

Disabled Children's Register Parent/Carer Survey 2017

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Summary Report of DCR Parent/Carer Survey 2017

Background

The Disabled Children's Register (DCR) from time to time consults with members regarding views on activities available to children and young people with SENDs, the WAND card etc.

Our survey of the use of the WAND card in spring, 2015 revealed that users of the WAND card would like

- a) more parking concessions (since some cannot access a Blue Badge Card),
- b) more sports activities
- c) more support for carers

Since the 2015 survey we have expanded our existing parking concessions at hospitals and the Town Hall to include parking outside a WAND cardholder's school for pick-ups and drop-offs and free parking in Battersea Park car park on days when we hold pre-arranged events there. We have also worked with Enable to expand the disability sports offer and with other providers, such as Aspire. Most recently, we have succeeded in negotiating discounts with Flip Out and Go Ape to further broaden activities that are offered to WAND cardholders at a discount.

The 2017 survey

Mindful of the call in the 2015 consultation for more support for carers, we have made support for carers a key focus of DCR's work in 2017, holding events in February and June specifically for carers, with more planned for the autumn. Our latest survey, launched in the spring of 2017 also focuses on parent/carers needs. Here is a summary of the findings followed by a more detailed breakdown of the responses, where questions permitted multiple choices, percentages should be used to determine a rank order.

Summary of findings

1. 122 Wandsworth parents/carers completed the survey, 95% identifying themselves as parents.
2. The majority (67%) of the children and young people cared for were in the age bracket 5-17
3. 52% said they knew about the Local Offer, 42% said they did not
4. In terms of services known to respondents, replies were: CaF (76%), DCR/WAND (73%), FIS (62%), WIASS (38%), Local Offer (31%), and WCC (5%).
5. 72% like to get information via email but other modes were also important, including paper communications, website, face to face and telephone calls
6. Looking ahead, the following were the top four areas likely to be of most help to parent carers: Leisure information (76%), Help with problems at school (54%), Help to cope with my caring role (49%) and Things to aid my health and wellbeing (49%)
7. 21% of carers thought the level of support they received was sufficient to balance their caring responsibilities with work/education and a life outside their caring role, 55% thought not.

8. What would make a difference in the future would be more: Part time or flexible work opportunities (40%), Family Friendly employers (34%), Help with childcare whilst at work or study (24%).
9. Asked if there was something else Wandsworth Council could do differently, responses varied, with frustrations vented around lack of resourcing but also some practical suggestions such as:
- *Give better training to schools to understand disabilities and that the children do need support even if appear to be OK. More bases (ASD) in primary schools and better SENCO training.*
 - *Some sort of information sheet / pack to give to employers explaining the issues employees have as carers and reminding employers of their legal duties!*
 - *Get shops in Wandsworth to accept WAND cards and if they do accept them display a sticker in their window to show you they accept them.*
 - *Social buddy service for teenagers.*
 - *Provide early bird activities @ local services e.g. Flip Out Wandsworth, leisure centres, restaurants, cinema.*
 - *More support (for carers).*

Full Survey Findings

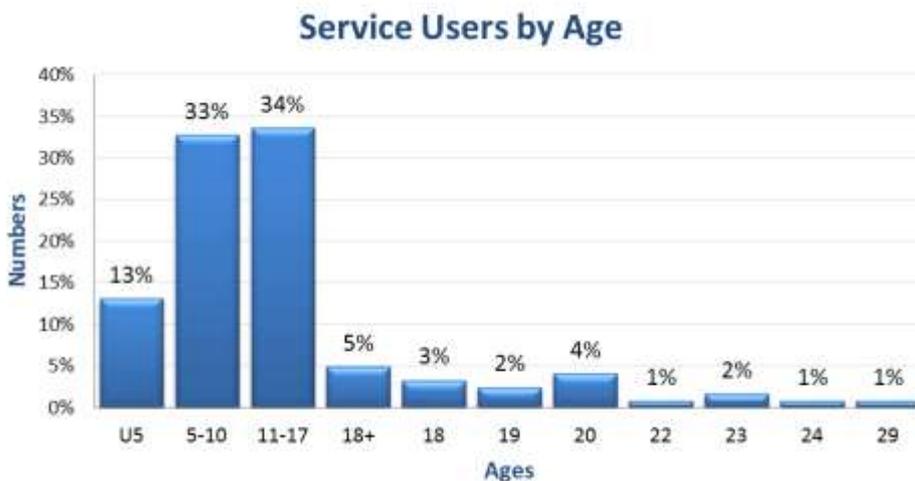
Q1. Who participated in the survey?

We promoted the survey online via the Local Offer website and also sent it out to our members in their May mailing. We also handed out the survey at events such as the 'Can-do Carers' event at York Gardens Library in February, at the SEND Reforms conference in March and at the Disability Fair at Tooting Leisure Centre in April.

122 people completed the form, 95% of which identified themselves as parents, the rest being siblings or other carers of a child with a disability.

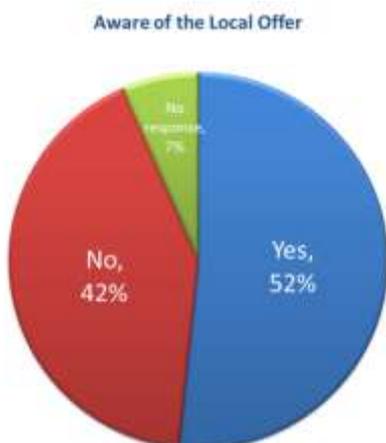
Q2. Age of children or young people?

67% of respondents looked after children aged between ages 5-17, 13% cared for Under 5s and 19% cared for young people aged 18+.



Q3. Knowledge of the Local Offer

Asked if they knew about the Local Offer, 52% of respondents said YES, 42% said NO, 7% did not reply.



Those who answered YES were asked what they had used it for with very mixed replies, some of which appear below (see Appendix A for full list);

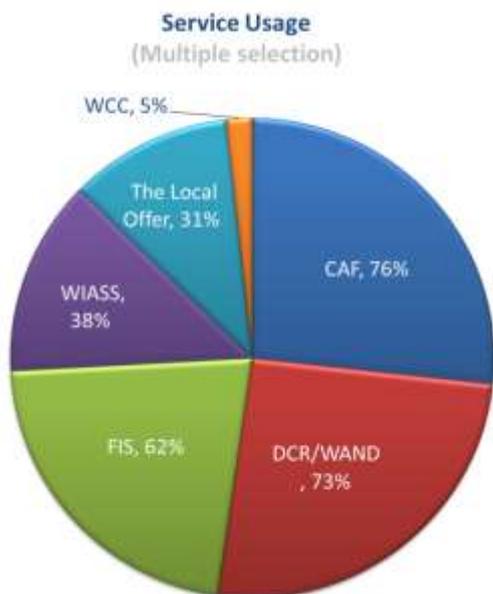
- *Is the Local Offer the WAND card? If so then yes. We love the WAND card.*
- *Information on sports and other leisure activities.*
- *Legal advice*
- *ECC - Therapies through the school - FIS - WAND card.*
- *Very useful for parking picking up school run.*
- *For activities during holidays and look for other services.*
- *Queen Mary's Hospital parking and Battersea park.*
- *Nothing. Never been able to find answers.*

Q4. Use of local services

The survey then asked what local services, people had made use of. These included:

The Local Offer, the FIS, the DCR/WAND, CaF, WIASS and the Wandsworth Carer Centres (WCC)

In order, most frequently mentioned were CaF (76%), DCR/WAND (73%), FIS (62%), WIASS (38%), Local Offer (31%), and (WCC 5%).



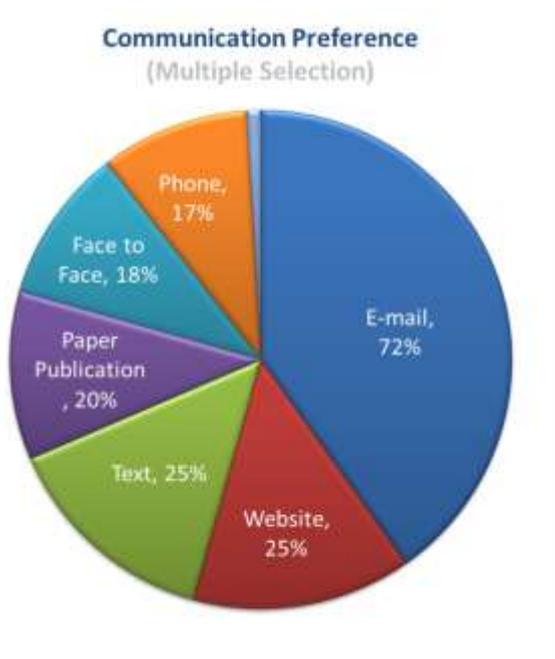
Those who answered YES were asked in what way they had been helped the most. Contact a Family was frequently mentioned but other services also got mentioned:

- *CaF have helped me with filling in DLA forms.*
- *FIS have answered many questions when I have called.*
- *Courses with contact a family + social event*

- *Information (CAF) and therapies (Carers centres).*
- *Meeting people and sharing information.*
- *Parking at school is a life saver.*
- *Short break (CAMP) WAND card - especially hospital parking and entry to venues.*
- *With WIASS's help my son is getting more help from school speech and therapist.*

Q5. Preferred methods of communication

The vast majority of respondents like to get information via email (72%).



There is also significant demand for a range of other methods of communication too: website (25%), texts (25%), paper (20%), face to face (18), and phone (17%).

Q6. What sort of information would be useful in future

The following types of information were most frequently mentioned:

- Leisure information (76%); Help with problems at school (54%); Help to cope with my caring role (49%) and Things to aid my health and wellbeing (49%)

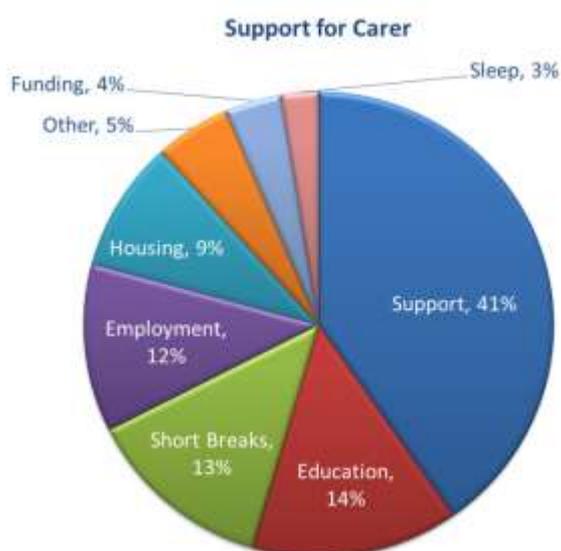
Other issues were:

- Housing info (36%), Returning to work (36%), Career development (33%), Relationships help (22%), and Money advice (20%).

Future Useful Information (Multiple Selection)	Responses	%
Leisure activities for my child/young person	93	76%
Problems with schools / college	66	54%
Help me to cope with my caring role	60	49%
Aid my health and wellbeing	60	49%
Accessing benefits and housing	44	36%
Help at work or getting back into work	44	36%
Personal development / future career path	40	33%
Support with relationship issues	27	22%
Advise about money management / debt	24	20%
Other	1	1%

Q7. What would make the biggest difference right now?

In terms of what might make the biggest difference, the top issues were: Support for carers (41%), Help with education issues (14%), Short Breaks (13%), and Employment (12%).



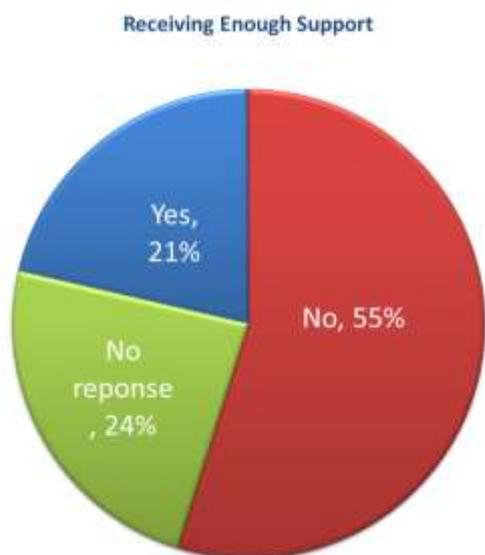
Also mentioned were help with housing, funding and sleep, plus some more specific items such as:

- *More understanding of how girls with Autism display differently.*
- *What is very frustrating is the constant repetition of information regarding my child's needs. He has a genetic condition it will not change or go away but for anything we do I have to provide evidence, hospital letters etc. to access any services or benefit including the WAND card.*

(See full list in Appendix A)

Q8. Is the level of support you receive adequate?

We then asked whether or not parent/carers feel they receive enough support to balance their added caring responsibilities with work/education and to have a life outside of their caring role.



Just over one in five, 21%, said YES. More than half, 55%, said NO.

What would make a difference in the future (Multiple Selection)	Responses	%
Full time, part time, flexible working opportunities	49	40%
Employers advertised as family friendly	41	34%
Childcare availability to help me work/study longer	29	24%
More confidence to return to work	27	22%
Help with reviewing my skills or change of direction	28	23%
Advice on housing & benefits for part timers	23	19%
Other	11	9%

Most frequently mentioned things that would make a difference to this in future would be:

- *Part time or flexible work opportunities (40%).*
- *Family Friendly employers (34%).*

Also important were:

- *Help with childcare whilst at work or study (24%).*
- *Help reviewing skills (23%).*
- *Confidence building to return to work (22%).*
- *Housing and benefits advice (19%).*

Other comments from respondents were:

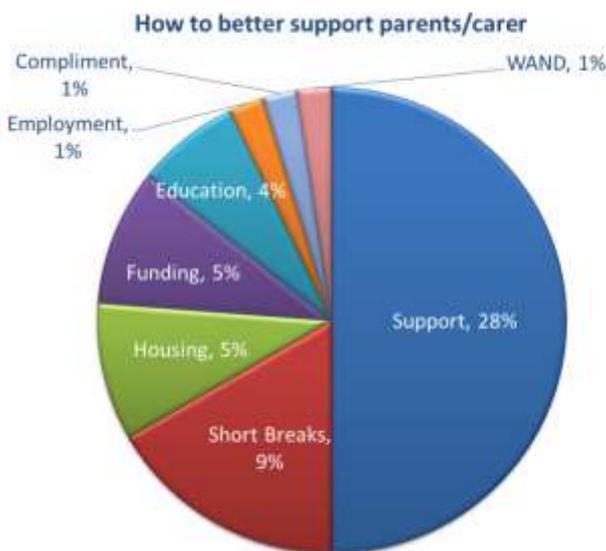
- *Info services and support outside working hours.*
- *Support for my children.*
- *Going back to school as a parent.*

- *Social services are very poor supporters.*
- *More support for team with learning difficulties.*
- *More advise on how to balance the needs of the family as things tend to be dominated by the needs of the special needs child.*
- *I have health issues and need sleep for new stroke. I need time away from my son to do things for myself because it's just me and him.*
- *Providing more direct support to the young person.*
- *I think it would be very helpful if the carers allowance was increased. I would find it very difficult to work due to the nature of my child's needs and don't feel my contribution to the care I provide is recognised financially.*

Q9. What else could the Council or others do to better support parents or other carers

Finally, we asked an open question about what else Wandsworth Council or others could do to better support parents or other carers of children or young people with SENDs:

Frustrations about resourcing and efficiencies were flagged up, in particular around availability and transparency of funding for special needs, speed of service delivery, housing and support, generally (see Appendix A for all comments).



There were also practical ideas:

- *Give better training to schools to understand disabilities and that the children do need support even if appear to be OK. More bases (ASD) in primary schools and better SENCO training.*
- *Some sort of information sheet / pack to give to employers explaining the issues employees have as carers and reminding employers of their legal duties!*
- *Get shops in Wandsworth to accept WAND cards and if they do accept them display a sticker in their window to show you they accept them.*
- *Social buddy service for teenagers.*
- *Early bird sessions Flip Out, restaurants in Wandsworth, leisure centre.*

And lastly, a positive: *Wandsworth has been great. Thank you.*

Appendix A

All replies to Question 3 regarding use of the **Local Offer**:

- *To register for WAND card.*
- *WASA, Balham Theatre, Calvert Trust.*
- *Information on Local Services.*
- *The website.*
- *Field trips to Bocketts farm, learn various workshops.*
- *Information on sports and other leisure activities..*
- *Legal advice.*
- *Nothing. Never been able to find answers.*
- *Like WAND card, contact a family.*
- *Information.*
- *Short breaks.*
- *ECC - Therapies through the school - FIS - WAND card.*
- *Information.*
- *Concessions for hospital car parking.*
- *Short breaks, WAND Card.*
- *WAND card.*
- *Battersea park zoo / recumbent bikes / Cineworld.*
- *Very useful for parking picking up school run.*
- *Nothing as yet.*
- *No used so far.*
- *To see available events in Wandsworth.*
- *No not really.*
- *Short breaks.*
- *My daughter will need to use a special needs buggy and I find that the bus drivers don't understand that the buggy is like having a child in a wheelchair.*
- *George Shearing Centre – Generate.*
- *I haven't (used it).*
- *Childcare availability.*
- *Parking and role model camp. Cinema card.*
- *Is the Local Offer the WAND card? If so then yes. We love the WAND card.*
- *information on education.*
- *Finding things to do for college.*
- *Swimming pool @ leisure centres.*
- *For activities during holidays and look for other services.*
- *Heard of it but not used the service.*
- *Helped me fill form, contact a family.*
- *Children's centre, library.*
- *QMH parking and Battersea park.*

- *Only WAND card.*
- *Do you mean Local Offer website? If so I know about it but have never looked at it on the website (remiss of me, I know).*
- *Information.*

All replies to Question 4 asking in what way people have been helped the most by The Local Offer; the FIS; the DCR/WAND; CaF, WIASS and the Wandsworth Carer Centres (WCC)

- *Contact a family - advice on application for DLA.*
- *Contact a family with outings and FIS for SEN play centres.*
- *Contact a family when our daughter was diagnosed. Local offer/FIS/WAND team - Information on sports and leisure activities in the borough.*
- *In the issue of advise, helping parents.*
- *EHCP. Support with DLA etc.*
- *Concessions for hospital car parking.*
- *Short break (CAMP) WAND card - especially hospital parking and entry to venues.*
- *WAND card.*
- *Get in contact with local authority.*
- *WIASS, FIS.*
- *Courses with contact a family + social events.*
- *Schools.*
- *CAF have been very supportive.*
- *Advice.*
- *Getting info for a situation we were totally unprepared for.*
- *I have ordered a WAND card in the past and need to renew it to access services in Wandsworth.*
- *CAF.*
- *Work with and get information for patients.*
- *Going to Battersea Park Zoo and its good to know that the local xxx xxx excepts them.*
- *By Contact a Family with our EHCP application and by the FIS with info on after school activities.*
- *Meeting people and sharing information.*
- *With advise and sign posting.*
- *Contact a family have helped me the most.*
- *Contact a Family.*
- *EITAC / School Placement.*
- *I have a WAND card.*
- *Charlie loves going to Battersea park.*
- *Contact a Family helped me with applying for family fund and gave me information.*
- *FIS.*
- *With WIASS's help my son is getting more help from school speech and therapist.*
- *Power of attorney.*
- *Activities for children with SEN.*
- *Activities for brothers with autistic spectrum disorder.*
- *Parking at school is a life saver.*

- *Information (CAF) and therapies (Carers centres).*
- *WASS.*
- *Information and getting WAND cards for my sons.*
- *Information and getting WAND cards for my sons.*
- *My son were refer to them by the police and spoke on the phone.*
- *WAND cards for Battersea Park (xxxx and access to café in zoo).*
- *Services available, benefit advice and workshops.*
- *With DLA application and EHCP.*
- *Helped with applying for an EHCP.*
- *Contact a family.*
- *DCR/WAND + CaF.*
- *My child has high functioning ASD + PDA. Despite good intentions from people I speak to I hit a lot of dead ends.*
- *WASS.*
- *Contact a Family have been very helpful to myself and family to talk to and receive advice.*
- *For WAND card for my son and helping with my son's disability forms.*
- *The WAND card for my son and also helping with my son's disability forms.*
- *CaF have helped me with filling in DLA forms. FIS have answered many questions when I have called them.*
- *Contact a Family EHC.*

All replies to Q7: What would make the biggest difference to helping me manage right now

- *If I had a support worker that my son could talk to.*
- *Joined up collaborative team work.*
- *More sleep.*
- *More understanding of how girls with Autism display differently.*
- *Funding.*
- *Improving my work/life balance.*
- *Information response times and CAMHS support.*
- *Me and my family are having big issues with housing all five are living in one bedroom flat.*
- *If the Council could look into rehousing parents.*
- *For my children to be happy. CAMHS need to listen as they are not. Waiting too long.*
- *To guide me with services that could help me.*
- *To have carers who will be able to help look after my son whilst my wife is convalescing from a necessary forthcoming operation!*
- *Camps / break time activities.*
- *More activities for children.*
- *Help with my son study at school.*
- *The support of Contact a Family.*
- *Meeting other parents and carers.*
- *Accessing the right service.*
- *Fast tracking queues for venues.*
- *Teaching my son social skills.*

- *Getting back to part time work.*
- *Finding a part time job.*
- *The right information.*
- *Better access to info & peer support for my son.*
- *To be listened to in the first place.*
- *Individual mentoring for job finding.*
- *Getting a job.*
- *Getting back into full time employment and managing after school care for our son.*
- *Looking at secondary school options as it's a big worry.*
- *Knowing that I would be able to get on the with my daughters special needs buggy. Sometimes I can't get on the bus because school children are standing in buggy space.*
- *Counselling for my son.*
- *To know more about organization in Wandsworth area.*
- *Having some sort of family support.*
- *Help me with information on how to get back to work.*
- *To find a part time job. Advice on how to cope with behaviour.*
- *Having control of situation.*
- *Housing.*
- *What is very frustrating is the constant repetition of information regarding my child's needs. He has a genetic condition it will not change or go away but for anything we do I have to provide evidence, hospital letters etc. to access any services or benefit including the WAND card.*
- *Help me cope with my son and knowing more about leisure activities for my son.*
- *Help with funding. Family fund helped but son is too old now.*
- *Information about how I can help my son become independent and prepare for the future.*
- *More outdoor, exercise related activities for children with SEN and more indoors spacious clean areas.*
- *Weekend and early morning activities dedicated to children with ASD and their carers.*
- *Sleep, but Wandsworth can not help with this.*
- *Help with career path.*
- *The therapies help with stress.*
- *My child can become very unhappy. We were referred to CAHMS but he was unable to talk about his feelings and found the experience excruciating. Other advice on mental health would be good.*
- *Help with transition from nursery to school.*
- *Someone to talk to, help making decisions regarding education.*
- *Understanding the facilities available and support that we can access.*
- *Helping my autistic son find employment or voluntary work during school holidays.*
- *How to manage his behaviour at school.*
- *Being able to know what life will be after college in 2018.*
- *Support around issues my son has at secondary school although SENCO is brilliant the rest of the staff don't seem to have any understanding of how my sons ASD/ADHD impacts his behaviour.*
- *If somebody could help me with lodging an appeal to the tribunal to dispute the EHCP.*
- *Sort out problems with school / college for my daughters who find it difficult to cope with secondary school.*

- *Housing, I have to girls with different needs and they are sharing a box room and its got so bad my oldest daughter is staying at her dads for a bit.*
- *Housing, I have to girls with different needs and they are sharing a box room and its got so bad my oldest daughter is staying at her dads for a bit.*
- *More staff at Wandsworth education and social services, special needs.*
- *Having a WAND car badge that allowed us to use the disabled section of QMH hospital car park. I know you can claim free parking there but this involves going down through transport after an appointment with a sometimes distressed child.*
- *Advise on how to handle situation with my son who is often refusing to go to school. Instead of receiving help it tends to be the opposite. Pressure is put on me.*
- *Help me with my anxiety about my son because he can easily be influenced, sometimes by the wrong thing.*
- *To be able to deal with my sons outbursts.*
- *Access benefits and housing.*
- *Housing.*
- *Access benefits and housing. Know about leisure activities for my child.*
- *Respite.*
- *Probably some counselling sessions.*
- *Help with kids at home would make the biggest difference right now?*

All replies to Q8: Other things that would make a difference in future

- *I think it would be very helpful if the careers allowance was increased. I would find it very difficult to work due to the nature of my child's needs and don't feel my contribution to the care I provide is recognised financially.*
- *Info services and support outside working hours.*
- *Going back to school as a parent.*
- *Social services are very poor supporters.*
- *More advise on how to balance the needs of the family as things tend to be dominated by the needs of the special needs child.*
- *I have health issues and need sleep for new stroke. I need time away from my son to do things for myself because it's just me and him.*

All replies to Q9: Something else Wandsworth Council or others could do to better support parents or other carers of children or young people

- *Wandsworth has been great. Thank you.*
- *Give better training to schools to understand disabilities and that the children do need support even if appear to be OK. More bases (ASD) in primary schools and better SENCO training.*
- *Some sort of information sheet / pack to give to employers explaining the issues employees have as carers and reminding employers of their legal duties!*
- *Get shops in Wandsworth to accept WAND cards and if they do accept them display a sticker in their window to show you they accept them.*
- *Social buddy service for teenagers.*

- *Early bird sessions Flip Out, restaurants in Wandsworth, leisure centre*
- *Joined up thinking and collaborative work.*
- *Better timeliness of outputs - why does it take 7 weeks to get a £240 seating solution that is orderable in 3 days.*
- *Yes in the area of housing my parents with special needs have suffered a lot looking after the special needs child. Having housing problems is another handful.*
- *Set out clearly the financial responsibilities of the Council of those with SEND.*
- *More money (ring fenced) & resources for all aspects of SEN.*
- *Provide funding for necessary equipment such as - SATS Machine.*
- *More fund for special needs and disability people.*
- *Yes, stop getting our hopes up when you agree funding for adoptions then turnaround and put us on your waiting list.*
- *It is sometimes difficult to find out about what help + advice is available.*
- *Better access to info & peer support for my son.*
- *Just support.*
- *It's almost impossible to get in touch with Contact a Family on the phone.*
- *Trying to get advice on stubborn friend.*
- *Having a big problem. Have advice but can't seem to do anything to change our situation for the better as the advise is generic and not disability specific.*
- *Opening up more special schools instead of going to other boroughs for schools.*
- *Respite care for my kid I am not having time to myself.*
- *Yes Wandsworth Council needs to support children in school with SEN and disabled children. Teachers are not fully trained and children not get care and support they should be.*
- *More information about caring for young people over 12 years.*
- *Early bird sessions Flip Out, restaurants in Wandsworth, leisure centre*
- *Provide early bird activities @ local services e.g. Flip out Wandsworth, leisure centres, restaurants, cinema.*
- *More and better experienced / skilled social workers.*
- *My children are 13 now and I feel I understand the SEN system better and also have more time than I did as I only work 2 days a week. When they were younger it was much harder.*
- *Operate a buddy system for parents whose child has just been diagnosed.*
- *Social services.*
- *Allocate a social worker who has experience on how to support the family in need.*
- *To understand that housing and own space is a must for any disabled child.*
- *Staff at W/W work if prioritised as crisis or statutory deadline. Basic support work appears to be unavailable due to cuts in budgets / staffing levels. Needs is still there.*
- *Have more joined up services where the different professionals have a combined approach.*
- *Help with getting an education health care plan.*
- *About short break activities in the borough during holidays.*
- *Thinking about saving money think about the children and help parent access all their needs.*
- *I need respite every Saturday.*

Appendix B

DCR Parent/carer survey 2017

Are you looking after a child or young person with a special need or disability?

Wandsworth Council's Family Information Service and the Disabled Children's Register are here to help families make the most of the borough. So we can develop the Local Offer and other services to help you as a parent or carer, please give us your views about what helps or hinders you in this role. This survey will only take a few minutes to complete. Please hand it to a member of FIS/DCR staff, a Parent Champion or return to:

FIS/DCR, 2nd Floor, Town Hall Extension, Wandsworth Town Hall, SW18 2PU

1. Are you a parent or other carer looking after a child or young adult with special needs or a disability?

Parent Carer Other _____

2. How old is the child/young person you care for who has a special need or disability? (if more than one, please indicate)

Under 5 5-10 11-17 18+ (please specify age if over 18) _____

3. Do you know about the Local Offer?

YES

NO

If you answered yes, what have you used the Local Offer for?

4. Have you made use of any of the following to help you as a parent/carer?

The Local Offer	Yes	No
The Family Information Service	Yes	No
The Disabled Children's Register/WAND team	Yes	No
Contact a Family	Yes	No
WIASS (Wandsworth Information, Advice Support Service)	Yes	No
The Wandsworth Carer's Centres	Yes	No

If YES to any of the above, please say in what way you have been helped the most:

5. How do you prefer to receive information to help you in your parenting/carer role? (please tick up to three from below)

Website	<input type="checkbox"/>	Text	<input type="checkbox"/>
Email	<input type="checkbox"/>	Face to Face	<input type="checkbox"/>
Paper publications	<input type="checkbox"/>	By phone	<input type="checkbox"/>

Other:

.....

6. What sort of information might you find helpful in 2017 or beyond (please tick up to 3)?

Information to:

- help me cope with my caring role
- know about leisure activities for my child/young person
- sort out problems with school/college
- help me at work/getting back into work
- support my personal development/ future career path
- aid my health and wellbeing
- access benefits and housing
- advise about money management/debt
- find support with relationship issues

Other:

7. What would make the biggest difference to helping you manage right now?

8. As a parent/carer do you feel that you receive enough support to balance your caring responsibilities with work/education and to have a life outside of your caring role? YES NO

If you answered **NO** to this question, what would make a difference in future? (tick up to 3)

- More opportunities to work part time or in other ways that are flexible
- More employers who advertise they are 'family friendly'
- More confidence in my abilities to return to work
- Help with reviewing my skills or changing work direction
- Advice about the impact on housing and benefits if working part time
- More childcare available to help me work/study for longer
- Other (please specify)

.....

9. Is there something else Wandsworth Council or others could do to better support parents or other carers of children or young people?

Thank you for taking the time to complete this questionnaire! Please return it to us by 31st May. We will anonymise all the information and feed back the findings to decision makers to help with the development of future services. The findings will also be published on the Local Offer website and reported in our Autumn 2017 newsletter to DCR members