

Short-Breaks Programme Consultation

Southwark Council

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Project Brief

All local authorities within England are required to provide short breaks for families with disabled children under the Children and Young Persons Act. Regulations from 1 April 2011 requires each local authority to produce a short breaks service statement to detail what services are available locally, the eligibility criteria for these services and how the services on offer will meet the needs of disabled children, young people and their families.

Thirteen consultations were conducted with service providers, children, young people and parents across the borough about a wide range of short breaks on offer. This information will be collated and used to inform the short breaks statement in terms of the current program on offer and looking to future service delivery.

A short series of questions was put forward during each consultation session, the results of which are included in this paper along with a brief summary of each group discussion.

General recommendations follow session summaries and reflect the overall feedback received.

	<ul style="list-style-type: none"> • Parent carers accessing services have care package reviews and find out about services • CYP have to be on the disability register in order to access services; being on the register means support but not necessarily a care package. Parent carers need good access to information about community resources and universal services to compliment specialist provision.
<p>Are you consulted enough about Short Breaks Provision?</p>	<ul style="list-style-type: none"> • Not enough input into Short Breaks provision. • Would like to ensure that provision being offered meets the individual needs of CYP and that there is flexibility in level of support required.
<p>Do you feel it's possible for parents and carers to access short breaks on short notice when required?</p>	<ul style="list-style-type: none"> • Most of the services on offer have positive feedback from service users. • CYP with challenging behavior and/or are on the Autistic Spectrum often can't be placed and may end up in a residential unit due to lack of available provision. • If there was sufficient day provision at weekends, overnight respite demand may decrease. • More foster carers and respite carers are needed, however criteria is so strict that many people who apply aren't successful; assessment process for successful applicants is too long. • The Family Link Service is small; there isn't capacity to manage more carers. • There is a gap in emergency provision should parent carers have an illness/overnight hospital stay, etc. and are without a support network. • Many carers are unable to stay with CYP in their home overnight, which means they need to be placed outside the home; parents would prefer overnight breaks in their own home. • There is a distinct lack of available foster carers for in-house overnight respite, especially at short notice. Looking after CYP in their own home (domiciliary care) requires a shorter assessment process and isn't considered to be fostering. • It would be helpful if Orient Street had an emergency provision, including for those CYP not known to them currently, as this facility already exists and is a well known, trusted provision.
<p>Training and Development</p>	<ul style="list-style-type: none"> • There is a lack of disability awareness across the council including information around HIV. • More specialist training is needed to ensure that

	<p>activities for CYP are more inclusive and that disabled children don't miss out due to communication difficulties or medical needs.</p> <ul style="list-style-type: none"> • The Social Care interagency referral form currently doesn't provide contact details for the Children with Disabilities Team. • More robust promotion of current e-learning packages and follow-up training around disability. • Referral and Assessment to increase signposting disabled CYP to appropriate services.
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Contact a Family

Contact a Family is a voluntary service that provides support to all CYP from 0-19 who have an additional need and their families, and remains a key source of information for Southwark residents. They are working with (approximately) 580 families and publish 'The Grapevine' newsletter as one way of regularly reaching service users. Services offered by the organization are access to information, family support work and events coordination.

The service offers various activities both locally and beyond for families to enjoy together, such as trips to the London Zoo or attend an Arsenal game. The cost for such activities is subsidized to help ensure attendance at events, however in some cases fees are refunded. Transport is often arranged so that families can travel together, helping to build community links and develop confidence to travel independently on public transportation around London. Contact a Family use text messages to remind families about events and meeting arrangements, which has proved successful, especially with Dads.

Supporting families to be confident to access universal services is an essential part of the work that Contact a Family does, to help families have broader access to their community and to build support networks with other families. Families need to build trust networks and links in the community, especially for some young people who will still require a high level of care and support in adulthood.

Contact a Family offers a menu of training courses, which can be delivered across the children's workforce and to parents and carers at a lower cost than commissioning training providers, a resource that can be maximized for both in-house and multi-agency training. Small workshops are offered to parents when requested, i.e. around the DLA, how to apply for different kinds of funding or relevant national issues.

Orient Street

Orient Street is a 4-bedded respite unit where profoundly disabled children are referred by Social Services for overnight and weekend respite. In addition to the children's unit there is also an adult unit with a similar configuration. An additional bedroom was requested downstairs, however when this bed is occupied Orient Street is fully booked and an extra member of staff is needed which requires additional funding – in most cases Social Services is unable to fund this extra place. All clients who receive a service at Orient Street are on the disability register.

The Unit Manager often covers shifts/part of a shift in an emergency, and agency staff is then employed and funded by Social Services to provide cover and relieve the Manager. Orient Street have 45 children and young people known to them currently who have been assessed and are receiving regular respite either monthly or every 6 weeks, either as a one night or two night stay. Carers can submit an advanced booking request of up to seven nights if they wish to go on holiday.

As there aren't sufficient funds for 1 to 1 support, the unit often needs to block a bed and allocate two places to one child which doubles their unit cost in order to ensure sufficient staff coverage. Some children stay during the week as they are unable to cope well with an entire weekend day; transportation is provided for them between the unit and school for weekday stays.

There is a panel meeting with the Children with Disabilities team to discuss referrals from Social Services and review care plans for service users. Prior to staying at the unit, children are visited at school, and their family is visited at home or they attend a site visit. Children also have a tea visit and then try a one-night stay.

Orient Street has capacity during the school day in term time (approx. 9:30 a.m. to 2:30 p.m.) to contract out the space for structured activities. This would help develop a higher profile of the provision, maximize the space and potentially generate revenue, as well as offering a cost effective venue for professionals and partner agencies who need a safe space.

Of current concern for Orient Street staff is the process for purchasing goods and/or services; the current system is time and resource intensive and doesn't provide good value for money. It would be helpful for this process to be reviewed to support service delivery.

Staff turnover is low at Orient Street, and managers and staff have a rota, overtime and flexible working system that works well and meets the needs of service users and staff. Occasionally additional staff is needed and there are systems in place to support this need. However, the unit is required to procure agency staff through Comensura who acts as a broker as staff can no longer approach individual agencies. However, Comensura often supply staff who don't have appropriate security checks when they present for work and therefore are not permitted to stay, leaving a staff shortage for that

particular shift. It is also felt that Comensura use lower paying agencies who often provide unsuitable staff for this specialist environment.

Peckham Park Carers

Carers at Peckham Park were consulted on its last day of operation before the site would become part of the Academy in the main school building. Various concerns were raised about future provision for the CYP who regularly attend and benefit from the Peckham Park Program:

What concerns do you have about the future for this particular group of CYP?

- Transition to the new site has not been planned - a staged transition would help these CYP adjust to a new environment better as keeping routines is very important for them.
- Staff consistency, wherever possible is also important, especially during times of transition. Long-term carers have invaluable experience with and information about CYP who attend this site – how will they be handing over this information to staff at the new site?
- Will the new site meet the needs of this group of CYP effectively?
- Are the staff at the new site experienced enough to manage these CYP as they have complex and profound needs and often exhibit challenging behavior?

What other concerns do you have as carers?

- Staff are not assured that the new provision has had comprehensive and appropriate health and safety checks completed; several staff members are considering not working at the new site because they feel it is unsafe for this group of CYP (i.e. securely locked doors)
- Rate of pay at the new site are significantly lower than staff are paid now in Southwark – has any provision been made for carers who have been working in the borough long-term?
- There appears to be less spending per child – concerns that this may reduce the quality of the activities offered.
- Some carers used to be re-imbursed by Social Services to pay for travel to accompany CYP on special trips – this is no longer being provided, which means that carers are using their own money to travel in London to support their client(s).
- Agency commission fees are extremely high – consider offering carers better rates of pay and utilize staff from local schools and other services in the borough that are already working in Southwark to keep costs down and provide better local knowledge.

Playscheme and After School Service, Cambridge House

The Playscheme Service provides a specialized comprehensive program during the Easter and Summer Holidays, 8 days and 16 days of activities respectively. The activities are varied and include physical and creative activities as well as trips to local attractions. All of these are specifically tailored towards the individual needs of clients with learning disabilities. This year funding permitted approximately 88 children and young people to access these services, however the need for these services extends beyond the amount of places offered this year.

Some parental contribution per day is required in addition to Social Services funding in order for their child/ren to attend these programs. Depending upon the family income, Social Services can also pay a proportion of these contribution fees, though the process for this is complicated and time consuming.

During term time, there are various after school programs on offer including a program for approximately 6 clients at Cherry Gardens School from 3:15 – 6:30 from Monday to Friday (including drop-off of clients) and an after school arts based program on Wednesdays at Queens Road, Peckham for 6 clients, average age being 8-16 from 3:15 – 5:30. Transport to home addresses is provided for clients participating in the Cherry Garden provision but there is no transport included for the Wednesday Afterschool service. Referrals to both programs are either from Special Schools directly or via Social Services.

Strategic marketing of these programs is essential in order to provide a service to a wide range of CYP with additional needs, including canvassing both special schools and mainstream schools with special units on site.

A summary paper will be available shortly in regards to the services provided and the outcomes of this year's program, which will set out the summer scheme in more detail.

The two most difficult areas for this program are similar to concerns raised by other services, so a detailed list of these challenges has been included below:

Staff
<ul style="list-style-type: none">• Volunteers were recruited through various local colleges including art students to provide art therapy, however only a handful of volunteers worked on the program; procuring volunteers requires more advanced planning than time permitted this year.• The program in some ways is easier to manage without volunteers, as they often have less training, less experience working in a professional environment and require extra supervision, which can be labor intensive.• For the summer program a more professional and experienced staff group was employed as a result of a comprehensive recruitment campaign.

- A new pool of staff was selected via a formal interview process with CRB checks undertaken from the point of hire.
- Experienced staff were also mixed with new members of staff to maintain a more professional and less familiar atmosphere.
- One off funding of was provided by United St. Saviours to deliver a Circus Skills based program for CYP with less severe needs. This ran simultaneously to the council funded program, providing for the division of clients by ability, which was positive because it ensured that all CYP were able to access a program that met their individual needs. The Circus Skills program was also designed as a sibling project; some siblings attended however not as many as desired.

Transportation

- This summer program used Lambeth and Southwark Community Transport (LASCOT) Transport instead of Ruskin as their rates were more competitive and they provided a more professional service.
- Parental contribution was required of £10 per day without transport, and £15 per day with transport
- Approximately 90%+ of parent carers wanted transportation to and from home.
- Coordinating driving routes for buses and measuring travel time is difficult, so the amount of transportation available has been slightly reduced.
- LASCOT buses are not large enough to accommodate a full group of wheelchair users. Therefore, for the second week of the program extra Ruskin buses were bought in, to better accommodate wheelchair users.
- For week 1 of the program the buses were divided by geographical area, which meant a mix of ages on the bus and all 5 buses had to arrive at the center prior to commencing any planned group activities for the day. This often meant a long wait time with individual activities at the center depending on traffic before the group could go for example on an off-site trip.
- For weeks 2-4 bus routes changed to make sure that they were divided by age groups (Under 8's, 9-11, 12-14, 15-18) with designated staff on each bus that families knew and were familiar with. This reduced travel time and improved consistency of personnel.
- There was also a Special Care bus for service users with profound difficulties of all ages.
- Wherever possible it would be helpful to have consistent drivers, however this proved to be difficult to manage. Training staff who work on the Playscheme in future to drive minibuses would reduce the costs, increase staff skills and employability and ensure a more consistent and tailored service was provided.

Resources for Autism

Resources for Autism provide a variety of short break programs in different areas, with staff being assigned to one particular borough to ensure continuity with children and young people.

The Monday night after school club takes place at Spa School from 6-8 p.m. and has capacity for up to 12 young people ages 14+ who are on the Autistic Spectrum. Staff wear matching orange t-shirts and/or sweatshirts, which immediately gives the impression of being part of a club or a team. Each week has a different activity focus such as baking, bowling or a treasure hunt, however free play is also incorporated into each session so that young people have a choice of what they would like to do. The final week there is an awards ceremony and each young person is recognized for something they have achieved during the term.

This club provides 1 to 1 support for those who attend and there was a good staff to young person ratio. The club has access to the school facilities including an art studio and a large outdoor play area so the building is well resourced for the program. Transportation is not provided, so young people need to be dropped off and picked up for the club unless they are able to travel independently. Referrals come from parents themselves or from school Senco's.

As it is the start of a new term, a few members of staff are new to the team and returning staff are just getting to know their clients and settling in to a new environment so feedback has been provided based on staff experience of working in Southwark:

- Swimming is regularly requested – would like to include in the program as much as possible.
- There are not enough places on the summer program for everyone who wants to attend so clients are offered one or two weeks instead of the full 3-week provision.
- There should be more resources for children under 8 on the Autistic Spectrum.
- Previously programs were divided by ability so that CYP could access more appropriate activities – staff generally felt that this works better than whole group activities and is preferred.
- This club can accommodate 12 young people – need to ensure that all places are being utilized to maximize the provision.

Salmon Youth Center

Salmon Youth Center offers a variety of short breaks and programs for CYP across Southwark. In addition to offering inclusive holiday provision for 12+ young people such as day trips (i.e. Cinema, ice skating, London Eye, Snow Center) and residential trips during the summer, Easter and half-term breaks, there is a weekly youth club called the “Mixable” for 14+ young people with an additional need. Transport is available for this program, however it’s limited and young people who can travel independently are encouraged to do so.

Feedback received about programs on offer is generally good; referrals are generally word of mouth, however the Children with Disabilities Team and Connexions often make some referrals, with one or two referrals coming from special schools. Generally, Social Workers and Teachers pass along valuable information about the young people being referred to the Salmon Center, helping them to provide the appropriate support.

Salmon also offers an inclusive young volunteers program, which currently has 12 volunteers, at least 5 of whom have a special or additional need.

The biggest challenge for Salmon at this time is that due to staff shortages, programs on offer are more limited than the center would like to provide. This also creates a shortage in available transport because there isn’t sufficient staff to release to drive the mini-bus. For those CYP who can travel independently with supervision, some consideration will be needed in terms of the ‘walking bus’ idea, or having volunteers accompany groups of young people to the center from school or a designated meeting point.

Advertising for programs would benefit from some support to help promote the center, and having a Disability Manager as a dedicated resource would improve accessibility to the center. Currently programs are first come first served, however it would be beneficial to offer a full program across the borough.

Salmon Youth Center may be one of the largest youth clubs in Europe so attendance at activities should be maximized!

Parents and Carers – Service Users:

Parent Carer Council (PCC)

The Parent Carer Council has a large number of involved families so information was collected through a series of consultation events at Cambridge House with both Executive Members and Council Members.

Access to Information and Services

- Parents would like a definition of ‘Short Breaks’ and ‘Short Breaks Services’, who it applies to and criteria for receiving services.
- It should be easier to find out what services are available and if there is a cost implication; service directories are often out of date.
- Parents feel that only CYP with learning needs are able to access services, physically disabled CYP often don’t meet the criteria for services. ‘Moderate’ needs don’t qualify for a Social Worker, which then prevents access to some services.
- Families viewed as ‘able to cope’ are not given services unless they declare themselves at crisis point; it is perceived that families with adopted children receive more services than those who have disabled children.
- Parents who empower themselves to access information about their child/ren’s condition(s) are often discharged from services.
- Parents signed up to the forum receive emails, newsletters and email from Contact a Family, PCC website and can access information at Sunshine House. Most information is received by word of mouth, as this is the most reliable way to learn about services. Libraries and schools/nurseries are also preferred sources of information.
- Eligibility criteria are unclear – packages vary greatly between CYP and parents often don’t understand how/why. It appears that packages are offered to offset a family breakdown, so those in crisis or those who articulate most receive more services.
- The ‘panel’ process isn’t satisfactory and there is the concern that personal judgments of some professionals may affect the care package (process currently under review).
- Carer assessments take too long and families are often waiting for a service.
- SEN Statementing process is very long and parents don’t feel supported during the process.
- For those families receiving the Disability Living Allowance, is there a monitoring

system in terms of how it's being used?

- Disabled CYP attending mainstream schools are often unable to access after school clubs and programs there without 1 to 1 support, as staff feel unable to provide the appropriate level of care.
- Universal services across Southwark are not accessible for disabled CYP in most cases, and families do not feel welcome by staff.
- Young people 19+ are often left without services and parents feel they don't know where to go to get help, including information about social activities and work experience. Vulnerable young people also need support to access transport and to be independent, which also isn't forthcoming.
- Parents who receive money for the 'Fix Yourself a Break' Scheme appreciate the gesture, however are left with finding their own holiday and some find this difficult as they are not signposted or provided with details of agencies who can help them find a suitable break.

Consultation

- Parents appreciate the opportunity to be consulted, however feel that they don't find out the results of the consultation and are not given sufficient explanations about why some changes can't be accommodated.
- Some consultation periods are too short so parents don't have time to meet the deadline
- Various methods need to be used to collect information (i.e. face to face meetings, questionnaires, electronic surveys, mail drop, phone survey) to encourage parent participation.

Direct Payments(DP)

- Some parents are using Direct Payments however it adds stress, as it requires extra administration time and IT access (i.e. computer/scanner/fax/photocopier - potential cost implication if no computer at home). Parents must manage carer payments, National Insurance, payroll/PAYE/Taxes and timesheets, as well as may need support to apply for an enhanced CRB for the carer. There have also been difficulties with some payments not being received, which creates extra work and stress.
- Parents feel DP should be easier to manage with more control over what they can purchase.
- The view is that with DP parents receive less support (i.e. 4 hours of care instead of 6).
- Parents feel that the transition to new provision is often delayed because of DP and the process (i.e. from Peckham Park to Camden Society).
- Experiences with Agency Carers have not been favorable on the whole; parents often have to find their own carers, which takes time and resources.
- If a parent manages to find a carer privately who isn't registered with an agency, a CRB may not have been undertaken (which has time and financial implications), and the carer may not have had recent training opportunities for their practice to stay current.
- Privately arranged carers provide more flexibility in terms of their hours and when they work each week, depending on the needs of the CYP and their family.

- Greater flexibility with/understanding of DP may encourage more parents to engage with this system. More information about Personalized Budgets would also be useful as this is likely to be introduced in the future.
- Some parents would prefer their child (ren) attend a provision that's paid for as it's more secure and structured, and easier to manage if it's paid for by Social Services rather than DP.

Professional Networks and Support

- General impression that there is not enough 1 to 1 support available so CYP are often missing out because they cannot attend some provisions without support.
- Mentors and Befrienders are viewed more positively than agency staff; experience is that agency staff can be inconsistent, are often poorly trained and difficult to find a suitable carer.
- There is a lack of male carers for boys
- Support networks for parents are very helpful but should include some events where parents can have a break and not focus on disability.
- Schools are viewed as not inclusive enough, and 'inclusion units' at mainstream units are often isolated/separate making CYP feel even more excluded. Need to ensure that CYP with additional needs at mainstream schools can still access after school activities.
- Some schools are not open enough with parents who sometimes find out things from their child (ren) after the fact.
- Families often feel socially isolated which can lead to mental health concerns for both children and parent carers.
- Need a more robust system around Team around the Child/Family meetings taking place; current view is that they usually take place as a crisis meeting, lead by Social Services.
- Most families do not have an allocated Keyworker or Lead Professional to help lead the professional network. Families are telling their story more than once and do not feel that professionals are working together to share information and safeguard CYP. Some parents are calling their own Team around the Child meeting!

Service Delivery

- There are many well-received services being delivered, such as Sports Camps and the hydrotherapy pool, which families are grateful for and appreciate.
- More 1 to 1 support available and/or more opportunities for parents to use direct payments to provide support so CYP can attend more activities.
- Waiting lists for services can be too long; in some cases if a provision is full, the CYP isn't offered an alternative provision.
- Families would like more provision that includes siblings as well as more inclusive programs.
- Parents need to feel secure during a time of significant change that they will still have services and provision available and that the buildings where their child (ren) attend activities are safe and secure environments, particularly for those CYP who often run away.
- Summer programs aren't long enough currently, so CYP are then required to

have various periods of transition during the summer: school to home/home to their summer program/end of program back to home/home back to school. The establishing of new routines takes time, and the current arrangements mean that the whole summer is spent moving from one phase to another, which can be difficult to manage, and upsetting for CYP who require routines.

Children and Young People – Service Users:

Monday Club @ Spa School

The Monday Club @ Spa School is run by Resources for Autism once a week from 6-8:00 p.m. There is capacity for up to 12 young people to attend this program who are 14+ and on the Autistic Spectrum. The young people attending this program enjoy their time at the club and engage well with staff. As it was the start of term they had some circle time to share something about their summer break, had some free play outside and then worked on an art project in the studio, which is well resourced.

On this occasion there were 5 young people who attended and they provided me with the following information:

- They would like more swimming
- If club could run another night of the week they would like to attend.
- Club is fun and they like being away from home after school

Peckham Park

Peckham Park is a specialist provision for CYP with profoundly complex needs, many of whom are also on the Autistic Spectrum. There is a 1:1 staff ratio given the level of needs of this client group.

Four young people with the help of their carers participated in an informal consultation session at Peckham Park in it's last day of operation before the building will be turned over to the Academy in the main school site.

At the time of the consultation, these young people would be returning to school without an after school/evening short break provision. One young person who had already turned 19 was still attending Peckham Park provision, as a transition to adult services had not yet been arranged.

Feedback from young people was as follows:

Which activities do you enjoy most?	Cinema Day trips to the city to see architecture/buildings around London
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	Riding the bus/train Rock climbing Space to run Sports Swimming Visits to the park
Which activities would you like to have more of?	Activities to help increase independence Increased space More trips – would like to visit LEGOLAND Residential trip for 2-3 days Seaside trip

Conclusion

In summary, this exercise has been successful in offering service providers, children, young people and parent carers an opportunity to feedback about their experiences with the Short Breaks Program in Southwark. Discussion sessions were welcomed and feedback was constructive in terms of what areas should be looked at in the coming year(s). **Overall feedback about services and resources was very positive and appreciated, with the view that the core offer is very good and delivers a high standard of short break for families.**

It is evident that children, young people and their families value their short breaks very highly, and would like more – as much as possible! These breaks are essential for families as they provide much needed respite as well as ensure that children and young people have access to social and recreational activities away from home. A clear message that was consistent across the consultation meetings was that with less short breaks, there would be a greater need for overnight respite care. Therefore, suggestions and feedback generated during consultation sessions should help inform future service delivery to ensure that Southwark maintains it’s short break offer and delivers services according to local need.

In addition, Southwark is fortunate to have such a wide range of service provision with very committed and dedicated staff that are passionate about the communities they serve and the work they do.

Shaping Future Service Delivery

Throughout this consultation exercise, feedback was provided in terms of looking ahead to the future and improving services for disabled children and young people and their families. While families understand that not all changes will be possible, it was

suggested that some areas of work would benefit from being reviewed even if only small adjustments could be made. Service delivery should also ensure that it is fully inclusive of all CYP in Southwark with an additional need, as many of these vulnerable clients will not be known to Social Services.

Feedback from the consultation exercises can be divided into 5 main areas:

- 1. Access to Services**
- 2. Commissioning**
- 3. Consultation**
- 4. Resources**
- 5. Safeguarding Responsibilities and Integrated Service Delivery**

More detailed suggested work plans have been set out in Appendix A, B and C to help inform future discussions.

A special thank you to those who participated in this consultation exercise and who have contributed to the content of this paper:

Children with Disabilities and Complex Needs Team
Contact a Family
Family Link Service
Linda Cleverly, Child and Young Person's Advocate (Disability)
Orient Street Staff
Parent Carer Council Executive Committee and Forum Members
Peckham Park Young People and Staff
Playscheme and After School Service, Cambridge House
Resources for Autism
Roger Weissman, CAMHS Social Work Team Manager
Salmon Youth Center
Young People @ Monday Night Club, Spa School