

# Having a Say...

**A COLLECTIVE RESPONSE IN SUPPORT OF RESOURCES FOR AUTISM**

Budget 2013+

# Having a Say...

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## Birmingham Consultation

*Dear Sir Albert Bore*

We are parents, carers and families of children and young people with Autistic Specific Disorders and write to you in support of Resources for Autism.

Resources for Autism is a voluntary sector organisation providing practical, essential and vital services.

We welcome the opportunity to have a say and hope we are able to influence your decision making when it comes to planning a strategy that reflects the priorities and principles of a responsible and fair council.

There is little doubt Birmingham's financial strategy will impact on us all, as residents of this City, in one way or another beyond 2013/14.

However, children and young people with autistic specific disorders already face unimaginable struggles each and every day. We, as their families urge you to put fairness at the heart of your decision making and target your resources to this invaluable service that provides a life line to families often only just managing to cope.

Our message to you is Resources for Autism delivers.

When it comes to the most important and vital services Birmingham needs to invest in this organisation as it consistently delivers practical high quality services direct to our children and young people.

We understand the following principles will guide you:

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## GUIDING PRINCIPLE ONE

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*Putting fairness at the heart of our decision making – targeting resources to those most in need*

*Research has established; “Family stresses related to the care of children with ASD have been shown to be significantly greater than the stresses experienced in the care of children with other developmental disorders.”*

“There is no time to switch off. Destructive behaviours are all around the house it is emotionally, physically and financially draining.”

“it is difficult to live with and care for a child with autism. I am lucky as my son can be very loving but other days he will be out of control and takes a long time to calm down.”

“caring is all consuming it takes every minute of your life.”

“you spend all of your time trying to meet their needs.”

“it’s a 24 hour job looking after my son, he needs constant care, I worry a lot and have no time for myself.”

“it is so tiring, as everything needs to be explained over and over and other people don’t understand or he doesn’t understand them.”

“it can be very hard and upsetting, everything we do or say we have to think about so we do not upset our son.”

“it is extremely hard, as he has so many difficulties, as soon as you try to overcome one issue you set a routine that then needs to be followed rigidly every day and then another issue arises.”

“it is very tiring and stressful, you must give 100% attention and supervision and this leaves no time for any other siblings or relationships.”

“My life is controlled by my daughter’s autism. I live with constant pressure, controlling behaviours, meltdowns and screaming.”

“It is so hard. His anxiety levels are often very high and his mood swings affect the whole family.”

“You need to live with this 24/7 to appreciate how bad it is. It is non stop work, having to watch him all the time.”

There are now over 200 children and young people receiving a service from Resources for Autism with 818 Birmingham families waiting for a term time service and 659 waiting for holiday play schemes.

We understand words on paper will never give you a true insight into the lives we lead and the challenges we face, as individuals and families sometimes just to get through a day. However we believe decision makers do need to take some time to consider the human cost of cuts to services already unable to respond to the magnitude of need.

## GUIDING PRINCIPLE TWO

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*Early intervention to prevent more costly problems occurring*

*It is well documented that research finds “parenting a disabled child goes beyond ordinary parenting” and that the “costs for care for a child with low functioning ASD are considerably lower if children live with their family.”*

*The All Party Parliamentary Group reported on the Impact of Autism advising ‘often preventative costs will save expensive crisis management.’ Researchers also report “social services support for children with autism suggests expenditure tends to be high when compared to that of other disabled children.” “Among children with autism costs for children with additional behavioural and communication problems are particularly high.”*

*Research’ “findings reinforce the importance of short breaks to health and well being (of carers) and their capacity to continue to care effectively for their disabled child.”*

“We rely on this service. Autism puts such a strain on the carer, siblings are left out, having a break just means time for the rest of the family. We would not cope without it.”

“If funding was cut we would be devastated.”

"This is the only place my son goes outside of school. Without this service my son will lose the only contact he has with people outside of home. He will withdraw into himself and it will be very negative for his behaviour and communication skills he has developed there."

"Without RFA I think I will feel no longer able to cope with living in our family home." (Father to Child A aged 9)

"We are under major strain (mother and father) relationships (without RFA) not certain our partnership can be maintained." (Mum to Child B Aged 6)

"Without RFA we, as a family, can't do anything 'normal' not even shopping."

"It would put huge pressure on an already difficult situation."

"It would have a bad impact on us as there is no other service like this for children with autism."

"We would be devastated. My husband would have to give up his job as it is too dangerous for me to care for my son on my own. This would put enormous pressure on the family and who knows what would happen."

"I have been feeling unhappy for years now. I struggle with work, as I am too tired. If we were to lose RFA it would have a severely detrimental impact on all of my family."

We firmly believe you will not save if you cut the money you invest in our children accessing Resources for Autism.

Many of our children cannot speak. We know how much they value and need these services because they show us in their behaviours.

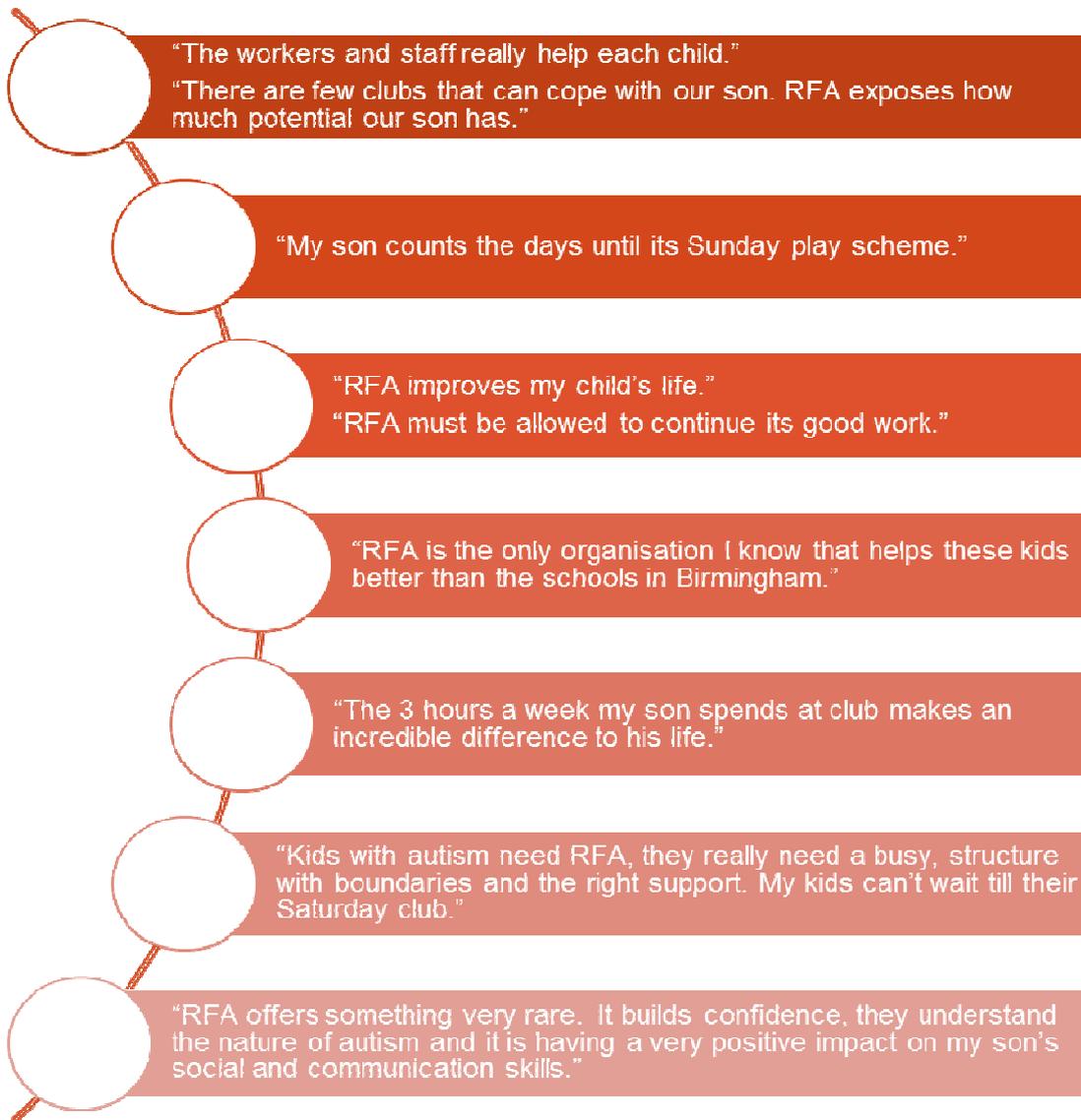
Some of those who can speak wanted you to know:

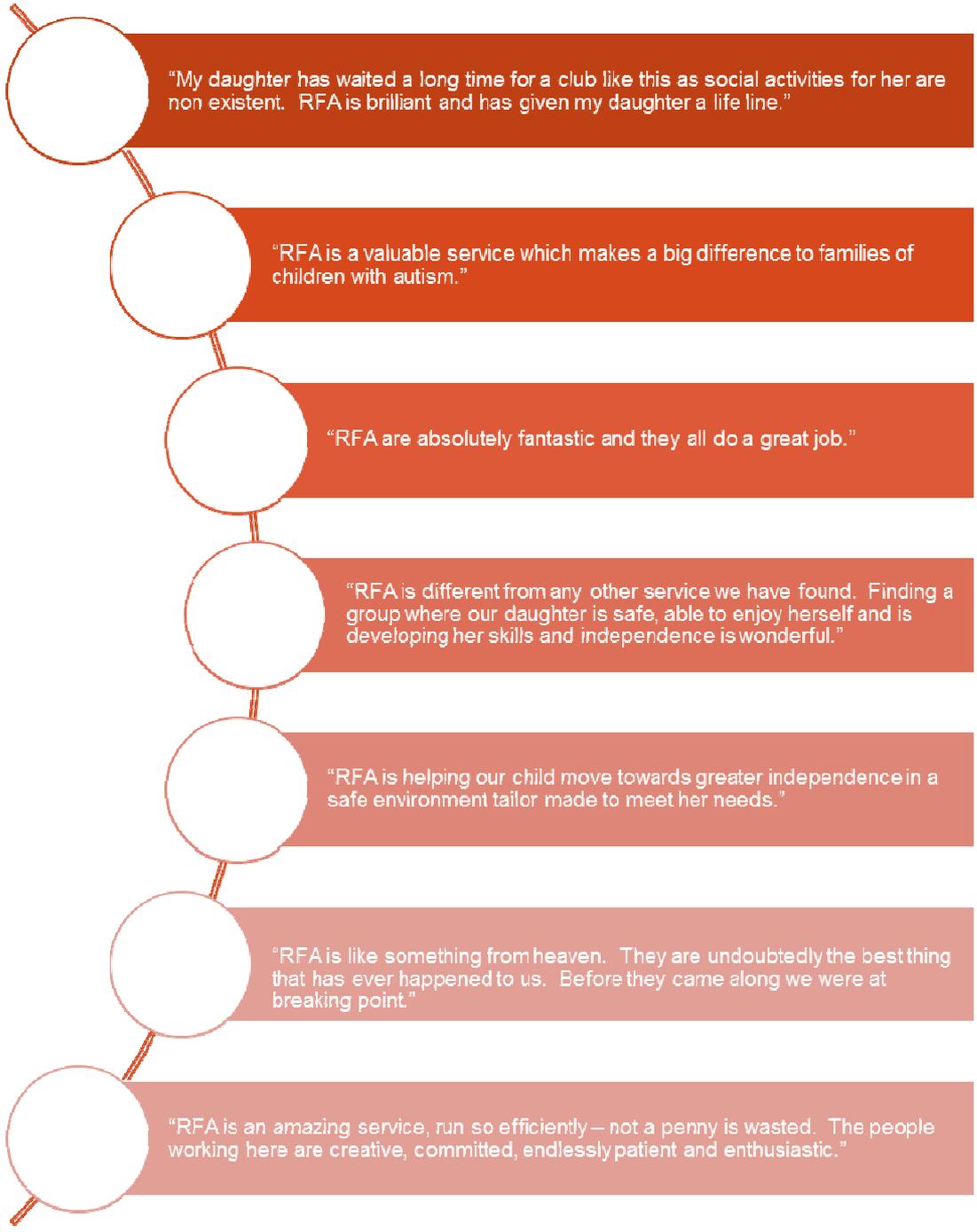


## GUIDING PRINCIPLE THREE

*Getting real value in commissioning by paying for services that deliver the right results*

*Resources for Autism offers practical, vital, quality services in a cost effect way and we say they deliver the right results to our children, our young people and our families.*





**We understand the Council (within the Budget Consultation Document) proposes the following aims:**

**“Our aim is to reduce the number of disabled children in residential care by providing targeted support to families in need.”**

**The document also contains a further aim:**

**“To reduce the voluntary sector budget that provides a range of services that includes preventative, targeted and specialist support. A reduction in budget is proposed that will result in more than 5500 children and young people not receiving services as diverse as short breaks for disabled children.”**

**We are concerned the twin aims are contradictory and wish to emphasize that it is our belief that any reduction in funding to RFA will not save the City in the short, medium or longer term.**

## *The real cost to any cut in funding to RFA are:*

### Preventative

- There is a wealth of evidence that the right specialist support at an early age prevents more costly care needs in the future.

### Human Costs

- Distress, trauma and suffering will be experienced by not only our children and young people with Autism, but also their siblings and us as their families.

### Media / Profile

- Adverse publicity may affect the image of the city.

### Legal / Litigation Costs

- Our children have legal rights (under the Children's Act 1989 Part III Section 17 as it is the 'general duty of every Local Authority (a) to safeguard and promote the welfare of children within their area who are in need; and (b) so far as is consistent with that duty, to promote the upbringing of such children by their families; by providing a range and level of services appropriate to those children's needs.

### Safeguarding Costs

- Our children are vulnerable and we, as parents and carers are often under immense and intolerable strain. RFA supports families to cope and continue to care for their child.

### Crisis Costs

- Managing crisis costs are far more than providing services via RFA. It is simply unacceptable to ignore or fail to respond to families in need.

### Child in Care Costs

- Our children are very expensive to care for as a Child in Care, because (often) their needs are complex, relentless and cause immense drain on a carer. Even if only a small handful of us collapse without RFA the care costs will be far greater than investing in RFA.

**We acknowledge the Council only has the flexibility to find savings against 37% of the budget.**

**However, investing in RFA represents a true cost saving and we believe it is the only option for a council committed to a fair, inclusive city that works in partnership to safeguard, integrate and care for its most vulnerable citizens.**

### *Friends of Resources for Autism*

Including:

Michael Lo

J Throssell

Louise Gent

Lynn Nolan

Ayesha Irfan

Janet Ternent

Karen Kings

Tracey Hadley

Kathryn Petts

Lorraine Turner

Juliet Fletcher

Debroah McGovern

A Mahmood

David Kirtly

Juliette Edwards

Dominic Maher

Sandra Collins

Maria Mackey

Paul Johnson

Alison Hope

Rose Shaw