

messages

FROM
ST
MARYS

JANUARY
2013



What would help make your family life better?

“We want to make sure the stars are reached, not just be shown in the sky as reachable.”

(Parent)

We asked all of you who came to our December curry evening at St Mary's what would help make family life better.

You had lots of good ideas. None of them were complicated or expensive. This newsletter gives a summary of what you told us.

“ I wish my mum had someone to help her clean so that I have a tidier home.” (9 year old girl)

What the kids said:

You told us that you want to do the same things that all children like to do.

Spending time with friends

You told us that you love being with other children and you want more time to hang out and play with your friends. You like making new friends as well as doing things with old friends.

Group activities

You told us that you love doing group activities with other children and young people. Your ideas for group activities included: baking, trips out, having tea together, swimming, artwork, playing video games, paintball and socialising.

Going to football matches

Some of you love football. You told us you would like to go to more matches. One of you told us that you would like to go to Sheffield Wednesday matches. (We think that others might prefer to go to Sheffield United matches!)



People to help you

You told us that you want people to help you who are: helpful, cheerful, kindful, happy and playful. Some of you wanted people to help you play and go to places. Others wanted people to help out at home. One of you wanted someone to help your mum out with the housework and cleaning. Some of you who already have a Personal Assistant or Support Worker told us you would like to see more of them because you get to do interesting and fun things with them.

Play

You told us that you love to play and would like help so that you can play more than you do at the minute.

Drama Workshops

Lots of you told us you love drama, music and performing arts. You would like to do more of all of these things.

Getting on better

A few of you told us that you would like help to get on better with each other. You told us family and friendship aren't always easy!

A big 'thank you' for telling us what would make your family life better! You have given us some brilliant ideas!

And this is what the parents said:



Making things work for your children

You told us that you want to help your children do the things that interest and excite them. You do not like it that your disabled children are often offered help from services that is prescriptive. You said that it is really important to you that your children are able to make their own choices and take part in activities that appeal to them. You felt strongly that it is not fair that your children with disabilities have to make do with whatever is 'accessible or usual' rather than what they want.

Having a vision

You said that it is important to you that others understand that you have a vision that nothing is impossible for your children. Just because they have a disability does not mean they should not be able to dream for their future. You also said that you don't want to be given 'empty promises'. It is really important to you that you can make things happen for your children.

Disability Sports

You told us that you want your children to have the support they need to access sport out of school. This includes support to attend tournaments as well as going to a group.

Doing things as a family

You told us that you wanted help to do things as a family. You said you wanted to be able to be physically active as a family, as well as being able to play games and have relaxation time together. The things you needed help with were different depending on your family circumstances and the ages of your children. For example, some of you said that having a playworker at home and to help you take the children out would be really helpful. Others said that you would like to go on holiday to a campsite where there were people to help you with your children. And others said that being able to access a sensory room would be helpful.

Activities

You all told us that you would like your children to be able to go to clubs and groups that all children go to. You said that you wanted your children to do lots of things like art, cooking, crafts, drama, writing, music and creative play. Many of you said you would welcome playdays taking place on Sundays as the weekend can feel long and lonely.

A big thank you for telling us what would make your lives better!



“We want to do things as a family. We want physical activity, games and relaxation activities.” (Parent)

Some emotional support

You told us that being a parent is hard work and that parenting a disabled child is made harder because it is hard to get help from statutory services. You find it very upsetting to see your son or daughter spending so much time at home simply because it is difficult for them to access the clubs and activities other young people take for granted. You told us that you also find it painful that they don't have many friends. You want good, kind people to help you.

Information

You told us you need simple, clear information about the support that is available and how to get that support. You said that you need information about finances; communication and signs; strategies for dealing with 'melt down' situations; direct payments; housing; clubs & activities that are available for your son or daughter; and updates about the way services are running. Those of you with teenagers said you need more information about what is possible when your son or daughter leaves school.

Advocacy

Those of you whose disabled children go to a mainstream school said that you would like an advocate to help you and your child as they make their way through school. This is because you find that staff in mainstream schools don't always understand your disabled child or see them in a positive light.

Brothers & sisters

Many of you told us that you feel that it is not just your disabled child who gets a raw deal. You said that you would like siblings to have more support. Once again you mentioned that the experience of having a disabled brother or sister in a mainstream school can be hard for siblings as well and you would like them to have some support.

Thank you to all you lovely parents who told us what would help you and your families!

What next?

We will apply for funding so that we can make some of your ideas happen.

We will find cheap and cheerful ways to make your ideas happen.

We will pass your messages on to people in the statutory services - health, education and social care.

We will keep asking you about things that would help you.

About ibk initiatives

ibk is a parent led social enterprise working to promote the inclusion of disabled children, disabled young people and their families in their local communities, and to challenge a disabling world that denies their right to an ordinary existence.

ibk helps families make their lives easier and more fun.



What we do

Advocacy: for parents and/or children & young people

Payroll & Budget Management Service: for families receiving a Direct Payment or Individual Budget

Performing Arts Workshops: for disabled children, young people and their brothers & sisters

Empowerment Workshops for parents: information, community development, sharing stories, relaxation & meditation

Monthly curry evenings at St Mary's: for families and friends

Plan with families: we help families think about their lives and put things in place to make things easier

Recruitment of Personal Assistants & Volunteers: we find Personal Assistants and match them with families

Bring people together: to understand each other, socialise, support each other, and develop new initiatives.

Write and publish books and articles: about the family experience of living with impairment in a disabling world

“This group is unique and asks for nothing in return; just gives support.”

(Parent)

Get in touch

ibk initiatives

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