



Oxfordshire Family Support Network is a unique organisation based in Oxfordshire. We provide independent information, advice and support *by families for families* of people with learning disabilities. Set up by family carers who wanted to use their experience to help others in the same situation we strive to improve the lives of people with learning disabilities and their families.

E-BULLETIN FEBRUARY 2015

We thought it was about time to reinstate our E-bulletin – *it's been a while!*

Please feel free to pass this bulletin on through your own networks. If you've received it via a friend or colleague and would like to be added to our database then get in touch... but if you don't want to receive it then please tell us and we'll remove you.

This first Bulletin (*for a long time*) is a bit of 'catch up' We want to let you know what we've been up to but it includes some future plans. Future bulletins will include more local and national news for families of people with learning disabilities and the professionals who work with us. We also regularly post news (as and when we receive it) through our Facebook page and on Twitter (details below)

If you have any news or events you'd like to share with others then please contact us so we can add to the next bulletin.

Best wishes

Oxfordshire Family Support Network

Visit our Website: www.oxfsn.org.uk

Email: info@oxfsn.org.uk

Find OxFSN (& like us) on [Facebook](#)

follow OxFSN on twitter:<http://twitter.com/oxfsn>

Gail's blog: <http://abitmissing.wordpress.com>

WHAT HAVE WE BEEN UP TO?

MOVING INTO ADULTHOOD & GETTING A LIFE – GUIDES FOR FAMILIES

The 'Moving into Adulthood and Getting a Life' guides are a series of guides, written by and for families of young people with learning disabilities. However, some of the information contained in them may also be helpful for families of older children or relatives and other disabled young people or those who have additional or special educational needs.

Each guide covers the many issues that families have to think and know about during the stage when their child is preparing for adulthood. This stage is often referred to by services as 'Transition'.

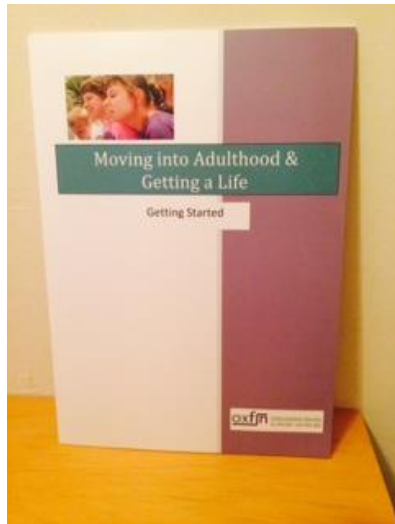
Click on the [purple](#) links to the guides currently available. *The rest will follow soon*

- [Getting Started](#): Where to start. 10 top tips, 'Jargon buster'. An introduction to person centred thinking, planning and approaches. The start of the preparing for adulthood stage. The Year 9 review. Person centred thinking tools.
- **Education Matters**: Further education - Staying on at school or going to college. Residential colleges. Adult education and lifelong learning
- [Money Matters](#): Benefit changes at 16. Managing money. Court of Protection
- **Social Care Matters**: Personalisation and choice and control. Personal budgets. 'Just enough support'
- [Finding the Right Support](#): What support are you looking for? Finding support providers. Checking out support providers. Employing your own staff. Keeping safe
- [Becoming an Adult](#): The Mental Capacity Act. Supported decision making
- **Health Matters**: Staying healthy and safe. Health Action Plans. Personal Health Budgets
- [Social Life, Having Fun, Friends and Relationships: Social life and having fun](#). Staying safe when out and about. Staying safe online. Growing up – sex and relationships. Circles of Support.
- **Finding a Job**: Work experience. Volunteering. Supported Employment.
- **Finding a Somewhere to Live**: Independent living. Supported living.

All of the guides stem from the belief that all young people, whatever their ability are capable of achieving a good quality of life as an adult. As parents we know that our children are all different. They are unique individuals with their own gifts, talents, difficulties and challenges. The 'one size

fits all' approach has never worked for young people and families like ours and so throughout these guides we have included information about how you can tailor the support your child needs and wants to live a good life. This approach is called person centred planning and everything in this series of guides centres around person centred thinking, planning and approaches.

***Watch out for news of further guides as and when they are available by visiting our website and Facebook page**



Our first Moving into Adult & Getting a Life guide was launched at the Moving into Adulthood event in November. We have some hard copies of this available so please get in touch if you'd like a copy. We will need to charge a small amount to cover postage and packaging – please contact Gail: gail.hanrahan@oxfsn.org.uk

MOVING INTO ADULTHOOD EVENT 2014



In November last year we held our first Moving into Adulthood event for families and the professionals who work with them. This [link](#) will take you to the programme and the presentations from all of the speakers.

Although it was a change from our usual family information fair it was felt that focussing on a particular topic was better. Numbers had gone down for the last two information fairs and although many of those who came told us they valued it some commented that there wasn't

enough time to visit the stalls and visit the workshops too. So, we decided to 'ring the changes' and do something a little different.

The event was a great success and the feedback we received was fabulous. We are planning to hold another event in November this year – so watch this space!

Comments and feedback from people who came along:

“Just to say what a brilliant and informative day it was yesterday. My head was buzzing by the end of the day” (Parent)

“I really enjoyed it yesterday it was so nice to speak to people in the same situation as myself. The speakers were wonderful and I got lots of really useful information.” (Parent)

Thank you so much for organising this conference this year it was so nice to be part of the workshops and learn....This was our 3rd year coming to you and we always had a good response from parents. As a service provider and we found it useful as we trying to support people with employment and it was interesting listening to that workshop and we took some ideas away with us and going to apply them to what we currently doing. (Service Provider & Stall holder)

“Just a note to say thank so much for a wonderful conference yesterday. I learnt so much and was very reassured to know that there is so much support and resources for the Moving into Adulthood Stage. Having got [son] happily settled at School, where he gets excellent support, I was rather dreading the 'black hole' of what happens next. I no longer feel like that thanks to yesterday.” (Parent)

FAMILY CHAMPIONS COURSE

At time of writing we are half way through our [Family Champions course](#), funded by the European Social Fund (ESF). 13 family carers from across Oxfordshire have enrolled on the course – our first accredited course through the Open College Network.

We have a fabulous bunch of family carers, caring for children and adults of all ages. Those attending will receive a certificate and OCN level 3 accreditation to help them with future career options.

Some are using the course to gain knowledge in order to help their relative... a few, we hope will eventually be working with us to support other families across the county – increasing our capacity and strengthening our network.

TRANSITIONS TRAINING FOR PROFESSIONALS – BUCKINGHAMSHIRE

OxFSN was commissioned by Buckinghamshire County Council to run a multi-agency training course for professionals working with young people and their families in the county. After delivering the face-to-face training Gail developed an online training resource for professionals (staff teams). You can see the training course [here](#)

OXFORDSHIRE'S BIG PLAN – FOR PEOPLE WITH LEARNING DISABILITIES

We've been working with Oxfordshire County Council to try to obtain the views of families on their 'Big Plan' for people with learning disabilities in the county. Our response to the plan has now been submitted to OCC and you read it [here](#)

LOCAL EXPERIENCE OF NATIONAL CONCERN

OxFSN supports the Justice for LB campaign.

LB is short for Laughing Boy, the name used online for Connor Sparrowhawk. Connor was a fit and healthy young man, who loved buses, London, Eddie Stobart and speaking his mind. Connor had autism and epilepsy.



On the 19 March 2013, Connor was admitted to hospital (Slade House Assessment and Treatment Unit run by Southern Health NHS Foundation Trust). He drowned in the bath on 4 July 2013. [An entirely preventable death.](#)

Last year we produced a report, commissioned by Oxfordshire Healthwatch. Our aim in producing this report was to contribute to the debate about how extremely vulnerable people with learning disabilities, autistic spectrum disorder and mental health needs or challenging

behaviours can be better supported and safeguarded by providing information, advice and support to their families. You can read the report 'Local Experience of National Concern [here](#)

You can find out more about the Justice for LB campaign and how to support it [here](#)

The Campaign are trying to change the law by proposing a new Bill called the [LBBill](#) – you can read the explanatory notes [here](#)

You can keep up date with news about Justice for LB and the LBBill on Twitter by using the hash tag #justiceforLB and #LBBill

Sara Ryan, Connors Mother started writing a blog called My Daft Life: the funny stuff that happens long before Connor died. They were a joy to read for any of us who have a child or relative with a learning disability. The focus shifted as she became frustrated by the 'transition process' and then when he was admitted to an Assessment and Treatment Unit (ATU) in Oxford. 107 day later he died. You can read Sara's blog [here](#)

SAFE PLACES SCHEME



Safe Places has been set up to help people who are feeling vulnerable or scared when they are out and about in Banbury. Someone who is feeling vulnerable might have a learning or physical disability, be feeling intimidated, lost, confused or being bullied; they might be elderly or unwell.

If someone is worried or feeling unsafe, they can go to a Safe Place, which could be a shop or a community centre or health and wellbeing centre and can request help to contact someone who supports them. The Safe Place displays the distinctive logo in the window.

We have been working with a wide range of partners, including My Life My Choice, Thames Valley Police, OCC and Cherwell District Council, Style Acre, Castle Quays Shopping Centre Mid –Counties Cooperative Society and Frank Wise School to set up a Safe Places Scheme in Banbury.

These stickers are distributed by the PCSOs and street wardens in Banbury and Safe Places are approved by Thames Valley Police who hold the database.

Contact cards, *like the one here* are issued to vulnerable people. These cards can be obtained from Banbury Police station and we have plans to also hold them at Castle Quays shopping Centre.

If a crime has been committed or it is an emergency, dial 999. If it is not an emergency call 101 or the Social and Health Care Team at Oxfordshire County Council on **0845 050 7666**

For more information, contact Jan Sunman at jan.sunman@oxfsn.org.uk or Bee Maidlow from Oxfordshire County Council: Email : Bee.Maidlow@oxfordshire.gov.uk . There are currently Safe Places in Wantage and Didcot too. In Wantage: contact Angela Young at Charlton Day Services: angela.young@oxfordshire.gov.uk

CHANGING SCENES

Changing Scenes is our older carers project and was set up with funding from Comic Relief. We are now into our 3rd year.

One of the greatest challenges we face as family carers is to consider what will happen to our loved ones when we become older ourselves. It can be a great worry to think about what will happen to someone when we are no longer alive, or when we can no longer support them because we have become frailer.

“I’d like to be able to retire, like other people do” (Carer in her 80s)



The project works with older carers to help them make long term plans which can help enormously to ease that stress. It provides information and support about the practical steps we can take to ensure that our loved ones have a good quality of life when we decide to share or hand over their day-to-day care as well as providing a chance to meet others in a similar situation. rroups are held around the county

So please contact Jan for more information jan.sunman@oxfsn.org.uk or telephone: 07596 784947

NHS ENGLAND

We have been working with NHS England South on a pilot to improve the experiences of families who have had relatives who have died in NHS care.

Some of us have also been trained to carry out Care and Treatment Reviews on behalf of NHS England to review the care of people who are still in secure units like Winterbourne View, to assess whether they can be moved back into the community where possible and to check that they are safe.

NHS England have developed a new guide [‘Getting it Right for People with Learning disabilities’](#): going into hospital because of mental health problems or challenging behaviour.

PERSON CENTRED REVIEWS: A RESOURCE FOR SCHOOLS, COLLEGES AND OTHER SERVICES

This resource is aimed at a wide range of people who work with children and young people who have special educational needs and/or disabilities. It has been informed by Oxfordshire Family Support Network’s (OXFSN) experience of working in Oxfordshire (and Buckinghamshire) since 2007. The guidance aims to bring together the range of good practice emerging across the country and provides advice on overcoming some of the challenges that have been identified in order to embed person centred approaches into everyday practice.

OxFSN has been promoting person centred practice to families and professionals through workshops and training for a number of years. The introduction of the Code of Practice (2014) for children and young people with special educational needs and/or disabilities strengthens the need to embed this practice to ensure children and young people achieve positive, person centred outcomes.

The resource can be found by clicking on the link [here](#) and will be up on our website soon.

SPECIAL EDUCATIONAL NEEDS & DISABILITIES (SEND) REFORMS

In September and October last year OxFSN worked with [Parent Carer Voice Oxfordshire](#) and Parent Partnership to run ‘The Change Ahead Roadshows’ a series of workshops for parents about the new reforms.



You can find out more about the changes and how they will affect you and your child by visiting <https://www.oxfordshire.gov.uk/cms/content/introduction-send-and-local-offer>

Gail sits on the SEND reforms Programme Board and was part of the Local Offer task group.

The Local offer aims to bring together all the information that families of children and young people with SEN and or disabilities need. Oxfordshire's Local Offer webpages are [here](#)

OxFSN is currently putting together a guide for families to help them fill in the 'All about Me' section of the new [Education, Health and Care plan](#) which are replacing Statements of Special Educational needs. Parent Partnership have put together [this helpful factsheet](#) click on the link to find out more.

Parent Carer Voice Oxfordshire Facebook page can be found [here](#)

WHAT NEXT?

Get involved with OXFSN

We are always looking for more family carers to get involved with us and help us to deliver some of the work we are currently doing and want to do in the future. There are number of ways to be involved.

Become a Trustee:

We are currently looking for family carers (or others with an interest in, or experience of working with children or adults with learning disabilities and/or their families) to join our board of Trustees. If you'd like to help support the work we do and would like to work with a group of people who are passionate about improving the lives of people with learning disabilities and their families then please get in touch to find out more. E-mail: info@oxfsn.org.uk

Become a member: Becoming a member of OxFSN is easy. All you need to do is contact us and ask to join

Come to our events: Feedback from our events is always great and we always want to do more, please come along and support them.

Tell us what you want us to do: OXFSN is run *by* family carers *for* family carers and we take our lead from you – tell us what you want us to provide, ideas for events and projects are always welcome.

Ask us to attend your events or book some training:

- If you run a support group or are an informal groups of family carers we can come along and talk to your members. Please contact info@oxfsn.org.uk
- Schools/colleges can ask us to run workshops for families or training for staff – available training includes –
 - Person centred planning, thinking & approaches
 - Person centred review training
 - Moving into adulthood workshops
 - Working with families

Become a volunteer representative:

We are looking for people to become OxFSN reps at their child's school or college. Getting information out to families about our events (especially to families of children in mainstream schools) is always problematic. We are aware that lots of families miss out on events and information or training opportunities because they didn't know they were taking place. It would be great to have one parent in every school /college who we can contact to make sure that other families don't miss out.

Fundraise for us:

Like all small charities we struggle for funding and are always looking for people who will fundraise for us. If you are doing a charity bike ride, or anything else then please keep us in mind. We have a [My Donate page](#) on our website but please let us know if you are doing anything so we can get you (and us) some publicity 😊

NEWS

OUR WEBSITE

We are in the process of revamping and updating our website to better reflect the work that we do. Keep checking for updates in our news section in the meantime for upcoming events and projects and activities www.oxfsn.org.uk

OXFORDSHIRE'S LEARNING DISABILITY PARTNERSHIP BOARD

Jan Roast (Vice Chair of OxFSN) and Gail have been longstanding members of the Learning Disability Partnership Board and they have recently taken on the role as co-chairs alongside Louise from My Life My Choice. We will share news from the Partnership Board regularly in this newsletter.

OTHER NEWS!

[The National Family Carers Network \(NFCN\) News Bulletin](#)

OxFSN is a member of the National Family Carer Network. The network is a registered charity that aims to promote the voice and rights of family carers supporting a person with a learning disability. Its membership comprise of both organisations and individuals.

You can find out more and join the network by clicking on the link [here](#)

The National Family Carer Network send out a weekly news bulletin, ours won't be as regular as this so we will collate the items that we think will be of interest to Oxfordshire families in future bulletins.

Their latest bulletin is [here](#)

[The Learning Disability Alliance](#)

The Learning Disability Alliance (LDA England) is campaigning to improve the lives of people with learning disabilities. You can read more about their vision [here](#)

LDA England is backed by the [National Forum of People with Learning Disabilities](#), the [National Valuing Families Forum](#) and a wide range of groups and individuals. It is a project of the [Campaign for a Fair Society Ltd.](#)

Find out more and how you can get involved here - <http://learningdisabilityalliance.org/>

[Kidz South Exhibition](#)

Thursday 4th June 2015 - Rivermead Leisure Complex, Richfield Avenue, Reading, RG1 8EQ
9.30am - 4.30pm

One of the largest, FREE UK exhibitions dedicated to children and young adults with

disabilities and special needs, their families and the professionals who work with them. Over 120 exhibitors offering advice and information on funding, mobility, seating, beds, communication, access, education, toys, transport, style, sensory, sports and leisure and more.....

Running alongside the event are FREE seminars for parents and professionals. Topics include: Moving and Handling, Sleep Issues, Contenance Issues, Direct Payments, Parental Experiences, Transition, Legal Advice and more ...

<http://www.disabledliving.co.uk/Kidz/South>

Check out this from - [Into the Garden](#)

Into the Garden is a horticultural project for people above 16 with autism. We will grow cut flowers, herbs and trees and sell them on farmers markets and the internet. We will be able to offer placements for two days a week and after September more days per week.

We can offer work experience and qualifications. Initially only ASDAN qualifications, but we are aiming to have higher qualifications from September 2015.

Please have a look at our website for more details. www.intothegarden.org.uk

And this from Andy Fowler at [Rhythm Zone](#)

Autism Awareness Week 2015

FREE activities! Come and celebrate with us.
Thursday April 2nd 10am - 12am
Mapledurham



Drum Circle
10-10.45



Tea and Cakes
10.45-11.15
(donations)



Circus Skills
11.15-12

This FREE and fun packed morning is brought to you by RhythmZone and The Disabilities Trust. We look forward to seeing you on the day.

Just call Andy Fowler on 07884231188 or email andy@rhythmzone.co.uk to save a place/places and to get directions.

Anyone who has been along to our Family Information Fairs will be familiar with the fab drumming sessions by Andy at Rhythm Zone. Andy will be leading fun activities for every ability at a free event on April 2nd in Mapledurham (Drum Circle, Circus Skills - and Cake Eating! mmmm). - Please share this around and help him to get a good turnout.



And Finally...In Loving Memory of Tracey Taylor



This first bulletin for a long time is dedicated to the memory of a wonderful lady called Tracey Taylor.

Tracey was an amazing volunteer, Champion, trustee and leader of the charity. She was a big part of their success over recent years and helped to gain greater respect for, and understanding of, people with learning disabilities in Oxfordshire. She leaves behind many friends and colleagues who will miss her dearly, including those of us at OxFSN.

Our thoughts are with Tracey's husband, Nigel and her family at this very sad time.

Tracey can be seen 'doing her stuff' in a film by My Life My Choice to support the Justice for LB campaign. You can see the film [here](#)

To find out more about our Friends at **My Life My Choice** and the brilliant work they do please visit their website <http://mylifemychoice.org.uk/>

[Bulletin Ends]