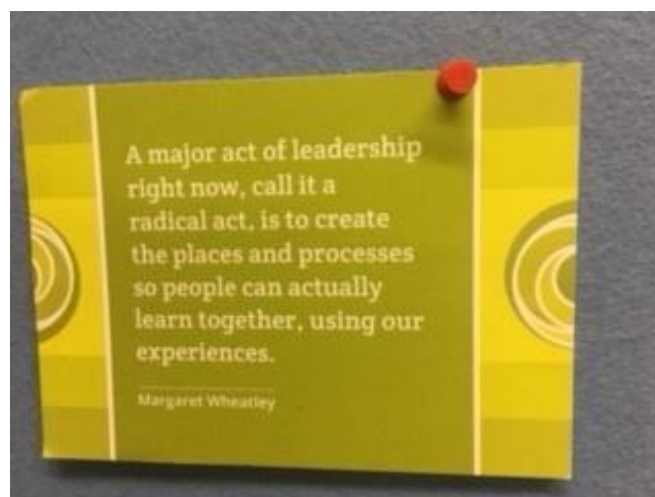




Better Together Event

November 8th 2018, Oxford



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Appendix 1: Organisations who attended

SECTION ONE

1. Introduction

OxFSN's Better Together event was held on the 8th of November at the Kassam Stadium in Oxford and attended by 117 people. 53 professionals from Health, Social Care, Education and the voluntary sector attended along with 60 family carers of children or adults with learning disabilities and/or autism and seven people with learning disabilities and their supporters.



The event was a 'World Café' with ten tables with one question on each table. The questions were chosen because these are some of the key the issues that families of people with learning disabilities come to OxFSN for help or support with. They were also designed to cover a range of issues affecting people at different ages.

The aim of the day was to have families and professionals working on the questions together to look at what was working well, what was not working so well and what would work better.

2. Family carers and professional's discussion café tables 1-10

Each table had a facilitator who took notes and guided the discussion. They each had different ways of capturing the information, so we have tried to format it in this report in a way that makes the most sense. We have kept the editing to a minimum in order to make sure as many voices as possible come through. There is some repetition, the same thing said in different ways – but we wanted to keep those perspectives in full. **Section 2** has the full details. A list of the organisations who attended is in **Appendix 1**.



3. Common themes

- A common theme was the issue of poor communication. Communication with families and between services.
- A lack of understanding of systems and processes by family carers and in some cases professionals was also highlighted.
- Information is available but many families still don't know about The Local Offer or the work on transforming care.
- Transition also came up as still being a major issue for families and was mentioned on most of the tables.



4. Actions from Better Together Event – noted on the day

We are keen to make sure that events like this are not just a ‘talking shop’ and some real, positive actions come from them. As family carers ourselves we are only too aware of how often we are asked for our opinions or feedback only to find nothing happens as a result. This report will be sent to everyone who attended and, hopefully, shared widely with those working in services. We will be specifically asking for clear actions from senior leaders within children’s and adults Social Care, Education and Health services in Oxfordshire, and here are the ones they committed to on the day.

Liz Williams - (Service Director Learning Disability Services, Oxford Health NHS)

- Publish Transforming Care information to show how far they have come as concerned that a lot of people had not heard of Transforming Care.

Kate Terroni - (Director for Adult Services, Oxfordshire County Council)

- Long list of actions
- Work with OxFSN
- Will report back
- Promote employment
- Will get input from people on Supported Living Strategy

Jayne Howarth – (Special Educational Needs and Disabilities Lead, Oxfordshire County Council)

- Improve communication
- Meet deadlines
- Transition & link in with adult social care, education and supported living

Sarah Ainsworth – (Disabled Children’s Manager, Oxfordshire County Council)

- Happy to be part of a focus group to talk about Direct Payments and do focus work on how they can be used
- Get better at using data to commission the right services

Robyn Noonan – (Area Service Manager – North, Oxfordshire County Council)

- Improve pathway in to adulthood – there is a new model coming
- Promote local offer as not many people are aware of it

5. Feedback about Better Together event

It's the first time we have attempted an event like this and the feedback has been very positive. We also had some very helpful feedback from 55 out of 117 people on what worked and what would have been better, and what we could do differently, which we are really grateful for. If you would like a copy of the detailed feedback please contact us and we will send it to you. However, we are sharing the answer to one question as we think it applies to everyone who came and will help us all to take action.

What changes would you like to see happen as a result of this project?

- Better information on services available
- Better communication between services
- I will take away knowledge of resources I can share with people I see and support
- Better communication between professionals and improvement in awareness culture around disability
- Parents to be more informed
- More efficient links between services and age ie young – over 18
- It would be very useful if all the information could be collated so that it was easy to find on a website. Possibly with different sections for different age groups
- Invite Police Mental Health team, Warneford Staff, GP, Tutorial College Tutor, Special School Tutor, Main Stream Tutor to take part in future events & sharings? – I have found them knowledgeable and supportive in the past in relating to late teens, autistic male with mental health issues.
- Improved communication between professionals
- Better outcomes for disabled children and adults
- People with lived experiences need more information
- Top 10 best practice outcomes from user feedback
- Points raised and recorded and fed back to those with responsibilities within OCC and their responses – what changes will be made??
- The views of society: people do not have to fit in the box – more 'person centred and holistic approach
- Better help & support in schools/employment ideas'
- Mental health – the best interest of the person.
- Key services working more together (time and money to do so!)
- User groups empowered to continue taking part in giving direct feedback
- I am interested in a charter! Let's discuss
- Get feedback to parents of actions done
- Better and more timely communication from the County Council
- Improvement to websites to make it easier to find information
- More integrated working; increased dissemination/sharing of support
- Better communication about the length of wait for services and regular update about where you are on the waiting list

- More collaboration between children & adult services to be able to provide holistic support to families (better communication) (dreaming I know)
- Suggestions made put in place
- An action plan jointly owned by OxFSN, OCC, CYP, & OCCG/OH; report to be presented to councillors/SLT (Senior Leadership Team) at OCC/OCCG & local MP's
- More co-production working together, more flexibility
- *change happens* - need for better training and preventative work;
- Early intervention - information knowing where to go
- Better signposting for assessment
- Better understanding of direct payment from professionals
- Greater involvement from parents/carers into strategy
- Professionals listening to parent carers to get the best for their child or young adult
- School exclusions reduced
- Mental well-being prevention to be on the school curriculum
- To continue to have these events
- Real outcomes
- Better transition from children to adult services
- Look into the needs of continuity from school age to adult and beyond
- Aim to get our NHS service put on to The Local Offer
- Lobbying the Government for better funding for councils to improve resources in all areas for all young people and to relieve pressure on services
- More acknowledgement of housing as a fundamental issue at the root of many others
- More training around mental health, mental capacity – parents and professionals in schools & elsewhere; what to do if you don't fit the threshold for support, transition to adulthood; what you are entitled to as parents have to fight for help; more support & meaningful activities & employment
- Feedback and a SEND strategic plan as Oxfordshire engaging key partners to deliver/implement the changes and evaluate feedback on a regular basis
- Some tangible, measurable outcomes & feedback on improvements achieved
- Champions for every family helping them navigate services and advocating for them

6. Next steps

This report and feedback on the event will be shared with key professionals for their proposed actions. We will gather this together and send out as soon as we have it. The report will also be shared with the Transforming Care Partnership Board

OxFSN will use the information gathered from this event to plan our work for the next year. This will enable us to focus on specific issues raised and continue to raise them through our networks with those who have the power to change things.

We are currently looking for funding to run workshops and events on many of the issues raised with a view to improving families and professionals' knowledge of systems and processes. We will continue to support individual families to get the support they need. And, continue to work with professionals in Health, Education, Social Care and the voluntary sector to influence change and improve service...

Because we really are BETTER TOGETHER!

Thanks to everyone who came along on the day to this event. A special thanks to our volunteer family carers who helped out on the day and the facilitators (who were given very short notice that they were facilitating) we couldn't have done this event without you.

And, a final thankyou to Comic Relief, who supported us from the very start of this event, by backing our initial idea and then giving us financial support.



Team OxFSN

January 2019, Oxford

SECTION 2

Detailed dicussions from the café.

Table 1 Mental Capacity

What would you do if someone you were working with was making decisions not in your family member's best interest?

What is working well?

What has not worked so well?

What could work better?



What's working	What's not working
<ul style="list-style-type: none"> • Oxford Health – learning disability – helpful advice • Hospital Passports are useful • Knowing your rights and having knowledge • My GP sees my son, provides good care and makes reasonable adjustments. • Only a good thing if people trail blaze! • Know someone really well – also trust those that know someone best • Inspirational and courageous families • Best Interest meetings – they can work • A good GP – they can be a real help (don't always work together though) 	<ul style="list-style-type: none"> • Deputyship (from the Court of Protection) is presented in a scary way • Where do you start with this? • It's complicated the words don't always feel right • Misconception – not just one thing not just a black and white issue - nuanced • Not static – it can change – time, context, time of day, life events • Not always people to call on to help • Fear the assessment unit (a punishment) • Not enough expertise • Furthermore a prejudice • A diagnostic overshadow • Sometimes (Court of Protection) Deputyship is used? only in crisis • "I don't want to hear from you" said a health professional • Schools need more expertise, knowledge and training • Increasing reasonable adjustment • It's a fight – shouldn't be • Difficult if you are not knowledgeable. • Parents are blamed – prejudice against parents • It seems that crisis is the only thing that gets attention – I'm given attention when crisis strikes • Huge caseloads • We seem to lose our rights when children become adults • Reaching hospital - unprepared professionals what will happen? • GP waiting is an issue • Training for carers/support workers – often requires an in depth approach • Do we understand the unique person • Some disabilities are invisible (memory loss) • Meetings in some environment can be traumatic • Stress/anxiety for social workers

What could work better?

- Increase trust and better communication
- Awareness of power
- Understand the whole situation
- Understand and listen to what families have to say
- Professionals – time to deal with anxiety
- Parent power
- Recognise when behaviour is pain not autism
- Understand and trust me and inform me as the 'named person' of decisions/work together
- How much power do we have in best interest decision making?
- Make reasonable adjustments
- A review of transforming care – the truth about Assessment and Treatment Centres
- If professionals had a more consistent approach
- To have a place here in Oxford when someone is sectioned (under the Mental Health Act)
- Working together, to maximise someone's chances of understanding
- Knowing where to start
- 'One page profile' – to help give continuity of care
- Detailed workshops would help - milestones, Deputyship
- Social workers - more time for being with families
- Be proactive - planning and decision making about hospital visits so we are prepared
- Having a conversation straightaway about capacity and decision making - be clear as a whole team
- To respect opinions when we disagree - best interest can change!

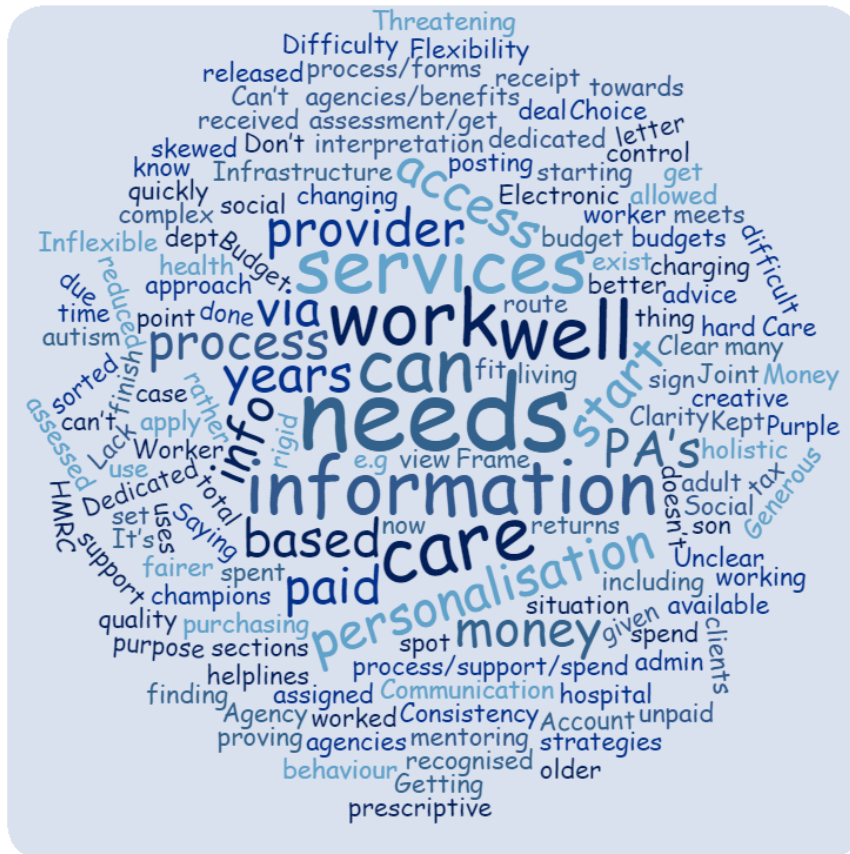
Table 2: Personal Budgets and Direct Payments

Do Direct Payments give your relative the flexibility to live the life they want to live?

What is working well?

What has not worked so well?

What could work better?



What is working well?	What has not worked so well?
<ul style="list-style-type: none"> • Agency care now paid via Direct Payment (not own money) • Account admin reduced • It's money! • The needs have been recognised • Personal Assistants quickly sorted via care provider • Generous Direct Payment but ... • Flexibility 	<ul style="list-style-type: none"> • Unclear what is allowed in terms of spending the money • Lack of information on services available to access • Too many agencies to deal with, complex process/forms not fit for purpose, and skewed towards older clients • Personal Assistants (PA's) not being paid on time

<ul style="list-style-type: none"> • Direct Payments meets needs (in receipt for 17 years) • Once set up can work well • Choice and control over the care received • Kept son out of hospital for 5 years (been hard work) 	<ul style="list-style-type: none"> • Money not released to Purple (current commissioned organisation by Oxfordshire County Council) • Threatening letter from HMRC due to unpaid tax • Care provider too prescriptive • Difficulty in finding quality support • Inflexible – can't use for access to behaviour strategies (autism) • Don't know where to start • Getting assessed proving difficult • Can't get a Social Worker • No sign posting • Framework interpretation too rigid for personalisation • Communication • Saying the same thing over and over again • Infrastructure doesn't exist for spot purchasing • More information is needed when changing living situation • Budget should be based on needs rather than needs based on budget
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What could work better?

- Electronic returns
- Clarity and information on process/support/spend
- Over view of total process start to finish including all agencies/benefits and fairer charging
- Consistency with advice given
- More information on creative uses for Direct Payments e.g. mentoring
- Joint budgets, adult social services and health
- Clear process /route on how to apply for an assessment/get a Social Worker and starting point for Direct Payment
- assigned case worker
- Learning disability dedicated helplines for all sections
- More personalisation
- Dedicated Direct Payments champions in each dept.
- More holistic approach
- More information that services Direct Payments can be spent on

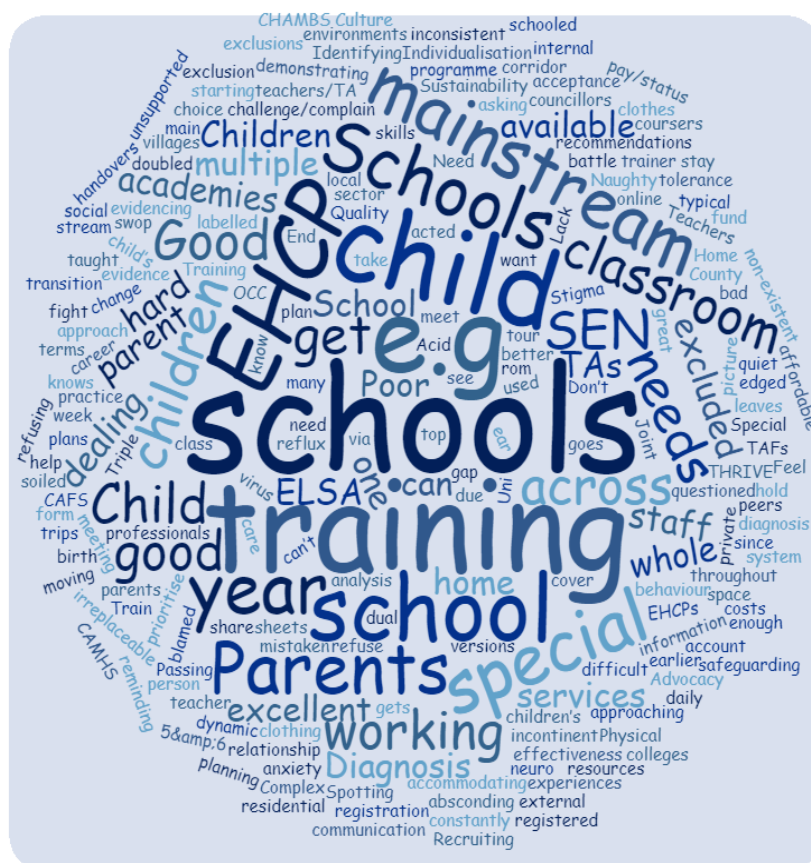
Table 3. Support in Mainstream Schools

Is your child falling through the cracks?

What is working well?

What has not worked so well?

What could work better?



What's working	Not working
<ul style="list-style-type: none"> • Good working relationship with schools • Good class dynamic • Teachers and Teaching Assistants (TA's) do want to help • Diagnosis via CAMHS great when you can get it • Culture of acceptance and tolerance in school e.g. when dealing with absconding • Joint working between mainstream and special schools and mainstream e.g. dual registration 	<ul style="list-style-type: none"> • Physical environments in village schools e.g. no quiet space • Parents having to hold schools to account • Parents constantly reminding /training staff • Child has inconsistent experiences across the same school e.g. good year /bad year • Individualisation on plans is doubled edged. End up with one irreplaceable person who knows the child and leaves

- | | |
|--|--|
| <ul style="list-style-type: none"> • Good transition planning between schools – starting year 6 terms 5&6 • Complex needs child in system since birth – no fight for EHCP or diagnosis | <ul style="list-style-type: none"> • Schools training children to be neuro typical • Advocacy for children at CAFS (Common Assessment Framework) and TAFs (Team around the Family) not available • Children being taught in the corridor and being excluded by peers • No choice over special schools when moving from mainstream • Recruiting Teaching Assistants due to pay/status • Not having resources to fund training for staff • Lack of available and affordable SEN training (e.g. ELSA (Emotional Literacy Support Assistant) training) costs £1k and then £600 pa to stay registered • Feel unsupported by other services e.g. social care and CAMHS over safeguarding • Not enough SEN training in colleges and University courses • Poor non-existent daily home communication e.g. re soiled clothes • Child excluded from trips and residential and classroom – main stream can be a form of exclusion • Child goes to multiple schools • Has multiple exclusions both internal and external • Poor handovers year to year • Children refusing schools • Home schooled or in private sector • Parents labelled as difficult or blamed for children’s behaviour if challenge/complain or question • Don’t see evidence of EHCP being acted on in schools • Schools dealing with incontinence in classroom • Schools asking parents to change clothing • EHCPs hard to get • Diagnosis hard to get - a battle |
|--|--|

- Naughty children - schools refuse to take child if can't meet need
- Too many versions of EHCP - one parent now has version 27!
- Stigma of being at a Community Special School as a parent or child
- Quality of EHCP not good!
- Acid reflux mistaken for a virus

What could work better?

- Training gap analysis for professionals and prioritise top 3 needs across Oxfordshire
- All About Me – sheets in EHCP could be used in school classroom
- Sustainability of training
- Identifying good practice across the academies
- Train the trainer - share the training across the academies
- More SEN training in teacher training throughout their career
- County Councillors to tour special schools with a parent
- Special Schools skills swop with mainstream for a week
- Spotting anxiety earlier
- School gets to know the child
- Parents approaching services directly, ie not waiting for the school to do it
- School accommodating child's needs
- Need whole picture of child at home and school by passing on information
- More online and local training from the County Council and funding to give cover for Teachers/Teaching Assistant training
- Schools evidencing that they are meeting the recommendations in EHCP - demonstrating effectiveness of the plan
- THRIVE (www.thriveapproach.com) approach whole school
- Triple P (Positive Parenting Programme) - excellent
- ELSA (Emotional Literacy Support Assistant) excellent



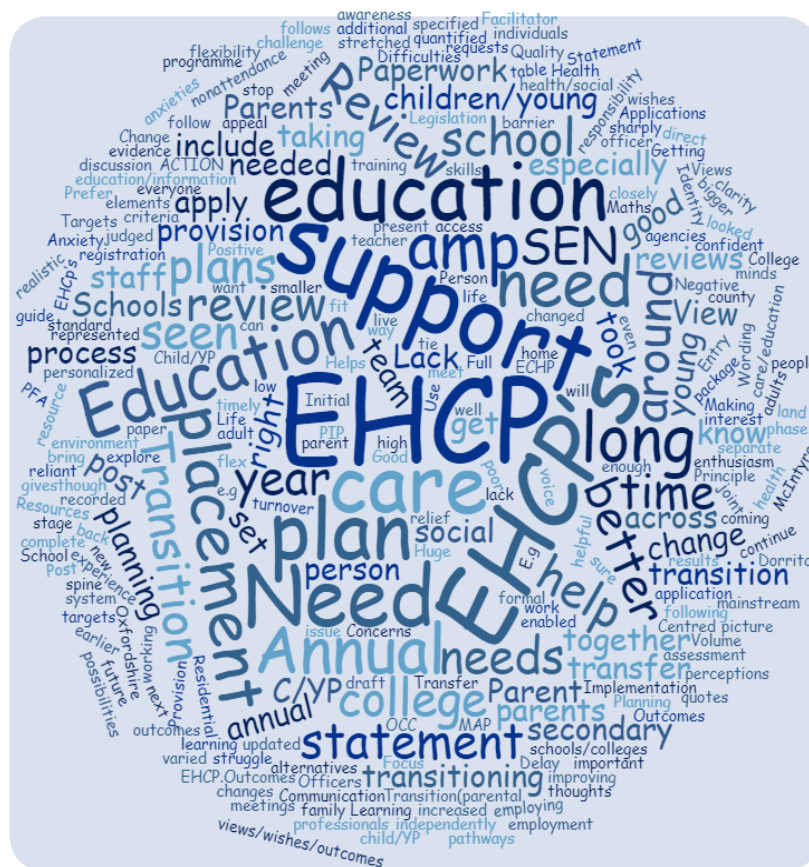
Table 4: EHCP's (Education Health and Care Plans)

EHCP's are intended to bring together education, health and care agencies to better support your child/young person in a person-centred way. What is your experience of this happening?

What is working well?

What has not worked so well?

What could work better?



What is working	What's not working
<ul style="list-style-type: none"> • Helps get right placement • Huge relief and support to parents • Good planning enabled a good transition • Initial meet and enthusiasm – well represented across agencies • Residential placement was helpful • EHCP help transition before and after college • Child/young person has more of a voice • Transfer from SSEN to EHCP • MAP (MacIntyre Abingdon Partnership): gives a bigger picture on how to support individuals with the MacIntyre programme • Health View: Quality of plan is improving • Principle good: • The SEN team will be reviewing its staffing to ensure that we have enough staff to undertake all statutory work, including the processing of annual reviews in a timely way. 	<ul style="list-style-type: none"> • EHCP application took too long • Implementation poor • Full EHCP review but only teacher and parent present • Schools need more training on EHCP process – high turnover of staff • Parents need more education/information about EHCP's. • Only seen as “education” plans • Education struggle to bring health and social care to the table • Legislation has not changed so health/social care/education all judged by same standard (appeal all elements even though some seen as ok). • Transition to new school placement (parental experience) – no Annual Review, no meeting to transfer team, no plan • Lack (in some) Annual Reviews of Person Centred Planning • Formal EHCP's are not recorded in a timely way following the Annual Review. Paperwork is joint responsibility of schools/colleges & SEN team • Wording of EHCP's is not updated as needs of child/young person changes • Communication with SEN Officers and placement • Annual Review process – out of county & nonattendance of SEN Officer especially around year 11. E.g. coming back in to Oxfordshire or in to further education • Delay with paper work – draft EHCP's • Lack of planning for post 16 • Education not working closely enough with Adult Social Care. • Lack of provision • Making sure ECHP & registration at college and school tie in • Use EHCP annual review to plan better, especially post 18

	<ul style="list-style-type: none"> • Volume of requests for an assessment has increased sharply- resources are stretched across the system. • Anxiety around transitioning to mainstream secondary • Identity needed at earlier stage • Transition needs to include support
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What could work better?

- Entry criteria, is a barrier for access for children and young people interest. Need to explore alternatives.
- If schools will not apply for EHCP, parents can apply themselves
- Should include direct quotes from child/young person as results in better outcomes.
- Need a school discussion re EHCP at year 4 to help year 6/7 transfer phase, and anxieties of transitioning to secondary.
- Views and wishes and outcomes - the facilitator needs to guide more realistic views/wishes/outcomes
- Post EHCP helping children/young person plan for their future. How do we support young adults who live independently to continue their education?
- Education pathways are varied. Need flexibility and better awareness
- Where does 'support at home' fit in?
- Outcomes and targets are an issue. Targets are set low.
- Annual reviews are a challenge for everyone: Parents, professionals.
- Prefer a Statement of Special Educational Needs (SEN) to an EHCP - school follows the SEN more.
- Need clarity in EHCP's to set them up for college
- College - what possibilities are there for employment?
- Transition to allow for flexibility as children/young people change their minds
- Provision – needs to be a more personalised package for children and young people



Table 5: What happens after school and /or college?

Growing up and becoming an adult can sometimes be a scary time for young people. What support do you think should be available to help them to live a fulfilling life in adulthood?

What is working well?

What has not worked so well?

What could work better?



What's working well?	What's not working well?
<ul style="list-style-type: none"> • Transitions • That it is a recognized issue and being addressed (Oxfordshire are doing well) • Schools/Colleges doing a great job (Frank Wise - Dean Cooke) • Co-production of the new transition model – services, staff etc. • More options then you might think - 6th form is doing brilliantly • There is the local offer • College is supportive 	<ul style="list-style-type: none"> • Differentiation of experiences across county in these transitional phases – OCC(Oxfordshire County Council) are trying to get a better transition • Communication about Local Offer and what's out there • Seeing same people in the same room at the same time – problem for individuals • Children to adults' services • Inconsistency of support across schools • Transport and Safety • No guidance/ideas for young people themselves • Understanding and the importance of family relationships • CAHMS (Child and adolescent mental health services) signposting • Waiting games!! • Struggle to get direct payments/social worker knowing about funding • More disaffected, more have to pay • Struggling to get into the system – disparities and to get a Social Worker • Funding for children/adults – just not there • Disparity between country/city/country (transport) • Integration in to the community • Care Act guidance does not happen – limited as to what we tell people they can do. (NOT JUST COLLEGE) • Finding out about services for after college (Local Offer, Events like this) In special schools knowing about opportunities • Barriers to work and work experience • No one knows about local offer • Rural kids - transport and cash • parent/child support • Need more support managers • Safety & risk taking (need to develop travel skills)

What could work better?

- Knowledge and understanding methods – are a challenge
- County/town provision
- Difference of support in mainstream vs special school support
- Social/health care linking with education system
- Communication and ownership
- Integration in to the community – target groups – age 17 and 10 and under
- Integration into community - children need to learn from others not parents – Personal Assistant (PA) network
- Guidance for PAs on what happens at 18
- Effective communication about things like the Local Offer and guidance advice & opportunities available to people
- Transport – link with a county/town imbalanced experienced by both users and service providers
- Opportunities around target groups (e.g. high functioning autism, under 10's) thinking more broadly about needs around these.

Communication Solutions

1. One person, one number
2. Year 9 annual review for ECHP's is the obvious route for information
3. Person to talk to connection officer for guidance
4. School/council connection
5. Alexa
6. Champions – either staff/volunteers and expertise to understand challenges – building trust.
7. More ethnic minority engagement.

Table 6: Work Opportunities

Are we preparing young people for going to work? What opportunities are available? Should voluntary work be a stepping stone to paid work?

What is working well?

What has not worked so well?

What could work better?



What's working	What's not working
<ul style="list-style-type: none"> • Ongoing support in the workplace • Supported internships work well • Volunteering works well – but it shouldn't be the path everyone is pushed into. • Really positive models – 'Style Acre' • Transport – 'travel buddy' scheme – My Life My Choice (MLMC) are widening the travel buddy scheme • Job Centre Plus – good experience • Without the pay element there are real opportunities for work 	<ul style="list-style-type: none"> • Negative experience of work and health programme leads to something? • Volunteering – not always valued for what we do – danger of being left in volunteering • Are we preparing people for work well? Not always. • The benefit trap is very real. • Draconian benefits system • Work experience is traditionally 2 weeks. Is this useful? • Are we preparing people for work? Not always • Access to work too clunky
What could work better?	
<ul style="list-style-type: none"> • Build Local Offer information packs • Use www.oxfordshire.gov.uk/localoffer • Offer support earlier in school – person specific • Work on choices – SEN tracking. 14 years is very young. • Could we use work hubs/learning hubs? Model must take in to account the individual so it is personalized. • Individual Training bridging the gap between employment support and specialist training. Secure places for hubs. • How do we support people with computer needs to work? • Work experience – need more information about the law. • How do we manage benefit traps? • Employment as we traditionally see it doesn't fit • Lack of information in one place & should be available at year 9. This should be easy in a digital age. On line is a 'critical pathway' Wiltshire CC have a good example. • Opportunities to develop a sense of purpose & to redefine employment • Activity in exchange for recognition, validity in doing something positive and 'meaningful' • No pressure of progression, we need meaningful activity in mainstream places • Information from professionals • Need coordination of opportunities • Access to ongoing support when working • What do we mean if we say someone can't work? Should everyone work? • Everyone should have a job – a draconian benefit system • Work is about more than just pay • Does voluntary work work? 	

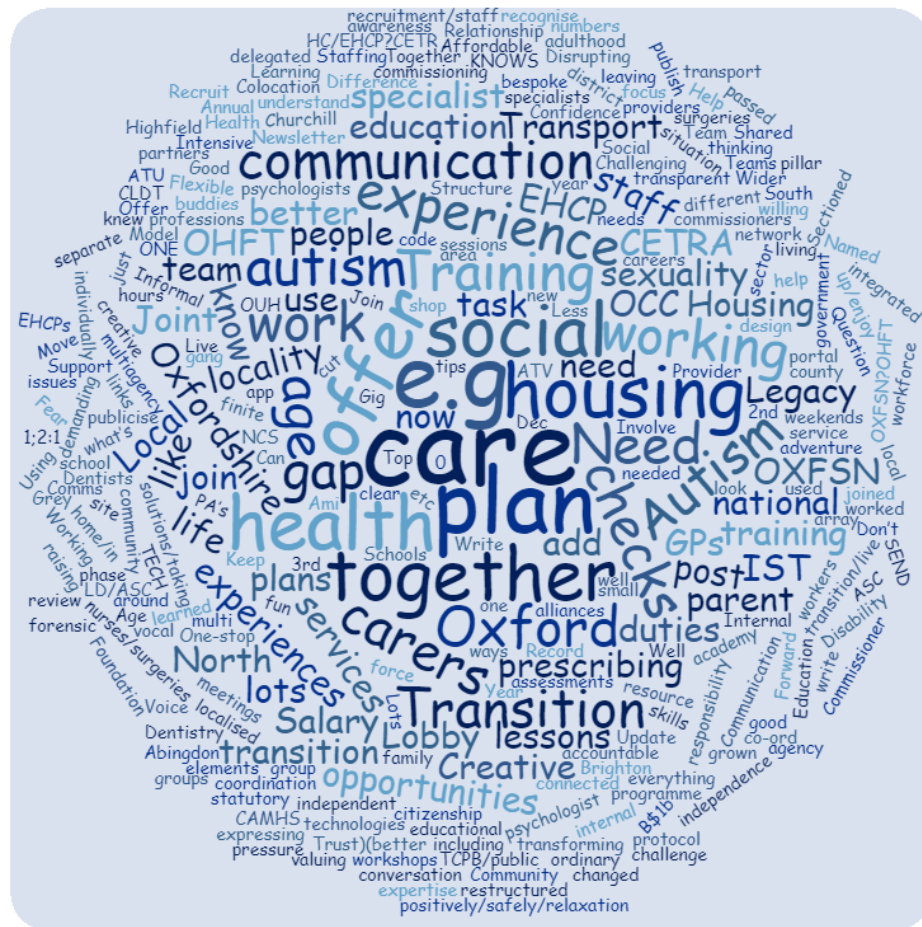
Table 7: Transforming Care

The Government's Transforming Care Programme is ending in March 2019 but NHS England have said that Learning Disabilities and Autism will be a priority in their next 10-year plan. What are the key issues that need to be included? Keep it local, what do we need to be focussing on here in Oxfordshire.

What is working well?

What has not worked so well?

What could work better?



Working	Not working
<ul style="list-style-type: none"> • All Age Intensive Support Team (IST) • Training and workshops • North Learning Disability Team worked well with Learning 	<ul style="list-style-type: none"> • What is transforming care? • What can they do /leaving school • Salary for staff! • Affordable housing - housing gap

<p>Disability CAMHS during transition (from Southern Health to Oxford Health)</p> <ul style="list-style-type: none"> • Community Learning Disability Teams- South Abingdon • GP good - some surgeries • Oxford Health better than before • IST (Intensive Support Team) all age now, but just learning disabilities 2nd phase will include Autism • Dentistry • Some health checks • Good array of providers – lots of experience • Do work together (including internal OCC services) in learning disability and autism • Voice individually before more - joined up thinking now by OxFSN • Co-location of Autism Oxford , OxFSN and Oxford Health and good relationship • GP locality plans 	<ul style="list-style-type: none"> • Finding staff willing to work and do 1-2-1 support • Disrupting carers' careers – transition care, care co-ordination • Under 5 parent support gap, groups have been cut!!? • Need to know numbers from EHCPs • Care, Education and Treatment Reviews (CETRs) • In forensic services – Highfield Unit have all age awareness • Shared care protocol and delegated health tasks • Transport • No multi agency working – passed from pillar to post • Commissioner under pressure to challenge • Year 9 review could be better • Using lessons and parent experience • The offer does not look like an ordinary life • Further Education in Oxfordshire – new conversation needed • Move Out • Don't know who to go to? Lots of separate organisations - no coordination or communication • Transition into adulthood • EHCP to 25 - we all knew this • Annual health checks – need to add into locality plans • Fear of raising issues – Sectioned / Assessment and Treatment Units • Grey area – sexuality and relaxation expressing this – positively& safely • Training – experience of sexuality - On local offer • Need health checks for people with Autistic Spectrum Condition
What could we do better?	
<ul style="list-style-type: none"> • Transition • Named Social Worker • EHCP recruitment/staff • All GPs and GP alliances 	

- Publish more CETRS , as per the NHS 10 year plan
- Local offer (now being restructured) go up to 25
- Local offer – living well
- SEND programme plan
- Join up Dec 2018? Newsletter
- Joint working 3rd sector – publicise this!!
- Record all meetings so all accountable and transparent
- Provider task force
- Confidence and communication – for all professions
- Training for ALL (different ways of training e.g. in Brighton connected to family needs)
- Use a TEAACH for Autism
- ‘Top tips’ – use lessons learned
- Challenging commissioners
- Internal multiagency work
- Creative solutions/taking responsibility eg Informal community support and Social Prescribing
- One-stop shop needed (in design “ Live Well Oxfordshire”)
- Lobby national government
- County Council bespoke situation commissioning, e.g. Flexible hours
- Housing gap – help social workers understand it (?district)
- Model other technologies
- Less of everything in the North
- Forward plan 16+ education together with housing
- Be clear on housing duties and social care duties and join up
- NCS (national citizenship service) – small opportunities and adventure weekends
- Legacy- fun creative, independent experiences, life experiences eg Gig buddies
- Creative use of Personal Assistants , gang up network eg What’s App group/offer skills/join up eg <https://montessori-ami.org/>
- Dentists specialist at Churchill (localised) - need specialists all around the county
- <https://www.psych.ox.ac.uk/research/autism> portal needs to be used more
- Recognised the difference between carers – eg age, some being vocal and demanding
- Autism specialist nurses/surgeries
- More educational psychologists to do learning disability and autism assessments
- Lobby for resource in education
- Write a plan together and then keep to the plan and update all
- Transforming Carer Partnership Board - Gail/Paul, as Co-chairs to publish updates
- Better coordination between health and others and pathways clearer
- More preventative work for specific cohorts with social care
- Sexuality support and capacity
- Care as a whole. 750 workers per year every year – providers need to be on board
- OCCG and OCC commissioners work closer

Table 8 – Engagement

Engagement is a term used to set out how health and social care services actively engagement with the people using their services and work with them to improve services.

What's working well?

What's not working?

What could work better?



Session 1

- Only so many times parents can give feedback without a resolution
- It is good to share feedback
- Want to be able to give one positive response amongst a range of negative issues
- Need to find out what is working well
- Is there a budget to support resolutions?
- Feedback is very different depending on the nature of the services
- Feedback can be adult led needs to include young people
- Need to share what is going on and what projects are happening (can host on OXFSN website)
- There is too much information to process
- Support often accessed through networking which is lead by parents not services
- Delivering treatment/therapy within the child's environment is important

- Contact private therapeutic organisations to survey parent's feedback on why they are accessing private not NHS
- Need to get feedback from families who have been discharged and/or not in crisis
- Parents who are trying to be proactive are in the voluntary sector
- Families not in services- don't want to access services - want prevention
- Is there an option to have central directory online/feedback point? This is being addressed for children and young people - local offer starting point
- Not everyone uses websites
- 'Live well Oxfordshire' – Directory not feedback
- Carers often don't know what is available – this is a key issue for families - need to know what there is
- Need to pick up support for the families who don't get a diagnosis
- Taking siblings to local doctors – key problem, often not listened to
- Not always opportunity to give feedback at GPs – some GPs offer a text to get feedback
- Can feedback on time and location but need to feedback on quality of appointment
- Need to ensure accessing views across demographics /cultures/ ability/age

Session 2

- Keep it simple
- People often not asked for feedback
- Time – how well you were prepared?
- Huge inconsistencies across services
- There is a disconnect between physicians and therapists
- Different budgets - the one thing they have in common is the child/adult
- Less support is available when you become an adult but level of need doesn't change
- Parents continue to need support

Session 3

- More times needs to be spent preparing for appointments
- Never asked for feedback on how the appointments goes
- Don't know what help and support is available - appointments can be too long
- Talking about appointments beforehand really helpful - wasn't asked for feedback on experience - also put in complaint/accolade
- Appointments are hurried rushed /don't allow for needs
- Need to be asked if you need assistance - Reasonable adjustments are needed
- It is better to have a conversation before an appointment than be asked for feedback after the appointment
- Need consideration when planning multiple appointments
- Need to link with Oxfordshire Parent Carer Forum

- Need to be able to access feedback from people who haven't needed services but will do
- Opportunity to feedback the positives- email/PALS (NHS Patient Advice and Liaison Service)
- Parents new to services need help to navigate services
- They need support on what to ask for
- No connection between services - clinical colleagues need to be aware
- Making yourself known through media /support groups
- Texts could be a starting point
- Need a One Page Profile or Hospital Passport to explain needs of child
- Services can have 'autism alert' posters but don't address need in reality
- Hidden disability lanyard to flag disability (e.g. sunflower)
- Difficult to access Disability Liaison Nurse
- When people 'don't engage' they get discharged
- Need a single feedback portal
- Having direct access to personal advice is invaluable and having direct access to clinicians
- You can be honest with practitioners who have the ability to listen and understand
- There isn't always flexibility in services
- Transitions are difficult to support – not aware of available support

Session 4

- Reminders sent out for appointment working well, GP survey by phone rate services in OX4 and OX5 works well for annual health check
- Inconsistency across the county
- Not everyone reads notes beforehand. Consistency in GP is good – but not experienced by others necessarily
- Location of appointment is important and needs to be included in the feedback
- Important to find out what makes an appointment successful
- Professionals feel uncomfortable about asking for feedback when you are sat next to them
- A conversation is better than a long survey/questionnaire - Is there something you want to tell me?
- Open attitude willingness to listen and feedback is important – it's a skill that staff need
- Appointments that involve taking the child out of school are disruptive
- Waiting is the biggest challenge and not knowing what is happening
- Conversation at an initial referral point to identify key important information and best times and locations
- No link/communication between departments in response to a big issues slipping through the net

- Making a complaint – concerned it will disrupt and spoil relationship with professionals that have taken a long time to build
- People are frightened to make complaints as it will impact on care
- Professionals are fearful of negative feedback as they will lose their job
- Need to change practice to meet the needs of everyone not just 1 or 2 people
- Need to be able to give constructive feedback that isn't just seen as a complaint
- PALS (NHS Patient Advice and Liaison Service) have a good process when you find it
- How can you feedback on the wider experience when you are involved in lots of different services?

Session 5

- Need to know more about the situation of carers – age/health – how can you plan for future supported living if you don't know that information
- Carers give feedback but you don't hear anything from it need more you said we did actions shares
- My Life My Choice (MLMC) represent a particular group of people and are not representative of everyone – they are the go to group and decisions are based on their experiences
- Decisions are made around more able people
- We need to find out more about who feels their voices are being heard or not
- Older carers won't speak up because they are worried about losing carer services
- We need to understand more about home situations
- Need to identify older cares
- Yearly reviews for individuals instead of forms - can the care manger go to the family and find out about the family situation?
- Talking to people is more meaningful than filling in forms that have little meaning

Table 9: Supported Living

People with Learning Disabilities and /or Autism and their families need support when the family member moves out of the family home.

How can we ensure that they get the right support to meet their needs and help them to have a good quality of life?

What should good supported living look like?

What should family carers and their family member expect from Supported Living?

How much involvement should you expect as a family carer?



Not working and could be better

Choice – not being placed

- Choice of where, who with and care provider
- How to facilitate guests staying over?
- Lack of choice and involvement of family once someone moves into supported living
- Need to ensure good social work to support and enable choice

Addressing problems

- Takes too long
- Not addressed correctly,
- Feels like provider/Council doesn't do anything

Equity

- How do elderly parents get support for their children?
- Balance different people's needs
- Provision in different areas of the county

Transition from children's services

- Don't have a Social Worker
- How to get the right information
- Things can be slow and frustrating.

Feedback on parent and user involvement

- Services pick up complaints
- Need to make sure family know who to contact
- Lack of support for complex needs especially autism
- Joining up support from different organisations and by carers in a support living house

Demand

- Long-term vision - more supported living and being independent

Family

- How to collect information about people supported in family home and their family?
- How to listen to family better?

Buildings

- Needs to be suitably designed
- Lack of housing in Oxfordshire

Transition from family home

- How to do this in a planned way?

When things go wrong

- Difficult when housing and care are linked
- Direct payments v contracts with the County Council – there are pros and cons

Assurance

- That people are supported well
- Getting support hours paid for
- How is care shared?

Families want to set up own supported living

- What support is available?
- Support to access information about supported living

- Passed from one person to another

Support

- Getting the right social work support
- Joined up support needed

Voice

- How to ensure listening especially when there is no family carer?
- Use of apps, wikis – a place for families and professionals to share information , multimedia can help

Staffing

- How to recruit and train to meet people's needs?
- Changing staff to key worker status
- Too much use of agency staff/turnover
- Appropriate use of shared staffing
- Making sure people can access the community



Table 10: Mental Health

Do you know where to go to get help for your relative if they have either a mental health issue and/or anxiety or exhibit distressed behaviour?

Do you feel that support is available early enough?

What is working well?

What has not worked so well?

What could work better?



What's working well?	What's not working well?
<ul style="list-style-type: none"> • Transition through school is planned positively • Peer support/acceptance • Lived experience • Independent/Charity Advocacy • Sibling support through school • School driving and individualized support – massage and mediation 	<ul style="list-style-type: none"> • Transition handover to health – Pathways! • No mental wellbeing or PREVENTION • Recognition that needs come from issues elsewhere that lead to mental health problem

<ul style="list-style-type: none"> • Lots of good people doing their best 	<ul style="list-style-type: none"> • Requirement for mental health 'problem' to get a service – what about trauma and emotional needs • Categorising people – understand and respect people's background • Holistic working • Tend to focus on diagnostic and labels rather than need • Team around the child – crisis – paper work is too heavy. • Training needed in schools – younger and younger kids needing support and what to look out for • Distressed communication – under 5's services • Lack of practical & ongoing support • Services in rural areas • Courses on behaviour that challenges • Well-being of carers – and help with medication use • Access to information • Criteria to be able to access services • Professionals – over reliance on signposting • Professionals/services- over stretched • Transport – impact of knock on effect – 'little things' that make a big difference • Follow up of diagnosis • Transition – 16-25 • Funding for training or access to training for teachers • Funding for schools and parents waiting for CAHMS • Caseloads are too high • Specialist input – ABA (Applied Behaviour Analysis) in schools • Knowing the uniqueness of each person • Teachers workloads • Expectations on professionals – nurse, education, social worker • Well-being of professionals by employers • What is in between diagnosis and crisis – reactive, symptom management • Language used is negative and not inclusive
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What could we do better?

- How can we influence society?
- Can we be creative & try something different?
- How can we be an Inclusive society?
- Continuity and communication – handover in transition
- Health input to EHCP's
- Recognize the impact on carers and families
- Support before getting to crisis
- Training of people – attach to a person/family for long duration
- Training of people – too academic – need to look at prevention
- Holistic approach around the child/person
- Making mental health part of the culture & the norm – embrace the difference by starting in education
- We can lead in co-producing videos in promoting mental health and disabilities by positively talking about mental health and disabilities and open up different perspectives
- Impact of hate crime – would it lead to reduced mental health and trauma issues
- Diagnosis – once have a diagnosis get access to services.
- Specialist Autistic Spectrum Disorder Consultant – Autism nurse
- Diagnosis – open & closed door
- Medication substitute – other approaches and monitoring
- Mentors – point of contact
- Early intervention/prevention
- Knowing what service exists and involving wider family planning
- Using wider services – i.e. holiday/respite options
- Access to local free training
- Knowledge on knowing what to do – suicide, behaviour etc.
- Staff wellbeing



Appendix 1

Organisations who attended

Abingdon & Witney College - Pathways

Alexander House of Joy

Autism Oxford

Botley Primary School

Camden

Childrens' Hospital - John Radcliffe Hospital NHS FT

Connect-Up

Dimensions

Family Information Service

Farmability

Frank Wise School

Guideposts

Holy Trinity Catholic School

Independent

KEEN

Mencap

No Limits – Abingdon and Witney College

OCC, Adult Social Care, Commissioning, Children and Families Services, Education

Oxford Brookes/Farmability

Oxford Health NHS FT, Intensive Support team, Engagement team, , Transforming Care

Oxfordshire Clinical Commissioning Group

Oxfordshire Employment Service

Parent Care Forum

SENDIASS

Witney Community Support Service