



Derby City Council

Consultation with Umbrella Service Users and Stakeholders on reduction in funding

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1. Background and Methodology

A 12 week consultation period was held with Umbrella stakeholders and service users about the affects of funding cuts throughout December 2011 to February 2012.

Three different forms were designed to capture feedback from:

- Service Users
- Stakeholders
- The organisation

The organisation was provided with paper versions of these surveys to allow service users, stakeholders and other parties to complete with their feedback.

In total 81 responses were received from Service Users, with 28 received from stakeholders and 1 completed on behalf of the organisation. The response from the organisation can be found in appendix 3.

The survey contained mostly open ended questions, which allowed respondents to give a qualitative response and therefore pass on their feelings. When analysing the results main themes have been identified for each of the questions and comments have been defined into these themes. Respondents also gave multiple comments to a question.

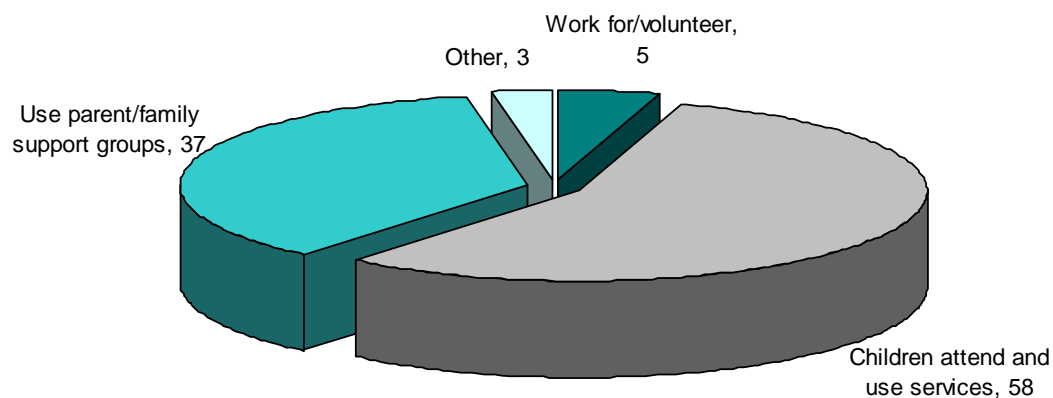
2. Service User Feedback

In total 81 respondents completed the service user's survey. The main findings from these services users can be found in this section. All comments can be found in appendix 1.

2.1 How do you know this organisation and which of their services do you use?

The majority of respondents know Umbrella either because they have children who attend the service (58 respondents) or they use the support groups for parents (37 respondents).

Figure 1. How respondents know Umbrella



Comments - some example:

I have a child with ampical autism and a learning disability. We have used Umbrella for support, to get to know other families and attend their forums and information days. Also he has attended Christmas parties.

I have worked alongside Umbrella for years in my role at YMCA and now as a volunteer supporting young people with disabilities.

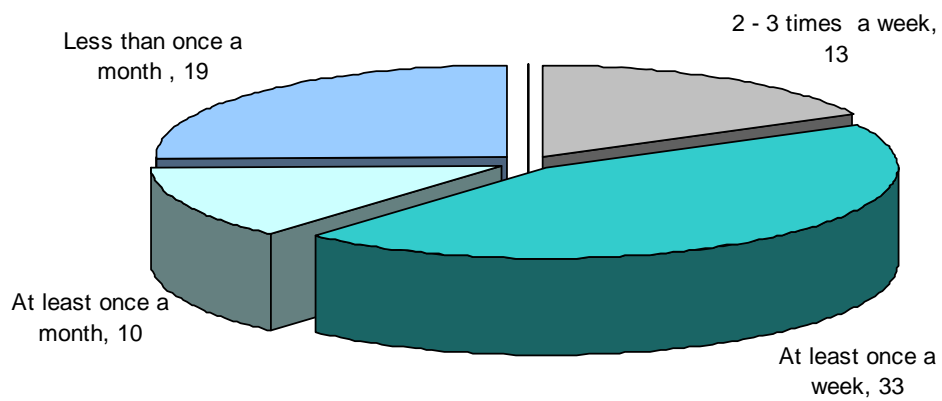
I have a severely disabled child. Umbrella provides support and a volunteer service.

Social events, family support and one to one service.

2.2 Frequency of using the service

Respondents were asked how often they used the services from Umbrella. 13 respondents use Umbrella 2-3 times a week, with 33 respondents who use them at least once a week. 10 respondents use them less than once a month and 19 respondents use them less than once a month.

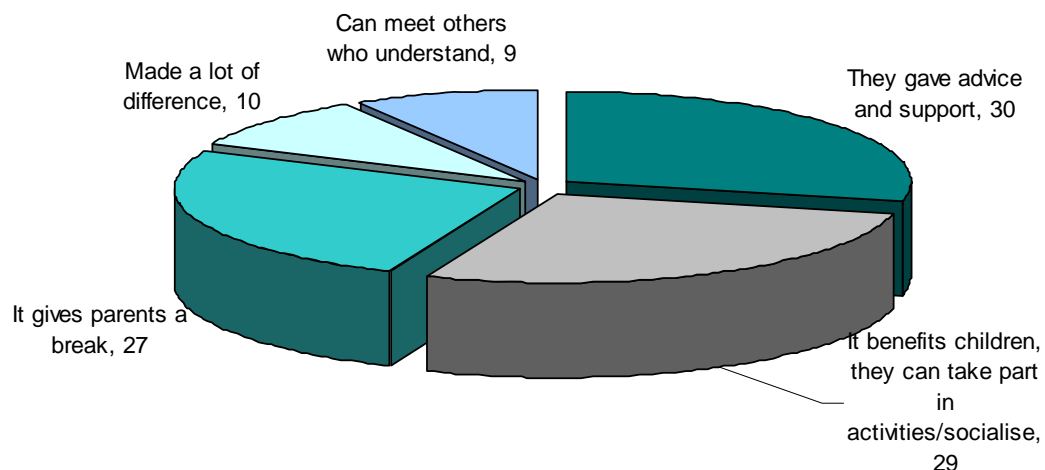
Figure 2. Frequency of using Umbrella.



2.3 What difference does the service make to you?

Respondents were asked what difference the service Umbrella offers makes to them. 30 respondents said the service provided them with advice and support, with 29 respondents who said that it has benefited their children as they can take part in activities and socialise with other children. 27 respondents said it gave parents some respite from their children and time to do other things.

Figure 3. What difference the service makes.



Comments - some examples:

Every difference! - The time we get allows us to spend valuable time with our children. Also it gives us time to breathe our son is a very intensive 24 hour job. Child does not sleep.

As well as helping my child develop it allows me to spend time with my other two children. Impossible in the holidays other wise.

I need a support group like umbrella to help with every day problems, asking for advice like a disabled child, filling in forms, speaking to other parents like similar problems.

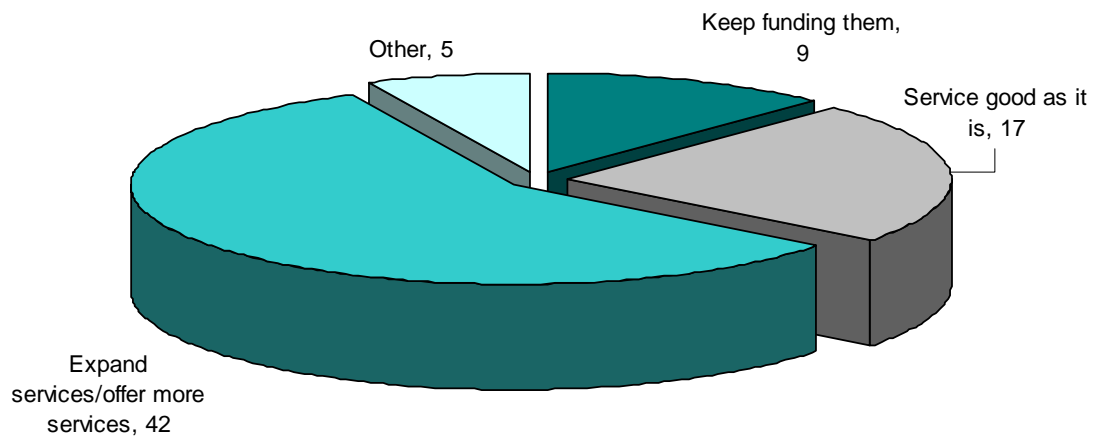
It is a lifeline - it is great to meet other carers and to get vital information to help me in my role as carer. The family support worker is very supportive and has organised lots of events which have kept me sane.

Made a lot of difference to our son's life and ours. He goes to the youth club every week without fail because he loves it so much. And we get the support that we need.

2.4 How would you improve the service for you?

When asked how the service could be improved, 42 respondents said the service should be expanded or more should be offered. 17 respondents said it is good as it is with 9 comments stating to keep funding umbrella.

Figure 4. How would you improve the service?



Comments - some examples:

The service is already brilliant - keep it - especially Daybreak and Side by side.

Keep it going! This is a vital service and helps lots of carers - without it there would be a lot of carers in crisis and the pull on resources (health and social services) would be much higher.

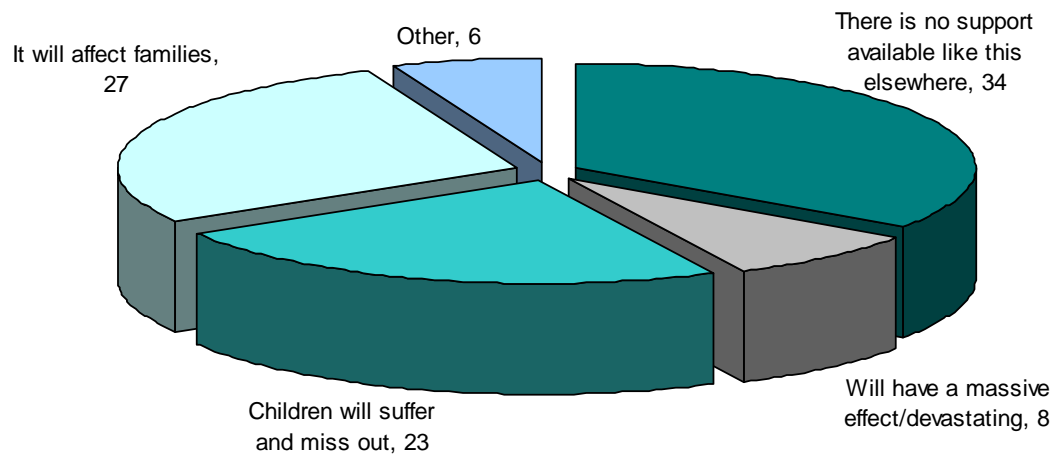
I would benefit from more respite with my children if there was an after school activity club or in school holidays, where children could be looked after.

At the moment the 2 hours she receives doesn't include travel time so this restricts the activity and means I have to drop her off. Including travel time would be a great help.

2.5 What would be the impact on you of not having this service be?

When asked what the impact of not having this service would be, 34 respondents said that there isn't any support like this available, 27 said their families would be affected by this, 23 said children would suffer. 8 respondents stated there would be a massive or devastating affect.

Figure 5. The impact of not having the service.



Comments - some examples:

Our family life would suffer. My disabled child's behaviour and sleep would worsen. My mental health would probably deteriorate.

It would be devastating for our daughter and us, because she would lose precious time with her friends and time away from us and would lose time to spend with our other children.

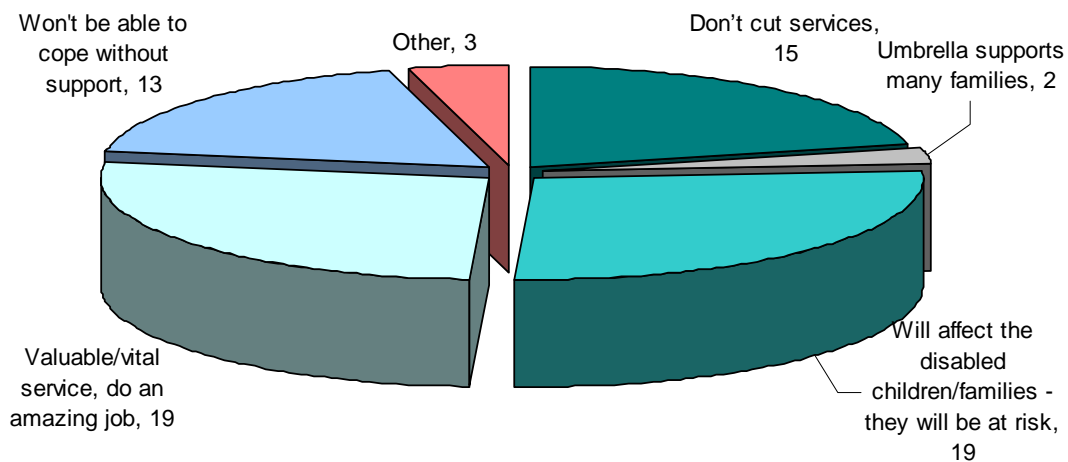
No help in school holidays would put me and other siblings under great stress. Also child will lose out on fun activities in safe environment. I am a single parent with 3 children, 2 who have autism and LD. Not safe for me to go out alone.

It would have a lot of impact as I don't know anywhere else that provides this kind of service.

2.6 Do you have any other comments about these proposed changes?

When asked if there were any other comments, 19 respondents stated that the affect on families and children would leave them at risk, 19 comments said Umbrella offer a vital service and so an amazing job. 13 respondents said they wouldn't cope without the services.

Figure 6. Any other comments on proposal.



Comments - some examples:

There is very limited support for families with disabled children but Umbrella supports so many. I think that it is awful that this is not seen as a priority organisation with so many volunteers make so much difference.

Do not cut back on these services as they are vital to families that have disabled members.

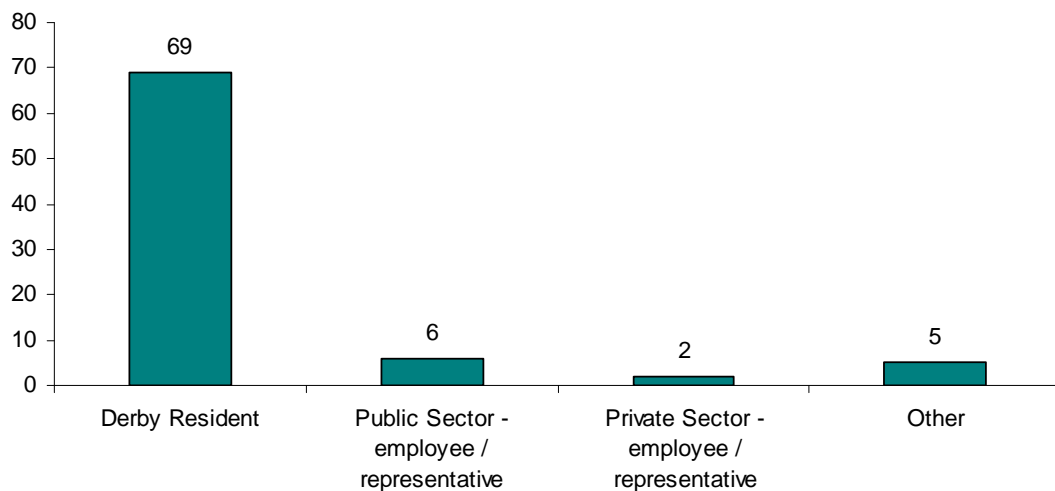
Living with a severely autistic child is hard enough, and the opportunities that are available to them are very limited, cutting facilities like this one, would seriously affect the lives of the whole family.

It makes me feel very angry/frustrated that yet another service is being cut. Having a disabled child is very challenging, stressful and can isolate the parent, any service, especially Umbrella, is very gratefully received.

2.6 Demographics of respondents

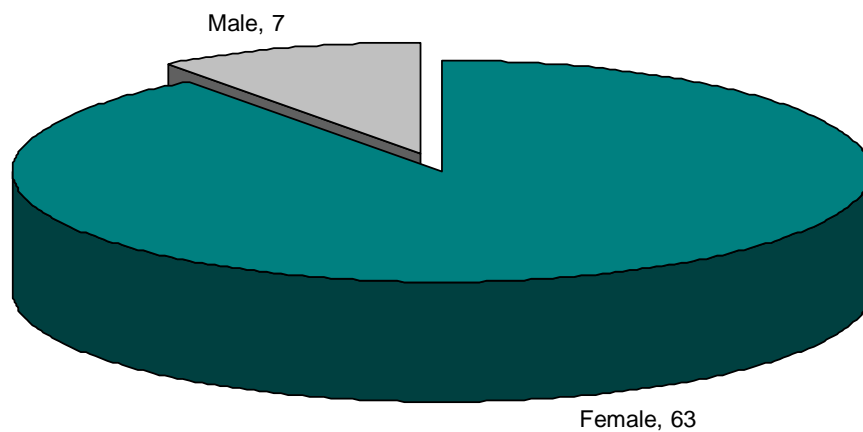
The majority of respondents completing the survey were Derby Residents, with 6 of the respondents who stated they are a public sector employee or representative and 2 respondents who are a private sector employee or representative. 5 respondents stated other.

Figure 7. Completing in what capacity.



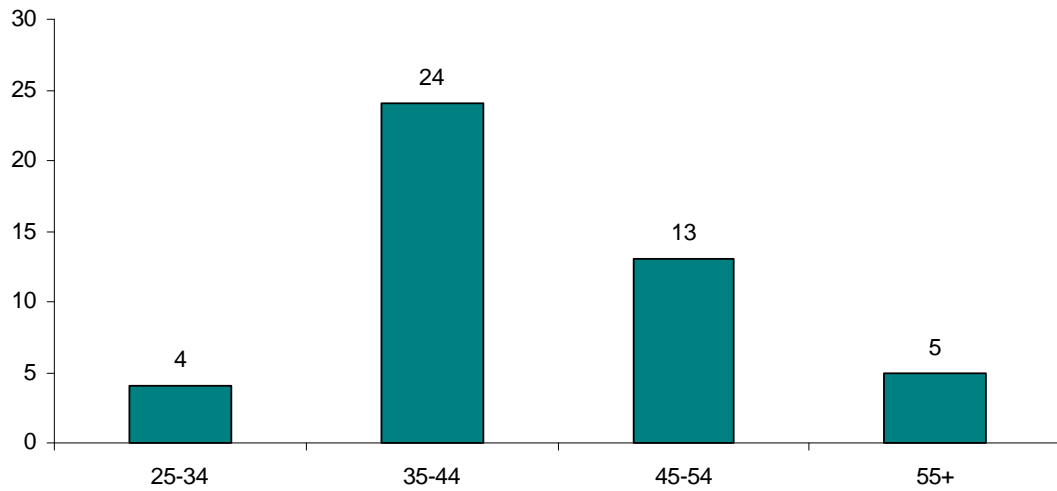
63 of the respondents are female with 7 respondents who are male:

Figure 8. Gender of respondents.



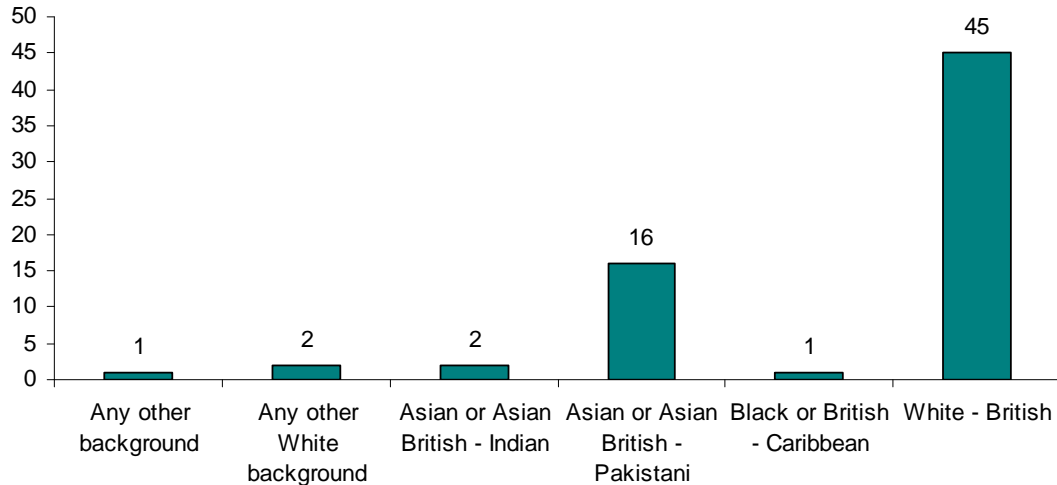
4 respondents are 25-34, with 24 who are 35-44, 12 respondents are 45-54 and 5 respondents are over 55.

Figure 9. Age of respondents.



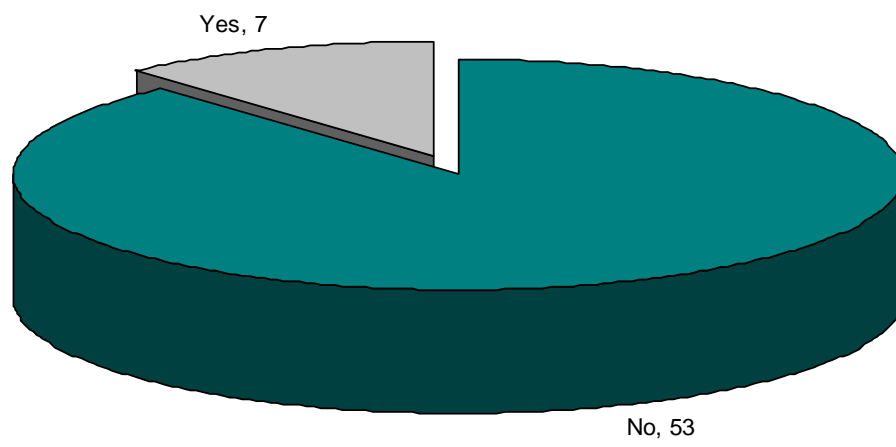
The majority of respondents are from a White – British background, with 16 respondents who are Asian or Asian British Pakistani.

Figure 10. Ethnicity of respondents.



7 respondents consider themselves to have a disability.

Figure 11. Disability



3. Stakeholders

In total 28 stakeholder surveys were completed. 10 responses stated they had heard of Umbrella with 18 who have used the organisation.

3.1. How have you used Umbrella's services?

Respondents had used or heard of Umbrella from accessing their facilities or services and from referring families, or were aware that families use the services of Umbrella.

Table 1. How heard of Umbrella

	No of comments
Referred families	9
Used services	10
Aware of families who use the service	5
Other	1

3.2. What difference the service has made

When asked how the service has made a difference, the majority of comments made were about how Umbrella provides a much needed service to families with disabled children. Other comments are about how supportive staff are, how invaluable the service is and how these needs aren't met elsewhere.

Table 2. The difference the service has made

Provide services for families with disabled children	20
Staff supportive	7
Invaluable	4
The needs aren't met anywhere else	3
Other	1

3.3. How important are the services of this organisation for the well being of Derby residents as a whole

When asked how important they feel the services of this organisation are, 27 respondents said that they felt it was very important with 1 respondent who said they felt it was important.

Respondents were then asked to give the reasons why they felt these services are important. Respondents made a variety of comments; these can be seen in appendix 2. The main theme of the comments is that the organisation supports vulnerable families with disabled children, who otherwise wouldn't be able to take part in activities and socialise. The service provides parents with practical support and somewhere that they can go to where people understand their situation and what they cope with. Comments were also made that no other organisation offers this service and there could be a gap in provision if funding was cut.

3.4. How important do you think it is that the Council continues to fund this organisation?

When asked how important they feel it is that the council continues to fund this organisation, 27 respondents said that they felt it was very important with 1 respondent who said they don't know.

Respondents were asked to give their reasons why they felt it was important that the council continues to fund Umbrella, many of the comments made stated that Umbrella provides an invaluable service to help parents cope and support them. Removing funding would impact on families, no funding would impact on a loss in service.

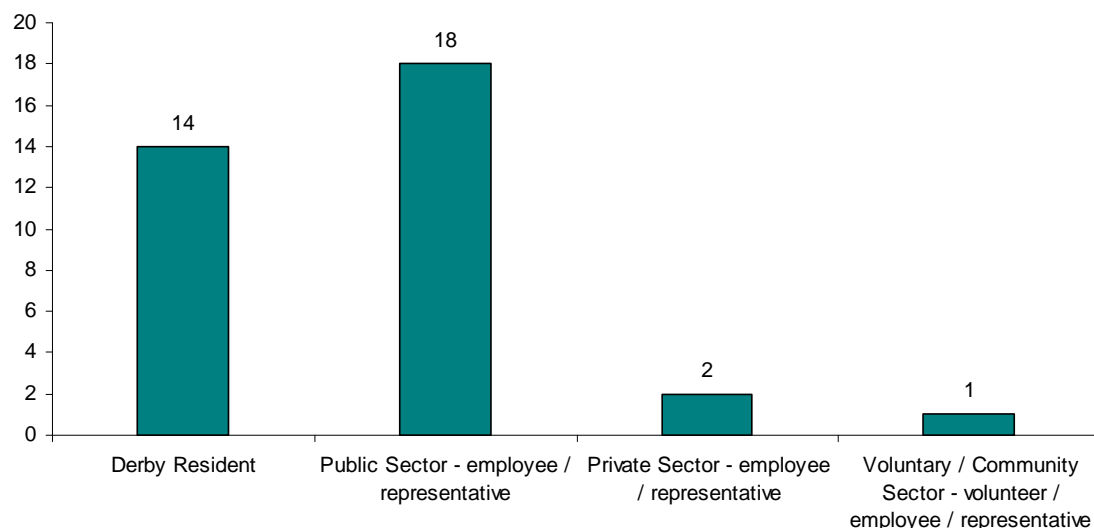
3.5. Any other comments

When asked if they had any other comments, respondents gave many varied comments. The main theme of the comments were around the fact that Umbrella is a well used service, that provides a vulnerable group who deserve supporting with vital services, where would these families go if the funding was cut.

3.6. Demographics

14 respondents stated they are a Derby Resident, with 18 respondents who are a public sector employee or representative.

Figure 12. Capacity of respondents completing.



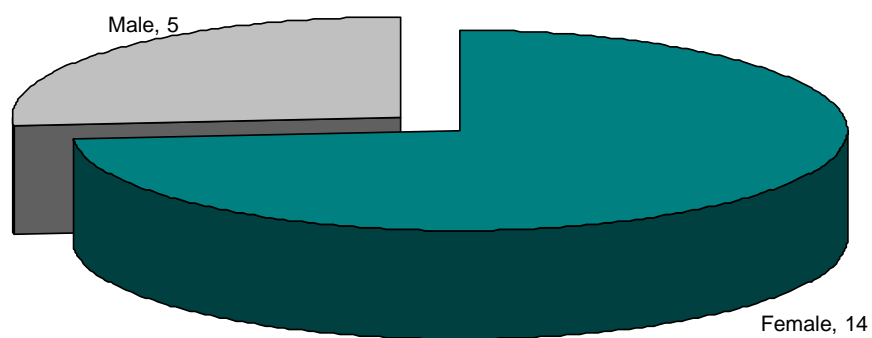
The respondents are from as variety of different areas:

Table 3. Where respondents represent

Kite team Royal derby hospital.
NHS
Derby Hospitals
Teacher of the Deaf.
Markeaton Primary School.
The Light House, Integrated Disabled Children's Service.
Home-Start Derby.
Derbyshire Healthcare Foundation Trust. Community Paediatrician
Carer
Nacro Osmaston Family Project.

14 respondents are female with 5 who are male.

Figure 13. Gender of respondents.



17 respondents who provided their ethnicity stated they are White – British, with 1 respondent who stated they are from another White background and 1 respondent who is Asian or Asian British Indian. None of the respondents have a disability.

Appendix 1. Service user comments

Q2.

I have worked alongside Umbrella for years in my role at YMCA and now as a volunteer supporting young people with disabilities.
My son has used Daybreak, Your Turn, Side by Side (Play schemes). Family support, parents support group (Once a month) Sibling group (Daughter attends).
Daybreak - Trips for disabled children usually in school holidays. Parent support groups and seasonal events e.g. Christmas party knew about it through Ronnie Mackeith centre at the Royal Derby Hospital.
I have been involved with Umbrella since its inception in 1986. I was the sitting service organiser from 1991 to 1996. I am now a sitting service volunteer and have been since 1996.
I am a volunteer and chair of trustees.
Partnership working in a number of areas - Children with SEN + Disabilities, Parent Forum etc.
We have used many of the services over the past 15 years or so. Although we are not currently using any services as our young person is now 20 we may use some of the services for young adults in the future.
A teacher from school. Side by Side, youth club, support group.
I have a disabled daughter and they have helped with there support.
Information through specialist health visitor. Family support, Daybreak, Day trips, SIBS Group. Have used - Your Turn, Volunteers.
I am a parent of an Autistic child. I do not use any service at the moment, his volunteer finished last September.
Day Break.
Our son has profound additional needs and the organisation + its people has been a big help + support over the years.
From visiting Derby Royal was told about Umbrella. Tyler has attended Daybreak, Trips, Party's and fire engine days. I have a volunteer who babysits for me.
Daybreak Youth club (And when there is space - Your Turn or Side by side).
My son is autistic and I have requested help and support from them.
I am a trustee and also because I have a disabled son.
Daybreak Outings Support
I was referred by Narinder Gleis (Specialist health visitor). I go to Surestart for support with problems with my English and also Family support.
Introduced via Ailsa Kinson - community nurse for children with learning disabilities. 1:1 Support for leisure activity (trampoline).
Daybreak - Alanah's been a member for years. (I think it started with a newsletter, but cannot remember).
Family support Family trips Information service.
I was contacted by a family support worker.
The specialist health visitor @ RMC. I attend the support group.
Since my son was diagnosed with Autism, Umbrella organisation has given so much useful advice.
From Michelle Gee in SureStart. I receive support from family support. I have been to the support group before. I make an appointment at Surestart to see my family support worker.
Daybreak, trips social activities.
My son has been involved with Umbrella for 8 years. He uses the Daybreak service.
Through a doctor who recommended it for my older son also friends and the autistic group recommended it.
We taken part in organised events. My son enjoyed when gone Drayton Manor and farms.
Accessed Play schemes - introduced by Soc Services (children's). Access over 18's services now.

Day break. (Easter) (Summer).
Through my daughter who has special needs. The services my daughter uses is the youth club, Side by side, and also my daughter did curling.
Volunteer service Play and leisure Side by side Parent / Carers support group Trips
Volunteer services Support groups for carers / parents Christmas parties Circus
Volunteer service for my son. Family telephone support.
Daybreak Telephone support
Referral via clinical psychology. Support services for my child - educational and recreational.
From Michelle Gee at Sure Start. We use family support and information service.
From health visitor Narinder Ghei. Information and Aiming High with Umbrella (computer club). Family support / bilingual worker / HVs, also Daybreak.
From Ivy House. Family support / bilingual. Support group. Information. Your turn.
From Narinder Ghei specialist health visitor. Information. Family trips. Family support.
I can't remember, it was a long time ago. Daybreak. Information. Family support / Bilingual. Play and leisure.
I found out from my friend. My daughter has been a part of SBS group. We've also been on family trips. Support group - family support / bilingual.
Tayba supports me with my child. Family support. Information.
Were members and my daughter has her name down for youth club.
By Tayba. Information. Family support.
They provide essential services for children and families with special needs.
We found out from Michelle Gee at Sure Start. Family support / bilingual. Information.
From family friends. Family support for disable children.
I have a child with ampical autism and a learning disability. We have used Umbrella for support, to get to know other families and attend their forums and information days. Also Jack has attended Christmas parties.
We work in partnership with this organisation; Out of School Inclusion Pilot Scheme - umbrella are able to deliver bespoke training to a group of childcare providers that care for school age children and are available to offer support to providers that are having difficulties caring for disabled children. This pilot scheme was instigated by the out of school development officer. DCATCH (Disabled Children's Access to Childcare) - partnership work took place after Umbrella were invited to put in a tender along with other partners. This pilot scheme was very successful and we were able to provide childcare for many disabled children of all ages across the city. One of the services that Umbrella were able to offer to our childcare providers was for an experienced adult to accompany children and young people to the setting and help them to settle in, sharing their knowledge. and skills with the staff team. We were also able to appoint a brokerage officer to assist parents in finding appropriate childcare for their child/children, the post was very popular with parents/carers and childcare providers alike and successfully placed over 50 children in childcare who had not previously been able to access a place. Further training was delivered to approximately 40 nurseries, out of school clubs and childminders across the city. This broke down barriers and gave providers the confidence to work with disabled children. This pilot scheme was government funded and came to an end March 2011. PATH (Parents at the Helm) - we attend this parents group that meets about four times a year and is facilitated by Umbrella. All parents/carers that are a member of this group have a child or children that is disabled. One of the events that we get involved in is the parent/carer forum, that takes place annually. Our involvement is in the form of advisory, support with disseminating information, fliers and newsletters and we have a stand at the forum advertising the information, advice and guidance services that Families Information Service deliver. When we need to gather information for the Childcare Sufficiency Assessment the organisation support us in gathering information from parents/carers that have disabled children through questionnaires and parent/carer focus groups. Information Helpline - Families Information Service uses this service for help and advice when we have brokerage cases where specialist care is needed.
My son has cerebral palsy, learning difficulties, epilepsy. Day break, side by side and information office to name a few.

Derby Down Syndrome Group. Used their Your Turn service in the past, no longer exists! Would like to use the play scheme in the holidays.
I have a severely disabled child. Umbrella provides support and a volunteer service.
Social events, support, help, advise, (trips - one to one support with my son).
As a result of Our Granddaughter having various disabilities and impairments and also living with us we have been fortunate enough to not only be able to access groups and activities for Meghan (our granddaughter). In the form of social interactions but also afforded us both invaluable support as grandparents and eased our "Isolation" by creating like-for-like groups/support.
Through Ronnie Mackeith. Centre after ASD diagnosis. Family support. Daybreak and trips out as a family.
We use side by side service which is brilliant for Jake, he really enjoys it and looks forward to when he is going out.
My 14 year old son has used this service for 9 years because he has severe learning difficulties. Daybreak. Support for carers and parents scheme.
Known Umbrella for 25 years. For Jamie I use side by side fortnightly. Daybreak scheme during Easter and Summer Holidays
We started using this organisation when we adopted a little girl with additional needs. We further started using this organisation with the foster placement we have at present. Daybreak 1 to 1 support worker Advice
Through the Ronnie MacKeith Centre. Daybreak, side by side, Parent Support Group. Have also used Your Turn in the past.
Social events, family support and one to one service.
I know this organisation through the support group which I access on a regular basis. Have also been on shopping trips and attend parties.
Having a child with a severe learning disability has brought me into Umbrella. We use daybreak, play scheme, support group, siblings and having the support of people I have met at these groups.
Umbrella has been supporting our family + disabled daughter since she was four years old (she is now nearly 20!). Over the years we have used Daybreak, Play services, Volunteers in our home + continued support for us as carers.
I attended the carers/support group (Derby Support Group)
I was told of this service from Jack's school (St Giles) and through talking to other parents.
Member for 10 years Daybreak, holiday clubs, xmas party, trips, computer club
I know umbrella through Ronnie Mackeith Ctr. Our family enjoys joining the events as pamper day, xmas party, parent group, holiday events
Support group
From my consultant at the RMC. I come to the support group.
Sitting Service: This allows me time to go out myself once a month. Daybreak: Safe & secure environment for my daughter to have fun and enjoy a leisure activity with people who understand her and can best support her. Family Support: Knowing there is someone available to listen to me. Again someone who understands the everyday stress and strains of bringing up a child with an additional need. Support groups offer opportunities to meet up with others in a similar position and get information and advice and tips.
Daybreak
I have heard of the organisation from Umbrella meetings which are held once a month.
Volunteer service (now cut) Daybreak, side by side, Aiming high
My daughter attends the Daybreak Play scheme

Q4.

Umbrella gives me the chance to support young people and see the invaluable service provided to families.
Umbrella has been a very big part of our sons life from the age of 5, he is now 16 nearly 17. Umbrella has been there for us for a long time and the staff have become friends with us. This service has been a life line to us as a family. It has been around for 25 years and needs to be around for us and others like us in the future.
Advice, support, not feeling alone, safe appropriate events for my severely disabled child - the only practical help re trips out is through voluntary sector organisations.
I sit for a single parent family who has two daughters, the youngest being 11 and diagnosed with autism. This enables mum to spend time with her older daughter and to have a social night with friends.
I man a helpline to give advice on special education. Most weeks I get 5 or six queries and support families in need of advice on schools.
Gives us a much wider support network.
My son would not have had the opportunity to have such a wide range of experiences in a safe and welcoming environment. My son attended the gym with the Your turn project several years ago and continues to attend the gym, albeit no longer supported by Umbrella.
Made a lot of difference to our son's life and ours. He goes to the youth club every week without fail because he loves it so much. And we get the support that we need.
I feel the support is there when ever I need it with the very understanding staff with experience in the matters that count. Unless you have a disabled member of the family you would not understand many situations.
Umbrella has supported us for the last 12 years.
Meeting up with parents in similar situations, Someone to Turn to in times of stress, A break from child care in school holidays and time with sibling. Always been there for me.
Fantastic. I meant I could have an hour to myself without worrying.
I have a disabled child and daybreak in the holidays makes all the difference. My son has a great few days going on trips and doing various activities and I get a break because my son is a very demanding child.
The service makes a very difficult life for our family just a little easier it gives us support and help especially in school holidays and also through their volunteer services.
A huge difference Dawn sits for either Tyler or both children so I can have some free time. Support with my problems that arise and support educationally.
Umbrella services have enabled my daughter who has severe epilepsy and learning difficulties to go out with her peer group in safe and meaningful environments outside school.
Advice about facilities my son can access. Advice from people who understand autism and strategies I can use to help my son. Spa days for me to relax and unwind as a carer.
Respite during school holidays from daybreak support for family. Day trips on coach, Invaluable.
It makes a lot of difference. If it wasn't for Umbrella I don't really know who to turn too.
It gives my child the opportunity to access a mainstream activity without my having to stay with him. It gives him more freedom and independence - improve his social skills.
Quality time with Alanah's sibling.
A lot! Knowing someone is listening to you and your problems.
A lot - I always come to the family support worker for help with anything I need.
It has been a great source of respite, meeting other mums and receiving information.
I get plenty of advice.
A lot. I depend on Umbrella for support and information.
Gives me a break from looking after my daughter, able to spend one to one with other child.
Gives me respite and valuable time to spend with my daughter.
It provides help and support to families of disabled children and helps in lots of ways.
Gives us different activities and services that are available for my child to use.
Give us opportunities to go out with people with same problems as my son.
Things organised so I don't have to do it myself.

It gives my autistic daughter time out of the house without the family. It allows her some social inclusion, a chance to learn new social skills and put them into practice.
It allows me to spend quality time with her younger sister.
A lot of difference to the well being of our daughter, she gets time to relax and enjoy meeting people and socialising.
My daughter enjoyed many happy times at her side by side group out in the community without me. She enjoyed this time in the company of friends who knew and understood her needs. This time out offered me a well earned break time for me.
It's nice to know someone is there and information is available when needed. Always someone at the other end of the phone.
When my son's volunteer was visiting I could go out for a meal with my husband, attend Parent's evenings at my daughters school, etc. From the Family Support team, I found out about Kiloran respite for carers.
Incredible. Without Umbrella parents would be lost. What would my children do in the 6 weeks' summer holidays? My son needs support and continuity - to be with people who care and meet his needs.
Provides an essential peer group opportunity and respite for me. Broadens the range of experiences of my child and gives access to Life Skills and independence.
It has made a lot of difference. We have received a lot of information from the bilingual worker.
It made a lot of difference. My son has benefitted a lot and so have I.
It has made a big difference. If it wasn't for services like Umbrella we wouldn't know where to turn.
It makes a lot of difference because without it we don't know where to go.
It made a lot of difference because I have 4 children with the same disability and I have received a lot of support from the bilingual service.
It has made a lot of difference. My daughter enjoyed the SBS group a lot and I have enjoyed coming to the support group.
Tayba gives me advice and I meet other mothers who are in the same situation as me.
It's important for my daughter to socialise as its one of her main problems.
It makes lots of difference. It changes your life.
Always available for support and information about any aspect of special needs.
It's made a lot of difference especially information that we couldn't get elsewhere.
My son is more confident and for me I have got more time spare for myself.
Good to have people at the end of the phone for support, advice and information. The information given on day events I have attended have enabled me to learn about services available and ensure my son has opportunities to be involved and included in our locality. Events, activities etc.
Umbrella acts as a specialist service which helps us to deliver the Local Authority's Information Duty under the Childcare Act - s12. Enables our team to have contact with parents/carers of disabled children.
My son get to play with other children. I get a break. I can talk to other parents and to get information.
Reassuring to know as Freya my daughter grows older there will be social, sporting etc...events she can access when she is no longer able to use mainstream groups.
Support is at the end of a phone - at monthly support meetings and I meet other parents in the same position.
If it was cut we wouldn't have much in the way of children his age for social interaction with people like him.
It allows us to not only ensure that Meghan has "Inclusion" in activities she would not normally be able to access - But gives us both a "unique" "Shield" to be able to relate and deal with the Day to day pressures and feelings of isolation.
Feel supported in the school holidays when there is little or no child care for children with Autism, learning disability and complex behaviour. Trust staff to keep child safe as they know children well.
Having the service means, as my son Jake goes out with Umbrella, I am able to have a break and spend time with my other children too.

A lot of difference. My son enjoys his time away from us and his brothers enjoy going to places that my son is not able to. I get some free time that is so much needed.
It allows me to have a bit of time for myself as I have no family to help out and I am a single parent who works full time so I don't time for myself without these services.
This service provides quality support to parents, children and families who need extra support for one person or another. We use this service for advice, for practical support in school breaks. This makes an incredible difference to us as we have no access to other support.
Umbrella makes a huge difference to us, both as a family with support with Adam at the beginning after he was diagnosed, also with Play Schemes for Adam which he always looks forward to with much enthusiasm! Recently we have also received much help from Umbrella Support Worker, which has helped us as a family no end.
Very beneficial for supporting the family. Having someone there when you need to have a chat.
Gives me information on what is going on in the community + a chance of getting out and meeting other parents/carers.
I access different services within Umbrella and I really can't imagine how I would be able to cope without these.
The support we received helped us to continue to care for our daughter in our family home until she was 18 years old. Due to my ill health + my husbands work commitments without their support we feel we would not have been able to cope.
It is a lifeline - it is great to meet other carers and to get vital information to help me in my role as carer. The family support worker (Alishe) is very supportive and has organised lots of events which have kept me sane.
It gives me time to catch up with other jobs, quality time with my husband, quality time with my daughter.
It helps my children with their social skills, the volunteers support is essential on trips etc as I could not take them on my own.
I need a support group like umbrella to help with every day problems, asking for advice like a disabled child, filling in forms, speaking to other parents like similar problems.
Someone to talk to about issues I have as a parent with a child with a disability. Just to chill out and relax, help others with issues.
It makes a lot of difference to my life, coming and seeing other mums with children with a disability.
This service has been a real benefit for me. so many times I have been at crises point, feeling very low and feeling on my own and I would just pick the phone up to speak to Umbrella. I am a single parent coping with two daughters, one with special needs and one mainstream. Umbrella staff understand and have the workers who work well and support me and my girls. Umbrella have staff who themselves are parents and carers of a disabled young person and really have that understanding.
Every difference! - The time we get allows us to spend valuable time with our children. Also it gives us time to breathe our son is a very intensive 24 hour job. Kirk does not sleep.
I think my child would real benefit from the Umbrella Services.
As well as helping my child develop it allows me to spend time with my other two children. Impossible in the holidays other wise.
This service enables me to spend quality time with my other daughter which is so important to me as her sister takes up so much of my time due to her care, emotional and social needs. It also gives me the time to catch up with my husband and to catch up on household ores etc. Leaving your child with complex needs can be very difficult as you need to be able to trust the service provider completely. This is why services like Daybreak are so important, as I always feel my daughter is in a safe, secure and friendly environment.

Q5.

Keep the funding as the cuts would dramatically affect families and the support they need.
Fund it adequately so it can continue offering much needed and valued support.
Shame that local parent support group no longer available - but I could travel to another one c.10 miles.
I believe the service works well for the family as it is flexible - I can sit during the day or evening, weekends, weekdays, holiday periods.
Umbrella always aims to support families from the initial call through to a successful outcome. This may mean school visits, review meetings and even tribunals. Even as a volunteer admin back up is needed.
Reverse current funding cuts - cuts put additional pressure on our work.
By expanding the range of services available, the age range of services and the length of provision.
Just to keep the staff that is there now.
Do not change a thing. Unless the council can provide more funding. This organisation is more important than spending all that money and time on the Derby Hippodrome.
All year round SIBS group would be good as eldest child doesn't qualify for young carers.
More days.
The service does what they can with their limited funds but it does not go far enough, so how would I improve it, I would make the organisation bigger and better and available to all who need it.
Things for Tyler to go to like computer club or Youth club. Things to do as a family.
Happy with the existing service and with the proposals Umbrella has for its improvements.
There is not much to improve it is very well managed.
More of the above not less!
I would like more support with looking after Sukhjiat after school or at weekends to give me respite.
I would like to include swimming as a second activity on a regular basis.
Umbrella do a fab job anyway, I do understand all about budgets, in an ideal world more outings on Daybreak instead of on site, but still very happy.
Keep it the same.
I would like more support with my child at home after school or at weekends.
When the S.G first started we used to go on trips and outings but that has stopped now. It would be good if it started again.
We should have more sessions. To keep us up to date with information.
Can't think of anything at the moment but will let you know.
More volunteer needed to support children in out of school activities.
More days would be lovely.
More events please.
At the moment the 2 hours she receives doesn't include travel time so this restricts the activity and means I have to drop her off. Including travel time would be a great help.
More days.
Move Umbrella house closer to Chellaston where we live.
Umbrella services, all of them, are wonderful - please do not take it away. More money for this service to continue to grow.
More activities for my son, who is using a wheelchair but does not have a learning disability.
This service suits my family and the only way to improve it would be to have some more hours please, not reducing them or taking them away all together.
Service is wonderful for me. I am really happy with the days my son gets to attend Daybreak.
Greater range of support for the buddy service - putting peers in touch to deliver friendships which would otherwise be impossible.
I can't think of anything, I expect I will find out when my son is older.
I think we would like for my son to receive more of a service like Daybreak because this gave us respite in the school holidays.
We would a service that provides transport, so we can concentrate on our other children.

I can't think of anything as I got lots of support from the beginning.
I would benefit from more respite with my children if there was an after school activity club or in school holidays, where children could be looked after.
I wish there was some service like SBS in the community for older girls; my daughter is now over 19.
We would benefit from school holiday activities as my son gets bored.
More social events.
Give us the latest information.
More funding so they could support families, even more.
There needs to be more links between nurseries and schools so that information can be shared. There should be a way where every parent can find out.
More classes like dance activities for children from down syndrome.
Umbrella - has had to introduce charges due to cut in council funding. If the council introduces funding - my son can access Umbrella services - if it doesn't I can't fund this.
More play scheme places that can be accessed in the holidays.
More events for.
More things for my son in this area around this age group.
Quite simply – More of it!!
More support in school holidays. More 'your turn' and side by side services.
For the play scheme to be available more often.
Would like more time for myself as this is the only support I receive at this time.
This organisation is a god send - nothing is too much trouble for them. More funding would allow them to continue and improve their worthwhile services to people who depend on them.
I don't think I could improve any of the services we have accessed. Extending these services so the staff who are extremely well informed about a range of disabilities can continue to help us and other families through difficult times.
A difficult one, as the service is excellent on all aspects.
Would be nice to hold the groups fortnightly and also be able to go on trips maybe once or twice a year.
This service is already just fantastic the only way I can think of would be to have these breaks more often.
To provide more support during six weeks holiday (you can feel very isolated at this time and worn out). To provide an emergency provision (IE when my mother in law died very suddenly hadn't got anyone to care for my daughter).
Keep it going! This is a vital service and helps lots of carers - without it there would be a lot of carers in crisis and the pull on resources (health and social services) would be much higher.
I feel it is an excellent service anyway but because I can't drive Jack can only go to things locally unless my husband is about. Although Umbrella have been able to provide an escort to bring Jack home after after-school club so he can attend.
More funding so we could access more.
Keep umbrella going, involve parents and children in events like pamper day, coffee mornings, chance to talk about problems like disabled children.
More often, a bit more time for things to do.
I think we should do more activities instead of sitting and talking.
The service is brilliant as it is. Why change something that is working?
You do your best - it would be helpful to have more. It has been acknowledged that we need more help. Our girls would be more neglected that they are now and we would get no rest.
I would like to keep the services going as the children really enjoy it and look forward to going.
The service is already brilliant - keep it - especially Daybreak and Side by side.

Daybreak is such a LIFELINE to me and my family. The thought it may not be around scares me, as there are no suitable alternatives for my daughter. Daybreak is the only play scheme around now that gives families a real break as it runs from 10-4pm and you really need that time. Daybreak needs to run every school holiday and not just Easter and Summer. This scheme should be invested in as it helps support so many families. My daughter is nearly 13 therefore Independence and social opportunities are very important part of her development. With all the cuts these opportunities are very limited so increasing the Daybreak provision would make a huge difference to her.

Q6.

I find the volunteer work extremely rewarding. The service is valuable to the families that I support and this will result in less support.

Sons social life would be limited. Daughter would not be able to mix with others in a situation similar to hers. Being able to talk with others who understand what she goes through living with a brother with a disability, support would be limited for us and many other families like us of which there are many. Not only is the disabled person affected but many friends and family also, we fill in many questionnaires, attend forums, etc, talk to commissioners etc etc. Please listen to us and have you thought about who? Is going to tell the children that Umbrella is finished for Derby City. We have gone through this and then we are the bad guys.

The services would just NOT be available elsewhere. I have no local family to support me and HELP with a disabled child is vital.

I consider that removing the sitting service would increase stress within families who have a disabled child. It is a positive service peopled with volunteers patients know are checked, trained and supported - most importantly, people they can trust.

Many families would not be able to secure the schooling their child needs.

We would not be able to offer an acceptable level of support to parents/carers of children with SEN + Disabilities.

Without the services from Umbrella I would not have been able to continue working.

Would not get the support that we need. Only now doctors are helping us after 16 years. Umbrella has helped us very much.

Where else could we go for the support? There is no where is Derby.

My life would be a lot harder without the support of Umbrella.

No chance to share information with other parents, the good and bad times, help with advice a break in school holidays. Family day trips we wouldn't be able to go on.

Devastating! I am a single parent, so my son is my full responsibility. I need Umbrella!!

Difficult to answer, but could be as serious as the breakup of our family which due to the stresses of day to day life is put under serious pressure.

Massive - My husband is in the Armed Forces and works away so Dawn is the chance I get to have some time to myself.

My daughter is very difficult to manage when not going to school - where there is a structured supported environment. She wants to see her friends at weekends and during holidays - Umbrella services have provided a range of support networks to help parents cope with these needs.

As a parent, you need help and support at the end of a telephone. I need that security.

The service would not be able to get things done or find out information. I would be stuck.

No daybreak, little social outlet for disabled child. No family support.

If not Umbrella, I wouldn't know where to go.

My child would miss out on an independent activity that he really enjoys. He shares this activity alongside his siblings who don't have the responsibility of worrying about his needs, so it gives them the freedom to enjoy themselves too.

Alanah would miss out on socialising with friends that she's made and also Ellie her sister would miss out on quality time with mum.

Where else would I go. I would miss the support.

It would be very sad not having this service, I wouldn't know where to turn.

I don't know of any other service like this and it would be a huge impact if the support group was no more or if we did not have Umbrella to turn to for advice and information.

Umbrella gives good resources of information without this service we wouldn't know. We would also hold a petition.
I would be lost. I don't have much in the way of family for support either and I depend a lot on my family support worker to be there when I need help.
Having to find a scheme (play) that would meet my daughters needs.
All services are being cut, not having this service would just highlight the stress/tension of the holidays.
Very much its a wonderful service for its children and the parents that use the services it provides.
No information on services for my child.
Not having social aspect. Or if we need to talk to someone that is not close to us it helps.
I would have to look for things to do myself which isn't always easy.
Massive! It's the only chance my daughter gets to socialise independently of the family and gives us time to spend together without her which we need.
No socializing for Alanah or very little with her friends. No quality time for sibling.
We would greatly miss this service and feel that it is very valuable.
I do not know where else I would have managed to get a break safe in the knowledge my daughter was happy and well cared for. I have met many other carers through Umbrella who are now friends and we support each other. I feel less isolated.
No central organisation if Umbrella is not around.
I would not have had a carers break in 'Kiloran', once with my husband and once with my daughter. I know Umbrella are a caring organisation and I would miss them very much for all their support and information.
School holidays are very hard and adds pressure, so days at Daybreak offer structure for my son - a chance to meet his friends from school.
Social isolation, reduced self esteem, emphasise differences between siblings, reduced life experience, increased carer stress.
It would be a big problem for us as we have had a lot of support and will miss it.
It would affect us a lot because I wouldn't know where to go.
It would have a big impact because we wouldn't where to go for support.
It would be a big impact because we wouldn't know where to turn.
It would have a lot of impact as I don't know anywhere else that provides this kind of service.
I don't have the support of Umbrella anymore and I wish I did as I don't have anywhere else to go.
No support, isolated. I would not know where to turn for information.
She wouldn't see people as she doesn't go out much and finds it hard to interact with people so with these events it helps her to come out of her shell a bit.
Would feel lonely and helpless. We would have no service.
Wouldn't even like to think about it, Who else in Derby provides this sort of support? Our children would possibly have no social life outside of the home environment!! At present:- we get DAYBREAK - Holiday Club, Christmas parties, Outings to Drayton Manor etc. In the past - we have had Side by Side, Computer Club, Your Turn to name a few.
Without the support of Umbrella we would not have found out about the family fund and would have had to pay for our needs. We would also have to look elsewhere for support but there is nothing.
I was be on my own with my all problems and with my own son kept for 24 h.
Lose access to information, advice and meeting other parents. Speaking to those parents many rely heavily on Umbrella for play schemes, respite and volunteers helping at home without which the pressures of caring for children with severe disabilities will become extremely difficult.
We would lose the information and experience held by this specialist service which we regularly use to support the information and advice we give to parents. If this specialist service was not around to support families we would probably be the next port of call for families regarding signposting and so this would increase the amount of enquiries that we deal with.
We would be isolated my son would have no contact with other children during school holidays.
Will have a very lonely teenage daughter in the future and will put a lot of pressure on the family

to find social outlets for her.
I would be very isolated.
Devastating effect! Isolated.
Quite desperate, if I'm honest as we feel a very real dependency on the org and its people as I'm sure many do and quite rare for one such organisation can meet so many different needs/requirements.
No help in school holidays would put me and other siblings under great stress. Also child will lose out on fun activities in safe environment. I am a single parent with 3 children, 2 who have autism and LD. Not safe for me to go out alone.
I wouldn't be able to have a break without this service
Even though we love and care for our son very much, the time apart is needed for each of us to recharge our batteries and for my son to experience activities with teenagers his own age and needs, so it would be devastating for everyone.
Would find life extremely difficult as I am a SINGLE parent.
It would be devastating for our daughter and us, because she would lose precious time with her friends and time away from us and would lose time to spend with our other children.
There is no other service like Umbrella in Derby, we know that we always have somewhere to turn and Umbrella are there to help in many ways even if it's just a listening ear, and because many of Umbrella workers have experience personally of disabled children, they know the difficulties it faces you with. We would be lost without them and Adam would be lost without the play schemes as they are always a big hit!
Very disappointing and missing out on many social events.
Would not be aware of courses or workshops that are happening in the area.
Our lives for myself and my 2 children would be very empty without Umbrella and the amount of support we all get would be greatly missed. :(
We feel like most families coping with a child with challenging behaviour, we would not have been able to cope. Umbrella was a lifeline to us. Take this away, I feel you will see more family breakdown.
Would feel v. isolated and wouldn't know where to find out information and help.
Not having a break - it can be stressful as Jack cannot be left for long periods on his own and I feel to aid his social needs Jack needs to mix with other adults/peers outside of the family.
My children would have no support and would be isolated stuck at home.
I would be completely lost, because I have not found any other group which provides that service.
Feel a loss as support network would go, do not know if any alternatives are available.
It would have a huge impact on my life as I wouldn't know where to turn for information.
I would not know where to turn to without Umbrella. Social services would have a real crisis on their hands as I am sure there are families who rely on Umbrella services. Sometimes we feel as parents nobody wants to know and then we give up asking.
Our boys condition is having a physical and mental effect on the whole family. Holidays are an endurance test. We would not cope without these services.
I have not really had much from Umbrella but I would like to us there services.
Our family life would suffer. My disabled child's behaviour and sleep would worsen. My mental health would probably deteriorate.
My daughter would simply have nowhere to go as everything else has ended. Children like my daughter are restricted to what they can access because of their needs and I feel like they are always the easy target when it comes to budget cuts.

Q7.

There is very limited support for families with disabled children but Umbrella supports so many. I think that it is awful that this is not seen as a priority organisation with so many volunteers make so much difference.
I feel very strongly about cutting funding for Umbrella and others like it. I think that you don't realise what affect your proposed changes make to so many. Life with a family member is difficult enough without losing very valuable supportive services. There seems to be lots of money wasted in my opinion on other services and projects, ie: Orange bags for cardboard, etc, etc, etc. To name one. We all live in difficult times financially and realise cuts are sometimes required. I do this all the time now I am the only wage earner, my wife can't work - ill health but please consider carefully before finishing off the likes of Umbrella.
Please don't pick on an easy target - the disabled only have a very small "Voice" and suffer much discrimination. The delight involvement with the organisation gives children is a joy to witness!
The sitting service started with a pilot project in 1990. It has developed in over 21 years to support many families now and in the past. I would consider that it continues to be an invaluable support to families and enables parents to enjoy a social life together or spend time with their other children. At the same time, their disabled child is benefitting from time with someone they like and trust and who completely focuses on them during the 'sitting time'. The sitting service comprises a body of people who have built up considerable skills and expertise - this is an immensely valuable resource which should be preserved.
Umbrella has already received major cuts in funding. We will do our best to still offer the same service but if we have any cuts it will be difficult for us to manage the same level of service.
Funding cuts to Umbrella have made a significant reduction on the services which can be offered to parents/carers of children with SEN + disabilities and their families and at a time when local authority services are being severely depleted and vulnerable families are more at risk.
Our son and daughter goes to Lees Brook school what is falling down. You can spend money on the council house. But leave Umbrella without funding who help families very much with everyday life. We would be lost without them.
Do not cut back on these services as they are vital to families that have disabled members.
Umbrella do an amazing job and without the support of the dedicated staff we would have not been able to cope with everyday life.
Short sighted, cost more in the long run - Family breakdown, draw to mental health services. Personally, Have a son with V. rare genetic condition and no particular support group, and I myself have a mental health issue.
If services like these finish due to lack of funding it will leave parents with disabled children with no support/respite. In the past I have used Day break which my son loved, having lots of new experiences in a safe environment, which helped him with social skills.
Absolutely disgraceful - Umbrella should get more funding - not be subject to cuts.
The services, voluntary or public which were in place before any cuts or talk of cuts, were inadequate in the first place. To see funding being cut to organisations like umbrella fills me with despair because I know I can't do this without some help.
Very sad that changes May cause significant disruption to SN family's. Most of whom will also have other issues they are dealing with IE health, education, etc.
As a parent and a sibling of special needs - over 50 years personal experience therefore - I feel services should be consistent - That is - The aim should be to improve them not cut them. Umbrella services have worked diligently with limited funding over many years to provide an excellent and fair, far reaching service.
Not very happy with it, it already has very limited funding as it is.
No funding means no service to families who really need it.
Living with a severely autistic child is hard enough, and the opportunities that are available to them are very limited, cutting facilities like this one, would seriously affect the lives of the whole family.
Hopefully Umbrella will get Vital funding to carry on. We just need Umbrella SO much.
The services Umbrella provide are so needed.
It makes me feel very angry/frustrated that yet another service is being cut. Having a disabled child is very challenging, stressful and can isolate the parent, any service, especially Umbrella, is very gratefully received.

Cuts to the services provided would remove the breaks/rest for both parents and carers and siblings.
If finance is cut and this service is no longer available, it will put massive strain on families. Also if the service is cut and my daughter doesn't develop the social skills she needs, to go out independently, then she will be dependent for longer, so will need to use more resources and ultimately cost the authority. These cost cutting exercises do not save money. As a result of cost cutting I have had to give up work to support my children and I'm now dependent on benefits.
No more cuts!!
Please Do Not cut any more services for people with special needs because it is very much appreciated what is done and we feel it need to carry on.
I am very upset about these cuts in funding. Social services can never provide what Umbrella do. They are a personable, caring organisation who always make me feel special.
Very unfair to cut a vital service for many families. Derby City Council should reconsider.
Yes, do not cut their funding. Umbrella may be a small organisation but they make a BIG difference to family's lives. Social Services will end up with lots more parents in crisis - suffering from stress and depression and nobody else to turn to.
Things will be very hard for families who rely on Umbrella for the variety of wonderful services they offer. Children will go into care. Massive strain on other services if Umbrella do not get funding.
Please do not cut funding to this service.
I think Umbrella is a very good charity and we have been very happy to receive their services.
We are very pleased.
I think a lot of the people who use umbrella will have problems with the social side of things and to take it away from them would be quite disappointing for them as they look forward to going out and seeing people. Funding is important for social events as a lot of people struggle financially.
Please do not take this support away from your families, it is our life line!!
We are happy with the service offered by Umbrella and the awareness they have raised giving us information about other services.
Lots of people rely heavily on the Umbrella services to enable them to cope with the demands of caring for a disabled child or more than one disabled child. By removing them you will take away the life-line or remove the small time of respite carers/families receive. This may be the only support some families. To remove that support for some families will be the difference between coping and not coping. Prevention of family situations breaking down, which Umbrella do is far better and more cost effective then dealing with families in crisis. To remove those play schemes, youth clubs etc for disabled children will lead to them becoming isolated, bored and unfulfilled. Disabled children deserve the access to clubs, leisure activities as there non-disabled peers have.
Q5 - As a disabled parent. I can't afford the increase charges - Umbrella is having to introduce. I tried to access Derby City Council summer play scheme at Moorways Sports Centre 2 years ago - but was told they couldn't take Aiden due to his disability unless I stayed. I asked if other parents of 13 years stayed - the answer was no because the other children didn't have any disabilities. My son was 13 not 3 and he didn't want me to stay.
I feel that we are being excluded. Our family can become very stressful and cutting services can cause more severe situations - we need Umbrella to meet other people in our situation to discuss our problems.
Don't cut Umbrella, we need more of it. Money and Umbrella. I am a single parent and Umbrella have supported, through the worst times ever.
Speaking from a personal perspective, Whilst there are many service "cuts" within our cities' very many different depts./organisations it can sometimes be much more "Economical" to "invest and nurture".
Umbrella are a charity, all the staff have worked there many years and have a great deal of knowledge of the families and services needed. Family support and Daybreak are fantastic services. I am dreading school holidays without Daybreak as this will hit us hard as a family who is already near crisis point. Short breaks are essential.
There is nowhere apart from school that my son can be independent, and be with people that understand him and understand his way of thinking. The support I get as a parent meeting other parents makes you feel you're not on your own. An end to these services would be unthinkable.

We think it is dreadful that Derby City Council would consider cutting funding to such a worthwhile organisation - but be prepared to spend thousands of pounds on public toilets that are notorious for being used for unsavoury acts by gay men! (Markeaton Park) and spending a ludicrous amount of money on the Council House.
I am disgusted to hear that a lot of provisions given by Umbrella are being cut. This organisation was set up originally by parents for parents. Over the years they have helped many families to come to terms and carry on with a disabled child providing them with the much support we need and by taking this service away, you are letting parents of disabled children down more importantly, you are letting disabled children down. This service needs funding as it is invaluable.
Isolated on my own, social event interaction with other families. The family obvious, one to one support with special needs, boy coming into the home and taking him out. A lovely break.
I think along with most of my family and friends we feel that it is vital that this charity to be funded 100% to give carers and families continued support.
I understand that funding cuts are being made in all areas, but I feel disabled children and young people are the most vulnerable and isolated in our society. If cuts do have to be made I would urge you to make them in other areas, as it may cost more to yourselves in the long run with children being taken into care or residential schools because families are unable to cope.
Very worried about the impact of cut backs on umbrella. The benefits of services provided by umbrella are wide spread and go beyond what may initially be thought. Many carers are coping with a 24hr job on carers allowance (50 per week) and need support to continue this job. If they don't get that support, crisis situations can easily occur and then the cost of looking after these children would be enormous. Umbrella needs to be supported and given more funds to keep and develop their services.
I think the umbrella service is vital for children with special needs as it is vital for children with special needs as it is extremely important for parents/carers to get a break every now and again as it can be really hard work and challenging at times and obviously if there are any other siblings they need quality time too as sometimes their needs can be put to one side.
We would be very upset if access to daybreak and school holiday trips are taken away as we have no other means of support. We feel it is vital our disabled children have access to socialise with peers outside of school and home as they cannot make friends easily.
Why does money come before needs? Keep umbrella going!
It's sad that services have been cut, there is such a need.
Umbrella support is a real lifeline for my family. Currently I am struggling to support my other daughter who has real resentment to her sister with additional needs.
I consider myself lucky to be married to a good husband. Without this stable family unit, our son would be in care. We are in a constant state of exhaustion. Without these services we would not be able to take care of our son and the rest of our children properly. These service is an essential life line. We don't get out as a family. My husband and I have been out twice in the last 18 months. It is not as if we use these services as babysitting.
Any cuts to these services would severely affect the disabled child and their families.
I strongly feel that a council representative and/or local MP's should come and observe what wonderful work Umbrella do at Daybreak and to talk to parents so they can share what Umbrella means to them. Maybe then someone will sit up and realise the huge impact on the families and the Council if Daybreak was no longer around.

Appendix 2. Stakeholder comments

Q2.

Volunteers in the home Bilingual service Specialist Play services Support for parents/carers Volunteers in the home.
1/ Support with attending after-school activities 2/ Social activities (support).
I have referred families to Umbrella in order to access their services. The main ones that I am aware of that parents have accessed are - Daybreak, Specialist Play Services, and the Support for Parents drop-in.
Signpost parents to the education advisor. Provides a support network for vulnerable families.
We have used a range of services provided by Umbrella. Umbrella have always provided useful and helpful services that have prevented family breakdown.
As a social care OT I am aware of a number of children on my current and previous case load that regularly use and value the services offered by Umbrella. For some, it is their only social/fun activity.
Volunteer services for babysitting/coffee mornings for parents.
I know of many people who use this valuable service. They not only receive valuable information and support, but their quality of family life is much improved due to the personalised services offered by Umbrella. Umbrella are also experts in their field and have a true understanding of the real needs of parents and their children.
Home-start Derby has supported families/children to access and use specialist service which Umbrella provide for children with disabilities including Daybreak, Specialist Play Services, Support for parents/carers.
Supporting parents at school review and workers have knowledge on help and benefits parents can have when they have a disabled child.
I have referred patients to the organisation who have then had support in all areas.
I have referred many families for leisure activities, and for help from volunteers. Families have also received a lot of general advice and support from staff members.
Referred patient for all aspects of support.
I refer families its all service. I use newsletter for an outlet to pass info on to families. I use advisory service for info to pass on to families.
I am a student social worker in the Disabled Children's Team - Light House. I have referred two families to Umbrella, particularly the activities they provide in school holidays.
Referral of parents after diagnosis of disability in a child for information, advice and support.
Volunteer Services Day break.
I used Umbrella wen Brent was younger.
I have used side by side and we have used the day trips and days out for parents
I use all Umbrella services by referring my families to them for support - emotional / practical, enabling children with disabilities to access universal services, the fantastic specialist holiday schemes.
Daybreak Volunteer Support Information Services Days out
Daybreak, voluntary services
Day Break in Holidays.
None / tried but not really able to access due to funding abilities that limit the service already.
Nacro Osmaston Family have supported a number of families who have children with a disability and who have benefitted greatly from a number of the services that Umbrella provide.

Q3.

As the lead nurse for a team of Specialist nurses based at the children's RDH, I have used the above services on numerous occasions. Many of the families we are involved with care for children with disabilities/complex health needs. From diagnosis the parents lives are turned upside down with devastating news of their child's illness, disability. They are then discharged home to care for a child with complex health problems/disability with no training and very little support. They then have to find their way round the health service, the benefits they are entitled to, specialised equipment they need whilst caring for a child who is often unwell, irritable in and coping with their grief associated with having an 'abnormal' child. Umbrella service has provided parents with the much needed support these families need, providing advice support to organising cheap spa days to give parents a well deserved break. The kite team provides specialist nursing support and advice but we are limited in our knowledge and resources regarding all the other services Umbrella offer. We cannot provide play schemes or respite for the families whilst have a break.
Enabled child to attend and gain confidence.
Parents of hearing impaired/deaf children who have additional needs are able to access - information; services to support them; quality play provision in settings that understand the needs of the children during the school holidays.
This service provides an objective advice service for parents. The educational advisor has helped some parents liaise with school and the Local Authority over difficult issues. It has, over time, provided independent information, help and guidance to some of our parents who have disabled children.
Keeps families informed and helps makes links between them so they can 'self help' and prevent having to use social services resources.
It is the service of choice to recommend to parents of children who do not access other social/fun activities.
It helps my families know they're not the only ones with a disabled child, that there is someone to talk to. Enables them to have a break.
I have seen the Umbrella volunteering programme develop into a beacon model and one which is held in extremely high regard. Volunteers are supported by a highly committed, highly skilled staff team to support children and parents affected by disability. Volunteers report having a wonderful experience and I do know that service users and families value the service immensely. Volunteers are the lifeblood of the organisation; the roles are clear and the outcomes are clear; without support from trained volunteer befrienders, the families would not have the respite they need.
Their ability to cope is much improved, their understanding of disability and support available is invaluable. Respite services increased quality of life for all parties involved.
It provides a service which enhances the lives of children/families whom we (at Home-Start) come into contact/work with at a time when families are very distressed and vulnerable.
Support and help in areas I do not have knowledge in.
Invaluable-often no other help available.
The service offers opportunities to disabled children and their families, which would not otherwise be available. The activities are appreciated both by the children and their families. Parents are able to meet other families, and share experiences.
Meets a need not provided elsewhere.
As the service manager at The Light House I am well aware of Umbrella. Many children who receive a respite service here either also benefit from extra care provided by Umbrella, or as an alternative to The Light House. For many parents this is an invaluable service which gives them a well earned break from the arduous task of looking after a child with disabilities. Many families would break down without this service. The difference it makes to me is that The Light House service would be even more stretched without Umbrella and the service to families further watered down.
Very important with support they can give to the families I work with.
The holiday provision and after school club is vital for the families I work with, both to give the child and family a short break.
Hugely important to families especially in early days after diagnosis - I know they can get

help if need be when I can't be there for them.
It has made a massive difference. Our volunteer has been with us for 8 years so is a major part of lives.
If they are helping my son then I am happy with that.
It gave our daughter chance to get out and have an independent social life without us it also gave us a chance to have time to ourselves
The services make a difference in many ways. Mainstream services can fill up some capacity by referring to Umbrella. The support to families (highest incidents of family breakdown nationally is for families with children with disabilities) reduces risk of family breakdown and all the consequent emotional and familial implications.
Huge difference!! The staff are extremely supportive, knowledgeable and helpful. They have enabled me to meet other parents and build relationships.
A huge difference. The most important was it allowed me to spend time with my other child. My child with the difficulty demanded a lot of my time constantly.
Provides much needed rest and 'charging of batteries' and to provide valuable time with other siblings.
None as not able to assist without full parental supervision
The day break service was particularly beneficial to a number of our families. During school holidays, it is a very stressful time as parents try to meet the needs of their children with a disability and those without. Having the play scheme meant that whilst the child with the disability was being well cared for the rest of the family could access other activities.

Q5.

Because there is no other organisation that provides this comprehensive service. The Ronnie McKeith advice centre enables parents to call in when they visit for physio, OT or hospital appointments.
No other similar services as easily accessible. Very valuable to families with disabled children.
They support a group of children who frequently fall outside the care of other services giving them the opportunity to discover skills, enjoy experiences not easily available. They also give the families a very important break.
As 3 above. It is hard enough coping with a child with special needs, and even more so if your child has complex needs. To feel that there is always someone to turn to for help, support, and friendly advice is paramount. Many parents feel guilty that their child has special or complex needs. These children receive specialist support in education. Their parents need specialist support too. "A disabled child means a disabled family", the work of Umbrella goes a long way to "enable" families.
Provides emotional and social support for the most vulnerable families within the city. This support helps to enable other organisations (such as schools) to have positive and sustainable relationships with families and children.
Disabled children, young people and their families do not have a wealth of opportunity out there. Umbrella is well established and reliable.
Children with disabilities are an under represented group in Derby society, with few mainstream services offering the accessibility or support needed. The local authority cut-backs have negatively impacted on the community services offered by the Light House, etc. It would not be unusual to find that a child with a disability had no community interest/access beyond school attendance and that is why the service offered by Umbrella is so vital.
As above Q3, very little support for families of disabled children, this is a key role that is vital for these families.
The way the organisation recruits, trains and supports its wonderful team of volunteers is professional and exemplary. Volunteers from long lasting relationships with service users and their families, learning key skills and increasing their personal/professional development along the way. Volunteers have gone on to win awards and to secure employment in related fields as a result of their positive volunteering experience. Service users and their carers have formed long lasting relationships with others as a

<p>result of their involvement with Umbrella. I believe that families affected by disability will need more support from Umbrella in the future. At a time when centres and services are closing due to funding restraints, more investment in the programme is needed to ensure vulnerable people are still able to receive the support and engagement they deserve.</p>
<p>Families needs would be much increased if this service were not available. This service, without doubt, actually saves statutory services vast amounts of money by ensuring things 'don't escalate' and reducing the need for statutory intervention.</p>
<p>Children benefit greatly by being able to socialise, enjoy activities etc which improves their well-being and mental health. It addresses equal opportunities for children unable to access most main stream play and social activities. It allows parents to see their children enjoy themselves and engage in activities out of the home.</p>
<p>Help for parents with children with a disability.</p>
<p>Disadvantaged families often neglected and this is a point of reference that families and children with disability are able to contact.</p>
<p>Disabled children are unable to access many activities, that are taken for granted by the able bodied. The leisure activities provided by Umbrella are simply not available elsewhere.</p>
<p>Because families of children with disabilities need practical support from people who understand their situation, who are easily accessible and provide services that are not provided by other areas eg social services.</p>
<p>Derby residents without a disabled child would probably be unaware of Umbrella but families with a disabled child will definitely find the service invaluable and quite vital. The range of services is also important as disabled children find things like integration into 'mainstream' activities like youth clubs or swimming baths hard to access and Umbrella also provides help with community problems like these.</p>
<p>Emotional support. Advice + info - impartial. Perspectives of parents = Child = disability for parents in similar situations. Linking families together respite.</p>
<p>Families of and disabled children are facing a squeeze on services. Umbrella provide a vital source of practical and, as important, emotional support to them.</p>
<p>Parents need a place to go - particularly to get relevant help from people who aren't doctors but do really understand their predicament.</p>
<p>We have had a very rough time recently and without Umbrella and it's services I wouldn't have got through this.</p>
<p>Cause kids are happy with the services.</p>
<p>It helps the child's development and helps the parents</p>
<p>Without these services the most vulnerable children in society will be disadvantaged - setting us back 20 or 30 years in terms of provision and recognitions of the needs of the children and their families.</p>
<p>The service takes pressure off social services, The Lighthouse and social workers. Enables disabled children to become involved in community activities.</p>
<p>There are limited places that allow children with special needs. It's extremely difficult during the school holidays. It would be a devastating blow if services are stopped.</p>
<p>As Q3.</p>
<p>Because they can assist certain types of children and parents dependent upon supervisory abilities.</p>
<p>Services to support families with children with disabilities seem to be diminishing very quickly which is increasing the strain of overall family life.</p>

Q7.

It is an essential service for the parents to enable them to cope with a disabled child at home. Without the support of Umbrella the council may well be facing increased costs in relation to family breakdown/find foster care placements. Numerous research articles identify that parents caring for children with complex health needs experience in depression and mental health problems/marriage breakdown. Advances in medical technology means more children are surviving, but this puts strain on the family. Funding should be increased NOT reduced or withdrawn.

Support for disabled families INVALUABLE!

The loss of this organisation would leave many families isolated, with much reduced respite care, and for some families have a very detrimental impact on their quality of life. There are many charitable organisations, all busy avidly fund raising. Many people have not heard of Umbrella and would not therefore necessarily think of donating. I do not think that Umbrella would be able to continue to provide their vital services without the support of the Council.

Funding from the Council sends a message to the most vulnerable group of families and children that they matter. In order to work towards raising the achievement of this vulnerable group of children, services need to be maintained (and ideally expanded).

Umbrella support prevents some families needing social services.

For the reasons stated above and because Umbrella are a professionally run and staffed organisation who care about and have got everything RIGHT for children with additional needs/disability.

I feel it is important for the Council to invest in Umbrella for the reasons mentioned in Q5. The group of people served by Umbrella have complex needs and require specialist support!

Because there are no alternatives for this group of children/families. Because the service is excellent value for money and provides a front line service to a disadvantaged group of children and young people.

Umbrella need funding to enable them to provide a service to parents with disabled children.

No funding will result in loss of services.

Umbrella is able to raise some funds, but not enough to maintain services.

Because they do not provide these services in a fashion that is easy for parents to access and provided often by families who have experience of having a disabled child.

I feel that disabled children and families deserve all the help they can get and the council should prioritise this service. To cut or abandon this service will put even more pressure on families and in the long run I think would lead to greater expenditure if families fail and children consequently are (for example) received into care of the local authority. This service offers a lifeline to families with disabled children and gives them something to look forward to. It is also a chance for them to spend quality time with their non-disabled children.

For reasons in section 6 and b. Look at wider picture if this organisation didn't exist respite pressures on LA would also ask of family breakdown would and requiring more social care input. Meets statutory requirements LA not otherwise meeting.

Umbrella have developed very good services over a period of time. To use their services would be a very high blow to families.

Disabled children should be supported by the whole community.

Without Umbrella and its volunteers, many families would be without any support at all.

Cause it helps when families need it for their kids.

Because all of the staff are very dedicated in what they do and I don't know what I would have done without them

Whilst a lot of the work is undertaken by volunteers there must be some funded structure in terms of staff but also running costs to provide for example the holiday schemes.

Parents of disabled children need Umbrella's help. Without it the council will have to pay out more in social care as parents will not be able to get support anywhere else.

Day Break and other services rely on council funding. Without it they couldn't provide an important service. My son enjoys attending Day Break. They are extremely kind and

helpful and provide difficult activities for the children.

Helps to provide much needed support to families with disabled children.

Support in this area is vital to the parents and children who access the service. If you take this away (Do they all sit in a circle of chairs like the elderly)??

Umbrella is a well-established professional organisation offering excellence services across the City. Without their services, vulnerable young people may have no other appropriate service that they can access.

Appendix 3 – response from Umbrella

Q1. Name of organisation and service you wish to comment on;

☒ Umbrella ☐ Nacro ☐ Homestart

Q2. So we can really understand the strengths of the organisation, please tell us what difference you feel the service currently makes to its service users and residents of Derby;

Umbrella is a registered charity supporting disabled children, young people and their families. Established in 1986 we have recently celebrated 25 years of service delivery. The aim of Umbrella is to improve services and opportunities for disabled children and young people from birth to 19 years who live in the City of Derby and Southern Derbyshire. This year we have introduced a new service supporting young disabled adults, under 25 years, to make the difficult transition to adulthood. Umbrella was set up when a Consultant recognised that parents needed support from other parents, Umbrella has always been parent led, the Trustees at Umbrella genuinely understand the pressures faced by parents whose children have a disability. We shape our services at the request of children and young people. Umbrella is an integral part of the Ronnie MacKeith Child Development Centre, at the Children's Hospital. We enjoy close links with the parents and professionals who visit the Centre. We have enjoyed excellent partnership working arrangements for many years ensuring that families needs are met we are available from the point of diagnosis and sadly sometimes until a child passes away. We offer a professional, non judgemental service to families and are able to empower and build parents confidence and trust, sometimes where the statutory sector have failed. This initial support then enables us to encourage families to engage with the statutory sector to access services. With the exception of Information Services the "core" services at Umbrella are all under threat. The core services have enabled Umbrella to engage with hard to reach families and for them to access our contracted services. Parents know that Umbrella staff are always available if they have concerns, they have built good relationships which makes them confident to leave their child in our care, knowing we will provide an excellent service.

Q3. Are there any other benefits from the service and what has been achieved? Please provide any supporting information;

Daybreak was set up in 1998 at a request of Derby City Council. The request was made as two families had reached crisis point and their children were accommodated in the respite facility. Social Care recognised this would put huge pressures on the remaining families if respite care wasn't provided. The scheme was a huge success and DCC prioritised funding to enable the scheme to continue and extend. Over 50 families benefit from full days provision during the Easter and Summer School holidays, the number of children in care as a result of family breakdown has reduced considerably since Daybreak commenced. Close links with the Light House are in place. Ofsted approved. Bilingual Project a further request from Derby City Council to engage with families from BME backgrounds. It was identified that families particularly Pakistani families, where the number of children with disabilities is higher, were not accessing services. Support Groups and drop in centres were set up to support the families in their community, including language and cultural support. . Support has also been given in order for families to engage with statutory sector including support to attend safeguarding, school meetings etc. Specialist play opportunities, eg young women's groups have been set up to reduce isolation. Specialist Play a project to support disabled children to access play/leisure opportunities. When the project was originally set up leisure opportunities for disabled children were practically non-existent. Parents were empowered to set up play opportunities for their own children with the expert guidance of Umbrella, including the successful Leapfrog playscheme at St Giles School. Play successes include establishing a football club, starting at a very basic level which progressed on to the young people representing the disability league for the East Midlands including a visit to the David Beckham Academy. Computer Clubs, Youth Clubs, Scuba Diving, trips out, Christmas/Eid parties etc etc. Disabled children and young people grew in confidence and new friendships were made. Volunteer Services a project to enable families to enjoy quality time whilst safe in the knowledge that their disabled child was being cared for by a trained volunteer who was competent to meet the needs of the whole family. Recruitment and training of volunteers to a very high standard to enable them to support disabled children in many settings. Voice for Parents With the excellent links/feedback from families including support groups and our base at the RMC etc Umbrella have been able to give a clear and objective opinion of gaps in service provision and ideas of how services could be improved. We worked very closely with the City Council to ensure more support was given to specific unsupported disabilities including Visual Impairment and children with physical disabilities who were cognitively able. Umbrella staff have been asked to sit on a number of Boards including IDCS board, and were instrumental in the consultation and design of the Light House and Shine buildings. Our views are valued and regular requests are made for us to sit on interview panels for new appointments. We also offer staff induction packages for City Council staff.

Q4. How will the organisation plan to reshape / develop the service from April 2012?

We have applied for a number of grants to continue some of our services, however completion for grants is very high and we are not confident that our funding applications will be successful. Daybreak - We have been awarded 12 months funding from the Early Intervention Grant to part fund Daybreak. However the funding is insufficient to run the much needed play scheme at Easter and Summer and sadly I believe this will place huge pressure on families and will inevitably lead to an increase in the number of children taken into care. Bilingual. We will continue our links with the local Children's Centres to ensure that some of the families needs are met. Umbrella hopes to secure some generic Family Support Worker funding and if successful will continue to offer support to BME families but will be unable to overcome the language barrier and therefore a number of families will become isolated. Specialist Play. We will be unable to continue this service. Sadly some children will lose services as they are unable to access Short Breaks Services. Volunteer Services -This service will end - please see case studies attached. Voice for Parents - We will continue to listen to the voices of parents but will be unable continue with our excellent service ensuring that parents views are heard at essential meetings. We will however always continue to raise concerns from parents with the local authorities via e-mail.

Q5. What could be the potential impact from the organisation as a result of the decision not to fund the organisation - please select all that apply;

- ☒ The organisation will cease to exist ☐ New initiatives will be stopped

- ☒ Paid posts will be reduced ☒ Alternative funding will need to be sourced (please give details below)
☐ The service will cease / be reduced ☐ Other (please give details below)

Alternative funding will be needed/other - details

Umbrella has carried out a complete restructure which has sadly reduced in the loss of 5 posts. From April 2012 families will see a reduction in their services. We have a fundraising strategy but sufficient funding will not be secured by April 2012.

Q6. Does the organisation have in place any contingency plans to help with the withdrawal of funding?

We are working very hard to ensure that further funding is secured for our family support work including BME families.. We have a fundraising strategy and are working very hard to ensure that further cuts will be unnecessary. We have introduced a charge for families to attend Daybreak - however this charge will not prevent the reduction in services. We will make more referrals over to the Social Care team, who sadly are already overstretched.

Q7. Do you feel that a specific group in the community will be disadvantaged by the proposed funding changes?

- ☒ Yes ☐ No

Q8. If yes, which group/s will be affected - please select all that apply;

- | | | |
|--|--|---|
| <input checked="" type="checkbox"/> Older people | <input checked="" type="checkbox"/> Disabled people | <input checked="" type="checkbox"/> Men |
| <input checked="" type="checkbox"/> Children aged 15 or under | <input checked="" type="checkbox"/> New and emerging communities | <input type="checkbox"/> Faith communities |
| <input checked="" type="checkbox"/> Lesbian, gay, bisexual or transgender people | <input checked="" type="checkbox"/> Women | <input type="checkbox"/> Other (please state below) |
| <input checked="" type="checkbox"/> Young people aged 16 to 24 | <input type="checkbox"/> Minority ethnic communities | |

Other please state:

Q9. How do you think they may be affected?

Children with disabilities do not live in specific areas or are not born to specific groups of people. We support single parents, parents in same sex relationships, carers, grandparents, BME communities, Dads, Mums, couples.

Q10. Do you feel that a particular geographical area in the City may be adversely affected?

- ☐ Yes ☒ No

Q11. If yes, which areas? - please select all that apply

- | | | | |
|---|-------------------------------------|---------------------------------------|-------------------------------------|
| <input type="checkbox"/> Derwent | <input type="checkbox"/> Allestree | <input type="checkbox"/> Darley Abbey | <input type="checkbox"/> Spondon |
| <input type="checkbox"/> Alvaston | <input type="checkbox"/> Boulton | <input type="checkbox"/> Arboretum | <input type="checkbox"/> Sinfen |
| <input checked="" type="checkbox"/> Normanton | <input type="checkbox"/> Abbey | <input type="checkbox"/> Blagreaves | <input type="checkbox"/> Mackworth |
| <input type="checkbox"/> Littleover | <input type="checkbox"/> Mickleover | <input type="checkbox"/> Chaddesden | <input type="checkbox"/> Chellaston |

Q12. How do you think this area(s) may be affected?

I believe our BME families will be affected by the loss of our bilingual project. All other services are more generic.

Q13. Are there any other additional comments you would like to make?

I am seriously concerned about the inevitable rise in the number of children entering the care system. For children with complex needs the cost is in the region of 250,000 per annum per child. To continue Umbrella services will cost a fraction of this amount and will result in fewer family crises. Families of children with disabilities are under constant pressure and I believe without the services from Umbrella, family breakdown will take place.

Q14a. If required would you like to take part in any further consultation;

☒ Yes

☐ No

Q14b. Would you like us to send you further information relating to this consultation;

☒ Yes

☐ No

If you have answered yes to Q13 please provide contact details below;

Name Ann Rowlands, Umbrella House, 64 Birdcage Walk, Mackworth DE24 4LD

E-mail address Ann.rowlands@umbrella.uk.net

Telephone number 01332 785658

Other