



Merton's Forum for Parents of Children & Young
People with Disabilities or Special Needs



Merton's Forum for Family Carers of Adults with
Learning Disabilities and Autism

Newsletter

When you see this symbol, the
information may be useful for
parents/family carers of both
children & adults



With contributions from Kids First and Adults First members

Welcome to the latest edition

of our parent carer forum newsletter which
I hope you find this edition informative and
helpful.

Don't forget this is **your** newsletter and we always
welcome your contributions. So, if you have any
useful information that you think would be
beneficial for other parents and carers to read about
(that is not time limited) please let us know. This
could include details about other charities or
organisations you have found to be helpful, books,
publications, websites, helplines, activities, days out,
etc. You can send contributions for the newsletter
throughout the year, and we'll file it away until we
need it. Please keep telling us about the issues you
are experiencing with statutory services and the
good things too - we only know if you tell us! Our
steering groups use the issues you tell us about to
inform their representative work and take any
emerging themes to meetings. So please let us know
what is going well, and what has not gone so well, or
what you would like to see improved. Don't worry,
we will keep all contributions completely secure and
confidential and we only discuss general patterns of
feedback with the Local Authority, not individual
issues.

A BIG THANK YOU to all our wonderful steering
group members who volunteer their time to
represent you at local committees and meetings in
Merton, to ensure the voice of parents and carers
continues to be heard. We couldn't run the forums
without their continued support. THANK YOU!
Wishing you all a happy and healthy 2024!

Tracy Blackwell, Parent Carer Forums Manager



MertonMencapTV – Forum Workshop Recordings

Some of our meetings have been recorded and
posted on our YouTube channel Merton Mencap TV
(<https://bit.ly/2X0QZ0I>) members will be notified
when they are posted.



Here are a few examples of our fantastic recordings
below:

Adults First, Thinking Ahead:

<https://youtu.be/XgRZbmkyIjk>

Kids First, Independent Travel Training:

<https://youtu.be/sgSpLWH8njI>

We have a number of helpful recordings plus more
on the way! Keep an eye out by **subscribing** to our
YouTube channel to stay up to date with our
sessions & workshops.

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Merton Mencap's services

Information about all Merton Mencap services
can be found on our website

<https://bit.ly/2MuL66G>

Kids First is Merton's Forum for Parent Carers of Children and Young People living or educated in Merton, aged 0-25, with a special need or disability (including mild to severe learning disabilities, complex medical needs, physical or sensory impairments, autistic spectrum disorders and others). We receive funding from the Department for Education and the London Borough of Merton. Our money is used to support representative work, help members to have a voice on how services for children and young people with SEND are shaped and delivered locally, and run our very popular events and information exchange meetings. We are members of the National Network of Parent Carer Forums.

The aims of the forum are:

- to make sure the voice of parent carers is heard in the design and delivery of services in Merton which affect children and young people with SEND
- to empower parent carers with information and knowledge
- to provide opportunities for parent carers to meet, share experiences and reduce isolation

The forum does this by providing regular educational workshops and events with experts, local service providers and key decision makers in the borough to give parent carers a voice and influence on local issues. We support parent carers to be representatives at all the important local meetings, committees and Boards in Merton, produce this twice-yearly newsletter, and keep our members up to date with the latest news throughout the year including forthcoming events and new local services.

The forum is run by a steering group of volunteer parent carers, who decide on the business of the forum and represent our members at meetings and focus groups in Merton. Our steering group members currently represent you at the following meetings:

Autism Partnership Steering Group: oversees Merton's 5 year Autism Strategy and action plan which is due for a refresh and review this year. The aim of the strategy is to ensure that Merton is an autism friendly borough in which autistic people are able to reach their full potential at all stages of their lives, encompassing children, young people and

adults with autism, and taking into consideration the needs of families and carers.

CAMHS Partnership Board: Partnership working between health care services, education, social care and community and voluntary sector organisations overseeing work around Merton CAMHS and service provision for the organisation and delivery of mental health and wellbeing services in Merton.

Employability Forum: oversees employability support and the development of supported internships in Merton.

i-Thrive working group: focussing on the emotional health, wellbeing and support of children and young people with Neurodiversity.

SEND Local Offer Focus Group: focussing on improving the Local Offer, the look and feel, ease of navigation and making it easier for families to use.

Merton Health and Care Community Voice Forum: see Adults First section for description of meeting.

MIASS Advisory Board: The MIASS Advisory Board fulfils the twin roles of supporting the service in meeting the minimum standards and enabling inter agency discussion about its current and future role and the improvement and development of the service.

Preparation for Adulthood Board: oversees and monitors work to improve transition planning and preparation for adulthood and highlighting areas for improvement.

SEND Strategic Governance Board: An overarching high-level Board that discusses all things SEND discussed at other meetings and Boards that sit below the Governance Board.

SEND Strategy Refresh: reviewing and refreshing Merton's SEND Strategy for meeting the needs of children and young people aged 0-25 with SEND.

Stakeholder Reference Group: see Adults First section for description of meeting.

Supported Living Framework: see Adults First section for description of meeting.



The Kids First steering group needs YOU!

We are always delighted to hear from anyone interested in joining our Kids First steering group as a volunteer so we can have an active voice and representation for our children and young people. We need parents of children and young people of all ages and from all communities in Merton, so that we are truly representative of all. You don't need to be an expert on anything. Your expertise is being a parent of a child or young person with SEN or a disability. It's never too late to volunteer; why not try it out? Get in touch if you would like to find out more. See contact details on page 16

Tell us your issues!

Are you experiencing any problems with statutory services, the NHS, your child's school, etc? If yes, please tell us about it. You can use one of our issues forms (download from our website) or just email us with the information. All issues are logged and used anonymously in our representative work with the LA and the SW London Integrated Care System. We also record positive experiences, so please tell us about them too! kf.admin@mertonmencap.org.uk



Updates from the Local Authority

*Submitted by Elizabeth Fitzpatrick,
Assistant Director, Education and Early Help,
the London Borough of Merton*

The Voice of Children and Young People in our local plans

Merton's Children and Young People's Plan sets out the Council's key activity to ensure we improve the experiences and outcomes for all children in the Borough. The current plan is coming to an end, and so the Council's Participation and Engagement team launched a borough-wide survey earlier this year, to ensure that children and young people directly influence the shape of the next plan. We received responses from over **2350 children and young people, 12% of whom identified themselves as having a special educational need or disability**, and

also heard from focus groups from across our communities. This included focus groups with young people in our special schools. **The findings will directly impact the new plan for 2024-2028.**

Local Area SEND Strategy

As you may already know, the local area SEND Strategy is also being refreshed. As a local area strategy, it is not just a Council document, but directs the work of the whole partnership across education, health and care. Thank you to all the parents and carers who attended sessions, both in July, and then again in November, whose views are helping to shape the new strategy. Following this input, and also input from children and young people, from professionals working across education, health and care, as well as from schools, we are currently pulling together the strategy, for presentation to the SEND Governance Board early in the New Year, and for launch in the spring. We are very grateful to the Kids First Steering Group who have been an invaluable sounding board as this work progresses.

SEND Youth Advisory Forum

At Merton Council, we're really excited to announce that in October of 2023, we launched our SEND Youth Advisory Forum. Once a half term, we meet to discuss the issues that are most important to young people with SEND in Merton, with a view to building a campaign and effecting positive change. This space is currently open to young people who are part of their school council at **Cricket Green School, Melrose School** and **Perseid School**. However, in the new year we hope to open the forum to all those with a Merton Education Health and Care Plan. In our last meeting, members designed a logo which you can see below.



Family Hubs

Merton continue to develop their approach to Family Hubs. The best way to keep up to date with activity is to follow us on Face Book www.facebook.com/MertonIFF and our webpages: <https://bit.ly/41AYKrG>





Start for Life

More recently we published our Start for Life Offer, please do visit our website pages to find out more: <https://bit.ly/48ruDoP>. We will be reviewing this resource and developing supplementary information, so please do let us know of additional services and any information that families may find helpful via the fsd@merton.gov.uk email address.

If anyone is interested in joining our **Parent/Carer Start for Life panel** for families who are pregnant and/or with children up to 2, please do contact us on familyhubs@merton.gov.uk

Parent/Carer and Young People's Feedback regarding an EHCP

The Local Authority has procured a quality assurance tool called **Invision 360**. Invision 360 has a feedback questionnaire which collates parental feedback as part of the Annual Review process. A link is sent to the school and parent allowing for a 5-minute questionnaire to be completed after the meeting. The feedback from the questionnaire is collated within the IT system and will provide the Special Educational Needs and Disabilities Integrated Service with invaluable feedback regarding the Annual Review process and what is working well and what requires development. **This process will go live in January 2024.**

The SEND Youth Advisory Group are working with the SEN team to develop the child and young person feedback forms. The Advisory Group is meeting again in December to finalise the feedback forms which will go live in **February 2024**

The Parental questionnaire for feedback following and Education Health and Care Needs Assessment is being reviewed following a year of use and will again go live in **January 2024.**



Schools' SEND Update

On the 2nd October, new '**Ordinarily Available Guidance**' was launched to all Merton schools. This guidance identifies setting based interventions and services that all Merton schools, early years and post 16 settings should be able to provide for children or young people, including those with SEND. By outlining these expectations, we are encouraging consistency across schools and settings across

Merton and supporting schools to further develop their inclusive practice.

The guidance covers four broad areas of need:

- Communication and interaction
- Cognition and learning
- Social, emotional, and mental health
- Sensory or physical needs.

For each area, there are suggestions for strategies and interventions that can be used by all members of school staff and families alike, as well as examples of good practice.

The launch of the guidance is now being followed up by a significant package of workshops designed to help staff in schools develop their skills and confidence to support children and young people with SEND.

Also, to support schools, we have a team of six SEND advisors including SENCOS, senior leaders and Specialist Leaders of Education (SLEs) delivering Merton's School Inclusion programme. The programme has been, or is currently being delivered in 20 schools, and has a focus on the SEND support process and practice, and adaptive teaching.

Attachment and Developmental Trauma Awareness Programme

19 Merton schools (across the primary and secondary phases) are involved in this programme of evidence based learning and development to facilitate awareness and good practice in the area of attachment and developmental trauma. It has a focus on whole-school development, supporting inclusion and belonging for all children and staff. It is particularly supportive for children with SEND, and children who are or have been in care.

School Attendance

As you may be aware from the national news, levels of attendance in schools across the country are below what they were before the pandemic. In Merton, attendance in our primary and secondary schools is above the national and London averages, but is still below the very good levels we saw before 2020. We are working with our schools and the wider group of professionals, to raise awareness of the issue and to improve levels of attendance. We have also created [a School Attendance Guide for Parents](#) which you may be interested in.



Additional places in our special schools

Following the significant increase in the number of children locally with EHCPs over the past few years, the Local Authority continues to increase the number of special school and Additionally Resourced Provision (ARP) places. Over the past two years we have done the following:

- Whatley Avenue (provision for children with ASD and communication needs, part of Melrose school) – works completed for 80 children for September 2022
- Melbury Medical Provision – more capacity at Lavender, London Road Mitcham from September 2022
- West Wimbledon primary school – expansion of the ARP. Phase 1 opened September 2022, phase 2 completed September 2023
- Hatfeild primary school – expansion of ARP completed summer 2022
- Cranmer primary school – new ARP. Phase 1 opened in September – 2022, permanent scheme completed in summer 2023

In addition, the following are being planned:

- New Special Free School - planned opening in September 2026, for children aged 4- 16 with learning difficulties and complex needs including challenging
- Sutton Special Free school - for children aged 11-19, just outside Merton in Rosehill Recreation Ground. Planned opening now September 2025 – some extra places for Merton residents
- Additional secondary school ARP
- Perseid School further expansion by September 2025

Other news & Information

Parent Carer Needs Assessments

If you are a Parent Carer of a child with a disability you are entitled to an assessment of your own needs. This is called a Parent Carer Needs Assessment (PCNA).

In practice, an assessment of your needs, and the needs of any other adults or children in the family, will be combined with an assessment of your child with a disability. However, you do have the right to

ask for an assessment of your needs separately from that of your child, if you wish. The assessment should discuss the help you need to look after your child, and also your own wellbeing. If you would like to request an assessment of your needs you should contact the Children with Disabilities Team at Merton Council.

Tel & Email: 020 8545 4200

Children.WithDisabilitiesDuty@merton.gov.uk

<https://www.csmerton.org/parent-carers/parent-carer-needs-assessment/>

Merton Pathway 2 Employment booklet

Merton have recently produced a Pathway 2 Employment booklet which provides information on some services young people and families can access for employment support. See here:

<https://bit.ly/3RMeEMv>



General SEND Info

The Council for Disabled Children (CDC) send a range of free newsletters and e-alerts depending on what you're interested in. Follow this link:

<https://bit.ly/4avoJov>

contact *For families with disabled children*

Free School Meals webinar: What to do if your disabled child is missing out!

Watch Contact's free webinar here:

<https://www.youtube.com/watch?v=P-6pTrPuJmE>

Contact have rounded up some general themes that emerged and have answered those questions for you - <https://bit.ly/47lIlZv>

Plus! Human rights lawyers have written a free school meals guide explaining how you can access free school meals via alternative arrangements, depending on your situation. And in response to requests from parents, Contact have written more template letters to cover different situations where eligible children in England, Wales and Scotland can't access a free school meal due to their disability. They have heard from lots of parents who have successfully used the free school meals template letters to request an alternative, such as a voucher, to their child's free lunch.

Check out the free school meals guide and template letters here: <https://bit.ly/4azeOhC>

Have you seen Contact's e-publications? Some of their most popular parent guides are now available in their e-publications library. Once downloaded, you can read even when you are offline.

Here's some examples:

[Money Matters.](#)

[Claiming DLA For Your Child.](#)

[Services And Support From Your Local Authority.](#)

[Understanding Your Child's Behaviour.](#)

[Siblings.](#)

EHCP's

Here's a link to Contact's information and factsheet which also includes an assessment timetable showing timelines. **Link 1:** <https://bit.ly/48nWxBR>

Link 2: <https://bit.ly/41tEMyN>

Make sure you're not missing out on vital financial help

Raising a disabled child already costs three times more - and because it's so difficult to juggle work with caring, families are sadly at greater risk of poverty. It's crucial that you claim all the financial help you're entitled to. There's lots of help on Contact's website about this:

- Use the [Benefits Calculator on our website](#) to make sure you are not missing out on benefits you are entitled to.
- Find out what grants and discounts your family might be eligible for by using the [Turn2Us grant finder on our website](#).
- [Download the pdf of our Money Matters guide](#) for a breakdown of financial help schemes for carers in England, Wales and Northern Ireland. It's also available as one of [our e-publications](#).
- Make sure you apply for the main benefit for disabled children, Disability Living Allowance. [Watch our short animations about DLA](#) to find out more.

Fledglings are a non-profit shop that helps children and adults with additional needs by supplying products and equipment that help with everyday challenges. They provide an easy and trusted

environment to find the right solutions and allow people to connect and share their experiences. Most products are for children but some are for adults too. <https://www.fledglings.org.uk/>

IPSEA (Independent Provider of Special Education Advice) offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND). IPSEA has a suite of free downloadable [guides, resources and template letters](#) available to parents and carers. These guides are complemented by a free [Advice Line](#) and [Call-in Helpline](#) which provide legally based information and next step advice on any educational issue that is a result of a child's SEND. IPSEA's [Tribunal Helpline](#) gives next step advice on appeals and disability discrimination claims to the SEND Tribunal and is also the gateway to their [Tribunal Support Service](#) where a referral can be made for more extensive casework support from a volunteer, including representation at the hearing. Their advice services are delivered by a national network of around 100 highly-trained volunteers, supervised and supported by IPSEA's Legal Team members. **SOS!SEN** provide a range of information, advice and support. They offer a free helpline, walk-in advice centres, 1:1 appointments and training workshops and webinars to help answer questions about your child's case, plus booklets, information sheets and more: <https://sossen.org.uk/>

Check out their Help Centre which takes a look at common issues and questions they get asked: <https://sossen.org.uk/help-centre/>

Health update

What is children and young people's continuing care (CCC)?

Some children and young people (up to their 18th birthday) may have very complex health needs. These may be the result of congenital conditions, long-term or life limiting or life-threatening conditions, disability, or the after-effects of serious illness or injury. These needs may be so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community. A package of additional health



support may be needed. This additional package of care (POC) has come to be known as continuing care. This is not the same as Continuing Health Care (CHC), this is the adult framework and is assessed differently and has different criteria for eligibility and provision.

CCC is not a statutory provision and differs from an implementation perspective by individual Integrated Care Board (ICB). South West London ICB has ensured that the practice across all 6 places Kingston, Richmond, Wandsworth, Merton, Sutton and Croydon have aligned their practice and assessment processes.

Continuing care does not take over from your parental responsibilities and is to support you in caring for your child, short breaks and respite come from Social care to give you a break.

The process

A professional involved in your child's care can complete the referral form with the family, all evidence of the health needs **MUST** be submitted with the referral, including medical reports from the last 6 months, recent child and family assessment from social care, EHCP and any incident logs from school. The consent form on the referral must be signed to enable the nurse assessor to contact any other professionals involved in your childcare. If the referral meets criteria for a full assessment, the nurse assessor will then be in contact to make an appointment to come and visit you to undertake a full assessment, this will be done in conjunction with your social worker.

Following the completion of the assessment and the Decision Support Tool (DST), the nurse assessor will score the needs of your child on a scoring tool called the CHATT tool, this then calculates the number of hours your child can receive from the ICB to support you in caring for their health needs. The nurse assessor will discuss with you how you would like to use any hours that may be awarded by the health panel. This is usually nighttime, weekends and after school, however it is important to realise that with CCC hours a responsible adult able to care for the child must be present at all times.

If you receive a POC from the ICB this will be reviewed after 3 months of starting and then annually to ensure the POC remains appropriate.

Contact the Continuing Care Team:

swlicb.continuingcareteam@nhs.net

National Framework for Children and Young

People's Continuing Care: <https://bit.ly/3TsWYjJ>

St George's Audiology

For non-appointment related queries

contact: 020 8725 1151 /

audiologist.enquiries@stgeorges.nhs.uk. For

appointment queries contact: 0208 725 1122 /

audiologist.appointments@stgeorges.nhs.uk.

For St George's paediatric hearing aid repairs, please contact them for an urgent appointment or, alternatively, drop the hearing aid(s) to the Trevelyan House site (1st Floor, 160 Tooting High Street, London SW17 0RT). Please ensure you tell the receptionist it is a child's hearing aid and therefore requires urgent repair. They will then contact you when it is ready to collect.

St Helier Audiology

Contact: 020 8296 3490 / audiology-sth@nhs.net

For St Helier paediatric hearing aid repairs, they also offer a drop-off repair service for hearing aids.

Please post your hearing aid (using the envelope provided) in the box outside the department at St Helier. An Audiologist will check it and repair it if required. They will post it back to you.



Activities

Merton Vision – Eye Can Do It

Merton Vision are currently running a person-centred program designed to help visually impaired children and young people in Merton improve their social and independent skills. One of the programs is called Eye Can Do It, this is a club where children/young people meet once a month on a Saturday to take part in fun and exciting activities. For more information contact Nneamaka Eleje, the Children's Outreach Worker

Email: Nneamaka.Eleje@mertonvision.org.uk

Tel: 020 8540 5446

MertonVision



Sense for deaf blind people

Sense offers a huge range of free events and activities to support people who are deaf, blind or who have complex disabilities. Come along to an activity session from inclusive boxing to sensory play: they have a range of activities, in-person and online, for you to take part in. They have over 100 online activities for you to try at home whenever you like. <https://www.sense.org.uk/our-services/arts-sports-activities-for-disabled-people/>

EcoLocal Cycling



Inclusive Cycling sessions for young people and adults aged 14+ at the David Weir Leisure Centre, Tweeddale Road, Carshalton, SM5 1SL. Have fun on accessible cycles suitable for all abilities and disabilities, including side-by-side cycles for cycling with a companion, wheelchair cycles, accessible trikes, hand cycles, recumbents, go-carts and more! There is also a wide range of two wheelers for those who would like to learn to ride or regain cycling confidence with friendly cycle instructors on hand to help. £5 per session (carers free).

<https://www.ecolocal.org.uk/ecolocal-cycling/cycling/adult-inclusive-cycling-sessions/>

Merton SEND Local Offer provides support and service information for children and young people with special educational needs and disabilities, and their families. <http://www.merton.gov.uk/localoffer>

Enable: Social Prescribing Service for Young People in East Merton & Morden

People referred must be aged 13 - 19 (or up to 25 if they have additional needs) and live in or go to secondary school or be registered with a GP practice in the East Merton or Morden areas to access the service.

Social Prescribers are there to listen to young people and help them decide what they would like to do to feel healthier – mentally and physically.

They can help with managing stress, loneliness, meeting new people, learning new skills, exercising, or learning more about employment, benefits, housing and legal advice.



This is done by:

- Exploring what is important to the young person in their life and their wellbeing
- Identifying local activities or services that they will find helpful and enjoyable
- Offering support and encouragement to achieve their goals

Young people can be connected to the service via their GP, school nurse, someone from Talk Off The Record, their youth worker, etc. Or they, or their parent/guardian can contact the service directly by calling or messaging them on 07756868692 or emailing cypmerton@enablelc.org.

Off the Record

Has online, telephone and face to face counselling for 11-25-year old's, including self-help materials, webinars, and workshops.



<https://www.talkofftherecord.org/merton/>
Saturday Support – talk to a counsellor on Saturdays from 10am-1pm, 020 8175 6776

MAPS – Merton Autism Parent Service



A support, information and advice service for parents of 0-25 year olds with a diagnosis of autism or who are likely to receive a diagnosis (e.g. referred for an assessment). Parent Advisors offer support on communication, challenging behaviours, self-harming, sleep issues, anxiety and many other challenges.



We run on Wednesdays during school term time, between 10am-1pm. To book a session, contact Maria Solari on 07709 715206 or maps.coordinator@mertonmencap.org.uk

Merton Special Educational Needs Information, Advice and Support Service (MIASS)



MIASS is co-commissioned by Merton Council and the NHS to provide free, confidential and impartial information, advice and support to children and young people (aged 0-25) with special educational needs or disabilities (SEND) and their parents/carers who live in Merton.

Based at Joseph Hood Primary School
Tel: 0208 543 8854

Email: miass@merton.gov.uk



Adults First

Adults First is Merton's forum for family carers of adults with learning disabilities and/or autism, aged 18 and over living or receiving services in Merton.

The aims of the forum are to provide information to carers which supports them in their caring role and to make sure the voice of carers is heard in the design and delivery of services which affect them and the person they care for.

The forum does this by providing regular educational workshops and events with experts and local service providers, which also provides the opportunity for carers to meet each other, share experiences and practical support. We support carers to be representatives at all the important local meetings, committees and Boards in Merton and campaign on issues which improve the lives of carers and the person they care for. We also produce this twice-yearly newsletter and keep our members up to date with the latest news throughout the year.

The forum is run by a steering group of volunteer family carers, who decide on the business of the forum and represent our members at meetings and focus groups in Merton. Our steering group members currently represent you at the following meetings:

All Saints Respite Quarterly Monitoring Group: monitors respite care provision at All Saints Respite Centre in Merton.

Autism Partnership Steering Group: see Kids First section for description of meeting.

Carers Strategy Implementation Board: oversees implementation and progress of Merton's 5 year Carers Strategy launched in 2021 to improve the identification, recognition and support available to Carers in the borough.

Employability Forum: see Kids First section for description of meeting.

Healthwatch Merton Operational Committee: oversees strategic development of Healthwatch Merton and its operations.

LD Forum: A rep attends meetings as well as planning meetings of the forum. Highlights issues raised by forum members and updates attendees about forum work and upcoming forum events.

Merton Health and Care Community Voice Forum: hearing the voice of local people including the voluntary sector, faith groups, other community

groups, patients, carers, people using adult social care services, etc. Discusses issues that affect all Merton residents and to ensure the voice of local people is heard, including those with LD/ASD and their carers.

Preparation for Adulthood Board: see Kids First section for description of meeting.

Stakeholder Reference Group: overseeing Merton's review of day opportunities for adults with learning disabilities and/or autism to ensure the best possible outcome is achieved for people using the services and their families.

St George's University Hospital Foundation Trust, Governors meetings: Healthwatch Merton appointed our rep on Healthwatch Merton's Operational Committee to represent them on the Council of Governors at St George's Hospital.

Supported Living Framework: oversees the work around Merton's commissioning of the Supported Living Services Framework. This work involved looking at the specification and expectations from providers, co-creation of tender questions to providers and model answers and the possibility of being involved in the evaluation of tenders and longer-term involvement in monitoring meetings.

Tell us your issues!

Are you experiencing any problems with statutory services, such as issues relating to day services, direct payments, support living, health, Merton Adult Learning, planning for the future, respite, transport, communication, etc? If yes please tell us about it. All issues are logged and used anonymously in our representative work. We also record positive experiences, so please tell us about those too!

Af.admin@mertonmencap.org.uk

We would love to have more steering group members so that we are truly representative of our membership. If you'd like to find out more about joining the steering group please contact us (see page 16 for contact details) or have a chat with us at one of our sessions. And don't forget to read the minutes of steering group meetings to keep up to date with everything that is going on.

Carers Card Update

Submitted by Sally Burns, Adults First steering group member

After the online consultation with carers and professionals back in October, all the feedback was used to draw up a service specification - in other words, what Merton want the cards to be able to do



- and it is now awaiting clearance from the legal department. Once that has come through, it will be published at the end of December or early January. It's not going to be an open tender - only the three organizations that took part in the presentation will be asked to bid to become the provider of the cards. These are: **Carers Card UK, National Disability & Carers Card** and **Forward Carers**. The aim is to get them up and running by April, alongside the new contract for carers' services. Merton will be asking for feedback on how the new cards are working once they are in operation.

Carers Support Merton

Check out these easy to understand short films from Carers Support Merton with information covering carers assessments, carers allowance, emergency plans, planning for the future and more!

<https://www.csmerton.org/for-adult-carers/how-we-support-adult-carers/videos-from-carers-support-merton/>

CSM will add to these videos over the coming months. You can also subscribe to their YouTube channel.

If you have any comments about these short films, or suggestions for new topics, please email Nada, Digital Project co-ordinator at Carers Support Merton – nada@csmerton.org. Find information about Merton Supported Living provision here: <https://www.merton.gov.uk/social-care/adult-social-care/supported-living-service>

Carers UK information and support

Carers UK provide information and guidance to unpaid carers. This covers a range of subjects including:

- Benefits and financial support
- Your rights as a carer in the workplace
- Carers' assessments and how to get support in your caring role
- Services available to carers and the people you care for
- How to complain effectively and challenge decisions.

Their telephone Helpline is available on **0808 808 7777** from **Monday to Friday, 9am – 6pm** (excluding Bank Holidays). If you have a more complex query, they suggest emailing on advice@carersuk.org as they can provide more information. For financial and practical help and advice:

<https://www.carersuk.org/help-and-advice/>

Read the Carers UK State of Caring Survey 2023 - The impact of caring on: health:

<https://www.carersuk.org/reports/state-of-caring-survey-2023-the-impact-of-caring-on-health/>

All Saints Respite Service - Vibrance

Submitted by Helen Bridges, Assistant Director of Operations

All Saints Respite is in Colliers Wood, we have been providing respite care for parents, carers, and service users for more than ten years.

Our six-bedroomed service is quite unique due to the varied range of service users we have staying with us at any one given time – there's never a dull moment.

All Saints provides 24- hour short break accommodation for adults with learning disabilities some of whom may have additional healthcare needs.

All Saints is a bungalow with a large front and back garden. All accommodation is on the ground floor and fully accessible for people who have mobility and physical needs. There is an accessible shower room, bathroom, hoists/lifting/turning equipment, and profile beds in 4 bedrooms.

We encourage service users to be as independent as they can be during their stay, staff will support people with all aspects of their daily living. When at All Saints Respite Service users can continue to attend their usual activities such as college/day centre/volunteering, PAs and Merton transport can continue during their stay, if preferred.

We offer a range of activities, including watching movies, cookery, playing musical instruments, arts and crafts, shopping trips, coffee shop/restaurants, parks and cinema, to name a few, choice is very important. We also know that, because we offer respite care, some of our service users just want to relax in our comfortable 'home from home', and that's just fine with us too.

Our respite service is registered with CQC, all staff receive mandatory training including Manual Handling, Food Hygiene, Medication, First Aid, H & S, Infection Prevention Control, Fire Safety, COSHH, Positive Behaviour Support (PBS), Safeguarding, MCA & DoLS, and GDPR. Bespoke training is also delivered depending on the needs of the service users including Epilepsy (recovery medication Buccal Midazolam, Rectal Diazepam), Diabetes, Autism, Intensive interaction, Anaphylaxis/Epi pen, Dysphasia, MH awareness, PEG feeding, Stoma care and catheter care. We offer active, person-centred



support for each service user while they are with us, so training is kept under review, and we respond to service users changing needs. The core staffing depends on how many people are staying, there are usually 2 staff on each shift and 1 waking nights staff. Night-time routines vary depending on the individual and will be identified in the assessment.

We actively encourage involvement from parents, carers, and service users at every step of the way. This helps us to ensure that the needs of each service user are fully met.

Parent and carers should discuss their individual care and support needs with Merton's Learning Disability (LD) Team. If a referral is then made to All Saints Respite the manager of the service will carry out a robust personalized assessment to establish if a person's needs can be met.

When an allocation has been agreed by Merton's LD team, stays can be booked by calling All Saints Respite as you would to book a hotel stay. Staff will check the diary and if available you will be offered a booking. If your preferred choice is not available, you may be offered an alternative. If additional staff are required, this will be arranged by All Saints respite. 24-hour cancellation is required.

Parent and carers are asked to complete a checking-in/out form which identifies how the person has been since their last respite stay, any changes for example to medication, health, items that are coming into the service – clothes, personal possessions, money etc. When the service user leaves the stay, staff will complete the checking-out form, including how the stay has gone. Feedback from parents, carers and service users are also encouraged after a stay.

Merton Shared Lives Scheme

Merton Shared Lives Scheme offers an accommodation based service for people that need some support in their everyday lives. The scheme is for adults aged 18 and over, with a learning disability or with a mental health issue.

Within Merton Shared Lives Scheme, you are helped and supported by a Shared Lives Carer. They may be sharing their own house with you, or they may offer you floating support in another property. You may be offered somewhere to stay for a short break or somewhere to live for a longer period. Shared Lives Carers can help the people they care for to: look after themselves, keep healthy and active, manage money, share domestic tasks like cooking and cleaning, complete forms, understand letters, learn

new skills, meet new people, enjoy hobbies and activities.

For more information contact **the Merton Shared Lives Team**: Email: shared.lives@merton.gov.uk
Telephone: 020 8545 3900
<https://www.merton.gov.uk/council-tax-benefits-and-housing/sheltered-and-supported-housing/shared-lives/overview>

Contact webinar recording on Supported living for people with learning disabilities and autism

Aimed at people who are looking to make long term plans who are currently in or approaching transition into adult services. This session was presented by Steve Harris from Progress Housing Group and covers; how supported living works for people who want choice and control over where they live and how they are supported, the transition period and options for young people and families including residential care and supported living, how housing, care and support works together, specialist organisations and services they can offer and LA and NHS responsibilities, funding housing and support and how this links with housing and support provision. View the recording of this session along with the presentation here:

Recording link: <https://youtu.be/vDHxxdkQjwI>

Presentation link: [Keeping it Local \(contact.org.uk\)](https://www.merton.gov.uk/social-care/adult-social-care/supported-living-service)

Find information about **Merton Supported Living provision** here: <https://www.merton.gov.uk/social-care/adult-social-care/supported-living-service>

St George's Learning Disability Liaison Team

About us:

The Learning Disability Team are here to support patients with Learning Disabilities and their families when they attend St Georges Hospital. We work Monday- Friday 9-5 (excluding bank holidays) and the team includes one Senior Nurse Practitioner, two Nurse Practitioners and one Support Worker.

Ways we can help:

- We can visit you on the ward to support you and liaise with the clinical team and your family/carers on the best way to support you
- We can attend appointments with you where possible if you require this
- Our support worker can offer psychosocial support, do activities, and generally spend time with you.
- We can help you to understand information to help you make decisions about your care



Phone: 02087250097

Bleep: 8386 Email:

learning.disabilityreferral@stgeorges.nhs.uk



Guidance for hospital staff on Reasonable Adjustments for Inpatients with a Learning Disability

- The individual may require a family member or carer to stay overnight. They may also need a carers bed
- The Learning Disability team can provide easy read information about care or & treatment
- Please ask for the patient's hospital passport, have this printed at the bedside for all staff to familiarise themselves with
- Please ensure you are fully informed of the patient's eating/swallowing abilities and refer to SaLT guidelines if applicable
- Please have the patient's communication passport or be aware of their alternative form of communication i.e. talking mats, communication symbols, Makaton
- Allow time to give new information as people with learning disabilities may take longer to process information
- Please offer a side room for the patient where possible
- The patient's family & carers will be able to provide clarity on issues or questions you may have related to their care
- Please consider consent and capacity to make decisions about care and treatment and support the patient to make decisions where possible. If there is reason to doubt capacity, please complete the MCA & best interests process where required

Guidance for hospital staff on Reasonable Adjustments for Outpatients with a Learning Disability

- Individuals with a learning disability may need the first appointment or to be fast tracked for appointments
- Please consider bigger rooms in clinic where possible as patients may have wheelchairs or come with carer's & other support
- If there is a quieter area or space for patients to wait, please consider this.
- You may need to book longer appointments to ensure enough time
- The Learning Disability team can join the appointment to support once made aware in advance
- Allow time to give new information as people with learning disabilities may take longer to process information
- The patient's family & carers will be able to provide clarity on issues or questions you may have related to their care
- The Learning Disability team can provide easy read information prior to the appointment that may support the patient to understand what is happening
- Please consider consent and capacity to make decisions about care and treatment and support the patient to make decisions where possible. If there is reason to doubt capacity, please assess capacity and complete the MCA & best interests process before any procedure.

Merton ADHD/ASD Diagnostic service for adults

The Merton Adult ADHD/ASD Service is based at Jubilee Health Centre and is a service for adults aged eighteen or over, who are registered with a Merton GP and who do not have a learning disability. It is an ADHD and ASD specific, non-urgent, part time service which offers specialist assessment and diagnosis of ADHD and ASD, ADHD medication initiation and titration focussed OT work for ADHD (group based for the majority) and specialist medical review for those with an established diagnosis who

are taking medication for ADHD. Due to high demand, the service does operate with a significant waiting list. Referral is via your GP or other health care professional.

[Merton ADHD/ASD Diagnostic Service](https://www.merton.gov.uk/adhd/ASD-Diagnostic-Service)
(swlstg.nhs.uk)

Royal Mencap Supported Internships

Supported internships are open to young people aged 16-24 with an EHCP. They may be the ideal programme for young people not currently in employment, education or training who want to work.

Mencap's supported internships are delivered to small groups and provide access to work experience opportunities with a wide range of employers across lots of different sectors, supporting people to find paid work at the end of the programme. To find out more about the programme, please visit their website: <https://bit.ly/4apbyW2>



Merton Welfare Benefits Service (WBS) is for:

- Welfare benefit enquiries
- Requests for a welfare benefit check
- Requests for welfare benefit appointments
- Requests for assistance to complete welfare benefit forms

Opening times: Monday-Friday 10am-4pm

Tel: 0208 545 4178

Email: WelfareBenefitsTeam@merton.gov.uk

<https://www.merton.gov.uk/council-tax-benefits-and-housing/benefits/benefits-advice>

Social/Leisure



The Giving Back Club

Based in Wimbledon, the Giving Back Club supports young people and adults with mild or moderate learning disabilities or autism, aged 16-24, to 'give something back to their communities', such as by undertaking volunteering and work experience placements, supporting local campaigns, and helping people in our communities.

The club is self-referral, and takes place every Saturday, 10am-12pm.

Contact: giving.back@mertonmencap.org.uk



Pryzm Kingston presents, Discobility!

Disco for adults with disabilities **starts** 7:00 pm, **ends** 11:00 pm. Tickets £5. Carer goes free! Tickets must be booked!

<https://www.pryzm.co.uk/kingston-discobility/>



Generate UK

Works together with people with a learning disability, autism and other disabilities to have better lives and connect to the community. They focus on people's strengths and promote independence and inclusion, through learning, work and leisure opportunities.

Some of their activities include cooking sessions, footballing and dance sessions. Read more about this here: <https://generate-uk.org/cc/group-activities/>

They also support people to go on independent trips or trips with their friends. Some past destinations include Paris, Budapest & Centre Parks.

Tel: **020 8879 6333**

Email: enquiries@generate-uk.org

generate
your life your support

The Squad

The Squad is based in Wimbledon and runs **Thursday evening clubs** for people with learning disabilities. Club nights are fun-packed and educational, and members enjoy socialising with their friends whilst also trying out new experiences.

The club is split into two age groups: the '**Juniors**' club is for **under 25s** and the '**Vets**' club is for **over 25s**. The clubs are run separately, and both have their own programme of age-appropriate activities.

Members are the most important part of The Squad. They help to run the clubs, vote on what should be included in the activity programmes and are involved in decisions about The Squad's future. For more information:

<https://thesquad.org.uk/about-us/>

Contact them here:

Vets Club: ivana.orsinova@thesquad.org.uk

Juniors Club: keeley.reed@thesquad.org.uk



Goals Wimbledon - Football for Wellbeing

Inclusive, welcoming, and stigma free football sessions for adults of any gender, dealing with neurodivergent or mental health challenges. Free for participants and all abilities are welcome. Fridays, 4:30pm – 6pm

Sign up at: <https://join.motspurparkfc.com>



Fulham Football Club Foundation

Fulham FC Foundation delivers various programmes for young people and adults with a wide range of disabilities. Some of their projects & clubs include Active Autism, Pan Disability Football Clubs, Blind and Partially Sighted Football, as well as many others.

Contact them here:

foundationinfo@fulhamfc.com / 0208 336 7547



Keen2go

<https://www.keen2go.org/>

An activities and events provider committed to delivering a wide range of opportunities for young people & adults with autism and learning disabilities with services based in Sutton and Richmond. They offer a selection of weekly sessions and special school holiday programmes with all activities rooted in their core principles of inclusivity, compassion, and personal development. They support members with a wide variety of needs and support is delivered on 1:4, 1:1 and 2:1 ratios. They run dedicated sessions for young people **aged 11-16** and there is **no upper age limit** on adult services.



Free swimming for over-65s

People aged over 65 can swim for free at all three of Merton's leisure centres at certain times each week. To access this, you must book in advance, and you must put in your correct date of birth when signing up to the BetterUK app.

Learn more about this here: [Free swimming for over-65s | Merton Council](#)



LD Carers Support Service

We support carers of adults through the completion of carers assessments and reviews, help with problems and enquiries relating to your caring role, and offering a listening ear and emotional support. Contact Yvonne Dawes on 020 3963 0595 or ldcarers.support@mertonmencap.org.uk

Carers Caseworker

We aim to improve the lives of carers of adults with learning disabilities and/or autism in Merton. We offer a range of support including a listening ear to talk through problems and possible solutions and help to understand more about local services for the carer and the person they care for. Contact Carolyn Doyle on 07815 462913 or

LDCarers.caseworker@mertonmencap.org.uk

Community Facilitators

We provide support for adults with a learning disability and/or autism to plan their lives, reach their goals and get the most from life. This may involve helping someone to be aware of services that are available and offering short-term support during a particular difficulty including Covid-related issues.

Contact **Dymphna Graham** on 07592 042 432

or **Maria Solari** on 07709 715 206

Email: community.facilitator@mertonmencap.org.uk

Visit for more: [LD Carers Support - Merton Mencap](#)

Talk Autism

Talk Autism is a forum for parents and carers of children, young people and adults with autism. Talk Autism is free to join and provides monthly events for parents and carers on matters relating to autism – for example, a specialist speaker giving a talk on managing behaviours, establishing sleep patterns and routines. Talk Autism also includes social events where parents and carers may develop peer support and friendships.

Joining Talk Autism is free and easy. Simply contact Maria here: 07709 715 206 /

maps.coordinator@mertonmencap.org.uk

Read more here: [Talk Autism - Merton Mencap](#)



Everyone at Merton Mencap is deeply saddened at the recent passing of our fondly regarded colleague, Denyse Garrod.

For many years, Denyse was team leader at several of our clubs for young people with learning disabilities and autism including at our weekend sports club, evening social club and holiday playschemes. Everyone who knew Denyse will recall her huge dedication, and her setting the highest example to her teams of providing exceptional care and support for club members. Denyse always led from the front.

Denyse's work was instrumental in establishing our charity as a source of support for local families. We simply wouldn't have reached the families that we have done over many years if it hadn't been for Denyse's hard work. So, thank you so much Denyse - we will always remember you.



Upcoming Workshops & Events

Thursday 25 January, 10am to 12pm (Zoom meeting)

Leisure opportunities & social activities for adults with learning disabilities & autism

**with Mike Dignam, Chief Operating Officer, Generate, Robbie Keen, Director, Keen 2 Go
& Keeley Reed, The Squad**

Hear from 3 different local organisations about their fantastic programme of events & activities on offer for adults with learning disabilities & autism.

A great opportunity to find out more & ask your questions!



Thursday 29 February, 10am to 12pm (Zoom meeting)

Supported learning courses for adults with learning difficulties or disabilities

with Dilys Martin, Curriculum Quality Officer, Merton Adult Learning, Head of SEND, Richmond & Hillcroft Adult & Community College (RHACC), Kerry Macey, Head of Learning Centre, Orchard Hill College & Susan Aldridge, Community Learning Coordinator & Head of Department for Supported Learning, Sutton College
An update on supported learning courses in Merton delivered by RHACC, plus information about the supported learning courses at Orchard Hill College, Sutton College & RHACC.

Thursday 18 January, 10am-12pm (in person meeting)

Transition of children with EHCP's from primary to secondary school

with Georgie Tyrell, SEN Team Manager & EHCP Co-Ordinators, and Fran Turko & Shazia Khan from Merton's Information, Advice & Support Service (MIASS)

Don't miss this opportunity for year 5 parents to come & hear what the process for the transition of children with EHCPs from primary to secondary school will look like for a September 2025 start date (parents of children with EHCPs in other primary school years also welcome).

Georgie will be giving an overview of the process & introducing you to some of the team of EHCP Co-Ordinators. Fran & Shazia will give a short presentation on the legal framework, some top tips & what to expect from schools.

Chaucer Centre, Combi Room, Canterbury Road, Morden, SM4 6PX



Tuesday 30 January, 10am to 11.15am (Zoom meeting)

Merton Family Hub information and feedback session

**with Carolyn Castle, Strategic Lead for Family Hubs
& Beatrice Marett, Family Hub Participation and Engagement Manager**

The Merton Family Hub is a place where families & young people aged 0-19 & up to 25 for those with special educational needs & disabilities, can access the support, help & advice they need.

Listening to the needs of the local community is so important in planning the way in which Merton will deliver services as part of a Family Hub.

If you would like to learn more about the Merton Family Hub & get involved by helping Merton shape the way in which family services are set up & accessed, please do come along to this event.

Thursday 22 February, 10am to 12pm (Zoom meeting)

EOTAS (Education Other Than at School) Information session

with Eva Akins, Specialist in Education Law & Partner at Russell Cooke Solicitors, Ryan Stevenson, Co-founder & Director of Bright Heart Education & Fiona Ringwood, parent carer & Kids First member

Eva will talk through the key principles of EOTAS, how to request it, how it works & what can be included as part of an EOTAS budget, such as home tuition, different therapies, special equipment, educational trips & more. Plus provide a brief overview of the range of advice the Education Law team can offer around a child's right to an education & educational support.

Ryan will explain how Bright Heart Education work with families, local authorities & schools, to help students who have special educational needs who may need Education Other Than at School (EOTAS) & talk through the services they offer around home tuition & home schooling.

Finally, hear from Fiona, who will talk about her experiences of EOTAS with her son.

Friday 8 March, 10am to 12.30pm (Zoom meeting)

Practical Strategies to reduce extreme behaviour in SEND children and young people

with Yvonne Newbold, MBE, Newbold Hope

This 2½ hour session looks at the reasons why children & young people with additional needs can develop extreme behaviour, which may include physical violence towards other people &/or pets, other forms of aggression, controlling behaviour, avoiding demands, self-harm, property destruction & using inappropriate & offensive language.

Some of the areas covered in this session are sensory issues, communication, routines, resistance to change, transitions, processing speed, theory of mind, masking.

TBA, 10am to 12pm (Zoom meeting)

SEND Update

with Elizabeth Fitzpatrick, Assistant Director of Education & Early Help

A great opportunity to hear the latest information from senior officers in Merton & ask your questions!

TBA March, 10am to 12pm (in person meeting)

The role of the Merton CAMHS Team

& the neurodevelopmental pathway for diagnostic assessment of Autism Spectrum Disorder/ADHD explained.

Hear about the role of the Merton CAMHS Team & an update on the neurodevelopmental pathway for diagnostic assessment of ASD/ADHD in Merton. The session will cover information about the referral process, how referrals are screened, assessment processes, waiting lists & how the mental health needs of children & young people with ASD are being met.

Thank You!

Contact us!

Tracy Blackwell

Parent & Carer Forums Manager

E: kids.first@mertonmencap.org.uk /
adults.first@mertonmencap.org.uk

T: 020 3963 0598 / M: 07518 903260

Contact us!

Tuhina Shaikh

Admin Assistant for Kids First, Adults First

E: kf.admin@mertonmencap.org.uk /
af.admin@mertonmencap.org.uk

T: 020 3963 0597 / M: 07929 670645

