CONSORTIUM ADMINISTRATION

LEAD ORGANISATION

Last year Autism Bedfordshire continued to act as the Lead Organisation for the Consortium, and its Operations Manager oversaw the Consortium’s administration, quality review, financial planning and monitoring, and performance management.

CONSORTIUM MEETINGS

Three Consortium meetings were held last year, in May and October 2018, and January 2019. At the meetings Consortium members discussed issues relating to the Consortium’s funding, services and reporting.

CONSORTIUM FINANCES

Following the cut in funding in 2017/18, the gift funding received from London Luton Airport Ltd last year stayed at £280,000. This amount did not meet the full needs of Consortium members to maintain their services. Although the Consortium was again able to use some of its reserves to support members, an average cut of 2% in funding had to be imposed.

* To help maintain the level of services and the funding allocated to individual Consortium members and partners, the Consortium decided to use some of its reserves (£13,562) to help boost the level of gift funding received last year.

The table above only gives a summary of the Consortium’s finances. A copy of the full accounts for 2018/19 is available from Autism Bedfordshire.

KEY PERFORMANCE INDICATORS

A separate, supplementary report has been produced on the key performance indicators for the Consortium and the Lead Body, which are part of the Consortium’s funding arrangements with LLAL and LBC. This supplementary report is available from Autism Bedfordshire.

Tel: 01234 214871  Email: len.simkins@autismbeds.org

June 2019
INTRODUCTION

BACKGROUND

The Luton Voluntary and Community Sector (VCS) Short Breaks Consortium was set up in 2013. The Consortium brings together a number of not-for-profit organisations that provide short breaks services for children and young people with a range of disabilities in Luton.

The Consortium receives a gift from London Luton Airport Limited (LLAL) through its Partnership Fund. Luton Borough Council (LBC) works closely with the Consortium and provides expert guidance, when sought. The work of the Consortium fits into LLAL’s and LBC’s Corporate Social Responsibility Programmes, and meets the outcomes in Luton Forum’s Sustainable Community Strategy 2008-2026.

Autism Bedfordshire was appointed as the Lead Partner for the Consortium in 2013 and continues to act as the lead in dealing with the management and administration of the Consortium, as well as the allocation of funding to Consortium members. An Operations Manager at Autism Bedfordshire is responsible for this management work for the Consortium.

CONSORTIUM MEMBERS

The 6 Consortium members in 2018/19 were:

- Autism Bedfordshire
- Centre for Youth and Community Development (CYCD)
- CHUMS
- Friends of Bright Eyes (FOBE)
- Families United Network (FUN)
- Special Needs Out of School Club (SNOOSC)

In 2018/19 the Consortium also worked closely in partnership with Luton Parent Carer Forum, who were commissioned to provide services for the Consortium.

LUTON PARENT CARER FORUM

In 2018/19 the Consortium again worked closely with Luton Parent Carer Forum (LPCF), which is the parent led organisation enabling parents of children with special educational needs and disability to have a say in shaping future, local services.

The Consortium also helped to fund LPCF in 2018/19 with:

- A contribution towards the cost of LPCF’s general services — which included a survey of LPCF members
- A contribution towards the funding of LPCF’s Parent Mentoring Service
- Funding for LPCF to have an input into the Consortium’s assessment panel for its funding allocations in 2019/20

LPCF GENERAL SERVICES

LPCF’s general services in 2018/19

- Open meetings — 4 meetings were organised in 2018/19 on: Global Developmental Delay; and 3 meetings relating to Luton’s Area Inspection.
- Workshops — 4 workshops were organised: Talking through art (x2); Mental Capacity Act; and Finding your voice.
- Newsletters — 3 editions of the newsletter were published covering: LPCF workshops and events; LPCF’s Parent Mentoring Service; the Disability Register Carer’s Card; and the Luton Local Offer
- Website and social media services — providing information on LPCF activities.

LPCF PARENT MENTORING SERVICE

The funding from the Consortium allowed LPCF to continue to run its Parent Mentoring Service. Last year 80 mentoring sessions were held, providing 148 hours of access time, 110 contacts were made by parents, and, from these contacts, over 100 parents were signposted to Luton’s Disability Register and to local short break services, and 37 parents were given full 1-to-1 mentoring support. Sessions were held at the Edwin Lobo Centre, and some local children’s centres and primary schools. There continues to be very positive responses from the special needs co-ordinators at the venues, and from parents.

Quotes from parents supported by the Mentoring Service

- "You have provided me a lifeline. I have met so many mums like me"
- "The Disability Register was a great piece of information. I had no idea we could carry a card to get concessions. Thank you so much. I will register today"
- "Thank you so much. I feel very informed now and I didn’t receive any such support when my youngest was diagnosed"
OTHER CONSORTIUM ACTIVITIES

PLAY SESSIONS FOR AUTISTIC CHILDREN

Autism Bedfordshire organised 3 soft play sessions at the Future Fun Factory in Luton, which were promoted through all the Consortium members. The sessions were open to any children with autism and their siblings in Luton, and were held in the half-term holidays in May and October 2018 and in February 2019.

The play sessions were very successful and were attended by 31 autistic children (and 13 siblings). In total 88 short break hours were provided.

NB To avoid double-counting, the figures above have not been added separately to the Consortium’s overall short break figures report because they are already included in the Autism Bedfordshire figures on Page 6 of this report.

JOINT TRAINING

Last year, for the first time, the VCS Consortium organised some joint training for Consortium members. The training was a two day course on “Team Teach”, which is the recognised training required for staff likely to need physical interventions in their work.

The training was held at the FUN premises in Luton on 23rd and 24th January, and was attended by 12 staff from Autism Bedfordshire, CYCD, FUN, FOBE and SNOOSC.

Arranging the course jointly enabled Consortium staff to attend this much requested training at a reasonable cost. It would have been prohibitive for each member to organise an internal course for their own staff.

OVERVIEW OF WORK IN 2018/19

2018/19 was another very successful year for the Luton Voluntary and Community Service Short Breaks Consortium with members helping over 370 children and young people with disabilities (aged 0-18) from Luton and over 80 siblings.* Consortium members organised over 670 short break sessions which provided parents and carers in Luton with over 30,000 short break hours.

* Some children and young people (and siblings) attended services with more than one Consortium member. The number of unique children with disabilities supported by the Consortium was 285, and the number of unique siblings supported was 79.

SUMMARY AND FUTURE OPPORTUNITIES

Last year, despite another real cut in its funding, the Consortium managed to continue to provide a very wide range of services to a wide range of users.

There was a small (0.3%) decrease in the number of short break hours provided, compared to the previous year, but this was a good overall performance considering that Consortium members received an average 2% cut in their funding last year.

Despite the range of services provided, there were still some identified gaps in provision in 2018/19, and the Consortium will try to address these in the future, if funding and other priorities permit:

- Continue to attract more girls to Consortium services. (Only 35% of users are female)
- Attract more users from the LU1 postcode area. (Only 11% of users come from LU1)
- Provide some overnight short break stays. (None are currently provided)

Obviously a major concern for the Consortium looking forward is the uncertainty about the future structure of the LLAL funding system which is due to change in April 2020. It is very difficult to make future plans until there is clarity on the new funding system.
CONSORTIUM SERVICES

SUMMARY

Consortium members provided a wide range of short breaks services in 2018/19 including: after school clubs, weekend clubs, holiday playschemes, and trips and outings. The funds from LLAL help provide short breaks services for children and young people with disabilities aged 0–18, who live in Luton. Some Consortium members also encourage siblings to attend some of the sessions that they provide.

<table>
<thead>
<tr>
<th>Provider</th>
<th>Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Bedfordshire</td>
<td>Loads of Autistic Fun, Wanted Fun, Summer activity schemes (5), Other services</td>
</tr>
<tr>
<td>Centre for Youth and Community Development</td>
<td>After School Club, Saturday Club, Holiday schemes</td>
</tr>
<tr>
<td>CHUMS</td>
<td>Friday Club, Holiday Club</td>
</tr>
<tr>
<td>Families United Network</td>
<td>Saturday Respite Club, Holiday Club, Holiday Respite Club</td>
</tr>
<tr>
<td>Friends of Bright Eyes</td>
<td>Weekday evening clubs (6), Saturday Club, Sunday Club, Holiday schemes</td>
</tr>
<tr>
<td>Special Needs Out of School Club</td>
<td>Specialised Saturday Club, Specialised Holiday Club</td>
</tr>
</tbody>
</table>

In 2018/19, the Consortium also helped fund the Parent Mentoring Service, which was run by Luton Parent Carer Forum.

TYPE OF USER

Consortium users with disabilities are recorded under three categories of impairment. In 2018/19 the numbers in Group C (which covers children with more complex needs) increased from 7% to 11%. Some services also cater for siblings of a disabled child or young person, and the number of siblings supported is recorded separately. This support provided for siblings is very important because research shows that siblings of a disabled child are also significantly disadvantaged.

<table>
<thead>
<tr>
<th>User type</th>
<th>Consortium users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group A — Learning or developmental impairment (eg autism)</td>
<td>64%</td>
</tr>
<tr>
<td>Group B — Physical impairment</td>
<td>3%</td>
</tr>
<tr>
<td>Group C — Mixture of developmental and physical impairment</td>
<td>11%</td>
</tr>
<tr>
<td>Siblings — Not disabled</td>
<td>22%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

GENDER

As in previous years more males continued to be supported by the Consortium than females. This is because a higher proportion of males than females are affected by certain illnesses and disabilities. For example, various studies have shown that 3-4 times as many boys are diagnosed with autism than girls. However, an ongoing target for the Consortium is to increase the number of female users, and this objective was again met last year.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Consortium users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>65%</td>
</tr>
<tr>
<td>Female</td>
<td>35%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

The % of girl users increased to 35% from 34% in 2017/18

POSTCODE AREA

Consortium services are provided across Luton in all four of the postcode areas in the town. However, the numbers of Consortium users living in the different postcodes does not match the breakdown of the general population across Luton. There may be logical reasons for this, but nevertheless, the Consortium is trying actively to recruit more users from the proportionately under-represented LU1 postcode.

<table>
<thead>
<tr>
<th>Postcode area</th>
<th>Consortium users</th>
<th>Luton population (based on 2011 Census)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LU1</td>
<td>14%</td>
<td>20%</td>
</tr>
<tr>
<td>LU2</td>
<td>24%</td>
<td>27%</td>
</tr>
<tr>
<td>LU3</td>
<td>40%</td>
<td>29%</td>
</tr>
<tr>
<td>LU4</td>
<td>22%</td>
<td>24%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>
ANALYSIS OF CONSORTIUM USERS

ETHNIC ORIGIN

Luton has a very diverse population. Prior to 2016/17 the ethnic mix of Consortium users (i.e., disabled children and siblings) was fairly similar to that in the overall population of Luton. However, in 2016/17 and 2017/18 there was a significant increase in the percentage of Asian users in the make-up of Consortium users. In 2018/19 the figures were almost the same as in 2017/18. The number of Asian users was again higher than the number of white users. Users from Black and Minority Ethnic (BAME) groups continue to account for 67% of Consortium users.

<table>
<thead>
<tr>
<th>General ethnic group</th>
<th>Consortium users</th>
<th>Luton population (based on 2011 Census)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>33%</td>
<td>55%</td>
</tr>
<tr>
<td>Asian</td>
<td>48%</td>
<td>30%</td>
</tr>
<tr>
<td>Black</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>Mixed</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The two largest specific groups of Consortium users by far were:
- Asian—Pakistani: 35%
- White British: 31%

There was then a large gap to other specific groups:
- Asian—Bangladeshi: 7%
- Black—African: 5%
- Asian—Indian: 4%
- Asian—Any other Asian background: 3%
- Black British: 3%
- Other British: 3%
- Mixed—White and Asian: 3%

All other specific groups consisted of 2% or less of total users.

AGE

The Consortium’s services are generally open to children and young people aged 0-25 although the LLAL funding only pays for services provided to 0-18 year olds. Therefore only children aged 0-18 years old have been recorded in this report. The table shows that LLAL funded services were provided to a very good mix of different aged children. The breakdown of ages is very similar to last year’s figures.

<table>
<thead>
<tr>
<th>Age</th>
<th>Consortium users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 5</td>
<td>13%</td>
</tr>
<tr>
<td>5-9</td>
<td>33%</td>
</tr>
<tr>
<td>10-14</td>
<td>40%</td>
</tr>
<tr>
<td>15-18</td>
<td>14%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

CONSORTIUM PUBLICITY

CONSORTIUM FLYER

The Consortium produces an A4 flyer which helps to promote the Consortium’s services.

CONSORTIUM CALENDAR

The Consortium also produces a quarterly calendar which gives full details of the services arranged for the quarter. This is used in the Consortium’s planning process and helps to promote the full range of Consortium services.

CONSORTIUM WEBPAGE

The Consortium has a webpage on Autism Bedfordshire’s website. This webpage has links to the Consortium’s key documents (e.g., latest Annual Report), and links to the websites of each of the Consortium members.

www.autismbedfordshire.net/about-us/

LUTON LOCAL OFFER

The Consortium, and the services provided by each Consortium member, are publicised as part of the Luton Local Offer, which provides information on services for children and young people (aged 0-25) who have special educational needs or disabilities (SEND).

www.directory.luton.gov.uk/kb5/luton/directory/localoffer.page?localofferchannel=0
AUTISM BEDFORDSHIRE

Autism Bedfordshire is a charity that works across the whole of Bedfordshire — in Luton, Bedford Borough and Central Bedfordshire. It has been providing information, advice and support to autistic people, their parents and carers, and their siblings for 28 years. As a service provider in Luton, Autism Bedfordshire provides various short break services as part of the Consortium’s offer.

+ 2,155 short break hours provided
+ 82 disabled children helped (and 18 siblings)
+ 75 support sessions organised

Case Study

A is 7 and is new to the Luton LOAF group and has been coming for half a term now. He is mostly non-verbal and can sometimes display challenging behaviour, especially when he cannot articulate what he wants or how he feels.

Before the first session, Mum had said she was very nervous because A struggles in new situations. She was reassured that the staff at the group are friendly and patient, and have good skills in communications and managing challenging behaviours.

At the first session A came running through the doors. After 5-10 minutes of pacing around the venue, he then sat down and began playing and interacting with his support worker. This allowed Mum to have short break where she had tea with other parents.

The team at LOAF are determined to continue helping A to gain new experiences, despite his occasional reluctance!

SPECIAL NEEDS OUT OF SCHOOL CLUB (SNOOOSC)

SNOOOSC is a local charity which has operated for 18 years. It offers full respite services for children and young people with complex/profound disabilities including severe learning/behavioural difficulties. At all its short breaks sessions, SNOOOSC staff provide 1-to-1 care and intimate care services, and 2-to-1 care for some children. SNOOOSC is based in Houghton Regis in Central Bedfordshire and users come from the local area and from Luton.

+ 1,902 short break hours provided
+ 12 disabled children helped
+ 67 support sessions organised (with Consortium funding)

Feedback from parents

“Thank you for all your patience and support. Much appreciated.”

“All the staff are fantastic,”

“Very beneficial to me to regain some time while my is safe and happy. Very thankful to all the staff involved.”

Case Study

A has autism and ADHD and lives in Luton with his parents. He attends the Specialist Saturday Club and the Specialist Holiday Clubs. When he first joined the Saturday Club he was upset because it was the first short break service that he attended on his own. He was provided with 1-to-1 support and, with encouragement and lots of interaction from the staff, he soon became very comfortable with his surroundings. He has boundless energy and enjoys ball games. On group activities out in the community A’s behaviour is sometimes challenging but staff have now developed different strategies to cope with this.
**FRIENDS OF BRIGHT EYES (FOBE)**

FOBE is a local charity based in Luton. It provides a range of short break activity clubs, holiday schemes, and trips and outings for disabled children and young people with disabilities (aged 8+).

**Weekday evening clubs** - 6 clubs were held during the week in different locations in Luton — at Chaul End Community Centre; Dallow Learning and Community Centre; Stockwood Academy; and three clubs at Lady Zia Wernher School. Most of the clubs ran for 37 weeks in term-time, although the two Monday clubs only ran for 35 weeks due to bank holidays.

**Weekend clubs** - A Saturday Club (at Beech Hill School) and a Sunday Club (at Lady Zia Wernher School) ran for 37 weeks in 2018/19.

**Holiday club** - Clubs ran for 15 days during 2018/19 in the Easter, summer and winter holidays based at Lady Zia Wernher School. On some days outside trips were arranged.

• 8,161 short break hours provided
• 76 disabled children helped
• 307 support sessions organised

**Feedback from parents**

- "My daughter looks forward to attending FOBE as she doesn’t have many friends that she sees out of school. It lightens up her Mondays" (Mother of 15 year old with Developmental Delay)
- "He gets to go out and do activities, and enjoys FOBE more than anything else!" (Father of 11 year old with ASD)
- "My son loves attending the clubs. He has made some great friendships. The social aspect is really important for him. I'd just like to say thank you to everyone for their help and support." (Mother of 17 year old with Autism and Global Developmental Delay)

**Case Study**

J is a 14 year old with autism. He always found it difficult being in a group, especially being around smaller children. Initially he wouldn't talk a lot or engage socially, and had frequent meltdowns—often using bad language, and sometimes picking on smaller individuals at the club. J was shown how to say hello appropriately and was given a lot of positive encouragement. He now has a friendly approach and will actively go and say hello to everybody at the club. He is also much happier now in group games and waits his turn patiently without having an outburst. These positive behaviours are now habit.

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**CENTRE FOR YOUTH AND COMMUNITY DEVELOPMENT (CYCD)**

CYCD is a local charity based in Luton working mainly with the local South Asian community. As part of its **Access Disability Project**, CYCD provides a range of short break services for children and young people with disabilities. The project aims to change negative attitudes towards disability within the Asian communities by focusing on each young person’s abilities, giving them opportunities to develop to their full potential and demonstrating that each child or young person is valued.

**After School Club** - Children’s club for disabled children aged 6-11. It runs every Wednesday in term time at CYCD in Bury Park, Luton. 36 sessions of the club were held last year.

**Saturday Club** - Youth club sessions for children and young people aged 11-18. The club runs every Saturday during term time at CYCD in Bury Park, Luton. 44 sessions of the club were held last year.

**Holiday Playschemes** - These schemes were provided on 35 days during the school holidays for children and young people. The schemes included various activities and trips to local educational, recreational and adventure centres.

**Feedback from parents**

- "While my child is at CYCD, I can take my other kids out and have some quality time with them. I really enjoy the break and can spend time with the rest of my family and do other things."
- "My son has been attending ADP for over a year now and he absolutely loves it. He is a very hyperactive child but he loves to socialise and ADP provides a safe environment where he can release energy, socialise and meet new friends. It provides a much needed break for the rest of the family at home and gives us peace of mind knowing our son is in safe hands and is under proper care from the moment he is collected to when he is brought back."

**Case Study**

H attends the Saturday Club. When he started he became accustomed to using the computer room, and would not leave the room even for food and refreshments. He refused to engage in other activities and would have a meltdown if he was unable to use the computers.

The staff gradually built a better relationship with H and supported him to form relationships with other users. This has enabled him to start doing other activities. H now enjoys using the karaoke machine, participating in group activities, using the sensory equipment, and talking with staff, volunteers and other users. He now has a much more varied experience at the club.

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For more information, contact:

- 01582 966065
- manager@fobe.org.uk
- www.fobe.org.uk

- 01582 519500
- rob.burton@cycd.org.uk
- www.cycd.org.uk
CHUMS

CHUMS is a mental health and emotional well being service for children and young people, offering a variety of services across Luton and Bedfordshire. Services delivered in Luton include: bereavement support for children, young people and families, including a stillbirth and neonatal service; trauma support for those young people bereaved traumatically as well as those who have been subject to sexual abuse or witness to domestic violence; young carers support groups; individual mentoring programme and recreational therapeutic programme delivered using football and music. CHUMS is a member of the VCS Consortium because of its work in delivering its Friendship Scheme for young people with disabilities.

Friendship Scheme

Last year this Friday night youth club for children with disabilities aged 13-25 moved to a new venue at Kids in Action in Dunstable. The group meets to have fun, to try different activities, and, with support from staff, to devise a termly plan. 41 club sessions were held in 2018/19.

Holiday Scheme

The Friendship Scheme club members also meet up for activities and to go on outings for 3 days during the summer holidays, and for 2 days during the Easter holidays.

Quotes from users and families

- “The staff at CHUMS are really helpful, kind and polite. They put a smile on our faces”
- “CHUMS has been a great social activity for my daughter. She can hangout with her friends and meet other people in her situation. The staff are all lovely and friendly, and make me, as a parent, feel comfortable to leave my daughter in their care. I would like to say a huge thank you”

Feedback from a young person

“I started at the CHUMS Friendship Scheme in 2013. When I first went along I was nervous but really enjoyed it. We go on lots of trips. My favourites so far have been to Whipsnade Zoo and to Shrek the Musical.

Even though we have moved venues twice during the last two years, the current venue at Kids in Action is amazing because we have so much more space, lots of things to play with, and can have proper discos.

Through the Friendship Scheme, I have learnt so much, and look forward to more trips and excitement with others. I honestly don’t know what I would do without CHUMS.”

FAMILIES UNITED NETWORK (FUN)

FUN is a local charity which provides a range of specialist support services for children and young people with additional needs and disabilities, and their families, from the point of diagnosis to the age of 25 years. Members of FUN come from Luton and across Bedfordshire. FUN operates from large, multi-facility premises in Leagrave Road, Luton.

Holiday Club

This club was open for 31 days during the school holidays. Children and young people attend the club with their parent or a carer, and siblings are also welcome.

- 332 short break hours provided
- 17 disabled children helped
- 46 support sessions organised

Holiday Respite Club

This service is aimed at children with more complex needs who require 1-1 (or 2-2-1) support. The club ran for 8 sessions during the school holidays.

- 8,170 short break hours provided
- 136 disabled children helped (and 65 siblings)
- 62 support sessions organised

Saturday Respite Club

This club, for children and young people with disabilities aged 9-18, ran fortnightly in-term-time at FUN. There were 22 sessions held last year. Most of the users needed 1-1 support (and some even 2-2-1 support) which allows their parents to have full respite time during the club sessions.

Very successful respite clubs at FUN

Case Study

A is 14 years old. He has been attending the Saturday Respite Club for 16 months and has now also joined the Holiday Respite Club. He has severe learning disabilities and autism – and is also non-verbal, and unable to walk properly due to having curved feet. He was also born with twisted bowels and is incontinent. He can present challenging behaviour when he is frustrated or unable to comprehend or express what he is feeling.

A is on a special diet of meal replacement drinks which he has to sip regularly throughout the day. He hated having his pad changed and can have a meltdown at those times, including banging his head on the floor. Initially his parents were very wary about leaving him at the club because of his complex needs.

Since starting the clubs, A has come along way and has now got into a routine. He knows what he likes to do and has a specific place where he likes to sit. He is now able to walk himself to the ball pit and bouncy castle to play, and also likes playing Lego which he finds very calming. A has also gained confidence to dance. At the last music therapy workshop he watched the other children dancing and then, at the end, he came over and did a dance himself and started smiling. This is a massive outcome for a very complex child.