

Sense Play Inquiry: Submission from Rainbow Trust Children's Charity

Introduction

Rainbow Trust Children's Charity (rainbowtrust.org.uk) provides emotional and practical support for families across England who have a child with a life-threatening or terminal illness. We provide support when and where the family request it.

This response is the result of internal consultation with our nine Care Teams which each comprise of a Family Support Manager and up to six Family Support Workers. We also employ three Sibling Support Workers and a Cardiac Support Worker.

Please note that names have been changed in the case studies included.

Why we are interested in play opportunities for young disabled children

We are interested in play opportunities for young disabled children because play is an important part of life for all children, and especially for those children with terminal illnesses. We want the children and families we support to live life to the full. Enabling a child to have positive experiences through play is important for families to know they are making the most of the time that they have with their child.

Play activities carried out by Rainbow Trust teams include:

- Play in or out of the home between a Family Support Worker and the child or young person.
- Weekly or monthly drop in groups for families and their children to play together.
- Visits to 'soft play' or 'gym and play' sessions.
- Family activity days, such as picnics, outings, visits to a KIDS playground, or activities such as craft, baking, face painting, nail painting or temporary tattoos.

1. What is the impact of play on children with multiple needs and their families?

Play is highly valuable for children with multiple needs and in particular for terminally ill children.¹ In our experience play impacts on such children in a number of positive ways:

- Play can be an opportunity for a child to have positive and enriching experiences. The child can become absorbed in an activity which enables them to feel less stress and anxiety because their attention is focussed elsewhere. The fact that play allows children to create their own rules and use their own ideas can enable them to feel a sense of control, which is otherwise missing from their lives owing to their multiple needs.
- Play can support a child to reach developmental milestones. Play in the early years is fundamental for a child's learning and development in all areas. Play provides opportunities for children to learn about the world, and to develop, practice and consolidate physical, emotional and social skills. This is even more pertinent when a child has multiple needs and needs extra support to develop skills of any kind. If play is inhibited, the child's development will be inhibited.
- Play provides opportunities for social interactions and enables social inclusion. Children can get to know other children, with or without disabilities, and can take part in activities that other children take for granted.

- Play can open up channels of communication – for example, it can be a tool to communicate if the child has an impairment. Play can also enable children to express emotions that are less acceptable to show in other contexts.
- Play can aid understanding for children with multiple needs – a play therapist can show a doll with bandages for example, to explain a medical intervention. Play can turn an unpleasant experience into something more bearable – for instance, enabling children to manage a fear of needles.
- Play can normalise a situation at a time when the focus is mostly on a child’s medical or communication needs. For example, one Rainbow Trust Family Support Worker in our Central London team described making a cardboard car for a child out of a large and intrusive pile of boxes - used to deliver essential medical goods - in one family’s small flat. This enabled the family to find fun in an otherwise challenging situation.

There are also additional benefits that we would identify for their families:

- For children with a terminal illness, having fun and positive experiences through play is vital for families to know that they are making the most of the time that they have with their child. Play is a great way for families to spend good quality time together and for siblings of differing needs to spend time playing together – focussing on common interests and experiences rather than their different abilities.
- Parents and carers can feel they are enabling their child through valuable play experiences when they otherwise feel unsure how best to support their child’s development.
- Taking part in play outside of the home can provide an opportunity for peer support between families, enabling parents and carers to share experiences and skills. This can reduce the social exclusion that families may experience when their child has multiple needs.

Example 1: Use of a sensory suitcase with a child with multiple needs

Abigail was a typically active little girl until she was 18 months old. She could crawl, stand up, was trying to walk, could eat solid foods and play like other children her age. Her parents noticed that this changed one day when she suddenly couldn’t do all of those things anymore. She stopped crawling and would choke on solid lumps of food.

After eight months of opinions and tests, Abigail’s mobility continued to deteriorate. She was eventually diagnosed with Metachromatic Leukodystrophy, a progressive genetic disorder resulting in the signals from her brain not being able to get through to her muscles via the central nervous system.

A Rainbow Trust Family Support Worker got to know the family when Abigail was four years old, and took along a sensory suitcase on visits to see her in her home.

Her mother said: 'It can be very hard trying to find things to stimulate a child who can't respond to anything. The sensory suitcase is fabulous and I really think that the toys in it are what keep Abigail's brain active. She loves eye contact and closeness so [the Family Support Worker] is able to focus all of her attention on Abigail, the attention she deserves, while they play with the toys.'

Another positive experience has been the use of music. Abigail at first could not sing along but her eyes would light up with delight when others sang to her. Her favourite song was 'Three Little Piggies went to market' as she waited for the tickles at the end. After months of singing and seeing how much she enjoyed it, Abigail began to have one to one music therapy lessons, and astounded her mother when she sang during the fifth session.

For children with a terminal illness, such play is vital for families to make the most of every day they have with their child. Her mother said: '*Our Family Support Worker helps us to make the most of our time with Abigail and making what time we do have left with her special.*'

Abigail is now 10 years old and her family continues to be supported by a Rainbow Trust Family Support Worker.

Example 2: Using play to build relationships

Rachel was born with part of her brain missing. She has Cerebral Palsy and is blind. She has three siblings. The fact that she needs 24/7 care can put a strain on the family. Her mother explains: "*It's especially hard when I am in hospital with her as sometimes I can be in there for two weeks at a time.*"

A Rainbow Trust Family Support Worker was introduced to the family when Rachel was four years old and his role is spend time with her and play with her.

Rachel's mother explains: "*When the Family Support Worker first came into the house, he knelt down next to Rachel and just let her stroke his face. As she is blind this is her way of feeling safe with people and knowing they are friendly and he did it without batting an eyelid.*"

Rachel is now nine years old and her family continues to be supported by Rainbow Trust.

Example 3: Use of family drop-in groups for peer support

Rainbow Trust recognises that families living with a sick child need a chance to socialise with other families going through a similar experience. For that reason we run drop-in groups for the families that we support. These groups can provide play activities for children, including arts and crafts, baking, outdoor play and the use of sensory development equipment.

The drop-in groups have supported children like Ruby who was born with an undiagnosed condition that leaves her unable to swallow. This puts her at risk of choking on her own saliva. Life has changed dramatically for her parents and her five older siblings as they learn to live with a sister who requires 24-hour care.

The family had been living in isolation and their only support was a weekly visit from a health visitor. They were then introduced to a Family Support Worker and began using a Rainbow Trust drop-in group. Here they could use the sensory play room for Ruby and had the opportunity to meet other parents.

Attending drop in groups means families can discuss their child's condition with other parents. Siblings can play with other siblings without having to answer questions about their sick brother or sister. Sick children, who may have been taken out of school and feel isolated from their friends, have the chance to play and speak with other children facing similar challenges.

2. Do barriers exist to young children with multiple needs accessing play settings and activities? If so, please describe these.

Many barriers exist to young children with multiple needs accessing play settings and activities:

- Physical barriers and complications can arise from a child being in a wheelchair or having a gastric feed, for example.
- A lack of skill among professionals in mainstream play settings can prevent children with multiple needs from accessing them. A child may not need to go to a specialist play group if only minor adaptations are needed, but a lack of understanding by the supervisors of a mainstream play setting, or by the parents of other children, can be a barrier and can contribute to social exclusion. This can affect the confidence of families to use mainstream facilities even when facilities are potentially suitable.
- For those who do need specialist facilities, there are not enough facilities in reach of all families who could use them. Some families in remote areas can find it particularly hard to access such facilities.
- Another barrier can be the need for a referral to access some specialist settings.
- Specialist training is sometimes needed for professionals to meet the needs of particular children.
- Specialist equipment is very expensive for families and even specialist venues may not have appropriate toys for all children.
- A lack of specialised school places across the country is a further barrier. This results in some children only accessing a small proportion of their funding in comparison to other children without complex needs.
- Parents may themselves be unaware of the importance of play or may be unsure how to play creatively in order to support their child's learning.
- As an inpatient, a young child may lose access to outdoor play for some time.
- As a consequence of such barriers, a child can go from being 'a child' to a 'child with additional needs'. He or she may no longer feel an included member of society.

3. What can be done to increase play opportunities for young children with multiple needs? If you have any examples of good practice, please describe these in your evidence.

A range of ideas to increase opportunities are suggested by Rainbow Trust Family Support Workers:

i) Training for professionals

- Train staff in mainstream settings so that they are better able to work with children with multiple needs in their settings.
- Train more professionals to be able to provide one to one support to children.
- Train professionals to support families to create more opportunities to play in the home.

ii) Types of play opportunity

- Greater access to sensory equipment for the seriously impaired would be welcome. Increased funding for portable equipment such as sensory suitcases could enable more children to benefit.
- Play can be enhanced by using musicians and artists who are skilled at engaging with children.
- Play can also be facilitated by use of Makaton.

iii) Facilities

- Greater investment in facilities is essential. An increase in the number of facilities that families can access would be welcome, such as local parks with disabled access, and swings with wheelchair access. Specific playgrounds for children with multiple needs are much valued. A good example cited was the playground owned by KIDS in London.
- More children could benefit from access to sensory rooms if these could be used without the need for a referral.
- A good example of a centre with play facilities is the Kaleidoscope Children's Centre in Lewisham, London.

iv) Attitudes and awareness

- For both families and professionals, it is vital that they are made aware of the existing activities and facilities available.
- Families could benefit from workshops to give them practical ideas for playing with a child with multiple needs.
- Social barriers need to be addressed through awareness raising and education. Other families may be ignorant about what a child with multiple needs can safely do. Comments like 'Is it catching?' are not unknown.

v) Partnership working

- Stronger partnership working could better identify children for referral to bodies or agencies that can offer specialised play support.

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ⁱ For international academic research on this area, see 'The Role of Play in Children's Palliative Care', Boucher, Downing & Shemilt, *Children* 2014, 1, 302-317, available online at <http://www.mdpi.com/2227-9067/1/3/302/htm>