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COMMUNITY

A Message from the Team



A **HUGE** welcome to all our members old and new.

What a wet and windy start to the year we have had so far. I hope things have been much brighter for you and your families. With Easter on the horizon I'm sure many of the children (adults too) are excited to see what the Easter Bunny brings. Remember that all our family groups will continue to run over the school holidays, with activities to entertain the children, so please pop along for a chat. PODS ended last year in style with our Santa Visits and a Christmas party, we hope you all had fun, if you have any ideas for this year please get in touch. So far this year we have had a really positive start, with a sell out workshop with Autistic speaker Dean Beadle. our new Befriender training is underway, with all the new volunteers keen and excited about supporting our families. We have held discussions with the Ironbridge Gorge Museums and are delighted to be supported by them in being able to bring you passes for free entry to all their museums. Long may the positivity continue.

Our family groups have undergone a refresh based on feedback, with the return of an old favourite at a slightly different location. Our Wacky Warehouse session continues to be as popular as ever, with many of our families enjoying the opportunity to allow their children to play in a safe non-judgemental environment. We have also just started a dedicated family group for those parents with young people aged 16-25, please check our ebulletins and social media pages for times/dates and venues.

Uma has made a real impact with her new role with the introduction of a regular Lego club for primary school children, this will be available to older age groups on the next run. She also supports at many of our family groups and brings along her knowledge as a trained befriender.

Jo is full of ideas and enthusiasm; she has made a tremendous start in securing many

donations and small grants which she is utilising to bring you inclusive events and activities. She has also starred on the radio to help raise awareness and made many links with local business and gained their support.

Lin is heading up our Befriender service and is doing an excellent job in training, motivating and supporting the new befrienders. She is extremely passionate about her role and is looking forward to the service being rolled out to all our members over the coming months.

Kerrie continues to hold us all together and supports the other team members to keep everything running smoothly. She has worked tirelessly to pull together our new logo, flyers and other promotional material, whilst keeping our members informed and up to date with the ebulletin.

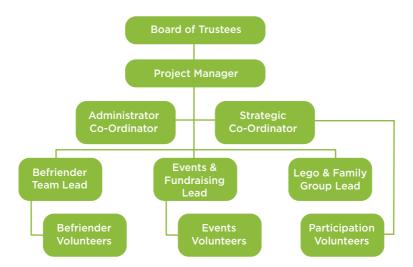
Jayne and her Team of Parent Reps meet regularly to discuss the things that matter to you the most. They ensure your thoughts and feedback on services and partner agencies are fedback to the correct people at the highest possible level. Jayne continues to strive to make all services better and more accessible for all, whilst delivering information out to our members in variety of ways to make sure they're well informed and empowered to achieve the best for their families.

Our team of volunteers have been extremely busy helping to raise awareness of our charity and reaching out to many hard to reach families. Val and her team have planned and held fundraising events and stalls to help bring the funds in to facilitate all the activities we put on. More recently they have been meeting as a group to discuss, research and plan this year's main inclusive trips.

A huge thank you to our team of volunteers, funders, staff and trustee's, without you none of this would be possible.

The PODS Team

Organisation Structure



We thought it would be beneficial for our members to know and understand our structure, this will help people direct their questions/queries to the most appropriate person.

Our ever-growing team of volunteers are instrumental to the success of our organisation and without them we would not be able to offer you the level of support we do. Our Befrienders provide 1-1 emotional and practical support when you need it the most. The events team organise and fundraise to bring you the inclusive events. The participation reps gather your views and opinions on services and ensure that your voice is heard at a strategic level with the decision makers.

Befriender Team Lead - Organises and supports the dedicated befrienders, they assess the requests that come in and match them to a befriender as well as providing ongoing training and support.

Events and Fundraising Lead - Helps manage the events, bookings and supports the volunteers alongside the Volunteer Co-ordinator, they also research and apply for grants, funding and donations to help fund our activities.

Lego & Family Group Lead - Runs our popular Lego therapy sessions and heads up the family groups which bring you that vital time to chat and gain support from people that understand and listen. Administration Co-ordinator - Holds everything together like superglue, she maintains our database, sends out the Ebulletins, organises the Newsletter, manages our website and supports the rest of the team.

Strategic Co-ordinator - Supports our team of Parent Representatives, attends strategic meetings within the Local Authority and partner services, conducts workshops and events to empower parents, provides crucial advice and support to our members, ensures your voice is heard as loud as possible.

Project Manager - Oversees the Charity and ensures we are meeting our aims and objectives, completes the reporting for our funders, sources and completes bids for new funding, works on our sustainability. They also manage the finances, set the budgets, HR support along with policy and procedure guidance, organises workshops and liaises directly with the Board of Trustees

Board of Trustees - These are volunteers from a variety of backgrounds that believe in our Charity and the work it carries out. They generously give up their time to guide and support us and ensure we are the best we can be and deliver on our objectives. They're there to make the big and sometimes difficult decisions whilst looking after the team's welfare and keeping us in line with our constitution.

Strategic Report from Jayne Stevens

(Strategic Co-ordinator)

Hope everyone is well. I'm writing this report at the end of February Half Term and wondering where the week has gone!! Like a lot of our families we're moving through transition years and now in 'college' world and heading into 'adult' world.

In a recent event that we organised with Dean Beadle (Autism/Aspergers speaker), I was reminded that lots of our parent carers are at different stages of their lives – whether that be the age of their child, or whether they have recently received a diagnosis, or whether they are transitioning into school or through the school life – from primary to secondary or secondary to further education and training. Alongside the needs of the children and young people, are the needs of our families that must also be recognised and strategies and guidelines and workshops etc to support our children and young people, also need to mirror the needs of our families to ensure they are resilient, cared for, listened to and supported in ways that matter to them. With this in mind, we continue to gather your views, through our family groups, events, befriending scheme, social media, adhoc conversations, phone/email, fundraising and community activities, coffee meetings in schools, inclusive trips and through sharing of information – all of which are covered on different pages in this newsletter and a diagram of how this works is shown below:

How Participation Works

PARENTS OPENING DOORS (PODS) TRUSTEES

PODS PARENT CARER FORUM & PARENT REPS

STRATEGIC PARTNER: HEALTH, EDUCATION, SOCIAL CARE, COMMUNITY

Activities, trips, inclusive events, crafty groups, Picnic, Fundraising Family Groups: "What's working Better If, Not working" Befriending:
Direct
experiences
around
emotional
and practical
support

experiences around need of children and families Participation
Opportunities
- events,
conferences,
workshops,
consultations,
surveys, etc

COMMUNITY GROUPS LINKS AND CHAMPIONS SHINING STARS, SNAC, COMMUNITY CAFES, FUNDRAISING TEAM

PROJECT MANAGER SUPPORT - ADMINISTRATOR CO-ORDINATOR SUPPORT

STRATEGIC VOICE AND PARTICIPATION RUNS THROUGHOUT FOR IMPROVED SERVICES DEVELOPMENT AND IDENTIFYING GAPS AND SHARING PARENT CARER VOICES Your collective views and experiences are shared as part of our strategic work where we attend the following meetings – many of which I attend, and some with support from our wider parent rep network who all have a key area of focus. Another way we have been gathering views is through the 'What we Love' postcards – we've collected lots of these at our events and family groups over the last few months and we are in the process of turning these into a printed book. We have lots of lovely comments from families and young people themselves – thank you to everyone who has contributed so far.

Key Strategic and Operational Meetings:

Autism Working Group

Aiming High Board

Child Development Centre

Early Years work, Transition and Preparing for Adulthood

Short breaks

Local Offer and Communications groups

Carers Partnership Board

Healthy Child Programme 'Pause for Progress' network meetings

Strengthening Families and Early Help

Social Care Transformation Programme (Inclusion and Acceptance, Market Development, Workforce, Training, Commissioning)

Joint Strategic Needs Assessment workstream

Health (BeeU and NHS Long Term Plan)

Parent Rep Focus Area:

Sarah R: Local Offer and Comms, School Coffee Mornings

Tina L: Local Offer & Comms, Shining Stars, Early Years

Karen E: Parent carers transition to adults, Housing

Keiron W: Commissioning (social care), Carers Board

Simon B-R: Short Breaks, Social Care

Deb S: Mental Health, MIND

Liz B-S: Inclusion and Acceptance, community activities

Uma B: Family groups and Haughton School

Elaine P: Autism and Core Comms

Support from wider team members for family groups and administration of the strategic meetings is also really important and very much valued.

This is not an exhaustive list and we have many ad-hoc/project meetings where input is used and valued throughout each month.







Social Care Transformation Plan

We have started looking at our Inclusion and Acceptance workstream of the Social Care Transformation Plan that we are leading on and as part of this we have identified that there needs to be some mapping of the wider community offer. Thank you to everyone who has inputted into this piece of work – we currently have 7 pages of community activities and whilst we understand that these might not be right for everyone, it demonstrates the range of families that we work with. This information will be collated, along with information from leisure, libraries, Ican2, community team at the council and lots of other stakeholders.

Other areas we are working on with this plan include:

Inclusion & Acceptance

Person Centred Plan Ican2 Short Breaks Market & Service Development Workforce Development

Market and Service Development

Much of this was discussed at the JSNA (Joint Strategic Needs Assessment) Event that we presented at, the end of February 2020, sharing 40 pages of parent carer experiences and feedback from our Annual Survey.

This report is too big to share in this newsletter, but is available on our website: https://www.podstelford.org/consultations-surveys/



The recommendation from CDC (Council for Disabled Children) workshops that we attended last year recognised "The commissioned services map is useful but additional contextual information and data would improve it further.

The aim of undertaking and collating a JSNA is to establish the current provision and need based on hearing a range of data, information and feedback; and to analyse the information to determine unmet need and improvement opportunities.

An equal relationship between people who use services and the people responsible for services. We work together, from design to delivery, sharing strategic decision-making about policies as well as decisions about the best way to deliver services.

Co-Production

Work towards co-production has been highlighted as part of our development work with SEND Partners and the basis for this is to widen this key ethos.

To support this, we are delighted to tell you that we are now going ahead with the "VOICES" project that you may have heard us mentioning at family groups.

A programme of work will begin in June, working with all our SEND Partners to strengthen working relationships with all our families – the 4 core principles of Welcome and Care, Value and Include, Communicate, Work in Partnership will be developed and nurtured to build trust. We are very excited to be bringing this model to Telford & Wrekin and is a result of many discussions, meetings and visits to Forums. The model has been developed from a strong parent carer base and by applying a systemic, critical narrative approach the VOICES team deliberately prioritises the voices of children and young people and their parents and carers, avoiding assumptions and redressing a historic imbalance, and creating a fresh platform for change and growth.

Our Four Principles:



Invitations for involvement will be going out to parent carers and to young people over the next few months.

Loneliness

We have been asked to review some reporting on Loneliness - this is led by a "HM Government Loneliness Annual Report" and comes a year after publication of the loneliness strategy. We are addressing this issue locally by ensuring that we have regular opportunities for families to meet, mostly through our family groups and events and it's a key area we will continue to have input into. We will work with other community organisations and have some exciting project ideas lined up. Least of all is our new befriending scheme that will also address this issue.

Home to School Transport

You may have been part of our discussions on the proposed changes to the Home to School Transport Policy Consultation exercises that took place (2019 for under 16s) and earlier this year for Post 16. We have reviewed these Policies and have given feedback on behalf of families (we also know families have responded individually) and worked with our National Partners (Contact charity) to feed in our response at a strategic level. At time of writing we await further communication



Sleep Pathway

We have begun some work, with our local CCG (Clinical Commissioning Group) looking to develop a 'sleep' pathway. This is based on some local research on the impact of sleep (or lack of quality sleep) that is affecting children. At time of writing, we are awaiting the outcome of the first workshop. In the meantime, we are sharing information from the recognised Children's Sleep Charity and information from Cerebra:



Tel: 01302 751416 www.thechildrenssleepcharity.org.uk

Relaxation Tips for Bedtime

Feeling relaxed is important in the run up to bedtime for both you and your child. If your child is experiencing difficulties sleeping it can make you both feel anxious. Children quickly pick up on the stress levels of those around them so it is important to try to keep calm as bedtime approaches.

The tips below may help:

- Turn off all screen activities an hour before bedtime eg computers, television and mobile phones. This will help your child to calm their mind. Screen activities can also inhibit the production of melatonin (the sleep hormone that makes us feel drowsy).
- Avoid physical activity in the run up to bedtime. Exercising too close to bedtime can actually wake your child up.
- If your child is a worrier set aside some time during the day to give them your full attention and to find out how their day has been.





- Dimming the lights in the hour before bedtime can help to promote relaxation.
- Fine motor skill activities such as jigsaws and colouring can be very relaxing and a great activity to do together.
- · Massage can help some children to unwind.
- Classical music can be very soothing and makes perfect background music in the evening.
- Teach your child to progressively relax the muscles in their body.
 They can begin by tensing their feet to the count of 5 and then letting them become relaxed. Work up to the calf muscles, thighs and so on until they have relaxed each part of their body.
- Encourage your child to concentrate on their breathing and imagine breathing in a beautiful white light and blowing out any worries or troubles each time they exhale.
- There are a number of relaxation CDs on the market that may help your child to feel calmer during the evening. You may however wish to talk them through an imaginary scene such as a favourite trip to the beach, asking them to visualise the scene and to feel the warm sun on their face.





Cerebra offer a sleep support service and also downloadable information from their website that includes the following (extract from website:

Our Sleep Cards offer different approaches to help you tackle some of the most common sleep problems experienced. They Cover: Bedtime routine; Calming time; Moving bedtime forwards or back; Graduated extinction; Gradual withdrawal; Reducing daytime naps; Positive sleep associations; Rewards; Sleep environment and more.

Sleep cards

More information can be found via their website: https://cerebra.org.uk/get-advice-support/sleep-advice-service/



Toileting/Continence Pathway

You may know that the NHS wants to improve toileting services for children and young people with special educational needs and disability aged up to 25 years. A national survey has been carried out

In addition to this we have discussed a toileting pathway locally, bringing together, alongside key professionals from CCG health, public health,



education, social care, voluntary sector and parent carer representatives. This is in the early days and we are continuing work in this area.

Part of the workshop we attended focussed on a hierarchy of support - from the universal offer through to the more specialised services and how all these link up and having a consistent pathway developed out of this.

As part of these discussions, there was a common acknowledgment that information from ERIC https://www.eric.org.uk/ is most useful and this can be shared with families, with a whole range of leaflets that can be downloaded, some of which are specific to children with additional needs.

Children with Additional Needs:

- Toilet Readiness Assessment
- Bladder/Bowel Assessment Chart
- Guidance for Parents/Carers using Disposable Containment Products
- Smearing the causes and approach





Emotional and Mental Health

We understand that through the feedback we receive on an almost daily basis and the conversations we have with our families and the results of the Annual Survey that the emotional needs of our children and young people are most paramount. With this is mind we have shared some information with you on what is happening locally to address this:

LOCAL OFFER HIGHLIGHT: Emotional Health and Wellbeing Panel

Extract:

Gover the last 18 months, as we have been consulting with schools and other partners, it has become clear that the Mental Health needs of young people across the borough are significant. This is displayed in many ways from heightened anxiety through to extreme behaviours. The range of needs covers a range of conditions from neurodevelopmental disorders such as autism, through to mental health disorders including self-harm and eating disorders. One of the biggest needs for our young people is around Attachment, the behaviours of a young person with attachment disorder can display in a very similar way to a young person with autism, although these are two very different conditions with different approaches needed.

Additionally, there is also a significant waiting list for the BeeU services (CAMHS) particularly around ASD diagnoses. It can take many months between a referral being made and the young person being seen. In a high proportion of cases, there is no formal diagnosis made and therefore no further support identified.

We are therefore working with partners to create an 'Emotional Health and Wellbeing Panel' (EHWP). The aims of this are to support schools and young people, by providing advice to schools, to signpost services and to ensure the students with the appropriate level of need are referred to BeeU. This should mean that the young people get the help they need in a timelier manner and that with only the appropriate cases being referred on to BeeU, we should start to reduce the waiting list.

This panel will meet on the first Wednesday of each month, at 9am, starting on 6th November. Schools will need to complete the referral form and submit this at least a week in advance of the meeting. We will then hear cases in groups of three so that the presenters from each school can gain the experience of hearing about other young people with different needs. The panel will be led by representatives from schools and will also have support from a range of professionals including Social Care, Specialist Nurses, Educational Psychology, BeeU, Beam, Behaviour Support, Student Engagement Programme and the Clinical Commissioning Group.

This EHWP should complement the support provided through the Inclusive Schools Forum and the Fair Access Panel. Schools will need to make a decision as to which of these would be most appropriate for the needs of the young person rather that referring to more than one of these panels.

NOTE FROM PODS: This panel will be reviewed after a 6 month period. PODS currently does not sit on this panel directly, but we will review this as part of the overall process.

NEW Mental Health Support Team (MHST) in Telford and Wrekin

Telford and Wrekin have been successful in gaining funding from NHS England to support the development of MHST locally. There is a well-defined and tested



Anna FreudNational Centre for Children and Families

framework that has to followed and adhered to when setting up and delivering the service. The team will work initially in 18 primary and secondary schools across south and central Telford.

The MHST has 3 core functions:

- 1) Delivering evidence-based interventions for mild to moderate mental health issues
- 2) Support the school they are working with the develop their 'whole school approach'
- **3)** Giving timely advice to school staff and specialist services to ensure the children and voung people (CYP) get the right support and stay in education.

The MHST has now been appointed and all will be in place by the end of March 2020. There are 4 Educational Mental Health Practitioners (EMHP), they have all started on a course at Derby University and it is hoped they will be signed off by the end of April to start to see CYP. Additionally, there is a service manager and 2 mental health supervisors. Details will follow from the team once all in place.

All schools are being supported to take part in the Anna Freud National Centre for Children and Families Link Programme, they would have all been through this programme by the end March 2020.

Key members of the PODS Team have also attended the Anna Freud information days over the last couple of months, to share some parent carer experiences and input into discussions around this important area.

School/College "Coffee Mornings"

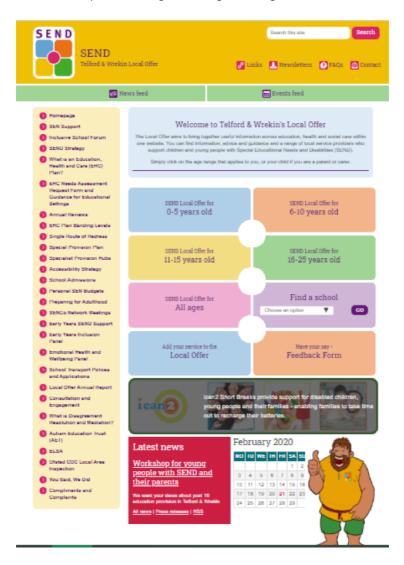
Making these links has also led to us being invited in to run "coffee mornings" in schools so please keep an eye out for your school bulletins and invites. We're also happy to make links with schools, and often do this in partnership with IASS – so please let us know if you want us to pop in.



The Local Offer and SEND Newsletters

A reminder that the Local Offer for all things SEND can be found via www.telfordsend.org.uk

Recent feedback from our Annual Survey has demonstrated a mixed response and highlighted that more work needs to be done on the accessibility of the information and this will remain a key area for the focus of our strategic involvement. Another way, to feed in comments to the Local Offer, If you can't find what you need on there is to use the 'Feedback form' option – this will then be reviewed as part of our regular strategic meetings.



A Parent's Insight into a Tourette's Action Parent Workshop

"I recently attended a workshop for parents run by the charity Tourette's action. My son was diagnosed with a tic disorder last year and I'd been battling with his heightened anxiety and tics for 12 months, previous to his diagnosis. I had been informed by IASS that Tourette's action was a good place to start when it came for advice and support for the many issues my son's tics were causing him.

The workshop was held at a hotel in Birmingham. I bravely attended the workshop alone and so glad I built up the courage to do so as it was simply brilliant. We had a presentation form DR Malik from GOSH. He went through lots of facts and treatment options, it was very informative and emotional, I was helped through the emotional parts with endless cups of coffee, snacks and lunch provided as well as hugs when needed. Tics cause my son great pain and discomfort and cause extreme anxiety to everyday tasks such as entering the classroom at school or eating lunch in the dinner hall. My son constantly worries that people are looking at him when his tics are troublesome and let's face it other kids can be cruel without really meaning to be. The workshop filled me full of information and I met at least 10 other parents with children of similar age to my son who have Tourette's syndrome. It was so lovely to talk to other parents in the same situation as myself.

The workshop had an inspirational speaker, a lady called Natalie. She gave an amazing speech and some amazing advice along with an amazing insight into the condition that she deals with herself daily, the stigma attached to it and the challenges she has overcome, it was emotional to say the least. It gave every parent in the room hope and relief that actually living with Tourette's is not impossible as an adult, yes it has its challenges but doesn't everything?!

So even though you have to make the steps yourself to attend such workshops if you have a little ticker like me then these workshops are absolutely amazing and offer the most informative way to help you to help your child. I feel like the workshop has empowered me to empower my son. I have been able to give his school lots of information and I have been able to support my son with information that has helped him to accept his tics as part of him, we looked at facts about the condition the fact I had biggest reaction from him with was "300,000 people

in the UK have Tourette's syndrome" His face lit up, he suddenly realised he wasn't so different after all, he isn't alone and what an amazing feeling that must have been for an 8 year old...

P.S we still don't have a Tourette's syndrome diagnosis; Tic disorder alongside ASD is all we have for now so don't think you have to have a diagnosis to attend the workshop."

By Kerry McLafferty (with her son Xander).

Tourettes Action have a website: https://www.tourettes-action.org.uk/ and a helpline: 0300 777 8427.



The SEND VCB Project

The SEND VCB (Violent and Challenging Behaviour) Project was set up by Yvonne Newbold in April 2017, in response to being contacted by several hundred parents following an interview on BBC Radio 4's Woman's Hour about violence in children who had an additional need. Like many of the parents who got in touch after the programme, Yvonne had been unable to access any services, advice or information about her own son's behaviour for many years, and had felt blamed, judged and ashamed of this issue which she felt must be all her own fault. She had also believed that this sort of violence was very rare and that her own family were very unusual. The programme was aired 15 years after the violent episodes had started in her own family, and she was shocked to realise how many other families were affected, and how, all these years later, that these hundreds of families were still unable to access any help or advice.

The Special Parent's Handbook

Yvonne wanted to write the book that she wished someone had been able to give her when Toby was first diagnosed. She wanted to pass on everything she had learnt about SEND parenting, including chapters on education, long-term hospital admissions, how to get the very best out of the multi-disciplinary meetings so that your child's needs have the best chance of being met, how to deal with the intrusion of so many professionals wanting to know about every aspect of your family life and how to ensure that all your children have the very best chance of a safe and happy childhood, making good memories to last a lifetime. It quickly became an Amazon #1 Bestseller, and is now read by as many professionals as parents. You can find out more about the book by following this link to the Amazon page, where you can also read the 40 Five star reviews https://amzn.to/2T4UiQo

In addition to the book, there is an active public page, a private page, and a specific support group for men (inc step-dads, grandads and uncles).

More information about Yvonne's amazing work can be found via her website: https://yvonnenewbold.com/

Along with being a mother and author, she is also an NHS Assembly Member, Advisory Group Member to NHS England and NHS Improvement on Learning Disability and Autism, Multi award winning Writer, Speaker and trainer with awards including: National Learning Disability and Autism Lifetime Achievement Award Winner 2018, PENNA Outstanding Contribution to Patient Experience Award 2016, LDT Learning Disability Champion Award 2015, HSJ Top 50 Inspirational Women in Healthcare Award 2014.

Work on the challenges of Violent and Challenging Behaviour (Child to Parent Abuse) is being addressed locally and we have been approached by a local trainer, who has secured funding to run courses for families, and we will be able to tell you more about this in the next month or so.











PODS Forum Family Group Information & Dean Beadle Conference Feedback



PODS Forum Family Groups from 04/06/2019-26/02/20
Held: 28

Attendees: 423

PODS FORUM DEAN BEADLE CONFERENCE TOGETHER WE CAN MAKE A DIFFERENCE

ATTENDEES: 47



HELD ON: 04/02/2020 VENUE: Ramada Hotel Telford



Cost of holding the Dean Beadle Conference per head: £28.44



KEY STATISTICS

- 95% Felt better informed
 97% Felt they'd been given an
- opportunity to 'participate



for more info www.podstelford.org

COMMENTS FROM PARENT/CARERS

Fantastic Speaker, really enjoyed it.

Very informative, relaxed talk, really enjoyed it.

Keep up the fantastic work! Thank you for today, I learnt a lot.

The truth from Dean was a great insight into his world. It would be nice to learn about others with different experiences.

Dean is fantastic, we need a yearly subscription to him please.



Annual Survey Highlights

The following information displays a 'snapshot' of some of the key survey highlights and thank you to everyone who contributed. This data along with the conversations and feedback we gather from families feeds into our core work areas and also helps to identify where we can work with partner agencies to help to meet the needs of our families.

Wider reporting is available and will be shared on PODS website or you can contact Jayne by email.



Social Care



Health







SEND Services

Independent Travel: 85% excellent 65% too little of it

SEN Transport: 76% excellent or good 37% too little

od 69% excellent, 43% too little

Early Years Inclusive Service 70% excellent. Portage: 100% excellent; 43% too little of it

Local Offer: 51% easy to use

SEND Team:

Transition & Communication

Adult social care: 65% said it was difficult
Adult health services: 75% found it difficult

Good support from: school, college, IASS, Future Focus

Poor support from social worker, health, local offer

Communication - Nurseries: 83% Good Communication - Schools: 79% Good Communication in Colleges: 71% Good

Difficulty in accessing health services

Not taking concerns seriously (50%)

Long waiting lists (66%)



Child finds waiting difficult (53%) Unclear referral routes (42%)



hope you like our new leaflet design, which incorporates all our key work areas





We work across the whole range of services including health, education, social care, and alongside our voluntary sector partners – at a local, regional and national level. We are also members of the National Network of Parent Carer Forums.

PARENT CARER FORUM

Parent Carer Participation is when parents and professionals work together, recognising each other's knowledge, to make informed decisions about services that make the best use of resources.

BEFRIENDING SCHEME

Accessing Peer led emotional and practical support from our Befriending Scheme to support you and reduce isolation and increase your wellbeing.

SEND INFORMATION

Improved knowledge and understanding of SEND Reforms and legislation through access to workshops, training sessions and annual conference.

FAMILY GROUPS

Reaching out and joining with other families through Family Groups run throughout the month. Offering mutual support and information sharing, plus speakers on key subjects.

INCLUSIVE TRIPS & EVENTS

Social Events and Fun Activities organised throughout the year. Please see our website for details of dates/venues.

FUNDRAISING

We hold a variety of fundraising events that take place in the local community, that support our families whilst helping to make our charity sustainable for the future.









What Our Families Say



"Spending time with my boys and not feeling judged"



"Knowing PODS was there for support and the children making friends with other PODS children"



"Families understanding as you're in the same boat. Speaking with other parents. Kids having a relaxed affordable trip. Feeling safe"

"Make our family confident to meet other families who have special children"



"Everything was planned really well. The team members were very helpful and supported"



"Great activities enabling us to make friends and trips we wouldn't otherwise be able to access"



PODS Befriender Scheme Update



We have recently reinvigorated and relaunched our Befriender Scheme for parents/carers of children with disabilities or additional needs aged 0-25 years. It is open to anyone who is registered with PODS who feels they would benefit from some emotional support you can self-refer into the scheme and you do not need to have a formal diagnosis for your child.

Our trained Befrienders offer 1-1 support in a variety of ways, this could be via home visits, support during family groups, through Telephone/social media, they are also able to meet with parent/carers in a café for a chat and a cuppa. As well as offering emotional and practical support they can signpost you to relevant services and activities in the local areas, but most of all they are there to help.

You may be new to the area and would like someone to introduce and support you to come along to the many family groups that we hold. You may have just received or are awaiting a diagnosis for your child and need a little bit of support on the way forward and how to deal with the emotional side. We are here to support you when you need it most, even if it's some advice or signposting you to someone more appropriate to help.

The support we offer is from trained Befrienders who have lived experience of your position and not only understand what you may be going through but offer a non-judgemental & friendly face as they know how difficult and isolating it can be.

We host many events and groups throughout the year, maybe you feel nervous about attending on your own, but with a little bit of support you may feel able to come and join us, this will in turn in enable you to get the full benefit of support from many other parent/carers in a situation like yours and make some new friends along the way.

We are currently in the process of both training and recruiting Befrienders, to ensure that we have people available to meet the needs of the scheme, if you are interested in becoming a Befriender or feel you would benefit from the support of one of our dedicated team please contact lin@podstelford.org or call her on: 07309753044

Lin \$ PODS Befriending Team



PODS Family Groups

PODS Family Groups provide a platform for the Parent/Carers to express their views on services available to them, know about any updates and access support from fellow parent/carers.





In our endeavour to reach as many families as possible, we have Family Groups in different areas in the town.

Our Family Group in Admaston is held on the 1st Monday of the month and has successfully been attended by parent/ carers, be it for Christmas Decorations activities, updates from IASS or just for catching up with other parents.

Our Family Group at Park Lane Centre started with the children's activity of 'Carve your Pumpkin'. A room full of enthusiastic children and parents enjoyed

the activities. The group also ran Christmas decorations activities and more recently Pancake Day celebration.

Our Hollinswood Family Group has now been restarted, the venue is the SNAC room in the Hollinswood Pavilion. The first session of this group was very well received by local parents and it was lovely to see the parents accessing peer to peer support, which is a lifeline for our Parent/carer community.

We are going to run a Family group specifically for parent/carers of young people aged 16-25 years old with the focus on services and activities available for them to help in smooth transitioning to Adulthood. This group is being held twice a month in two different areas, The

Wakes and The Newport Hub, so that maximum number of parents/carers can access it.

In our upcoming Family Groups, we also plan to invite experts who can teach us Mindfulness, Meditation and can run 'Relax Kids' sessions. We are also in the process of having a person from 'BeeU' to get an understanding about this service and how it can help our children. By holding these Family Groups, we hope to continue to be the voice of the parent carer community in order to shape a better world for our children.



PODS Lego Club

After running a successful PODS Lego Club on a pilot basis last year, we started this year with another group of 9 children joining the Lego Club. This weekly club is currently being run on Wednesdays at the Hollinswood & Randlay Parish Council Centre. We have primary aged children ranging from 7 years old to 10 years old.



In Lego based therapy, the children work in teams of three, with each child taking up the role of Engineer, Supplier and Builder turn by turn. By working in teams, they are practising good communication skills i.e. listening, waiting patiently, talking confidently and they are also forging new friendships by helping each other. We, as facilitators, help to guide them to work within the team and to prompt them when they are finding it difficult to communicate effectively. Working in a group is quite challenging for children who are used to building the Lego models on their own. However, the children pick up quickly to work in a team and develop skills through Lego play every week.

These children look forward to attending the Lego Club after their busy day at school, they have an enjoyable time and benefit from the PODS Lego Club, all through fun and play in their area of interest.

Below we are sharing a few pictures from our PODS Lego Club so far:



Family Group Feedback Snapshot



Feedback from family groups and events is now been gathered using these 'posters' – we have them for 'What's working well, Even Better If, and 'What's not working well'. They have been well received by our families and it gets lots of conversations started. Over the past few sessions key discussions have focussed around Schools – some good examples around support for teenagers in some schools, and the great work that is happening in the hubs, understanding of SALT, although improvements are needed around OT and sensory needs assessments; funding and short breaks is often discussed, BeeU and Transport remain main concerns for families, and of course we highlight those gaps in services – all of which feeds into our strategic meetings attended by Jayne and our reps.

A Diagnosis - what next?

We've had many discussions with families regarding a diagnosis of their child or young person and have used our social media PODS 'Chatspace' area to do a snapshot survey:

- **43** parent carers said "It means that I will understand my child better and be able to put the most appropriate interventions in place"
- **26** parent carers said "It means that I will get help from school that's not available without a diagnosis!"
- 17 parent carers said "I can answer my child when they ask why do they struggle or do certain things"
- **15** parent carers said "It means there is a better chance of support being provided for my child later in their life with FE & employment"
- 12 parent carers said "It means I will have 'answers".

Further discussions now, are highlighting that whilst the diagnosis is important to families for all the reasons above, the support following diagnosis is lacking and this is something we are working on.

** **STOP PRESS**** We have arranged for our local Women and Children's commissioner to join us at our groups at the end of April/beginning of May to discuss this face to face with our families.

Messages to Schools

As part of our work, we were invited to talk at the SEND Conference at the end of last year, and we gathered feedback from you with your messages to schools - this is what we shared there, and also through the JSNA project work which you'll read about in this newsletter.

"I'm struggling not misbehaving".

"If a child is coping well with support, don't remove it! Pulling the rug means they won't cope well in the future".

"Give me a choice and extra time".

"Failing our son".

"My son says that he gets on with the teachers that want to understand him, rather than the ones that want to control him".

"Thankful and very grateful for all the support he receives whilst in their care, nothing is ever too much for them".

"Supervise me better. An extra set of eyes in the playground doesn't help me navigate communication with my peers. Playtime is stressful".

"Just because they are doing very well academically doesn't mean they aren't struggling socially and emotionally".

"Thank you for all my son's support over the past year".

"We are creating a partnership, collaboration, great teamwork".

"Please listen to me, no really listen".

"Saying thank you isn't enough".

"Her best is good enough for me".

"Masking is a real thing, that's why behaviour is different at home than at school".

"Please read his provision plan".

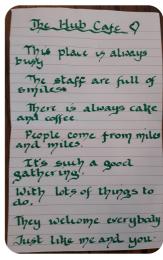
"School is not just about academic progression; I am more than a percentage on your results table".

"Take us (me and my child) seriously when we tell you about bullying".



The Hub Community Café

When I first met Val Edgley just over 4 years ago, she started telling me about her dream of having a cafe with young people with additional needs working in it, in Newport. I loved this idea and shared my vision for an inclusive community cafe, like I had seen in other places. We set about researching these ideas by visiting other similar cafes around the country and in Shropshire. It was hard work and involved drinking a lot of coffee and eating a lot of cake! We were particularly inspired by two cafes in Yorkshire -Outside the Box in Ilkley, which was well established and run by over 70 volunteers and 30+ people with disabilities. Also Cafe 21 in Headingley, Leeds which employs young people with Down's Syndrome. The two ladies who had set up Cafe 21 had no catering experience themselves but had created this beautiful, welcoming cafe - so it could be done! Back in Telford we loved Forge Urban Revival in The Wakes at Oakengates, We liked the light airy modern space and the range of community activities on offer. This is what we wanted for Newport! (But on a smaller scale). Over this time we were constantly searching for a suitable venue in





Newport, which was proving very difficult. But with fortunate timing, Newport Town Council took over as sole trustee of the charity The Newport Youth Cafe Project, which owns The Hub building in the town. The Hub was extensively refurbished with Telford@50 money, turning it into a beautiful modern space. We officially opened the Community Cafe on 12th February. It is definitely a work in progress and we have had a very steep learning curve. We were very pleased to be awarded 5 stars for food hygiene a couple of weeks ago.

We have so many people to thank - the trustees from Newport Town Council, who are allowing us to trial the cafe for up to six months and hopefully we will continue beyond this. We have worked with a group of members from Newport Rotary Lite who

have provided support, advice and expertise for the set up process and some have gone on to volunteer in cafe. Huge thanks to all the other volunteers who have come forward to help run the cafe and the community activities - they are all fantastic people, who just pitch in and get on with the jobs and bring lots of enthusiasm and great ideas. It's great to see our lovely team members (which is what we call the young people with additional needs), enjoying working in the cafe and being appreciated by the customers. We have had some great

feedback from the first few weeks and will continue to develop and improve the cafe as we go. We are open 10am-3pm Wednesday, Thursday & Friday. Come and see us!

Liz Bickford-Smith

Joint cafe manager. The Hub Community Cafe, 139 High Street, Newport TF10 7BH (next to the old Royal Victoria Hotel).





Namibia Wheelchair Delivery Trip

Last November Chas and I travelled to Namibia in West Africa on a self-funded trip with The Wheelchair Foundation UK to help deliver a consignment of wheelchairs. The wheelchairs were funded by Newport Rotary Lite and other local Rotary Clubs, so it was really great to see where they ended up. Namibia has a wealth of natural resources including diamonds, copper, gold, uranium and lead, but the majority of the population do not benefit from the wealth these resources generate and struggle to get even basic medical care. Anyone who needs a wheelchair is very unlikely to get one due to the high cost. They are reliant on being carried around by family members or simply do not leave their house. The Wheelchair Foundation UK works with local Rotary clubs in Africa to identify and supply wheelchairs to people who need them. The wheelchairs are quite basic but sturdy and low maintenance as they usually being wheeled around in guite rough, off road conditions rather than smooth



tarmac pavements! We drove over 2000 miles in just over 2 weeks, handing over wheelchairs in 6 different towns. On our trip we went to people's houses in the townships to deliver some of our 110 wheelchairs, which was a real eye-opener. We delivered a wheelchair to a 6 year old boy (see photo), who was being carried around by his sister on her hip prior to this! Now he has a wheelchair, he will be able to go to school with his brothers and sisters. Another wheelchair was given to a 15 year old boy - you can see in the photo how his knees are all dry and scuffed where he has been crawling on the ground. It was quite emotional visiting people and giving them a wheelchair especially if they had waited a long time to get one. We also took little knitted toys, sweets, pencils and notebooks to give out to children we met along the way which was fun. It was an amazing trip and I'm really glad we went. It made us appreciate how lucky we are to live in the UK where we can usually get most basic things that we need.

Liz Bickford-Smith







Shining* Stars *

Shining Stars is a voluntary parent led play group for children (under 5 years old) with additional needs. It's a place for parents to get support, advice and to meet others in similar situations.It is run by two volunteer parents that have children with additional needs so have lots of experience and knowledge and an understanding of the isolation and the issues and concerns that parents may feel. We are Tina, who has an 8 year old son with complex medical needs, autism, global developmental delay and other issues and Karen has a 7 year old daughter with Down's Syndrome. The group has many sensory toys including fibre optic lights, bubble tube, role play, a ball pit as well as many other indoor and outdoor toys. Weekly activities include painting, messy play and paper crafts. Makaton is also used.







16-25 Years Mental Health Peer Support



New 16-25's Peer support group starting 29th January.

This group is aimed at young adults who may be struggling with their mental health, including ASD and/or mild to moderate learning difficulty.

Time and Date

This support group runs on a Wednesday 4-5.15pm

Self-referral via:

Please contact: talk2@telford-mind.co.uk to self refer in to this group



Registered charity no. 5164

Telford & Wrekin Council's Children's Occupational Therapy Team

A Family's Experience

A little over 18 months ago our life unexpectedly changed direction, we had just welcomed our twins into the world blissfully unaware of the path we were about to go down. Within a few days we were informed that one of our twins had Trisomy 21, as time progressed, he was diagnosed with yet more conditions and now has an impressive 9 to his name. After a few months we were advised to self-refer into the OT service, they were very quick off the mark to support, coming out regularly to visit us at home, explaining



the processes well and how they could help. The team carry out in home assessments and advise what equipment would benefit your child the most. Their role is to help provide equipment which helps the child's quality of life within the home environment. We have had several different support aids over the past few months, currently we have an Otter Bath seat to support him whilst in the bath and help prevent drowning, we also have a Triton Chair for postural support as he is currently unable to sit unaided. They can also signpost and refer you to other appropriate services and organisations. Our experience with the OT Team has been an extremely positive one, we have found them both caring and supportive and the equipment they have provided has dramatically improved the life of our son.

Louise

FOCUS ON: A Hidden Disability

NOFAS-UK (The National Organisation for Foetal* Alcohol Syndrome-UK)

"Is dedicated to supporting people affected by Foetal Alcohol Spectrum Disorders (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy. NOFAS-UK is a source for information on FASD to









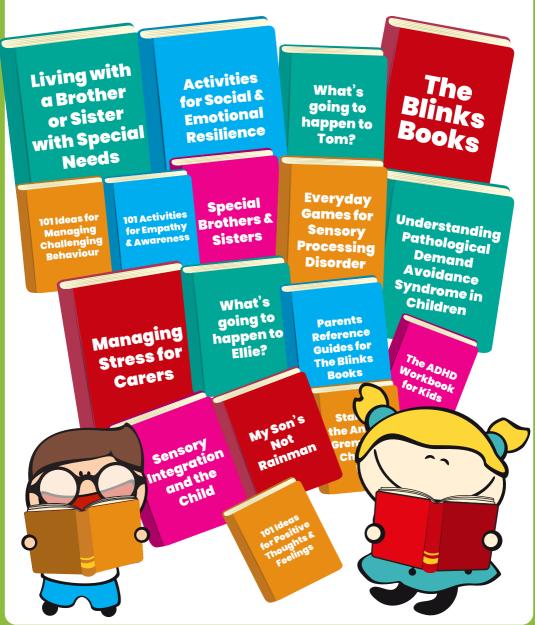


FASD may not be detected at birth but sometimes becomes apparent later in life and carries lifelong implications. Its effects are diverse and range from cognitive and sensory processing issues and Attention Deficit Disorder to heart problems and concerns with bones and organs. Quite often people with FASD have multiple diagnoses. One study listed more than 400 co-occurring conditions. Every person with FASD is affected differently. A common 'old-school' misconception persists that someone has to have specific facial features to have a diagnosis. This is incorrect. By some estimates, it is less than 10% of those on the FASD spectrum who have these distinctive facial features. All too often, people with FASD are undiagnosed or misdiagnosed. FASD, especially if unrecognised and unsupported, can contribute to serious social and behavioural problems.

The good news is that there are known strategies that can help someone with FASD to build upon their many strengths and to lead happy and fulfilling lives. FASD is often called a 'hidden disability.' They have a Helpline: 020 8458 5951 or email help@nofas-uk.org and website is nofas-uk.org

PODS Library at Stepping Stones Hub

Do you know that we have our very own PODS library at Stepping Stones Hub? We have a wide variety of books available to you, including:



PODS Events and Fundraising

The Purpose of Fundraising...

Fundraising is not just a means of raising money, but a way to promote our non-profit charity and create awareness of our aims and objectives, It's a means for our families to come together for a common purpose. However, raising funds is important to the continued survival of our charity. Without support and crucial income our charity simply cannot continue to fulfil the purpose it was intended.



Behind the scenes we have an army of dedicated volunteers and staff who work tirelessly, spending numerous hours filling in forms, meetings with potential funders, researching venues

and events, networking and organising for all our activities, and liaising with our dedicated supporters who are very generous with their donations.

The way in which grants are given is changing, this means we have to be more sustainable. We are making every effort to raise our own funding through the many events we create for our families. We have a very diverse group and where possible we try to cater for as many of our families as we can. If you have any ideas, please get in touch, by emailing Joanne Smith at: joanne@podstelford.org



Our Events

We've had some very successful events of late with many more to come. Here's a little reminder...In October 2019 we saw PODS first pumpkin carving session, in which many families participated and enjoyed, we had pumpkin donations from Lawley Morrisons community champion, Maxine.

In December 2019, we were very fortunate to take some of our families along to the Severn Valley Railway's Santa special thanks to the kind donation of tickets from SVR. Also, in December we had our Christmas party with disco, games and a special visit from Santa with a gift for all children and young people that came along. Thank you to Asda community champion, June. and County Fundraisers for their generous donations which helped to make the said events so successful.



We have some very exciting fundraising events and activities coming up throughout the year, for our families to look forward too. We have our Easter Egg Hunt and Crafts also our Fish n Chips Bingo is back by popular demand as is our Pamper Evening. In the summer school holidays we will be arranging two big family coach trips, and of course the fantastic Picnic in the Park at Admaston House on Monday 3rd August. There will be other events throughout the year so please keep an eye on our Social Media pages and Ebulletin.

We would like to say a $HUGE\ THANK\ YOU$ to our volunteers for their continued dedication.

Become a PODS Volunteer

Have you ever considered becoming a volunteer? Do you have some spare time, even an hour a month? Would you like to be involved in something special?

Would you like to give back to the community and at the same time make new friends? If you answered yes to any of these questions then we want to hear from you, please consider becoming a volunteer for PODS and help us continue to make a difference to so many families. Below is an explanation of the roles we have available.

The roles we have:

Befrienders - This role is for parent/carers who have lived experience of a child aged 0-25 with a disability or additional need. They offer a befriending service to our members that would benefit from some emotional or practical support. This support can be delivered in a variety of ways, either 1-1 meetings with the parent in either their own home or at an agreed public location, via telephone or social media or through attending one of our many family groups. Full training and ongoing support is offered to all Befrienders along with regular team meetings. To be eligible for this role it is essential that you have the lived experience as it is a peer led service and the families need to know that the Befriender understands their situation.

Parent Reps - As a Parent Rep your role would be to gather feedback and information from our members regarding a range of local services for children with disabilities or an additional need. This information will be collated in many ways, through our family groups, social media, chatting with our members and surveys. Once a month the team of Parent Reps meet, this is known as our Steering group. At the meeting the Reps will discuss the information they have gathered, each Parent Rep is assigned a different strategic board to work with, they then feed the information they gathered back to the relevant service via strategic meetings ensuring the parent/carer voice is heard. Lived experience would be beneficial but not essential, full training will be provided along with ongoing support.

Fundraisers - This is varied role and requires no previous experience, ideal for both those that want to be public facing or prefer to do a more hidden role. As a fundraiser, you could choose to research opportunities for Grants or fundraising activities or collect donations for use in our raffles or tombola stalls, you could even help or run a stall of your own. The fundraising team also plan and supervise all our inclusive events, so help is required to research activities and costings, gather views from our members about what they would like, also to be on hand at the events/activities to help organise and support our members and their families. NO lived experience is required, this role is open to everyone.

What we Offer - The opportunity to work with a highly motivated and supportive team who are passionate about everything they do. A chance to make a real difference in the community whilst learning and developing new skills. Gain some experience and help you back into the world of work or make new friends and do something amazing with your spare time. We will pay for all reasonable out of pocket expenses, this will be explained during your induction. We also have regular team meetings and activity days to help unite and build the team environment. Some of the volunteer roles will require a DBS, which we will cover the cost of, so please bare this in mind when applying to become a volunteer. Many thanks for your interest in becoming part of PODS, if you have any further questions please don't hesitate to contact the Project Manager Elaine Pearce.

Email: elaine@podstelford.org Phone: 07540 049759

Ironbridge Gorge Museum Trust free visit

As a member of PODS and a Carer of a child/young person with a disability or additional need, you can take advantage of this amazing offer brought to you by PODS in conjunction with the Ironbridge Gorge Museum.

The offer entitles you the carer and up to 5 other people of your choice free access to Ironbridge Gorge Museums for a whole week. Not only that you can also claim 15% off your purchases in the Museum shops when you spend over £5.

The pass allows you to visit:

- Blist Hill Victorian Museum
- Enginuity
- Coalbrookdale Museum of iron
- Darby Houses
- Jackfield Tile Museum
- Coalport China
- Museum of the Gorge/Tollhouse
- Tar Tunnel
- Broseley Pipeworks

You will require 1 pass for each person (including children) with a maximum of 6 available at a time, each pass will be valid for 1 week and you can visit any of the participating museums any number of times.

Passes are allocated on a first come first served basis, if you would like to use the passes please contact Elaine either by email elaine@podstelford.org or through our Facebook Page . All passes must be collected in person, there will be a £5 deposit per pass that will be refunded when the pass is returned by the agreed date. Passes can only be used with a valid form of photo ID and the carer it has been issued to is present. A full copy of the terms and conditions will be given to you at point of loaning the passes.

This offer is made in recognition of the important and valued role you have as a Carer and only available to PODS members.



Max Card





The Max Card is designed to make days out more financially accessible for families of children with additional needs/disabilities and Foster Families. All Families need to do is simply show their Max Card upon entry to a venue that supports the Max card scheme in order to obtain free or discounted admission. The scheme is designed to help these families save money on great days out both locally and throughout the UK. It can be used at locations such as castles, zoos, bowling alleys and many more. Visit www.mymaxcard.co.uk for more details.

The Max Card is available from PODS family groups and events at a cost of £3.00 each, only one card is required per family, each card lasts at least 12 months. A new batch of Max Cards have just been received - please join us at a family group if you wish to purchase one of for more information.













MONDAY 3RD AUGUST 2020

10am-4pm at Admaston House, Admaston, Telford TF5 0BN

Come along and join in the FUN, we will have: Gaming Van | Quad Bikes | Bouncy Castle | Go Karts Bubble Football | Glitter Tattoos | The Owl Man & Lots More! We look forward to seeing you all!

Please park in the car park opposite Admaston House

Telephone: 01952 458047 / 07775 342092

Email: info@podstelford.org Web: www.podstelford.org

Registered Charity Number 1150871



















FRIDAY 12TH JUNE 2020

Ketley Community Centre, Holyhead Road, Ketley, Telford, TFI 5AN 6.30pm-9.30pm

Come along and treat yourself to an evening of pampering at PODS Pamper Event! Open to all ladies and gentlemen who are members of PODS, including friends and relatives. Children are welcome to come along and make use of our craft area.

Treatments on offer are: Indian Head Massage | Eye Brows | Nails | Henna Tattoo's | Reiki & lots more!

> All treatments are £5 each. The event is free to attend and will include light refreshments.

Telephone: 01952 458047 / 07775 342092

Email: info@podstelford.org Web: www.podstelford.org

Registered Charity Number 1150871









FOR UPCOMING FAMILY GROUPS & EVENTS





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07775 342092

■ info@podstelford.org

www.podstelford.org

PODSForumTelford

🔰 PODSTelford

PODSTelford

♠ PODS (Parents Opening Doors) The Glebe Centre, Glebe St, Wellington, Telford TF1 1JP Elaine Pearce

Project Manager

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PODSTelford

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