

Grants for Organisations Supporting Disabled Children & their Families.

Since 2008 Kent County Council (KCC) has provided grants to parent driven charities to provide subsidised:

- Family Events which have included days out to zoos, theme parks, & pantomimes etc. with a subsidised cost to families,
- Family Workshops which have included sessions on Using Widget, Behaviours that Challenge, Benefit Advice, Surviving Christmas etc.
- Support Groups for families to have the opportunity to meet together

These grants are one of the ways the council provides Short Breaks for parents and carers of disabled children. You can read more about this in the KCC Short Breaks Statement on <http://www.kent.gov.uk/about-the-council/strategies-and-policies/adult-social-care-policies/short-breaks-statement/short-breaks-statement-about-short-breaks>

Kent County Council is aware that the demand from parents and carers of disabled children for these events varies across the county. We know this from the numbers who attend these events.

The current grant ended on 31st March 2016 and before a decision about awarding grants for 2017/18 were made KCC wanted to find out the views of parents in respect of the services funded by the grant.

In February 2016 KCC ran an online survey to ask parents of disabled children their opinions on the current provision so as to inform the decisions around future provision.

The on line survey was promoted via the parent driven charities and Kent Parents Carer Forum (KPCF)

Summary of survey

Overall there were some very positive responses in favour of the family events, workshops & support groups that have been funded via this grant.

As with all surveys the responses included opposite views on how the activities are offered/provided and whether they should be provided at all.

There were a number of comments about the family events not being suitable for ASC children and yet the majority of families completing the survey listed ASC as their child's primary disability. This would indicate that for some ASC children the activities were suitable.

Similarly the times of workshops & support groups (being held during the school day) were seen by 76% of respondents as being good but clearly for those parents who worked these times may the sessions completely inaccessible.

However, there were some very clear comments that would indicate that that some things would need to be done differently or better. For example:

1. How events are advertised
2. How staff facilitate family events
3. How support groups are supported by staff so that one person does not dominate or they do not become “clicky”

The number of topics that families felt they needed information on was far ranging and demonstrated the need for families to have access to information. More importantly some of the comments included mis-information and DCS commissioning are looking at how best to address this as families need clear and accurate information.

What Next?

Disabled Children’s Commissioning has taken into account all the information from this survey, together with Data Monitoring from the previous 2 years and will be developing a description as to how they will need the grant for Family Events, Workshops & Support Groups to be used.

The description as to what KCC requires will be informed directly from the comments made in the survey.

With regards to some of the issues raised in the comments please find in appendix 1 of this report a list of web links that may help with beginning to answer some of the questions. We are working on a further question & answer sheet on other issues or comments made.

Specialist Children’s Commissioning would like to thank you everyone who completed the survey

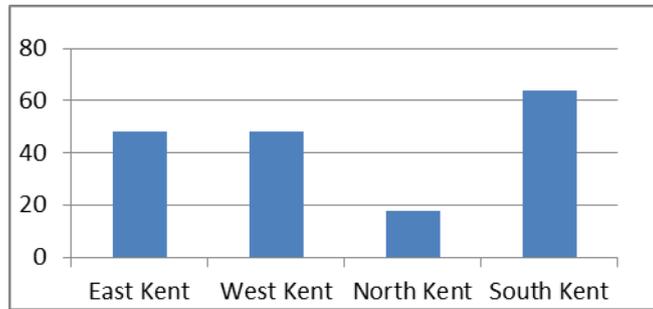
Detail about the responses

Who responded?

There were **181** responses to the survey

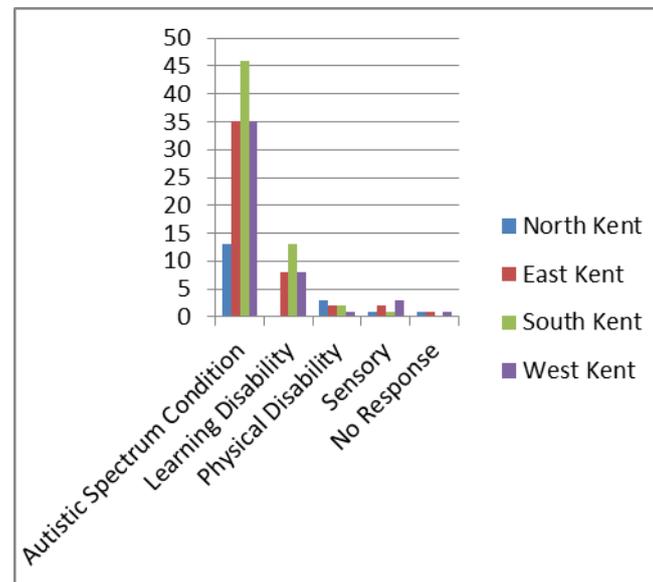
The highest number of responses, 36%, came from South Kent.

Fig.1 Graph to show where the responses came from.



From those who responded Autistic Spectrum Condition was listed as their child's primary disability by just over 71% of those who responded. This pattern was reflected in each area.

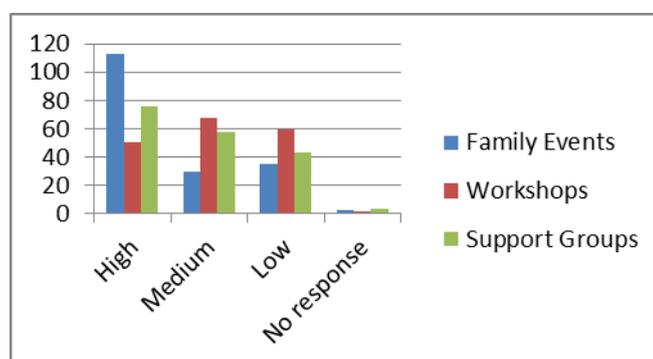
Fig.2 disability type by area.



Which activity was given the highest priority by those who responded?

Across the county Family Events were given the highest priority, with support groups being given the second highest priority.

Fig.3 which activity was given the highest priority by those who responded.



Family Events

Out of the 181 people who responded 157 said they had attended a family event and 147 of those thought they were useful events.

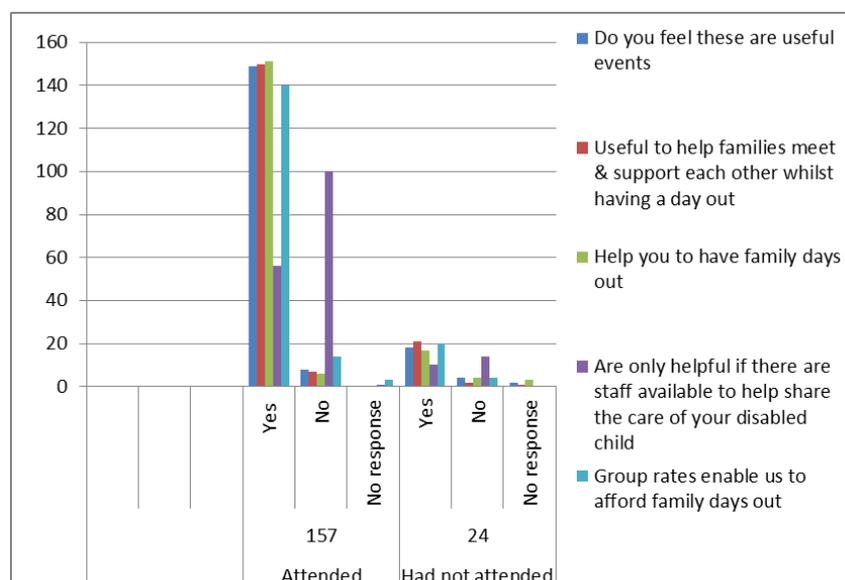
150 (just over 82%) agreed that the events were useful to help families to meet & support each other whilst having a day out.

151(83%) said that they helped to have family days out.

140 (around77%) said that the group rates enabled them to have family days out.

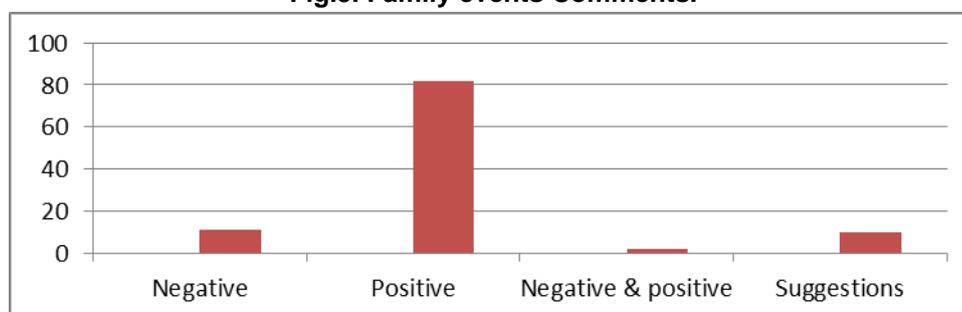
56 (30%) said that the events are only helpful if staff are there to help share the care of their disabled child.

Fig.4. how many respondents found the events useful & what elements of the events.



Overall there were 82 comments in favour of family events and 11 where things could have been better or different

Fig.5. Family events Comments.



Amongst the responses in favour of the family events there were many that spoke about the strength of going out in a group.

- ❖ *The family events are fantastic for children who may have difficulty mixing with other children. These groups so understand of the difficulties these children may face and as a parent it is wonderful to see my child able to take part in these events.*
- ❖ *Family events are a precious opportunity to meet other families with similar problems, and give the kids an opportunity to play with other kids (and see other kids) who are like them. There is also the "strength in numbers" thing - if you go on your own to an event and your child is disabled it can be really difficult when everyone stares - if you go in a group it is easier!*
- ❖ *Out with others who understand the issues of taking out children with behaviour difficulties.*
- ❖ *Going to public places is difficult and having an outing organised and a friendly facilitator just in case gives me motivation to tackle an outing also it would be impossible without the cheaper price.*
- ❖ *Vital opportunity for parents to support each other. Seems like an unnecessary extra but very important "preventative medicine "to keep us all going!*

There were 11 responses where things could have been better or different, amongst them:

- ❖ *I am not aware of any family events being available for families of kids with ASC. KCC neither seems to consider ASC as a condition that families need support with nor that the affected kids needs help to cope with.*
- ❖ *Whilst it was useful getting group discount, their staff were only there to give the tickets to us on arrival and were pretty pointless after that.*
- ❖ *Many events are unsuitable to autistic children due to being in noisy environments or use of coach travel. My children cannot cope with either*

There were also some useful suggestions:

- ❖ *good communication before the event, on the day you get greeted, lost child wristbands, a first aider and support throughout the day if any problems*
- ❖ *There seems to be alot of events/clubs for younger children but not that many for teenage/young adults.*
- ❖ *I would prefer if you got us a discounted entrance and we could get there ourselves... more flexibility if child is not coping you can leave if you have to,*
- ❖ *Private hire of soft play centres, several lanes of bowling etc.*

Family Workshops

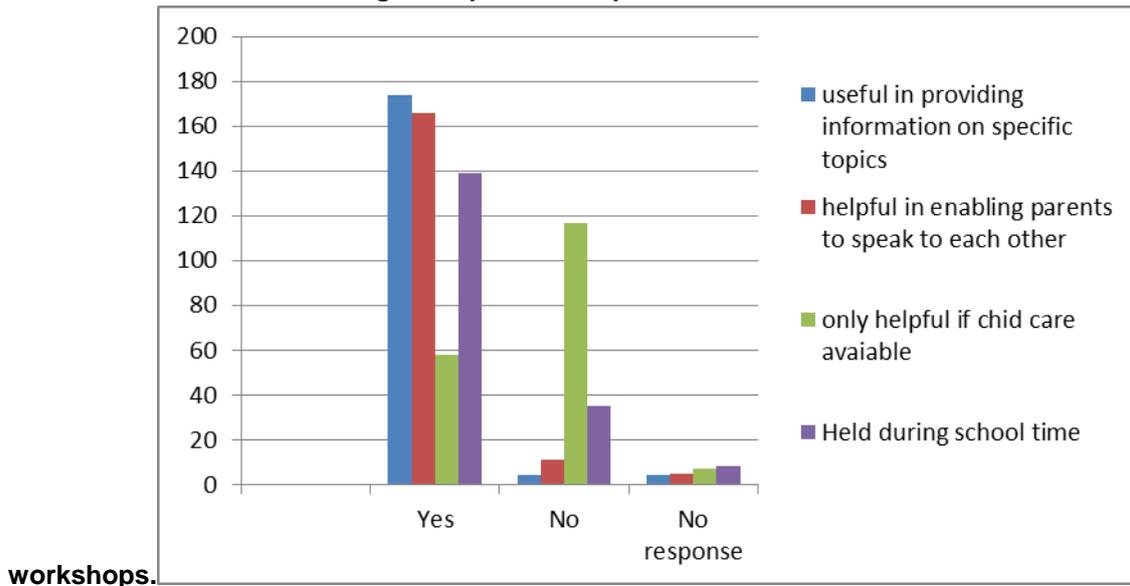
174 (96%) respondents agreed that the workshops were useful in providing information on specific topics.

166 felt that the workshops were helpful in enabling parents to speak to each other.

58 felt that the workshops were only helpful if child care was available.

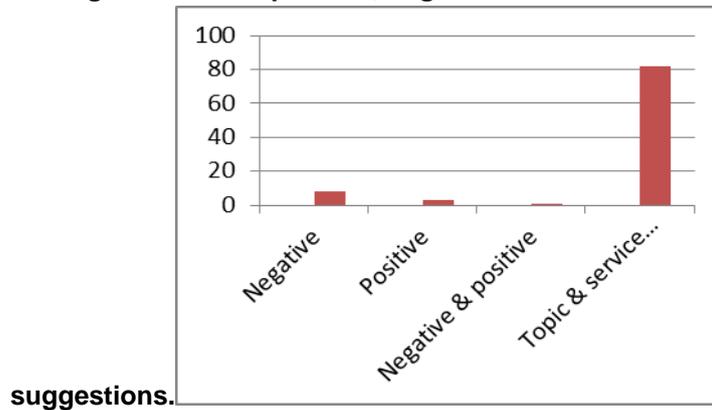
139 (76.5%) were happy with the workshops being held during the school day.

Fig.6. responses to question about



Overall there were 8 positive comments & 3 negative comments.

Fig.7 number of positive, negative comments or



Amongst the positive comments:

- ❖ *I've been to lots and so far they seem to cover everything that applies to my child.*
- ❖ *Workshops are brilliant and very informative.*
- ❖ *All topics are helpful because it's nice to understand about any disability and gives ideas how to help others*

Amongst the negative comments:

- ❖ *Total waste of public money*
- ❖ *parents had to specifically google just in case anything came up appropriate....parents need information to hand. Not to go looking for it*

Respondents were also asked *if workshops are held what topics/subjects would you like to see covered what subjects.*

There were numerous subjects that families felt they would like more information on a sample is listed included:

Disability specific information/ASC/ ADHD/New developments in research/Behaviour/ managing violent & aggressive behaviour/ disengagement techniques/ introducing change in routine/fears/defiant behaviours/Eating/Feeding issues/Toilet training/Communication/Makaton/ British Sign Language/ visual support/ How to communicate effectively with professionals /Speech & Language/Mobility issues/Mental health/Anxiety/Sleep/Bed wetting/Sensory processing/Moving to adult services/puberty/ Sex education/the future/Benefits/Wills & Trusts/Looking after the whole family/Health as a carer/support for siblings/Education/getting the right school/Education, Health & Care Plans/ Coping in mainstream school/Stress/ Reasonable Adjustments in School/College/Apprenticeships/18+ what is out there realistically/ Social Care Needs Assessments/Finding a PA/Puberty/ stranger danger/self-esteem/ social stories/ How to access care and support/ direct payments// what happens when your severely disabled child turns 18/ Communicating with schools/ First aid/relaxation / Dyspraxia Strategies-e Organising Thinking and Working Memory Development/ OT support/ etc.

Whilst 76% of respondents were happy with the workshops being held during the school day there were a number of other comments about when workshops should be held, amongst them the following:

- ❖ *I don't agree that workshops should just be in school time - what if parents work??*
- ❖ *I think workshops should be both during the day and in eves for working parents too Both of us work full time. Sessions needed out of school time! I'm a teacher!!!*
- ❖ *Please note, workshops always tend to be 10-12 but I work from 9-12. Could we please have 12.30-2.30 sometimes?*
- ❖ *I work full time - workshops during the day are difficult to attend.*

There were also a few respondents who felt that the workshops were not what KCC should be spending their money on amongst them:

- ❖ *These are free fromother organisations.... why are KCC funding these. Total waste of public money*
- ❖ *Other groups.... provide these free why are KCC funding them?*

With regards to the provision of crèche or care facilities for workshops families said:

- ❖ *Having staff at workshops to provide additional help / support / a crèche is very useful especially for parents of small children.*
- ❖ *The workshops are fine if your child is at school buy if it's a preschool child it would be useful if there was a crèche to help parents listen and learn.*

Included in this set of comments were observations about other services:

- ❖ *Accessing services and contact names within NHS. I know, impossible (!)...it's the Holy Grail for most parents and surely services could be all linked up? A clear list of type of disability, age of child, teams to contact, waiting times,*

courses available etc. It's a full time job and you have to keep on your toes to get help at the tight time for your child

- ❖ *I think there should be workshops for siblings of disabled children, as although as a parent you make sure they do not take on caring responsibilities or worries, they are living within the family and have to deal with issues such as very challenging behaviour on a daily basis. I think older siblings, say from 11 upwards, and need help in dealing with this and also on managing their own feelings. Currently there does not seem to be anything like this on offer, it is more geared towards giving children a break and fun things to do which is great but workshops run by a professional and geared towards teenage siblings would be a good source of support for siblings in my opinion.*
- ❖ *I would like to do a parenting course specifically targeting children with behavioural needs or problems linked to fasd or add etc. as generalised parenting programs don't cater for this and whilst the tactics and strategies may work on your average Joe it may not work on a child with additional needs.*
- ❖ *Help with paperwork /Support with the paperwork*
- ❖ *There is also no support for childcare for parents with children out of school due to anxiety, medical needs or those awaiting a special school placement*
- ❖ *It is particularly important to reach parents who are new to having a disabled child as this is when the information is most needed.*
- ❖ *All topics are helpful because it's nice to understand about any disability and gives ideas how to help others*
- ❖ *Help for children and families that aren't aware of support or are missed by agency*
- ❖ *Help for parents of children with Asc/Adhd needs who don't have an ehcp gain more confidence with dealing with teacher's in mainstream schools.*

Finally in this section there was a further request for a subject that was related specifically to foster carers.

Support Groups

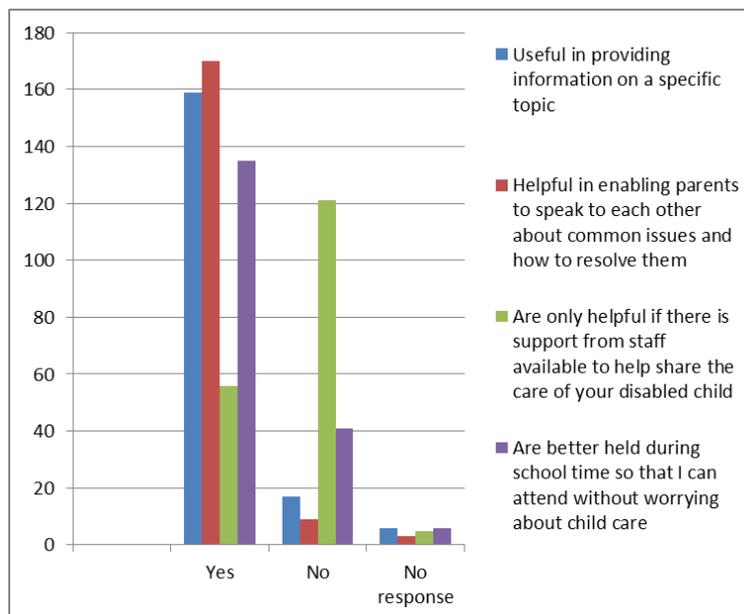
159 of the respondents felt that the support groups were useful in providing information on a specific topic

170 of the respondents felt that the support groups were helpful in enabling parents to speak to each other about common issues & how to resolve them.

56 of the respondents felt that support groups are only helpful if there is support to share the care of their child available.

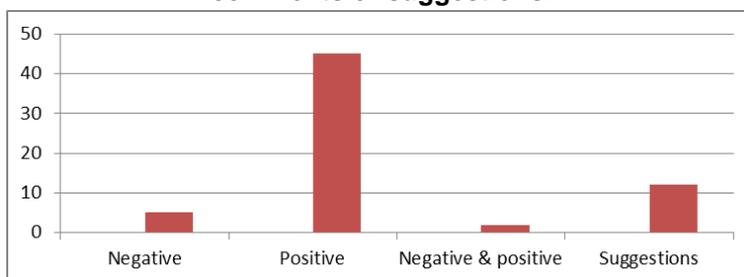
135 of the respondents felt that the support groups are better held during school time.

Fig.8 Graph to show which aspect of the workshops were helpful.



Overall there were 5 negative comments & 45 positive comments about support groups.

Fig.9 Graph to show number of positive, negative comments or suggestions.



The positive comments included:

- ❖ *Support groups help mums and dads from having a nervous breakdown. The stress of bringing up a disabled child is so huge that sometimes you just can't cope. The only people that can help are parents who are in the same situation as you. No one else truly understands. Support groups save lives.*
- ❖ *This is the only place I get to meet other parents going through similar issues and the support staff are excellent*
- ❖ *Lifesaving.*
- ❖ *My experience of life with dealing with my disabled son had been more improved and supported by meeting other parents/ families. Attending a support group has*

given me many friends at a time when I felt really isolated. I've made friends for life that can share my experiences whilst having people around that can offer advice and support without me having to trawl the internet with nowhere to begin. My son has met other people like him, whilst his brother has made friends with other children that have a sibling with an additional need. We'd be lost without my support group.

- ❖ *These are not held regularly enough = often standing room only, not everyone gets a chance to talk- please provide space and resources for parents to meet more often fortnightly would be ideal*

The negative comments included:

- ❖ *"They can be a bit clicky and exclusive. But it provides a good starting point for parents starting out on this journey. Organisers often know lots of useful things about services.*
- ❖ *It is difficult to attend if your child is out of school for any reason as they mainly cater for young children.*
- ❖ *Support groups don't need professionals in attendance...they are for anyone. If a parent is struggling, whether disabled or not, then they need help.*
- ❖ *Some groups spend all the time talking about one parents issues and the quiet members don't get anything from the meeting*

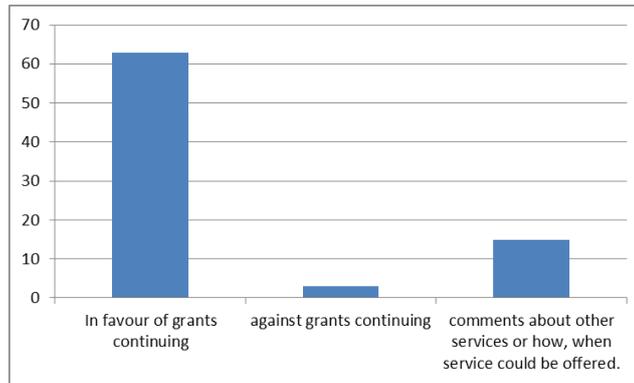
As with the other sections respondents also used the comments box to make suggestions about the times & other options available

- ❖ *"You have omitted online support groups which could be better placed to meet the need*
- ❖ *Some parents work, so eves are better but they may be shattered*
- ❖ *With modern technology it would be useful to have an online webchat*
- ❖ *They probably need a focus and meaning for each session to ensure that people know what they are going for and what they will achieve."*

Final Comment

Families who responded to the survey were given the opportunity to make any other comments they would like to make in respects of grants for family events, workshops & support groups.

Fig10 families felt that the grants should or should not continue.



- ❖ *I would hate to see funding cut, especially for support groups. They are invaluable*
- ❖ *Support groups, family events and workshops are not a substitute for services. Services for kids affected by ASC need to be developed. E.g. the provision of services to support them in socialising and developing their social skills and confidence out of school is woefully inadequate. They need these services to prepare them to cope as adults. Furthermore, I understand that KCC refuses to fund support groups etc. that advise and support families to fight for their and their children's rights under various relevant UK human rights legislation. This needs to change.*
- ❖ *"It would be counterproductive to not supply these types of services as they educate and support parents and carers to keep on top of difficult family situations, which without the appropriate support would escalate into far worse and traumatic situations where more services and revenue would have to be applied.
I.e. It's a false economy to do without such services for society as a whole."*

Web links for information on.....	
Direct Payments in Kent	http://www.kent.gov.uk/social-care-and-health/care-and-support/paying-for-care/paying-with-direct-payments
Education, Health & Care Plans in Kent	http://www.kent.gov.uk/education-and-children/special-educational-needs/education-health-and-care-plans-ehcps
Help if you have a disabled child	http://www.kent.gov.uk/social-care-and-health/care-and-support/disability/help-if-youve-got-a-disabled-child
Disabled Children's Register	http://www.kent.gov.uk/social-care-and-health/care-and-support/disability/help-if-youve-got-a-disabled-child/disabled-childrens-register
Short Breaks	http://www.kent.gov.uk/social-care-and-health/care-and-support/disability/local-activities-and-support/a-break-from-caring
Short Breaks Statement	http://www.kent.gov.uk/about-the-council/strategies-and-policies/adult-social-care-policies/short-breaks-statement/short-breaks-statement-about-short-breaks
Autism & Aspergers	http://www.kent.gov.uk/social-care-and-health/health/autism-and-aspergers
DLA for children	https://www.gov.uk/disability-living-allowance-children
Carers Allowance	https://www.gov.uk/carers-allowance