Suffolk Parent Carer Forum Newsletter May 2024



Suffolk Parent Carer Forum Newsletter

Welcome to our new and improved newsletter where you will find news, updates and events.

You may notice we recently changed our font to become more dyslexia friendly, we hope you like it!

We're making some changes to our website to incorporate the new font and updating the content. Please bare with us while we implement the changes.

You can provide your feedback here - SPCF Members Feedback Form

We're always looking at growing our member base and widening our reach in Suffolk. If you know any other Parent Carers they can sign up to be a member here - Membership - Suffolk Parent Carer Forum



SPCF Closed

Please note that Suffolk Parent Carer Forum will be closed from Monday 27th May and will re open Monday 3rd June when we will respond to any enquiries

Activities Unlimited Awards 2024-2025

Activities Unlimited have been processing the awards for this year. New applications have to be processed through their relevant checks. A new provider for "know your customer" checks had to be found. It has caused some delays but hopefully families will receive notice that their award has been paid very soon. SPCF recognise the delay can be difficult as well as not having funds available over Easter. We will feed this back at our next meeting with Activities Unlimited.

SEND Strategy 2024-2028

The 24-29 send strategy has been signed off and will be published in June. SPCF have spent a considerable amount of time on this. Many other meetings were cancelled or postponed by the local area partnership to prioritise the strategy. We were very concerned that there was a request to remove the word gaslit from parents and carers feedback. SPCF stood firm and would not remove the voice of lived experience. This involved additional meetings, calls and emails as well as giving up personal time at the weekend and consulting Refuge, practitioners and the Certain Curtain Theatre Company. We are pleased that our firm stance has meant parents and carers feedback is uncensored in the new strategy.

Executive Director for Children & Young People

SPCF met with the new executive director for children and young people, Sarah-Jane Smedmor. We gave her a frank view of the situation for families in Suffolk and the desperate and urgent need for change. The forum currently working with Sarah-Jane have found it to be a positive experience. We look forward to Sarah-Jane joining us and meeting parents, carers, children and young people in Suffolk.

Independent Improvement Board Chair

SPCF also met with Kathryn Bolton. We shared the difficulties and frustrations of families in Suffolk. We hope that her independence will help to lead positive change, meaning better outcomes for the children and young people of Suffolk.

Shadow Improvement Board Meeting

Social Media Presence

Social Media Reach is 16.6K, a 160% increase in the last 90 days

In the last 90 days we have had 4.6K visit our Social Media

207% Increase in Followers in the last 90 days

7% Increase in Registered Membership since January 2024

Our online engagement is up 167% in the last 90 days

Our content reached 3.6K people in a day in April

In the last 90 days we have seen a 231% increase in our online content interactions



Growth, Reach & Engagement

SPCF were pleased to show their membership and follower growth at this meeting.

Shadow Improvement Board Feedback from SPCF

We are concerned about attitudes from our experience as a forum and from feedback from families. In a nutshell these attitudes are demonstrating defensiveness and lack of listening. We need listening to learn not listening to defend.

Families tell us when making contact with Suffolk County Council they don't feel heard, they don't experience empathy and are met with defence. We agree. When we raise issues we are often asked how many people? It doesn't matter. We also do not have the time and staff capacity to make endless tallies. When we are met with this we feel Suffolk County Council are minimising.

Shadow Improvement Board Feedback from SPCF Cont.

We would like to be clear our feedback is from families. We do not make it up or simply feedback on our own experiences although they are just as valid. When we mention names it's to help you identify and resolve problems. It is not to single out or pick on anyone. It is natural that we will individually get more feedback from the parts of the county we live in because that is our community.

The issues over parent carer feedback in the SEND strategy have been incredibly disappointing. The suggestion to change parent carers views demonstrates a lack of understanding and awareness to the real, lived experiences and contradicts the strategy. We were disappointed to see ClIr Reids email. It included a quote from an American domestic abuse hotline which makes it bias to the situation. I spoke to Refuge in the UK who are part of the UK Domestic Abuse hotline who said..

"The dictionary definition of Gaslight does not include any reference to who may perpetrate this behaviour other than in examples of how to use the word in a sentence. They define it as "to trick or control someone by making them believe that their memories or beliefs about something are wrong."

I believe you are doing the right thing in standing firm to ensure parents and carers have their voice heard and gaslighting is a term very often used with regards to professionals, even outside of the context of a local authority."

However difficult it might be to hear, the truth is parent carers do feel gaslit.

Families tell us complaints are shut down and no empathy is shown. They are just met with defence. Families strongly feel the local authority ring fence. They feel they are gaslit. Families do not feel the complaints system is working for anyone but the local authority. The complaints system is broken! Families are not the problem for complaining, you are the problem for giving them cause for complaint!

Shadow Improvement Board Feedback from SPCF Cont.

Communications are corporate and not person centred. It needs to be remembered that these are real people's lives. We are talking about a child's future, not a transaction.

There is NO accountability. This is clearly demonstrated to the forum, to our members and those who feedback to us. We do not want lip service or procrastination. We want solid actions that change culture, actually hold to account and follow the law. These things are doing nothing to build relationships or trust. This feedback needs to be taken on board and not defended.

The most recent data shows the average current wait for a finalised EHCP is 36 weeks and 4 days. 62.1% are late and 13.6% over 52 weeks. We have been told that all draft plans are checked by a manager before they are sent out to families. We raised concerns over the competency of these checks as poor quality plans that are not specified or quantified are still reaching families.

Parent Carer Feedback







Trigger Warning The next page mentions suicide

Zero Suicide Alliance



Zero Suicide Alliance have developed Autism and Suicide awareness training.

Our chair of trustees, Sue Willgoss writes:

"I have been working with the Zero Suicide Alliance developing a new edition of their training to help people recognise and support autistic people who may be in crisis or suicidal. This was commissioned by Greater Manchester after their lead heard me present at a national meeting about Daniel, our loss and the horrific suicide statistics for autistic people. We launched on April 2nd, World Autism Acceptance Day, having over a 1000 people book to attend the live launch. This training is free and aimed to save lives."

Details of the launch and training can be found here: <u>Our NEW Autism and Suicide</u> <u>Awareness Training has officially launched!</u> <u>"Zero Suicide Alliance"</u>

SAMARITANS

Call for free on **116 123**

Shout
85258
here for you 24/7

SPCF Annual Survey

Keep your eyes peeled for our 2024 Annual Survey coming soon!





SPCF Open Event - Stowmarket

We are expecting to have representation from SES, Attendance, Travel Training, Sendiass, Particip8, NDD, Activities Unlimited, School Nursing, Beans, the voluntary sector and more.

The venue is close to main bus routes and there is a small car park at the front for use of attendees with mobility difficulties on a first come first served basis.

Suffolk Local Offer

Suffolk Local Offer provide a range of information and advice for families of children and young people with Special Educational Needs and Disabilities (SEND) in Suffolk.

> They cover topics including: Education Health and Wellbeing Social Care **Preparing For Adulthood Short Breaks & Leisure**

You can find them here -Home - Suffolk SEND Local Offer

Suffolk Inclusion Support Line



Advice, guidance and information for education settings to help meet the needs of children and young people with Special Educational Needs and Disabilities (SEND).



Call us today on 01473 265502 Email - localoffer@suffolk.gov.uk www.suffolklocaloffer.org.uk

Activities Unlimited is part of Suffolk County Council. They give grants to activity providers around the county, to enable them to put on high quality, inclusive groups, clubs and activities for



children and young people with additional needs and disabilities.

Here is the guide of providers for 2024-2025 -<u>Activities-unlimited-provider-guide-24-25 (suffolklocaloffer.org.uk)</u>

Short Breaks Personal Budgets

A Short Break Personal Budget is a sum of money paid directly to eligible families as a contribution to help your child access short breaks and to give you a break from your caring responsibilities.

You can find out more information and how to apply here -<u>Activities Unlimited Short Breaks Personal Budgets - Suffolk SEND Local Offer</u> Suffolk SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service)



is a confidential and impartial information, advice and support service on issues related to Special Educational Needs and Disability (SEND). It is free, easy to access and confidential. They can help children, parents and young people take part in decisions that affect their lives.

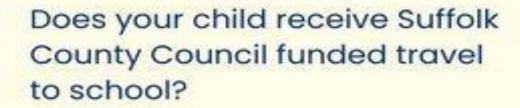
They offer information, advice and support to:

- •Children and young people (up to 25 years) with SEND
- Parents and carers of children with SEND
- •Practitioners (who might support children, young people or parents to access our service)

You can find a list of their Summer online sessions here - <u>SENDIASS-Summer-Training-for-Families-2024.pdf</u>

All of the SENDIASS workshops can be viewed after the event on their YouTube Channel here - <u>Suffolk Sendiass - YouTube</u>

Don't forget to opt - in!



If so, don't forget that you must 'opt-in' each year.

The deadline to 'opt-in' for school year 2024 -2025 is: 31st May 2024.

Visit: www.suffolkonboard.com for further information on eligibility and to re-new your application.





Join us for an incredible chance to boost your wellbeing through a hands-on 'farm' experience, specifically designed for individuals with physical, neurodiverse or neurological needs. Whether it's for you or someone you know, don't miss out on this wonderful free event!

Saturday 25th May

1hour sessions:

10:30am, 11:30am, 1:00pm, 2:00pm

This is a free event although booking is required due to limited spaces.

To book please call 01449 673947 or email contact@redgables.org.uk





A dementia and SEND friendly event

Red Gables, Ipswich Road, Stowmarket IP14 1BE







BRIDGE FAMILY HUB

Bridge Community Church, 68 Queens Rd, Bury St Edmunds, IP33 3EW

> 2024 10:30 - 12:30

> > April 30th May 14th June 11th June 25th July 9th



Do you have a child who struggles with school attendance?

'Bridge the Gap' is a drop-in support space for children and their families who struggle to attend school for whatever reason.

JOIN with other parents and carers
ENJOY activities for your child including sensory circuits, creative space,
lego station, games and separate sensory space.

CONNECT to gain the support and advice you need to overcome the barriers to
accessing school regularly

for further details
please contact
emma@bridgecommunitychurch.co.uk
07501 408608





PACT offer non-clinical peer-led support and resources for parents and carers. Their vision is to reach parents and carers across Suffolk who are caring for a child or young



person with mental health issues. They offer support (face to face meetups, online, and our outreach 1:1 service), training (including Youth Mental Health First Aid and parent guided CBT) and tools/resources to help both with a parent/carers wellbeing and via them, their child/young person too.

You can contact PACT at parentsandcarerstogether@gmail.com



"Supporting you, supporting your child"

Suffolk Support for parents and carers of children and young people with mental health issues www.parentsandcarerstogether.uk

Helpline number (07856) 038799 (not 24/7)

Support group for parents and carers of children and young people with mental health issues



@pactenquiries



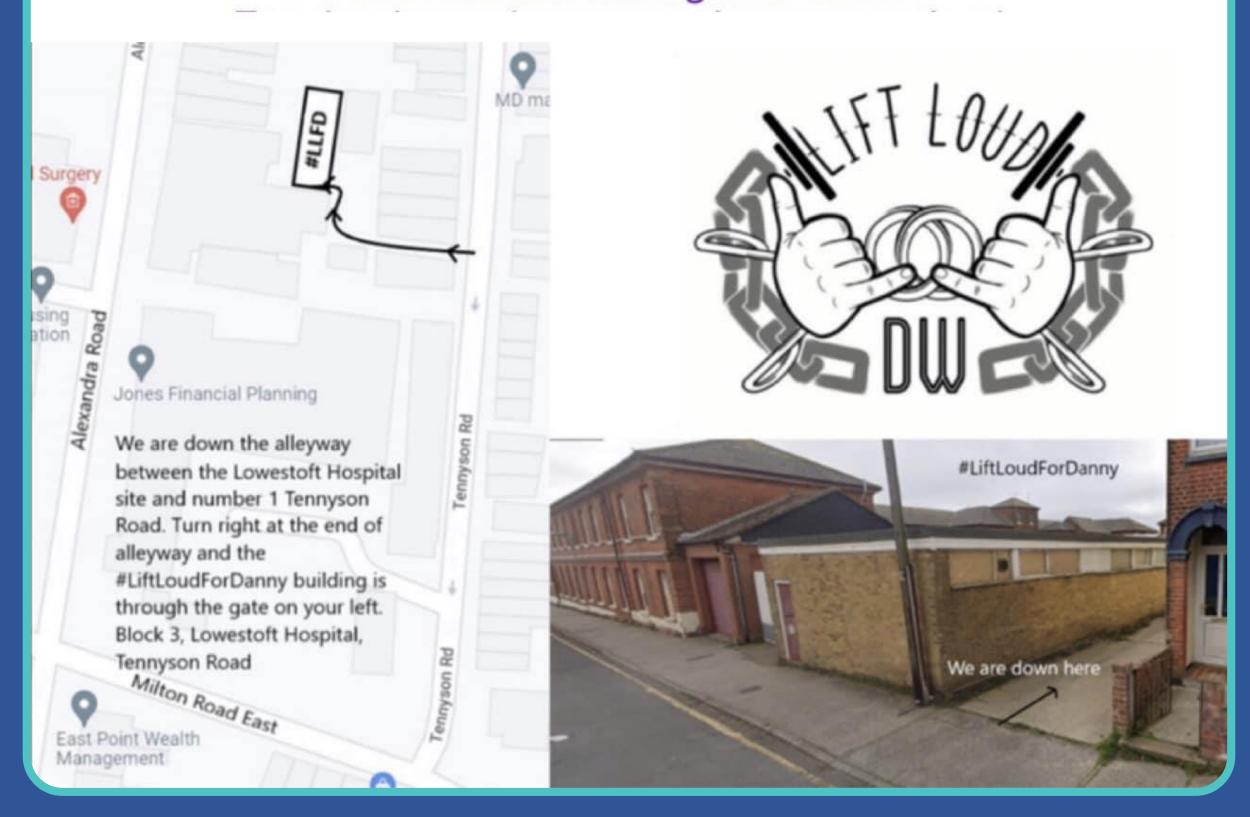
3rd Monday of the month 10.30 ~ 12.30 Lowestoft Parent/Carer Meet Up

Are you a parent or carer concerned about the mental health/ wellbeing of a child or young person?

If so, come along and meet up with other parents and find friendship, support, advice and training to help build your knowledge toolkit so in turn you can help support your child.

Support and advice ~ Supporting you to support your child ~ Training Events ~ Guest Speakers ~ Sharing experiences and gaining knowledge ~ Resource Library

VENUE: #LiftLoudForDanny, Block3, Lowestoft Hospital, Tennyson Road, down the alleyway just past the hospital building and before houses (at the telegraph pole) Parentsandcarerstogether.co.uk



Contact For families with disabled children

Contact are a charity that offer a range of services to support families with disabled children. They give information and advice, run a variety of workshops, provide 1:1 telephone appointments for parent carers needing emotional support and more.

You can find out more about the services they provide here <u>—</u>
Support for families

Their workshop calendar can be viewed here – Workshops and events (contact.org.uk)

They have a Podcast showcasing topics like money matters, annual health check tips and more. You can find it here -

The helpful podcast for families with disabled children - Hosted by Contact (acast.com)

Are you getting the right amount of Universal Credit as a parent carer?



contact.org.uk/uc

Carer element

Paid if you're eligible for Carer's Allowance (or if you meet the criteria for it but your earnings are too high). You don't actually have to have claimed Carer's Allowance.

Child element

Paid for each dependent child in your family. You won't normally get this for a third or subsequent child born on or after 6 April 2017.

Disabled child addition

Paid (at one of 2 rates) for each dependent child who gets DLA or PIP. If you're eligible but don't receive this addition, add a note to your journal. It should be backdated in full.

Childcare element

Covers up to 85% of your registered childcare costs if you work (any number of hours), up to a certain amount.

Family Action West Suffolk Neurodevelopmental Support Service

Parent and Carer Drop In

Do you have a neurodivergent child?

Drop In Sessions

- Meet other parents and carers
- Chat to our friendly Family Support Workers

First Thursday of each month, 10:30am - 12:00pm Term time only





01284 636 655



wsuffolk@family-action.org.uk



Oakes Barn, St Andrews Street, Bury St Edmunds, IP33 3PH



Family Action West Suffolk Neurodevelopment Support Service

Do you have a neurodivergent child?

NEW Parent and Carer Drop In

- Meet other parents' and carers
- Chat to our friendly Family Support Workers

First Wednesday of the month, 10:30am - 12:00pm First Drop In: Wed 3rd Jan 2024

No need to book
Free tea and coffee available



01284 636 655



wsuffolk@family-action.org.uk



Clements Community Centre Leiston Road Haverhill



Family Action West Suffolk



Neurodevelopmental Support Service

Family Action West Suffolk Neurodevelopmental Support Service support parents and carers of children in the geographical areas of Forest Heath, Bury St Edmunds Town and Bury St Edmunds Rural who are waiting for, or undergoing, a neurodevelopmental assessment, or where there has been a recent diagnosis of autism or ADHD or other neurodiverse condition. We offer 1:1 parent support, courses, peer support groups, and a range of workshops covering issues raised by parents/carers.

Their service is open Monday to Friday 9am to 5pm.

To contact the West Suffolk ND Support Service team:
Email: Wsuffolk@familyaction.org.uk

Telephone: 01284 636655

Parent Carer Drop in for those caring for a neurodivergent child or child with SEND



Opportunity for peer support and advice from a Family Advisor

> First Tues of the month (term time only) Starting 7th May 2024 10am to 11.30am

The Phoenix Family Hub, Tudor Rd, Sudbury, **CO10 1NP**

www.suffolkfamilycarers.org

Suffolk **Family Carers**

Universal Credit: Managed Migration



If you are confused or worried about what managed migration will mean for your family, we have lots of information that can help on our website.

contact For families with disabled children



We will be at the



29th - 30th May 2024

We will be at the Suffolk Show on the 29th and 30th of May at stand 439B to answer any questions about who we are and what we do - come along and say hi!









for anxiety and depression

Annual Health Checks

Adults and young people aged 14 or over with a learning disability who are on the doctor's practice learning disability register should be invited by their doctor to come for an annual health check.

Most doctors offer annual health checks to people with a learning disability. But they do not have to offer this service.

If your doctor's practice has not offered you an annual health check, you can ask them if you can have one.

If they say no, ask your local community learning disability team to help you get one.

Click here to find local learning disability services - <u>Find local learning disability</u> services

Mencap have an Easy Read information leaflet providing information about the Annual Health Check you can show your young person to help them Understand the benefit and what to expect.









Stowmarket United Reformed Church
Minister: Rev'd Robert Sheard
Secretary: Mr Brian Hewitt

www.urcstowmarketandvillages.com

TIME OUT

FOR CARERS
AND THE
PEOPLE
THEY CARE
FOR



COFFEE MORNING

Every 1st Tuesday of the month 11.00am to 1.00pm

Why not come along for a Coffee (or tea), a chat and put the world to rights.

ALL ARE WELCOME TO JOIN US



Young people between 10 and 15 years old who are neurodivergent and NEET, Home Educated or in Part Time Education



This is a 7 session course to work towards an RYA sailability award

Fortnightly sessions starting Weds mornings from 8th May 2024 SUA DEI

Funded by the Crane Fund

A-132

Introduction session will be offered before place is confirmed

To indicate an expression of interest please email michelle.jones@suffolkfamilycarers.org



Living Fuller Lives

Suffolk Family Carers offer advice and guidance, workshops and courses, a listening ear, support in hospitals and help you find time for yourself.

They have a range of events for Parent Carers both online and in person such as drop in sessions, swim and yoga sessions, Carer Rights workshops and more.

Here is a link to their upcoming events and workshops – <u>Parent Carer Workshops | Suffolk Family Carers</u>

PARENT CARER SUPPORT GROUPS

All information is correct at time of publication, we advise contacting the organiser directly for updates.

IPSWICH		
Suffolk Family Carers, Unit 9, Hill view Business Park, Old Ipswich Rd, Claydon, IP6 0AJ. For parent carers of ND children and young people.	2nd Tuesday each month 10:00-12:00	
MENCAP Community Carers Drop In, The Meeting Place, Limerick Close, Ipswich IP1 5LR	Contact Barbara Thorn 07766 103563	
Ipswich Opportunity Group Salvation Army Hall Woodbridge Road Ipswich IP4 4PH	Monday: 10.00 - 11.30 and 13.00-14.30 Friday: 10.00 - 11.30 Cost £4.00 per family	
Over 18's Neurodivergent Abilities Evening Social Club, The Golf Pub, 748 Foxhall Road Ipswich, IP4 5TR. We welcome Neurodivergent individuals, partners/carers of neurodivergent children.	Contact nd-abilities@outlook.com for further dates. www.neurodivergentabilities.org	
Coffee Morning - Neurodivergent Abilities and Suffolk Family Carers, The Key Café, St Margaret's Plain, Ipswich, IP4 2BB	Last Thursday of the month 10:00 -12:00 term time only	
Neurodivergent Abilities Men's Talk, The Golf Pub, 748 Foxhall Road Ipswich IP4 5T	Contact nd-abilities@outlook.com for further dates. www.neurodivergentabilities.org	
WOODBRIDGE/LOWESTOFT/SAXMUNDHAM/FELIXSTOWE		
Pit Stop SEN Sessions St Edmunds Church Felixstowe	Saturdays 10a.m12.p.m.	
BEANS, The Pavilion, Jetty Lane, Kingston Fields, Woodbridge, IP12 4BA. Group for parent carers of ND children and young people	2nd Tuesday each month 10:00-12:00noon	
Coastal Parenting Hub Felixstowe Library Crescent Road Felixstowe IP11 7BY	1st Wednesday of the month 13:00 – 14:30 (term time only).	
BEANS, Sax'cess House, High St, Saxmundham, IP17 1AE Group for parent carers of ND children and young people	4th Tuesday each month 10:00-12:00 noon	
MENCAP Felixstowe Felixstowe Ferry Centre, Ferry Road, Felixstowe, IP11 9RS All social clubs cater for a range of individuals with a variety of needs and provide a fun and supportive environment. Activities change throughout the year.	Drop-In - Age 2+ Saturdays 9.30am-11.45am Contact: Amy Peachey 07738902914 The Gateway Club - Age 16+ Alternate Wednsdays - 7-9pm Contact: Simon Jennings 07971 930226 Magic - Age 16+ 2nd & 4th Friday - 7-9pm	

STOWMARKET/NEEDHAM MARKET/BURY ST EDMUNDS/HADLEIGH/SUDBURY/HAVERHILL	
PACT (Parents and Carers Together) Walk and Talk at Needham Lake	3rd Thursday each month 10:00 -12:00
Parent Carers Monthly Meet Up Drop in Robins Family Hub, Quinton Road Needham Market IP6 8BP	1st Monday in the month 13:00 -14:30 familyhubs@suffolk.gov.uk
Family Action - West Suffolk, Oakes Barn St Andrews St Bury St Edmunds IP33 3PH. Group for parent carers of ND children and young people	1st Thursday each month 10.30-12:00 wsuffolk@family-action.org.uk
Family Action - West Suffolk, Clements Community Centre, Leiston Rd, Haverhill, Group for parent carers of ND children and young people to get support and advice.	1st Weds of month from Jan 2024 10:30-12:00
BEANS, Linden House, Kings Rd Bury St Edmunds, IP33 3DJ. Group for parent carers of ND children and young people	3rd Tuesday each month 10-12 noon
Parent Carers Monthly Meet Up Drop in Blossoms House, Crockett Road Hadleigh IP7 6RJ	1st Tuesday in the month - 13:00-14:30 familyhubs@suffolk.gov.uk
Parent Carers Monthly Meet Up Drop in Phoenix Family Hub 27 Tudor Road, Sudbury CO10 1NP	1st Tuesday in the month - 10:00 -11.30 familyhubs@suffolk.gov.uk
SEN Superstars: Stay and Play at Blackbourne Community Centre Elmswell IP30 9UH.	Thursdays fortnightly 10:00 -11.30
Embrace celebrating & supporting neurodiversity. Old Newton Church Institute IP14 4ED	2nd Wednesday each month 9:30 -11:00
The Arc SEN parent support group Stanton Village Hall IP31 2BX	Wednesdays 10:00-12:00
The Arc SEN parent support group Bay Tree Café Bury St Edmunds	Thursdays 10:00-12:00
Stowmarket ASD Club Parent and Carer evening meet up. Pallet Bar, Old Fox Yard, Stowmarket. Open to members and non members.	1st Thursday of each month 19:00
Stowmarket ASD Club Parent Café, Stowmarket Community Hub, Crown St, Stowmarket	Bi-monthly Saturdays 12:00-14:00 Contact stowmarketasdsaturdayclub.co.uk
VIRTUAL DROP IN SESSIONS FOR PARENT CARERS	
PACT Group (parents and carers together)	Every Friday 6pm on Facebook
A Time to Be, Home Start Suffolk. Virtual group for parents of children with additional needs.	First Wednesday evening every month 19.30-20.30 E-mail: tracy@homestartsuffolk.org
Join Speek; virtual group sessions for parents carers whose children self harm	Connect & Learn Sessions
SUPPORT GROUPS WHERE BOOKING IS ESSENTIAL	
Haverhill: SEND Families Unite Chalkstone Community Centre Haverhill support group for parents and carers of children with a diagnosis or undiagnosed special needs.	1st Monday 10:00 -12:00 noon. Places need to be booked call Stephen on 07925138186.
Stowmarket: SEND Families Unite Red Gables, Stowmarket IP14 1BE. Support group for parents and carers of children with a diagnosis or undiagnosed special needs	3rd Tuesday of every month 13:00-14:30. Places need to be booked call Vickie on 07754764477.

Parent Carer Needs Assessments

Did you know Suffolk County Council offer Assessments for Parent Carers?

The purpose of a Parent Carer Needs assessment (PCNA) is for you to have an assessment of your own needs, allowing you to discuss with a practitioner your caring role and how it affects your wellbeing, your feelings and choices about caring, what help you need to support you as a carer of a child/young person with additional needs and/or disabilities, and to find out what help and support may be available.

To request a Parent Carer Needs Assessment contact Customer First on 0808 800 4005

Find out more information here Parent Carers | Suffolk Family Carers



SUFFOLK

Libraries across Suffolk have a range of social groups, courses, play sessions and events to attend.

Find out what's coming up here - What's On | Suffolk Libraries



Working towards a brighter future for Suffolk's children and young people

- ♠ Suffolk Parent Carer Forum, Brightspace, 160 Hadleigh Road, Ipswich, IP2 0HH
- € 01473 760933 ⋈ info@suffolkpcf.co.uk 🔊 www.suffolkpcf.co.uk