who are burned.

While beyond the specific remit of the UK-based trust, the educational benefits to both injured children and to the hale and hearty British (and in some cases American) children who made items for them, are immeasurable. The trustees of both trusts believe that by educating children about disability they lose their fear of it; they become kinder and more thoughtful. They also recognise the tremendous challenge of surviving in a world where the frequent thoughtlessness of designers of day-to-day items makes independence difficult. The children who learn about Dorah and others like her, become tolerant of disfigurement. Of their own accord they start to reassess the way in which any child who is seen as different is frequently ostracised from social and sports activity.

Children of Fire wants to “pair” UK and other schools with special South African children in need of learning aids designed uniquely for them. To use the ingenuity and wisdom of children to design and make items to stimulate the thousands of burned South African children who get left in hospital wards for weeks or months with no family visits, no toys and only the bare minimum of healthcare.

We believe that long term two-way benefits will arise and that such contact might even give Africa due recognition on the agenda of future generations.

## 2. Multiple Disability Training

When we were looking for learning aids for Dorah, we found that many items designed for children with no or low vision were inappropriate, because they relied on a child having fingers. And yet, certainly in South Africa, the loss of fingers through fire is common. Hands are usually the first form of protection and take the brunt of the heat. Many children have remnant fingers fused together - which often could be parted if there was sufficient money and if there were sufficient surgeons available. As both of the latter are in short supply, special aids and attention are the next best option.

In Dorah's case Robert Orr of the Royal National Institute for the Blind devised the following advice for mother and child to work together. If planned operations to improve Dorah's sight proceed to plan, the methods below will change.

### **Dorah needs:**

**Proximity.** Her helper should stay close and should bring things up close. At the time of writing, with Dorah only allowed peephole vision, it does not matter if items are brought to her from the front or behind. She will be equally aware of them. Whole body wrestling games provide proximity.

Dorah needs to **explore.** To find, to feel or to sense in another way and to think.

Offer Dorah the opportunity to touch. Let her move her arm towards things rather than push her hand onto or into. Find her small places to play in: alcoves, big boxes.

Find low surfaces for her to stand by - with things on it that sound good and contrast with the surface.

She will prefer heavy things with interesting textures.

**Dorah needs shared attention.** Let her know that you are focusing on the same object, sound or smell that she is aware of.

And **Dorah needs “labeling”**. When her carer speaks, she should try to say what she thinks Dorah is thinking. Naming body parts and comparing body parts helps exploration. Comment on and (over) react to sounds (that you think Dorah heard), movements, feels, smells, senses, tastes, hot/cold, dark/light, rough/smooth, heavy/light.

**Dorah is likely to want to know:**

Who am I with?

Where am I?

What is happening?

How long will this last?

Is it finished?

Repeat things that Dorah seems to enjoy. Pause, get her to show you that she wants another go (non-verbal communication).

**The South African Situation.**

Without intervention, Dorah's potential would never have been realised. She would have been left in a corner as a nappy-clad dribbling adult. Thousands of children are not so lucky. In South Africa and in other countries where the health service cannot meet the needs of the population, it is all too easy for physically disabled children to be classed as mentally disabled; and for mildly mentally disabled children to be classed as impossible to educate (or not "worth" the effort).

Short term thinking allows a huge waste of money in the long term as it forces people into a life of permanent dependence. The fact that no-one saw it necessary to potty train Dorah meant that state or charity-funded nursing assistants would have had to assist her every day of her life with such basic bodily functions. At the same time Dorah would have been denied privacy, dignity or the chance to learn control. Dorah will become totally continent. Other children - and adults - could also be taught this level of control if people approach their well being with a long term view. The problem can be attributed to lack of training and commitment for staff at all levels, from nursing assistants to senior management. In South Africa it can also be related to low quality education across the board, and in particular to an authoritarian teaching style where the child who questions an adult is seen as difficult, rather than as an individual with encouraging initiative.

There are very few forms of state financial assistance for South African children in need. Bronwen Jones believes that some children have been falsely described as severely mentally disabled because this is the only way in which some charitable institutions can meet the true costs of caring for them. But, if communities and schools can be inspired to care for their own, and shown how, and given training and educational toys, the whole depressing picture could be overturned.

The selfless involvement of comparatively privileged British school children is a good place to start.

### 3. Benefits to date

These have been many.

According to teachers involved at Passmores School in Harlow, Essex, the British children who had the pleasure of working on projects for Dorah found the experience very rewarding.

They were able to empathise more and more as they came to understand and try to “put themselves in Dorah’s place”.

They learnt a great deal in practical terms and by trial and error about a culture very different from their own. They learnt at very close quarters what severe disability actually meant and how to be of practical help.

They were able to explore aspects of the curriculum in new and interesting ways.

They were able to see the person they were working for and know that they were really helping - and how - and why. Anyone who wished (and so many did!) was able to help - to be involved in some way.

A variety of personalities and approaches - including unconventional thinking - are a positive plus in this kind of work, so even students who sometimes integrate with difficulty were productively and happily involved.

## 4. Enriching the timetable

Schools involved with work for Dorah have found that the projects provided fresh and exciting ways of approaching many aspects of the National Curriculum. Areas that can be easily addressed in this work are given later in this guide.

But teachers at Passmores said that in addition to compulsory areas of education, the social curriculum was enriched in ways that could not have been previously envisaged. Children involved in the project were so enthusiastic. They worked very well co-operatively. Those who were challenged in some way in their normal schooling were able to play a full part. Over-enthusiastic personalities were a boon, not a problem, as 'brainstorming' or workshopping of ideas was so important and diversity of thinking so welcome - and the biggest learning curve of all, being able to really "step into someone else's shoes" for a while, actually changed lives.

Children who previously displayed a phobia of illness or disability, lost the fear totally.

## 5. Specific UK National Curriculum Tie-ins

### English

The National Curriculum asks that children:

- formulate, clarify and express ideas
- adapt speech to a widening range of circumstances and demands
- listen, understand and respond appropriately to others
- read, analyse and evaluate a wide range of texts including literature... from other cultures and traditions
- develop ideas and communicate meaning to a reader
- write in a widening variety of forms for different purposes

It states:

“The richness of dialects and other languages can make an important contribution...”

Pupils should talk for a range of purposes, including:

- telling stories both real and imagined... reading aloud
- exploring, developing and clarifying ideas... and discussing possibilities
- “To speak with confidence” is a key skill as is “taking into account the needs of their listeners.”
- Pupils should...”develop their thinking and extend their ideas in the light of discussion... taking different views into account.”
- Understanding “how their choice of language varies in different situations” is stressed.

Devising story or rhyme tapes for a child with special needs and taking into account the cultural background of that child, is a very good way of following parts of the course of study set down in the National Curriculum, giving opportunities for research and new approaches.

## **Design and Technology**

The National Curriculum (Design and Technology) states from KS1 that:

“Pupils should be given opportunities to...design and make products”... through “activities in which they investigate... and evaluate simple products.” They should “work with a range of materials... investigate how the working characteristics of materials can be changed to suit different purposes; apply skills, knowledge and understanding...”

Pupils should be taught to:

“draw on their own experience to help generate ideas... clarify their ideas through discussion...develop their ideas through shaping, assembling and rearranging materials and components...make suggestions about how to proceed... consider their design ideas... and identify strengths and weaknesses.”

In making, they should:

“select materials, tools and techniques ...measure, mark out, cut and shape a range of materials...assemble, join and combine materials and components...apply simple finishing techniques... make suggestions about how to proceed... evaluate their products... identifying strengths and weaknesses.”

They should be taught:

“how to make structures more stable to withstand greater loads...to relate the way things work to their intended purpose... people’s needs, and what users say about them.

Later, at KS4, pupils must:

“use...detailed specifications...design for product maintenance... recognise that moral, economic, social, cultural and environmental issues make conflicting demands when designing...consider an increasing range of users... generate design proposals against stated design criteria and to modify their proposals... be flexible in their working practices...provide alternatives to possible problems.”

From all of the above it can be seen that working to create aids to fit the specific needs of a disabled child is an excellent way of achieving many aims set down for the use of technology at all stages in schools.

## **Geography**

Preparatory work for any project undertaken will involve the children in research and learning about life in another country. They will have a context in which to investigate the climate and environment and explore differences and similarities between life in South Africa and the UK.

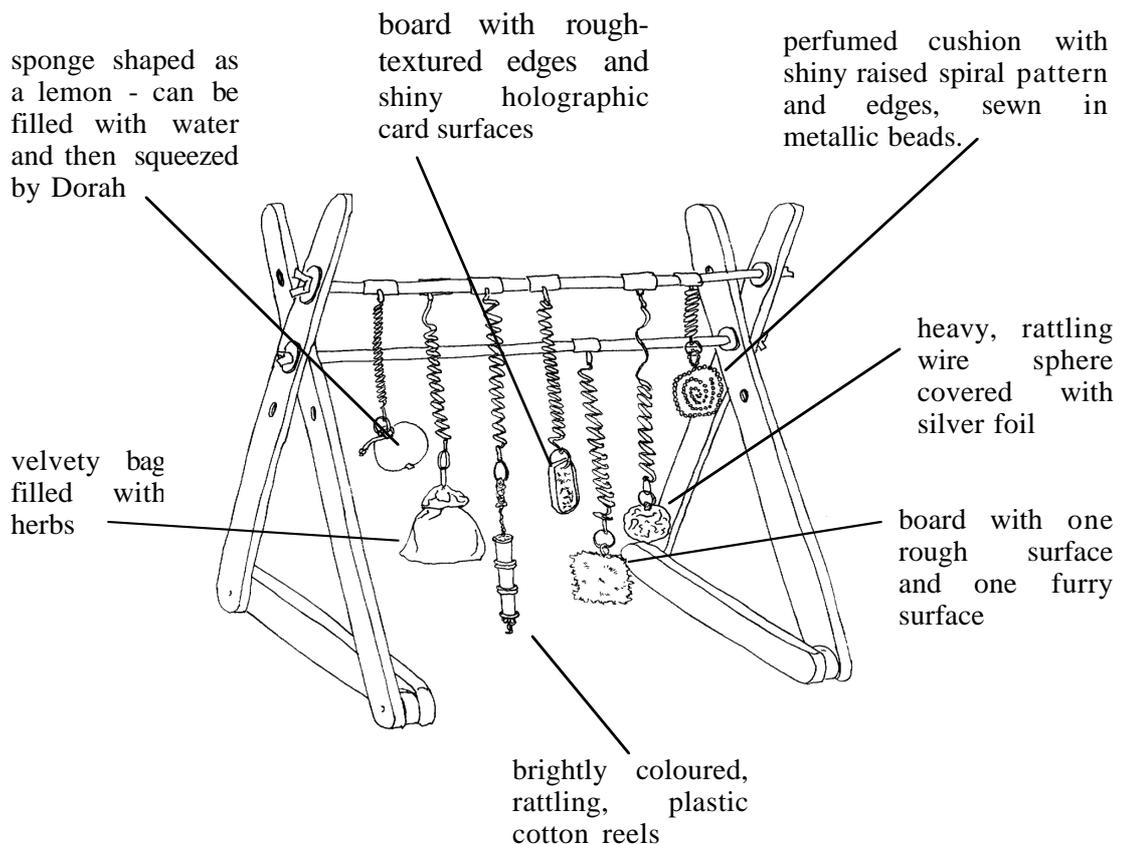
## **History**

A study of the dramatic developments in recent South African history, with the struggle to end apartheid, could make a fascinating part of preliminary studies.

- We are conscious that there is scope for many links with the curriculum and are working on developing and improving the content of this section. Suggestions and comments are welcomed.

## 6. Suggested Projects

- Dorah has a tailor-made wooden frame from which objects of interest can be hung for her to explore. (To touch, rattle, sniff, squeeze, shake or simply to observe their shine or feel their interesting texture.) Other children could benefit from similar devices constructed to an appropriate height for them.



**Dorah's frame.**

The items on Dorah's frame are attached with Velcro - more such items to be explored could be made - things which sound, smell, feel great - and are safe! The items - are suspended from brightly coloured coiled "telephone cable". Passmores found that the best source of this cable was on cheap imported keyrings. They simply removed the item already on the keyring and replaced it with a stimulating toy.

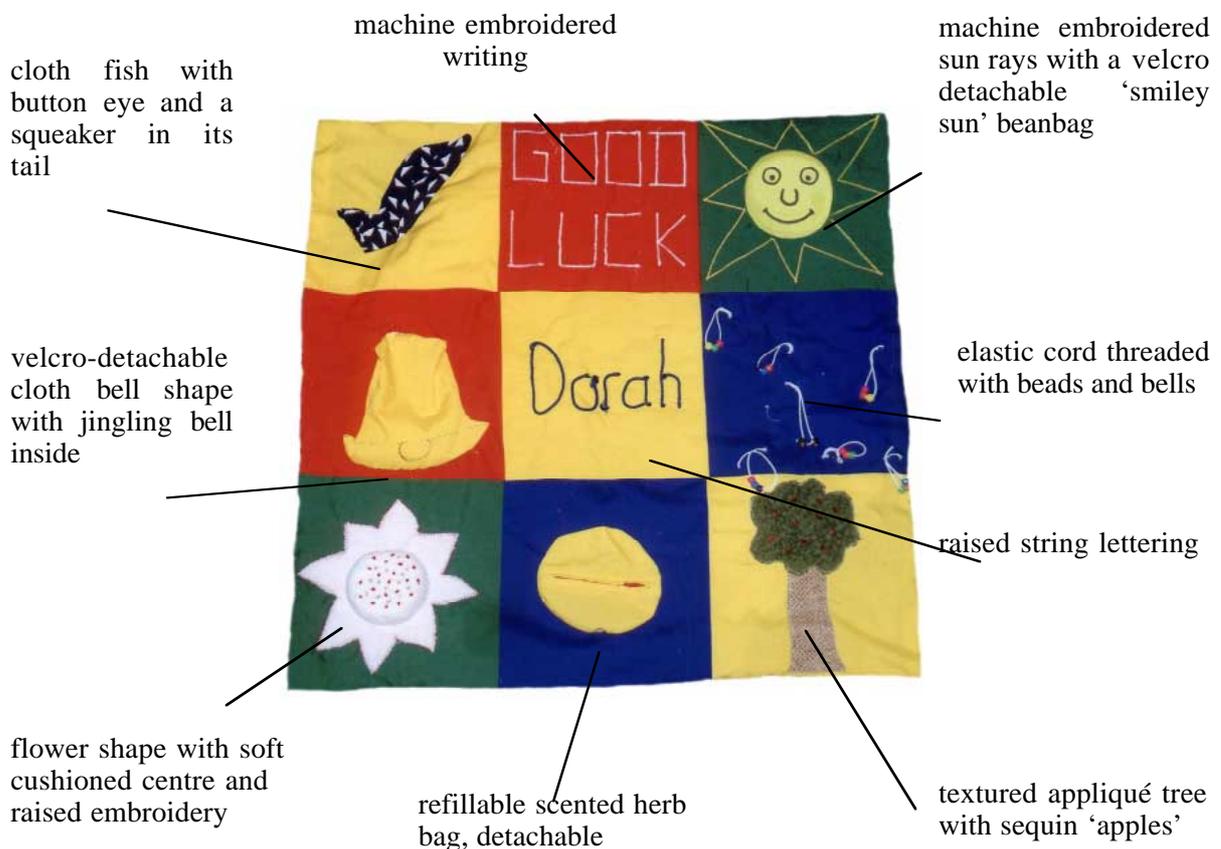
- Children could help to design Dorah's future home (or that of other children) by producing a plan for a wall or a floor or an attachment in a home for someone with a disability. If they produce a successful design they could make or source and cost the various components and devise the means of fitting. If, say, devising a stained glass skylight for a roof, they should note that South African weather patterns are very different from those in the UK. In South Africa there is very heavy rainfall for short periods throughout the summer (from about September to March) and a high incidence of lightning strikes and of hail. In winter there may be many months with no rain at all.
- The value of interesting textures, sounds, uses of light and bright colour cannot be over-emphasised, so projects involving texture mats, feely-boards, light panels, shiny mobiles etc., are great and very ordinary materials (tin foil, shiny plastic, stretchy elastic, wood) can be used.
- Audio tapes of substitutes for finger-rhymes (for children without fingers) to help children learn number, rhythm, repetition and anything else that can be covered in this way are really helpful. (But remember rhymes must be culturally appropriate – e.g. in South African languages, dogs are not necessarily described as making the sound “Woof” and while owls are symbols of wisdom in the UK, they are symbols of bad luck or evil to many South Africans.)
- There is a great need for accessible accident prevention information, suitable for people who lack strong reading skills. Pupils could design posters, leaflets, cartoons and video films which carry the messages of causes and prevention of accidents, or first aid for burns and other injuries. The best of these could go on to be used in lifesaving information campaigns in South Africa. They must take into account the cultural context in which they will be used, as, for example, most South Africans do not live in two storey houses – rather in bungalows or in simpler accommodation. This kind of project clearly offers scope for work in Art, Drama, English, Music, and could be linked to Science topics.

In making items to be left in hospitals it has to be understood that the hospital staff themselves are from such impoverished homes that they may feel little guilt in removing items given to sick children, to entertain their own children at home. Where possible items should be made that work best in a particular environment – such as fitting across hospital cots – and so

the temptation to remove them is itself removed. Alternatively the items that hang from Dorah's wooden frame would not be taken because they function with the frame that is too large to be readily removed.

The list of projects given here is deliberately short. The beauty of this kind of work comes from its diversity and the opportunities for lateral thinking and creativity - therefore, the advice is:

**Create, consult (so that you will produce appropriate aids) and then GO FOR IT!**



The quilt is made from primary coloured cotton squares and was designed to be fully washable. Designed and made by children from Passmores School

### Dorah's Play Mat

## 7. Burning Issues

In Western society, most burns occur within the home and victims are usually young children or elderly people.

Domestic burns account for 70 per cent of all burns with most caused by hot water and steam. Because children cannot see the danger in certain situations, they must be protected. Their parents must be taught to see danger for them; to note the trailing kettle cord or the full mug of coffee in reach of young hands. Elderly people are at risk because they are unable to move quickly out of danger and arthritic stiffness makes them more likely to drop items.

Burns are most commonly caused by hot liquids or fire; they can also result from cold (frost bite), high and low voltage electricity, acid and alkali chemicals, abrasion and friction, and irradiation.

Superficial burns cause redness of skin without penetrating and need little treatment.

Superficial dermal burns penetrate the skin but cause little damage to the outer layer. They need medical assessment and treatment and typically heal in three weeks. They are sensitive to a pin prick.

Deep dermal burns are not sensitive to a pin prick and medical treatment is essential.

Full thickness burns need medical treatment immediately.

All burns can cause great physical and psychological pain to the victim.

### Prevention:

- Keep all containers of hot liquids out of reach of children.
- Take care around open flames and supervise the use of stoves, fires, matches and lighters, cigarettes and candles.
- Be careful when working with steam and hot oil.
- Kettle cords, pot handles and coffee mugs should not be where children can pull them over.

Store dangerous chemicals out of reach of children - e.g. caustic soda, sulphuric acid, and other corrosive chemicals used for cleaning kitchens. Gloves should be worn when handling such materials and they should be stored out of reach of children. Swimming pool chemicals can also cause extensive burns.

Children are often scalded with too-hot bath water. The geyser thermostat should be set at 54 degrees Celsius. Always test bathwater temperature before putting a child in it.

Many children are treated in hospital because ignorant parents have thrown hot water at them for a “punishment”.

Treatment of a burn should occur as soon as possible and continue at least over the next 48 hours.

Infection is a big problem with any burn.

In South Africa, burns in the higher income groups are similar to those suffered in Western society. However for the majority of the population burns occur from children rolling into open fires in rural settings when they are asleep, from paraffin stove explosions in squatter camps; from children left alone with a candle for light and the candle tipping over and setting bedding on fire.

Millions of southern African homes still have no electricity nor running water. People are forced to use open flames for light and heat and when a fire starts there is no ready supply of water to extinguish them. Even where such rare luxuries as telephones and a fire brigade exist, the fire engines cannot usually reach the burning shacks because they are built too close together - and again there is no water supply to which fire engine hoses can be attached. Fire spreads rapidly in squatter settlements but most children caught in their path will die.

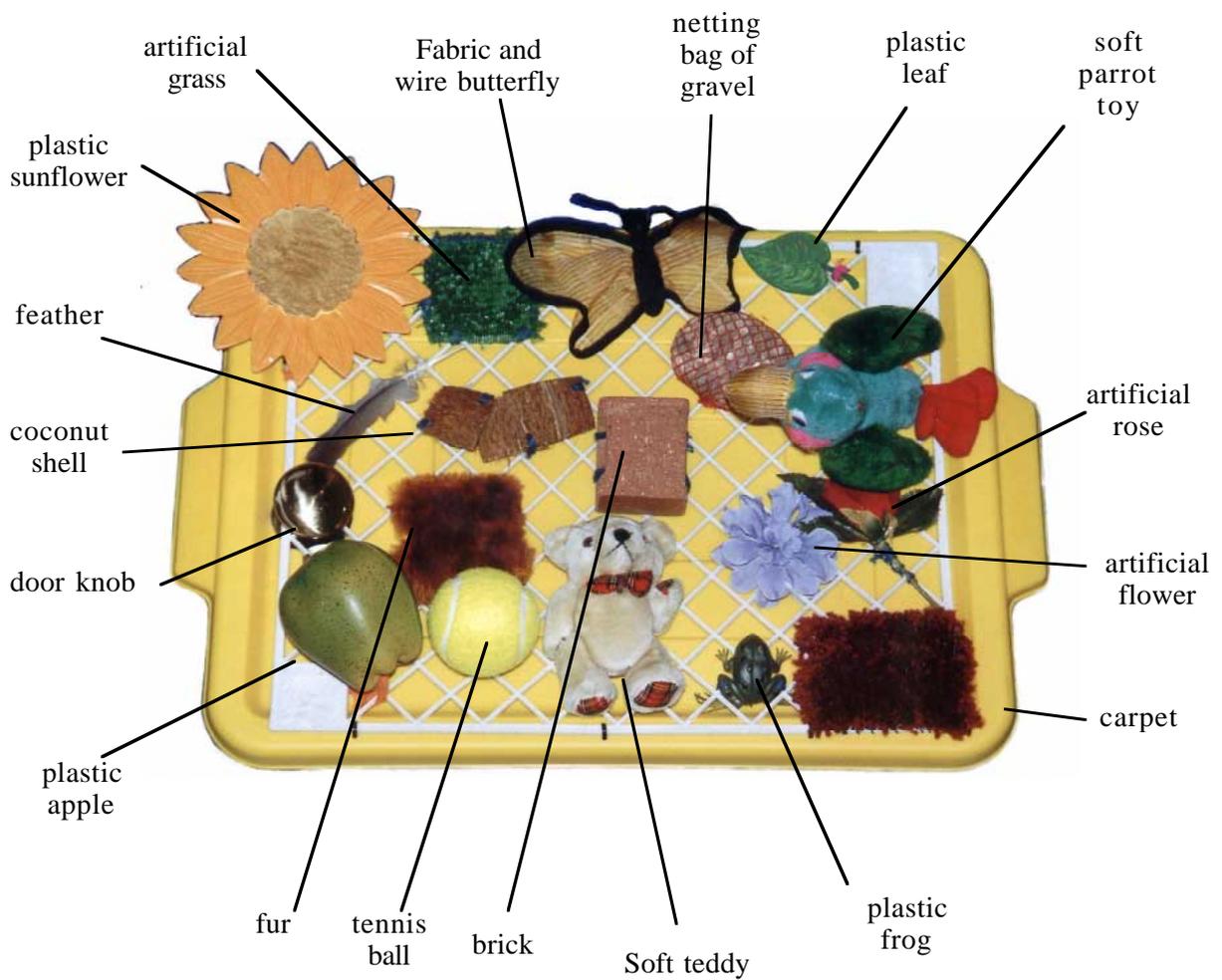
Even the phenomenon of leaving children alone cannot just be blamed on bad parenting. There is a social system left over from apartheid that makes no provision for childcare for a working mother and little welfare advice even on how to curb the growth of her family. Several children may be left in the care of another child as young as eight or nine years old. They have no idea what to do when a fire starts or how to treat a burns injury.

In slightly better quality housing, breeze block huts have burglar bars over their windows due to South Africa's high crime rate. A fire starts and there is no means of escape through the bars.

Education is the main way to prevent these fires, combined with electrification of settlements and the supply of piped water to all communities. For rural fires a simple circular fire guard could solve a large part of the problem. To date we do not believe such an intermediate technology device has been invented and yet it would be relatively easy to make.

# Sample worksheets from the Dorah project at Passmores

These worksheets were used in the creation of the story tape to go with the feely board, by a class of twelve year-olds.



**The 'feely board'**

## Dorah's Story Sheet 1.

Can you think of an exciting way or an interesting way to begin Dorah's story?

Remember:

It must be suitable for a three- to four-year-old.

It must include some things for the 'feely' board.

It must not include things she would not have heard of, or that could hurt her.

Dorah does not have fingers, so fastenings are not a good idea yet (though she will probably learn to do them with her toes later).

- Dorah is your central character.
- You are working on just a beginning.
- Try different versions and see what works best.

Here are some things you suggested last time:

*a gravel road*

tree bark

**cotton wool**

*grass*

**nuts**

a leaf

*fruit*

*carpet*

You can add new ideas if you feel they may work well.

Try to write a beginning that is about one side of an A4 page.

## Dorah's Story Sheet 2

A good story builds up to its most exciting part. For someone Dorah's age this must not be frightening.

Here below are some of your suggestions that might be good to include in the main part of the story:

*fur to stroke*    **crocodile skin**    a tiny teddy    *a feather*    **a silk flower**

satin ribbon    *cloth or blanket*    coconut shell

a small brush    ***an afro comb***    a large clock face

Again, if you have new good ideas we can add them in, but remember we need to put the things on the 'feely' board and they must be safe. Also remember that although Dorah has no nose at present, she can smell things.

- Try to build the story so that it grows more interesting as well as including 'feely' things.
- Experiment with different possibilities.

(Check tenses: it is easy to slip up!)

### Dorah's Story Sheet 3.

Our story needs a good ending – a proper finish. Can you help to draw it to an effective close?

- There has been a suggestion that Dorah might win a prize of some kind, or perhaps take home a treasure.
- Remember that a treasure for a three-year-old would not necessarily be a treasure to you!

Here are some suggestions:

A silver cup.

A piece of fruit (plastic).

Big, interesting buttons (that Dorah could feel with her toes).

A fancy, big key.

Try to ensure that your ending will make Dorah happy and will work with the rest of the story to be satisfying.

- Experiment with different possibilities.

How does the whole thing work?

Have we put love into it? Will it make Dorah feel good?

(Did you keep those tenses right?)

## **9. Contact information**

### Children of Fire

PO Box 1048, Auckland Park 2006, Gauteng, South Africa.

Trust Registration Number: 006/702/NPO.

Email: firechildren@icon.co.za

Website: <http://www.icon.co.za/~firechildren>

Trustees: Richard Steyn, Ann Metcalf, Bronwen Jones, Thandie Klaasen and Vhonani Mufamadi.

### The Dorah Mokoena Charitable Trust

#### Secretarial Office:

120, St Margarets Road, Twickenham TW1 2AA, UK

Tel: 0181 580 0730 Fax: 0181 580 0731

Registered Charity Number: 1070000.

Email: firechildren<averil@alphaomega.demon.co.uk>

Website: [http://members.tripod.co.uk/children\\_of\\_fire](http://members.tripod.co.uk/children_of_fire)

Trustees: Keith Dixon (Chairman) Dr. Averil Horton (Secretary) Bronwen Jones, Haydn Harris, Glynn Jones.

#### Chairman's office:

Maescelyn Cottage, Crickhowell, Powys NP8 1RB, UK

Tel / Fax: 01873 810320

Email: firechildren<kbdcons@easynet.co.uk>

### Regional Co-ordinator – Northern England: Frank Jarvis

4, Mariners Court, Amble, Morpeth, Northumberland NE65 0JY

Tel: 01665 712951

### Passmores Comprehensive School,

Tendring Road, Harlow, Essex CM18 6RW England.

Teachers involved to date: Phil Ridgway, Barbara Jeffery, Wendy Nightingale, Helen Gaize.

### Other Useful or Co-operating Organisations:

#### Changing Faces:

National charity working for people with facial disfigurements. Seeks to promote public awareness and social change about the issues surrounding disfigurement. Provides literature aimed at schoolchildren and teachers.

Registered Charity no.1011222.

1-2 Junction Mews, London W2 1PN.

Email: info@faces.demon.co.uk.

Positive Image:

Disfigurement Support Network  
Registered Charity No: 1061922/0  
PO Box 3, Carmarthen SA33 2YR  
Tel / Fax: 01267 241983  
E-mail: paula@positive-image0.demon.co.uk  
<http://www.positive-image0.demon.co.uk>

RNIB Education Centre: (source of teaching materials on low vision children): Garrow House, Kensal Road, London W10 5BT.

Further reading: Helen Keller's autobiography is available in an adapted form for children. A video of the classic film about her early life, *Miracle Worker*, is available to order from video stockists.

## **10. Donations**

May be made direct to:

South Africa:

Children of Fire  
Account No. 61492023919 held at First National Bank  
Gauteng Province, South Africa.

United Kingdom:

The Dorah Mokoena Charitable Trust  
Account no. 30299065 sort code 20-17-92  
Barclays Premier, Rose Lane, Canterbury, Kent, England.

Or may be sent to:

Mr Victor de Grey  
Barclays Premier, Rose Lane, Canterbury, Kent, England

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