

Better Together Event

November 7th 2019



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1. Introduction

OxFSN's second Better Together Event was held on the 7th November at Didcot Civic Hall. It was attended by 52 Professionals from Health, Social Care, Education and the voluntary sector along with 42 family carers of children or adults with learning disabilities and/or autism. 3 adults with learning disabilities and their supporters also attended.

The event followed the format of a 'World Café'. This year there were eight tables with one topic on each table. This was as a result of feedback from people attending the previous year's event who felt they needed more time to discuss fewer topics.



This year's topics were chosen based on a number of factors. Some are key issues that families of people with learning disabilities have come to OxFSN for help or support with. Others focused on areas that the Statutory Services are in the process of making changes to. 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, not only to look at what was working well, what was not working well and what would work better but also for professionals to hear if the changes that were been made at a statutory level were making a difference for family carers and their families.

2. Family carers and professional's discussion café tables 1-8

A professional from each relevant department was at every table to listen to what families had to say. There was also a facilitator who took notes and guided the discussion. Each person has a different way of capturing the information, so we have tried to format it in a way that makes sense. Some facilitators wrote up their own notes and were asked to keep editing to a minimum so that we could capture as many voices as possible.

This year, the event was filmed by Adam Burgess and his team from Challenging Our Behaviours. This will be available to view at a later date.

Section 2 has the full details. A list of the organisations who attended is in **Appendix 1**.



3. Common Themes



A common theme across all areas was the issue of poor communication. Communication with families and between services.

A lack of clarity and understanding of systems and processes by both families and some professionals was also highlighted.

A greater need for information. Even though the Local Offer is available, a lot of people are still not aware of it and even if they are, the information is not detailed enough to help them find out what they really need to know. For example how to go about getting supported living.

There has been little change in common themes since last year's Better Together event

4. End of Session Recap by Professionals

At the end of the event we asked the lead professional from each table to recap on the discussions they had heard and summarise any actions they were going to take as a result.

Tracey Lawrence

SEND Transport

We have done quite a bit of work already in delivering home to school transport. When it goes well – it goes really well and parents have lots of positive things to say about it. If not working well it can have catastrophic impacts on homes and families

Important to promote good news stories but also need to listen so can potentially make changes.

Main issue is communication ranging from content of letters telling families who the provider is with a telephone number that when dialled no one gets back to you.

Some quick fixes are putting the drivers name and contact details on the letter if they know who the driver is going to be so have a named individual For parents if something goes wrong/not working then they can contact someone knowing someone is going to get back to them

Recognises that some of the changes will require the Local Authority to look at deeper fix issues including reviewing contracts; monitoring performance; holding providers to account when not delivering; reliability; timing; training of drivers and escorts so that everyone receives a consistent service on a day to day basis.

Talked about a lack of flexibility with some of the arrangements such as dropping off at other family members house if parent not in – will be reviewing these issues.

Talked about travel training for those who may potentially be able to use other methods and modes of transport independently. As move in to adulthood travel training may enable young people to participate actively in other areas of life without getting lost or being anxious

Stephanie Ross (Learning Disability Liaison Nurse – Oxford University Hospitals NHS Trust)

Reasonable Adjustments in Health Settings

Heard examples of good practice and when things do not go so well.

Lots of positive feedback about dental services but not so much around optometry and eye services which need to be explored a bit more

Heard how critical it is in preparation to be able to share before hand what is and isn't going to work which led to discussions about Easy Read, Hospital Passports

Issues around staff awareness and how we can build systems so that they prompt those questions which need to be asked

Rob Sherrott (Team Leader – Financial Assessment Team, Oxfordshire County Council)

Financial Assessments and Client Contributions

Main issues that came up are:

How rent is treated when family member lives at home

Examples of Disability Related Expenditure (DRE) outcomes and clarity and explanations around those

Clarity around steps of appeal

Letters been accessible to all those who need to see them

Karen Fuller (Deputy Director for Adult Services OCC) – Adult Social Care

Consistent theme is that OCC made significant changes to the way they do their charging – a lot of discussion today has been about DRE.

Have asked Healthwatch to do an independent review. Will feedback some of the comments made today.

Anna Cheetham* (Co-director – Yellow Submarine)

CAHMS/PCAHMS and Mental Health

Key notes were setting expectations for families as to how long they would be waiting once they made the phone call and what practical things they might do during that wait and recognising that behaviours may escalate at home whilst waiting and the impact that has on the child and the family.

Thinking about first contact and how people get in touch. Have introduced a single point of access but not everyone is aware of that so people are still unsure how to get in touch.

Making sure that people who take that initial phone call listen and ensure the person feels well supported – families do not feel this happens

**AC facilitated at the table and fed back on behalf of the professional who had to leave.*

Natalia Lachkou (Change and Programme Manager, Adults – Oxfordshire County Council)

Transition to Adult Services/Moving in to Adulthood

Changes have already been made – there are now transition social workers which is a stepping stone to hopefully things which will be bigger and better.

Karen Fuller (Deputy Director for Adult Services – Oxfordshire county Council)

Supported Living

What came out was the need for better communication and a clearer understanding of what is Supported living?

Would be really helpful to look at how we can link together some of the issues discussed across the themes including transitions and moving from children to adulthood looking at what potential options may be available in terms of support

Also got constructive feedback about the information on the internet – adult social care number is not as easy to find - need to take that away

Once got all the themes from all the areas – look at cross links which can be simple to fix as well as how adult social care and health can work together in a more streamline way

Riham Abu Deep (Facilitator and Co-design Facilitator, Oxfordshire County Council)

A lot of professionals do not know what Supported Living is so do not feel equipped enough to have conversations with families and tend to back away from having a discussion.

Main two themes that came out today are communication and planning and the need for planning earlier and ahead.

Know so many people who will be needing/wanting SL in the future so need to start planning earlier and need better communication across agencies to be able to support that process so need to make sure that professionals have the information required to have those conversations with families.

Also need to make sure that the outcome of assessments matches the actual support that people need. Often once in Supported Living peoples support needs are not met as the assessment was not correct.

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

Navigating the Adult Social Care System and finding the right help in Adult Social Care

I will take away everything that have heard today and will keep trying to improve and to get better

Loud and clear was the need to promote ASC's telephone number. People were very clear that they did not know how to get in contact

The language on the website needs to be plainer and clearer and include the phone number that people need to use to contact ASC

Need a visual pathway to try and explain what the process is so people know what to expect and a second pathway about What Moving in to Adulthood pathway involves so people have a better understanding of what happens when

Recognise that not everyone has access to or chooses to use world wide web so need a leaflet to hand out
Annual health checks – can Adult Social Care number be on it
More promotion of Direct Payments
Closer contact with older family carers
Maintain better relationships with schools and colleges

Lucy Stanton (Business Manager, OCC Community Support Services)

Day Time Services

Talked about what a wide range of day time opportunities mean
People are uncertain as to what is available. Need to think how we communicate that to wider communities from the grass roots stuff to that offered by the council

Need to have information available not just digitally but in hard copy
Families with children with additional needs said that there was not enough emphasis on social care in the EHC plan

Day time opportunities not just cover 9.00 – 5.00 – discussed what might be available before and after those hours and at weekends.

Stephen Chandler (Director of Adult Social Care, Oxfordshire County Council)

Important to hear some of the key messages coming through before the detailed report is produced

In the time he has been in Oxfordshire he has been really impressed by a lot of the people he has met but also at times disappointed when he hears that one of the biggest challenges that has come out of today's event is that something as basic as Adult Social Care telephone number is not easily available.

Wants to get beyond having conversations about getting the telephone number and website right to ensuring that there are more of those services that people value but to also act quickly when people are not having a good experience or support. Everyone, not just parents should be interested in delivering ambition for their children and often professionals are told not to try and do anything as there is no money. Money is always an issue but there is lots of money and resources already within the system which needs to be used effectively.

5. Next Steps

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.

Consequently 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.

OxFSN will use the information gathered from this event to help plan our work for the upcoming 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 to the facilitators - we couldn't have done this event without you. Thank you also to Oxford County Council who have asked us to work with them on their Adult Social Care Strategy and who funded us to run the event.

And, a final thank you to all the family carers who make time in their schedules to come along and attend the event. We know how busy you are, but without your willingness to share your lived experiences we would not be able to help influence and improve the services for our family members.

Team OxFSN

January 2020

Section 2 - Table Discussions

Table One Transport

SEND transport is key to ensuring a smooth transition between home and school/college whilst Social Care provide transport between daytime support and home and/or respite. We know if things don't go according to plan it can have huge implications for the person using the transport, families and many others.

What is working well for you at the moment?

What do you think can be done better, including indicative timeframes to help to manage your family's arrangements (when do you need to know)?

Good News Stories

All parents agreed that we need to share these more. Parents were clear that when transport worked well, it was "amazing". In the cases where it was not working to expectations, they described the impact as being potentially catastrophic. Noted situations where parents feel unconfident that drivers and escorts are trained well enough to manage significant medical needs, that they have had to give up work, or those who had lost their jobs because they had to take too much unplanned leave.

- An emergency placement was arranged due to a serious family medical issue. The transport request was actioned and up and running within two weeks. This enabled the day-to-day arrangements to remain consistent for the children in the family (attending after school and holiday clubs).
- ITU services – this is the Local Authority bus service that you can hire. 'We hired them for a trip and they had an amazing driver. One of our young people was very distressed and we would have had to cancel the trip and bring the entire class home if it hadn't been for him. He does most of our trips, and because she was familiar with him, she was happy to stay with him and he was able to calm her down'. The drivers are SEND trained. The downside is that they are expensive at £210 per day, and I can't understand why they are not a preferred provider and so unable to bid for the work. I would have thought that the LA would want to be able to bid for its own contracts? There was a feeling that there was no competition from the firms so bids were "won" regardless

of cost – concern that LA not getting value for money or having any control of the situation.

- Drivers have good relationships with the kids. There have been times when I've needed to attend the school, and it was lovely seeing the children getting out of the vehicles and giving the drivers hi-fives! My daughter was more upset at losing her driver than she was at moving schools and not being with her friends and teachers.
- I want to say that transport has been excellent in general, especially the drivers.
- We have had a good experience with transport. We had the same driver and escort for two years.
- I've seen some great relationships with the drivers. My son took an interest in reading because of his. He's now read everything JRR Tolkien has written because the driver told him about Lord of the Rings.

Communication

This was not just about the level of information parents would like to receive, but also where they could go if they had some feedback

- Need for better communication between OCC transport and parents. If there is going to be a change to transport, we are only given a few days' notice.
- Making a request to change or cancel transport is clumsy (e.g. Parents attending the school for a meeting and taking them home instead). They used to be able to contact providers directly to instruct. Even if they call and notify the LA, they generally are unable to speak to someone, and are not confident that the transport will be changed as requested.
- We need to know beforehand if others will be travelling in the taxi/vehicle. The letter does say that arrangements are 'subject to change' but they don't tell you when that is going to be happening.
- There needs to be better communication for families with children who need to attend non-statutory education. A 3 year old was recommended to attend a special need nursery place. He was refused transport. At that point he had no EHCP. Once the assessment had been completed, a school place was named. Fortunately, they live within a mile and are able to make their way to the school, but still don't think the system is fair as there is a neighbour who lives on the same road as them and they do get transport.
- The escort was changed and no one told us. Routine is important, and we can plan for changes but we weren't informed. Our son has very specific needs when he is travelling, and I wanted to ask if they were trained (knew about how to keep him calm) but I didn't want to appear rude. Conversation about having the confidence to ask.
- From an agency who were supporting a young person due to concerns about changes in his behaviour. We are in no doubt that when it works well it is really good. We have witnessed the results of changes that aren't communicated with parents who then do not

have the opportunity to prepare their children. This young person's anxiety was increased and displayed as aggression. This was a barrier to him getting on to transport. Over time, appropriate adjustments were made and he had a trouble-free journey to school.

- There should be one place where you can go for information. (Local Offer?). Parent gave the example of the Pick-Me-Up service. Had not been aware that her son could use it for free with his concession pass until another parent mentioned it.
- There doesn't appear to be consideration in relation to the mix of children on the bus/taxi. Some are very noisy and shout for the whole journey and my son doesn't like it. (Explained that the transport team have conversations with the schools prior to confirming with contractors to ensure the groups of children identified will be safe to travel with each other).
- Passports do not appear to be routinely updated? When we provide information part way through the academic year, where does this information go?

Consistency and Reliability

There were lots of comments about the service families received from providers.

- Feedback from a young person who would travel in transport with a sibling who had SEND. My sister had a good experience with a private taxi company who took her to and from college. This lasted for two years and then the company changed. The main thing that was consistent was that they were either very late or very early. We no longer had a regular driver. This caused my sister anxiety. If the taxi was very late she would refuse to go to college because she didn't want to walk into the class and have everyone staring at her. Resolution – I passed my test so drive her myself.
- Taxis were consistently late. I called regularly, as I needed information about times as my son became very anxious waiting and thinking about missing the start of the school day. It was resolved this morning. The taxi arrived on time for the first time since school began.
- There was a young person who had a seizure. The driver just called an ambulance. My worry is what would have happened if that child needed medication? No one tells us whether they have been appropriately trained, and all too often the drivers change. I have no confidence that the driver or escort would be able to deal with any difficulties that might occur.
- What level of monitoring is there? When I challenged the firm who were taking my child to and from school because they were always late, they confirmed that they could not realistically be at a specific location within the timeframe because they had other work to

complete before that. The implication was that the job was bid for without realistic timeframes.

- Are drivers trained on what to do if there is an emergency? The bus broke down and there was no plan for contacting the parents. Why was this when most of the students were wearing passports? What are your policies? What should we expect in an emergency?
- I am worried about communication with my child. He doesn't always understand, and some of the drivers don't speak very good English.
- Some of the drivers made me fear for my safety. They drove very aggressively.
- You can't hear electric cars. They don't come to the door. It would be helpful if drivers could let us know that they've arrived – not by blasting the car horn! My driver used to ring the door bell and let us know he's arrived but for the last year this has not happened; it's difficult in the morning trying to get all the children up to be constantly checking the window over a 15/20 minute time period.
- Parent was not clear about whether this was public buses or specialist transport, but said they had been told to fold their wheelchairs up so that others could travel. Indicated that drivers should be better trained to deal with visible and invisible disabilities, and perhaps ask questions.
- We provided information about a change to our son's medication. This was not updated on his passport, which he always carries.
- We have a son with visual impairment, autism and other complex needs. No one told us that the taxi was changing, and he had a meltdown, refusing to get into the car. In the end my husband took him. This happened a number of times and impacted on his job until our son got used to the new driver. Our family would collapse if my husband lost his job. I do want to say that transport has been excellent in general, especially the drivers.
- For four years my son was in a shared taxi with five other children. It was a ten minute journey. Last year, the year of his GCSE's it changed. He was placed on to a minibus with seven other children and as he was one of the first to be collected, his journey became an hour and a half long. He couldn't cope with this and I had to take him. I felt that I couldn't do anything else with my day. Having transport is the difference between success and failure.
- What is the process if the taxi arrives at the home and the child does not get into the vehicle? No one let me know. (Story more complicated – child was staying with the other parent, they argued and child stormed off. Parent left to go to work. When taxi arrived no one at home. He walked the seven miles to school by himself.)
- In the course of a year my child had 13 different escorts. I didn't know who they were and none of them volunteered their ID.
- I can only think of one occasion when I was introduced to the driver in advance of the company taking over the contract. At all other times I was given the name of the firm, but not the pick-up time. The company was from Witney but they were travelling around Abingdon

and weren't familiar with how long journeys would take. Ideally, letters should have the details of the driver and escort and a contact number.

- I'm worried that some of the staff are not adequately trained. If they are going to commit to doing these jobs they should be appropriately skilled. This comment was specifically about transport from home to respite. The driver was not trained to give emergency medication. The child had a seizure and the driver didn't know what to do so called an ambulance. Parent acknowledged that it could have been much more serious.

Flexibility

There were a number of areas covered in discussions, with parents understanding the need to be stricter, but also noting that in some cases the decision (which was usually no) made no sense – financially or practically.

- There is a lack of flexibility in the system. I have asked for them to be dropped off somewhere en-route that is closer to the school than home and have been refused.
- School to club transport is difficult to get. Most students are required to go home and then a separate taxi will take them to the club.
- Sometimes we need to have more than one address on record for children to be dropped off at. Example - Single parent with other children may have to attend parents evening, and child care may be with grandparents.
- Shared care arrangements are enforced more rigidly – applied to those with parental responsibility without flexibility for alternate child care arrangements.
- One parent commended the flexibility of the arrangements and confirmed that they were able to change their drop off address as a recorded second address.
- Sometimes there are tools that could be used to distract or entertain some children who have difficulty travelling but firms are not happy for them to have a dry snack or a bag of sensory toys in their vehicle. Is there a reason for this?

Planning for the future – Independent Travel Training

Parents were keen that where this was possible, tools should be available to equip young people who have the potential to be able to travel using more independent means.

- Parent of an older person with additional needs. He received direct payments and she uses this to pay for private taxis. He had taxis to and from school when he was younger and that worked really well. Had training and could use a bus with a travel buddy. Once he started travelling on his own, there were a few hiccups (he didn't deal

well with the bus breaking down one time and had a meltdown). Mum concerned about his vulnerability.

- Occupational Therapists might support young people to develop independence as part of their intervention.
- Suggestion for better training for public services like bus and train staff. If they wore a badge saying they had been trained it might encourage young people to feel less anxious about using public transport.

Suggestions

Education provider (adults?) We have a group of young people who are all coming from the same area but are brought to the site in individual taxis. It seems silly that they are all in individual cars when they get on so well. We will contact the transport team to see if they can be placed on shared transport. It would be good if we could review the policy for Home to College transport. When students are 19+ their assessment focusses on social care needs (Sect 9 Care Act). It would be useful for the policy to be very clear about this so that expectations on all sides can be managed.



Table Two Reasonable Adjustments in Health Settings



NHS England announced in May 2019 that they were spending an additional £5 million to fund reviews to improve health care for people with learning disabilities.

What have your experiences of using health services been for your family member? This could be anything from booking an appointment with your local GP surgery, going to the dentist, being admitted to hospital or working with intensive support. If you have made a request to hospital staff that relates to a reasonable adjustment, are they heard and are attempts made to do things differently?

What is working?

Session 1

- Good easy read resources – easily available
- Basingstoke Hospital experience was very positive, even moving the child's own bed in to his private room – fantastic after care from the dietician
- JR Levy supportive of blended diet, but not everyone is

- MacIntyre delivering training on blended foods and peg feeding
- Paediatric dental services excellent
- Requests for printing on different coloured paper to make it easier to read are heard
- Positive experience responding to crisis and jumping the queue

Session 2

- Dentists are willing to make sure staff are consistent for individuals who struggle with change.
- Manzil Way consistently offer positive experiences
- Communication is amazing (JR and GP out of county)
- Tools for clearly documenting individual adjustments for invasive tests and screens
- Positive experiences with optometry – double appointment time offered

Session 3

- Working to provide social services and resources to better enable access to appointments
- Great individual practitioners
- Lots of work in the pipeline to train professionals on how to better support and be aware of the needs of the Learning Disability Community – not just clinical staff
- Play workers are great and flexible to individual needs
- Telemetry experience positive and staff willing to offer extra help and support
- Sensory boxes are valued and working
- John Radcliffe – despite the initial abrupt appointment invitation (same day requirement unfeasible) staff were very flexible offering an alternative time plus a short queue
- Didcot orthodontic services at Didcot hospital more positive (same service that developed short stories)
- One parent commented that they love the NHS services, though the feeling were that parents did need to fight to maintain them

Session 4

- Much willingness to acknowledge and implement adjustments
- Good adjustments made when parents take the initiative to make contact and ensure that it happens
- Good individual efforts to make adjustments
- Nurses and individuals are keen/willing to do what they can to accommodate reasonable adjustments
- Secondary dental services are fantastic e.g. checking teeth in the car

What is not working?

Session 1

- Easy read not available in eye hospital
- Hospital passports not easy to use for less pc- literate users. Word version is preferable
- Technology is not always fit for purpose, and nobody easily available to offer support
- Difficult to address individual issues, and calls not answered or replied to
- Hospital Passport Information is not easily communicated between services
- Minimal trainers
- Need more of a single vision/approach to coordinate plans /passports
- No single person/champion to approach with adjustment issues
- Lack of resource/funding in SALT (Speech and Language Therapy) in particular

Session 2

- Process going through multiple professionals is difficult and results in pain and distress (e.g. toothache)
- Professionals not advising of fast track options
- Important information is not easy to access – directors know where it is but not families or frontline staff
- Difficulty re transitions between school re vaccinations/medication
- Toolkits not communicated and resource to families
- Families not feeling like they are listened to/involved in disagreements pertaining to healthcare
- Very long drawn out response to specific sensory issues and pain experience. Years spent asking for support with pain and little engagement with these issues from professionals (doctors)
- Easy read information is difficult to access
- Professionals need more training and education re slowing down and pacing their interactions
- Sensory issues not catered for /listened to/believed
- Double appointments are difficult to get

Session 3

- Little flexibility/accommodation for families that struggle to get to hospital in time for appointments
- Communication is very difficult
- Outsourcing of communication to USA is creating very chaotic experiences with appointments
- No provision for when parents/adults need to stay in hospital with their child/family member

- Highly distressing interactions/lack of personalised communication from professionals (brain operation described with no prior prep/warning)
- No support for highly distressed/challenging behaviours
- Some poor/patronising 'advice' from professionals that do not know the individual
- Little accommodation for sensory difficulties, particularly in orthodontics. Lots of onus on parents to do specialist care for children and little support for them as they do it
- Need for guidance/information to be made available to families so they know what adjustments they could ask for and feel confident doing so
- Need for much better preparation when individuals with specific needs are coming to access services
- Long stay/living out of county due to lack of provisions in Oxfordshire
- Funding conflicts prevented child getting routine blood tests

Session 4

- Very difficult to overcome communication barriers re speaking on the phone
- Clunky systems do not make it easy to observe and implement adjustments – highly constrained
- Matter of luck that parent was advised by friend that they could phone ahead and request reasonable adjustment's
- Parents are proactive, but some professionals less so – a nurse was obstructive in approach to an individual's care, but consultant was responsive
- Some lack of understanding/appreciation of mental health and need for reasonable adjustments

Table Three

Financial Assessments and Client Contributions

It has been over a year since OCC changed the way client contributions are assessed and how much someone in receipt of Adult Social Care has to pay towards the cost of their care.

What has this experience been like for you and your family member? Do you understand how the final figure that your family member has to pay is decided? What do you feel would be helpful in making this an easier process?

People were concerned about:

- The total amount of money available for support, sudden changes (e.g. reductions stemming from new ways of assessing contributions), and the effect that this could have on family finances and debt.
- The fairness and transparency of the assessment process.
- Their interactions with the assessment team, which sometimes felt hostile and held a level of implied or explicit threat.
- The possibility that the assessment of DRE could go down as well as up.
- The lack of independent information and advice about money.
- How things like rent, utility bills, washing and cleaning etc. could be counted as additional DRE.
- The threshold (apparently £1000 a week) above which there was a more bureaucratically demanding system (for family carers) for managing direct payments.

OCC professionals were able to clarify:

- That there was an initial assessment of need (which included the way in which carers supported people's needs, and could also include an assessment of carers' needs).
- This was followed by a financial assessment which determines the amount that people would pay towards their care.
- That since the new charging arrangements, OCC would take a figure of 25% of people's disability benefits (typically PIP) and use this as an indication of the level of additional disability related expenditure (DRE). This would not be counted as income for purposes of the financial assessment (having the effect of reducing people's contributions by this amount).

- That if people disagreed with this figure, they could contact the finance team and dispute it as long as evidence was provided.
- There was then a process for appeals and requesting waivers, which could ultimately be followed by a complaint if unsuccessful (although they hoped this could be avoided).
- There is an OCC Forum which makes individual decisions about all of this. Budgets are held by individual team managers, and additional costs/reduced costs are allocated to this budget.

Suggestions included:

- Improving the transparency of the financial assessments by giving some fictitious case studies and examples of what might count as additional DRE.
- Reviewing communications so letting people know that the amount could go up or down didn't sound like an implied threat.
- Providing people with information about where to get independent specialist financial information, advice, guidance and advocacy. This could include when/how using the Specialist Information Service might be appropriate.
- Automatically sending people information about the whole process of appealing/asking for waivers and ultimately complaints in correspondence about financial assessments.
- Giving all information in easy read formats.
- Giving advance notification about what kinds of documents might be useful to provide evidence of additional DRE.
- Apparently the overview assessment contains an indicative budget for support with and without the care voluntarily provided by family carers. Carers could be routinely provided with this information.



Table Four CAMHS and Mental Health

Families have told us that CAMHS have an incredibly long waiting time? What impact does this have on you and your family member. Do you have any thoughts on how things could be done differently?

What impact does this have on you and your family member?

- People see CAMHS as a 'solution' and schools can promote this view
- Waiting time between referral and appointment causes **increased anxiety** and increase in **behaviours that challenge**.
- Affects **wellbeing of entire family**
- Frustration around **not meeting 'criteria' or 'threshold'** and feeling the need to use **'buzz words'** to increase likelihood of being seen
- Families at crisis point forced to make multiple referrals and still risk not being seen
- Suicidal thoughts and self-harming not deemed an emergency
- Families feel **unheard**
- Feeling of being **'bounced around between services'** and **'getting lost in the system'**
- **System and admin issues**, resulting in delays
- Families waiting for months to be seen, to be told the **referral has been lost or hasn't been made/received**
- Telephone staff lack knowledge; have appeared unfriendly/abrupt on occasion: when one parent described child biting himself, they were advised to remove the object he was self-harming with!
- One LD CAMHS worker was inexperienced with Down Syndrome (more focussed on ASC) and was unable to offer any strategy to help manage behaviour at school
- Lack of Trans and Gender Dysphoria support
- Female orientated service, with a lack of support for male carers
- Families with children with sleep disorders **unable to get melatonin from GP**, repeat prescriptions have been revoked, resulting in the need for reassessment and lag time. causing stress and distress
- Large waiting room a challenging environment for some using the service
- **Lack of practical support and signposting** to other services

- Voluntary agencies (e.g. SHIFT) are offering the practical and emotional support to parents that isn't provided by CAMHS – this is causing them to feel overwhelmed (as a group and as individuals).
- One family had a positive experience with LD CAMHS: short waiting time, now in receipt of 3 annual appointments with regular input; support offered with SPD and anxiety.
- Dr Moosa (Locum Consultant) in Banbury deserves accolade for his support and referral to CAMHS

Statement/Response from CAMHS at the event

PCAMHS no longer exists; there is now a **Single Point of Access** to all services (SPA), information is disseminated to the relevant team. There are now 8 new staff within LDCAMHS team and there is a new configuration of the service

How could things be done differently?

- More information about 18+ transitions
- More support for males carers including: groups, language used and **attitudinal change**
- Post diagnostic support delivered at suitable times for working families
- More information once a referral has been made to help **manage expectations**: including waiting lists and expected timeframes
- **Emotional and practical support**, including **signposting to other organisations** whilst waiting for an appointment
- Clearer **guidance given to paediatricians and GP's** about the referral process and CAMHS work
- GP's to prescribe Melatonin
- More grassroots intervention and **preventative** work
- Investment in young people themselves
- **Increased support in mainstream schools** to identify and support those at risk of needing CAMHS support in the future
- Face to face evaluation, to include school visits and observations not just telephone referrals
- Stronger links with community partners (agencies), with CAMHS offering not just financial help, but also emotional support and **recognition**
- Every service to have a 'participation lead' to seek feedback from young people accessing CAMHS (this is currently implemented at Raglan House)

Statement/Response from CAMHS at the event

CAMHS offer reassurance that this is in process: historically there were issues mapping and sharing information between CAMHS and Adult services, now parents and carers will be contacted around child's 14th Birthday to seek permission to share information

Prescribing Melatonin is being actioned as a priority and a sleep support service implemented at JR (there is no timeframe for this to be completed)

Potential Case Study:

A young person attended the event and was brave enough to share her story – but unfortunately CAMHS representatives had left. It was a very powerful story, which would have been invaluable for them to hear.

Two sisters who had very different experiences with CAMHS, including the use of one way glass which they were unaware of until the end of a session. One Sister was given ASC diagnosis at end of session and promptly discharged – despite accessing CAMHS previously for other non-associated needs. They both now feel ostracised and unwilling to re-connect.

The facilitator has her contacts and she is happy to be contacted if CAMHS feel this would be valuable.

Table Five

Transition to Adult Services/Moving in to Adulthood

Moving in to adult services can be complex and worrying. OCC have recognised this and are making changes. Have you experienced any changes? What suggestions do you have that would make this experience better? Have you any positive experiences that you can share that you think would help others in a similar situation?

Session 1

- **QUESTION:** What changes have been made by OCC?
ANSWER: Moving into adulthood co-production project in June 2018; ideas have been taken forward, e.g. dedicated transitions workers in each adult social care team (some are here today).
Other changes:
- Training for front – line staff.
- **You Tube video** by the co-production team
<https://www.youtube.com/watch?v=yR7w4OXFFFo>
- We get less complaints about the process and more positive stories about experiences.
- There is a shortage of transition social workers. Families at the table are on a “waiting list” for an adult social worker in Oxfordshire. “I am next on the list”, “...my son is “quiet”. It feels like he has been forgotten. School has been brilliant. We are waiting for an allocated adult social worker, but “I need support now”.
- Families have asked for a clearer role description: “who does what?”. In meetings, a transitions social worker and an adult social worker keep telling each other: “This is your role, this is my role”. Families said they “need to be proactive every step of the way”, as statutory workers are often not.
- **QUESTION:** When do adult social workers get involved? What was the process? Who decides when they get involved, e.g. when moving from one education setting to another?
- **QUESTION:** What happens during breaks and school holidays? Services available are different. Many local support services are full, have no vacancies (e.g. Style Acre).
- **QUESTION:** Where can families find about local support?
ANSWER: See “Local Offer Oxfordshire” and visit the OxFSN stand today.

- Joint working between children and adult social care teams assumes that all young people are known to children social care. What about children with autism who are not known to statutory services? This is a known gap in access to care.
- **QUESTION:** How do I access adult social care?
ANSWER: OCC have a single “front door” phone number and a team across all services. Oxford Health NHS Trust – mental health services – have own social workers, by agreement with OCC.
- **QUESTION:** How long do you stay involved?
ANSWER: As required based on assessed need and transition plan. We want our children to be independent, with support when they need it”
- Supported living in Oxford is full. What else is out there? What other service can we visit?

Session 2

- I do not have a social worker. My son is turning 18 soon. I would like him to be independent with support.
- My son lived out of county for 17 years. We have a different social worker or care manager every year. This does not help, e.g. we have difficulty organising his next annual review.
- My daughter had a “PA” / young carer as a young person. We assumed that this arrangement would continue when she becomes an adult. Our adult social worker struggled finding an adult “PA” - this is a gap in service.
 - Immigration residency rules inform access to direct payments/public funds. CAB offers specialist advice on these matters.
- **QUESTION:** Where is a good place to find this information?
ANSWER: Oxfordshire local offer, acknowledgement that it needs to be publicised better
- What shall we be doing / expecting at what stage? Suggestion to develop a timeline with advice and social care processes to show a possible transition journey.
- Day support for 18-100+ has not worked for my daughter. What opportunities are open for 16-30-year olds? E.g. Yellow Submarine is great. Behaviour that challenges services can be managed, e.g. via the enabling support services. My Life My Choice is a good group to join. SOFEA project.
- What can we do to improve support through transitions?
 - Start earlier
 - OxFSN plan to run an annual Information fair. Tell us what you would like to hear about?
 - Suggestion to run an “advice and assessment clinic” perhaps aimed at families on a waiting list for statutory services. A mix of

individual assessment and group advice and information. People like meeting and talking to other people in similar circumstances.

- Table observation: no one in this group has a positive transition experience to share (see feedback on specific services on previous pages).
- Supported employment opportunities:
 - Personalized flexible support does exist. We need more of this type of support. Real opportunities could be created by bringing providers together and enhancing with “enabling support”, e.g. Barnardo’s and Oxfordshire Supported Employment teams working together to develop more paid work opportunities.
- Transition continues into adulthood. Moving from one supported living setting to another is another transition point. Very positive and uplifting story of a son who is settled in an out of county setting: “...when I come to visit him, we go to town by bus and he knows almost everyone on the bus.”

Session 3

- “As a member of the “Moving into Adulthood” co-production group, I am pleased to see some of our recommendations having been put in practice, e.g. we now have dedicated transitions workers and there is a post16 education network. I hope they work together.”
 - Knowing different legal frameworks is an important area for professionals and can be confusing for parents. Knowing your rights, advice and rules.
 - Experience shared by a young adult at the event: “...It is easy to get lost during transition from childhood to adulthood... as you are often not told about other support available”. Autism support pathway has changed in 2018. “I can do a lot for myself, but I might benefit with support at college, looking for a job after college, help to appeal a DLA decision. My motivation to study health and social care at college has come from personal experience of transition and use of support for young people with autism. I want to improve services for others.”
 - Continuing health care thresholds change from children’s services to adult services. There is transition point in this area, including link do delegated health tasks. This information could be explained and clarified for families, e.g. on the Oxfordshire Local Offer.

- Oxford Health specialist's health services – update on the transitions:
 - Transitions register is being developed. Source of data is the specialist school nursing services (14-19 years of age). GDPR compliant. Started with specialist schools, data base set up, letters to families would be sent out soon.
- Families with young people in college experience last minute panic/ action to start planning imminent transition out of college. It is often last minute. We need children and adult social care joint working to start earlier. With realistic time frame for how long might be needed to put a plan into place.
- PIP assessments do not look into non – physical issues well.
 - EHCPs help to plan transitions, but not everyone is eligible to have an EHCP.
 - Transition/ options for sixth form students need to improve. Good quality career advice for students and parents is vital. This is linked to pastoral guidance at school and reasonable adjustments in mainstream services.

Session 4

- **View of a local supported living provider:** "Some things are changing. We still need to start planning earlier and plan well". E.g. it takes 2-3 years to develop a supported living service. If we plan too late, people go to short term placements, which work for some people, but not for everyone. There are also other supported living models available. Planning in a crisis is not good practice.
- How do we access social care?
 - Referral is at 16 – assessment by a social worker, usually around 17-17.5 years of age – support plan/ transition plan, means tested access to support and care (assessment is free).
- How could we make local offer more visible for people?
 - We need it plastered everywhere.
 - Education/schools/SENCOs have a role to play.
 - OCC to have a local offer on their social media platforms.
 - Advertise in Oxfordshire Care Providers Association's newsletter and at the bottom of emails.
 - Link to the Live Well Oxfordshire website.
 - Publish and publicise regular updates, what is new locally?
- **View of a transition's adult social worker:**
In place since February 2019. Good start, early days, settling into new ways of working.

- Improve access to information and people:
 - Put phone numbers on each page of the local offer
 - Provider association could look into producing a resource pack for residents and social workers.
 - OxFSN to think about writing a “guide / timeline / instructions” to transition written by parents for parents.
 - Having good quality up to date information is helpful to everyone.
 - Parents have the right to challenge local decisions, information about their rights needs to be published on the local offer.
- There are not enough (possibly none) referrals to independent advocacy service for/from families whose children are going through that transition.
- How many transitions social workers are there at OCC? **ANSWER: 8.**

We need more resources in the system:

- More money for support.
- More staff at front line.
- More time to plan together for a better future.

Table Six Supported Living

Do you know how to go about finding supported living for your family member? Do you know what options are available? Do you know what the steps involved are? What is your experience of supported living? Could supported living be a stepping stone towards people reaching further independence? If so, what do OCC need to do differently to achieve that?'



- *“What does Supported Living actually mean? And what kind of variety is there?”* (One of first questions from carers)
- For those who did know what Supported Living meant, they did not know how to go about finding it (so of course did not know what the options or steps involved in the process were)
- One carer was familiar with the concept of Supported Living and had enquired about it but says there is not enough in the South of the county where they would need it to be
- One carer had been told about Supported Living by her social worker and had ‘put a request’ in for it, but had not heard anything more, so not at all familiar with the process or what is actually available (see later quote under ‘experience’ question)

- One carer had a son in Supported Living, so was familiar with the process, but this was out of county as they had not been living in Oxfordshire at the time

What is your experience of supported living?

(9 carers joined the discussion throughout the day)

- none had experience of Supported Living in Oxfordshire;
- 1 had experience of Supported Living out of county;
- 1 had experience of residential placement out of county;
- 1 had experience of Shared Lives; this person is now moving out of county with her family as they feel there is nothing suitable in Oxfordshire for her
- 1 had second-hand knowledge of what they were referring to as Supported Living, but turned out to be Outreach Support
- 1 had put in a request for Support Living but has heard nothing back about it from her social worker
- 4 carers were thinking about Supported Living and wanting to plan ahead, but had no idea how to go about starting the process; 1 of these carers had gone directly to a provider as they had heard about them from another family and knew they were in the area
- a few carers knew of families who had had to buy a property themselves to set supported living support up, as there is a shortage of (suitable) availability for people (so either there was nothing available, or families didn't feel that what was available was suitable)

Residential placement experience

This lady's son was moved out of county because there was nothing available for him in Oxfordshire that would be able to support him in the way he needed. She hadn't wanted him to move, but it was years ago now and she feels for him to 'be brought' back into county would be another upheaval for him- he is happy and settled where he is now, and they get to see each other. But when it happened, she had no control over the decision: *"They just came in and took him away, I had no control or choice in the matter."*

Outreach Support experience

One carer knew of someone who had been moved somewhere and assessed as needing a certain level of support which was a lot less than what they actually needed. This had left them extremely vulnerable and she said they have been subjected to exploitation ('people have taken over his house to deal drugs at some point') and financial abuse (**nb: this person is no longer in that situation**)

This discussion highlighted that people are not aware of the difference between things like Supported Living and Outreach Support and that linked into the issue that was raised time and time again, in each discussion, about lack of clarity around the information that is out there, or even that there is information out there (**see General notes section later**)

Shared Lives experience

This carer said her daughter had used Shared Lives on a short-term basis, with a lovely Shared Lives carer, but “*all they did was sit and watch TV for two weeks...*” There was no stimulation for her daughter. Her and her family have been looking for Supported Living in Oxfordshire for months now, but nothing has come up and they feel that what they have seen/ experienced isn't right for their daughter. They have decided to move out of county to somewhere where they know there is a lot more availability.

Requested Supported Living and still waiting...

“What do I have to do to get a response? Am I meant to badger and push...? I'm not like that, and I shouldn't have to be like that. My husband died a couple of years ago and I'm alone now, and I'm in my eighties. I can't do what I used to...I have asked for Supported Living, but nothing has happened. And I know of people - younger people - who have asked for it a long time after I did and they have got it. I mean, what am I meant to do...? Is it really just that I have to badger all the time; is that really what it will take...?”

(NB: The out of county supported living experience was very positive)

Could supported living be a stepping stone towards people reaching further independence?

- Though people didn't have much experience of it, they felt it could be, as long as the support in place was right and people were encouraged to be as independent as possible- “*not just have everything done for them, as some people seem to think is needed.*”

If so, 'What does OCC need to do differently?' The facilitator asked this question at various points in the discussion, in response to the discussions being had and the fact most people did not a) know about Supported Living and/or b) how to go about finding out/ requesting it), so:

What does OCC need to do differently?

- Do more planning for the future to accommodate the numbers of people who will need supported living
- Prioritise supported living in terms of funding, etc- in some areas, it is ring-fenced; there is money available here, it's just not always spent in the right way
- Councillors need to approve proportion of housing within new builds that can accommodate a range of needs
- Fund/ create more supported living opportunities for people- not enough in the county
- Provide a wider range of supported living options to meet different requirements
- Address the gap in services between supported living and outreach support- housing for 'higher functioning vulnerable young people'

- Plan earlier so people don't reach crisis point; prevention, not reaction. At the point of crisis, inappropriate/ unsuitable support is often out in place, ad hoc basis
- Needs to be better communication between agencies to enable proper planning for the future – Council and other agencies have all the information they need to be able to plan properly if someone is open to health and social care; no excuse for not being able to plan ahead
- Provide information about supported living to carers when someone is 16, and start the conversation then; professionals need to be supporting carers to be thinking and planning ahead; too much 'here and now' care and support, not enough planning ahead
- Social workers need more specific knowledge around learning disabilities and what is available for people
- Professionals don't always feel equipped to talk to families about supported living as they don't have the knowledge or information about it; they don't therefore address it with people as they lack the confidence to and aren't clear about it. They need to be supported to gain the right knowledge so they can properly support and inform families (NB: this came from one of the professionals)
- Improve transition between children's and adult services; when people leave children's services, the family suddenly loses a network of support and links to information; *"it's like starting all over again..."*
- Don't put the onus on carers to find out or know - 'you don't know what you don't know'...
- Professionals should make sure carers know what the options are, then follow up on a regular basis with conversations about it. When information is given, it's often all in one go, and a lot of it; or at times of difficulty/ crisis, when people are overwhelmed. Carers are dealing with so much, all the time- they can't be expected to absorb all information because it was given to them once
- Produce hard copies of information for people and give this to them; not everyone uses the internet
- Make 'advertising' about what's out there and how to go about getting it a lot clearer and more widely available for carers to find
- Don't cut daytime support opportunities for people who go into supported living; they still need those opportunities. Doing this can put people off from moving into supported living

General notes/ comments/ questions.

Points in bold were repeated three or more times.

How do we know what criteria people need to meet to get supported living?

- **Mismatch between what assessment says someone needs and level of support person actually needs (this was either people's experience or people's fear)**

- Concern about how much say parents can have in the supported living process - either during the process of accommodation being looked for or once person has moved in
- **How is provision matched with need? And how is this followed through to make sure the right support is provided?**
- **Needs to be a wider range of options available to meet different requirements**
- **If carers don't push/ complain/ 'badger', they are not prioritised**
- **Every step of the process is a fight** (this was about getting support in general, rather than supported living)
- Extra Care Housing works really well
- **There is a lack of appropriate support resources generally**

Main themes

Information/ knowledge

- Lack of clarity about what supported living is, what it looks like, what options there are, where to go to find out (this is not just restricted to carers, but some professionals too)

Planning

- Needs to happen early (e.g. when person is 16) - agencies need to communicate better between themselves; conversations/ planning needs to start with families early, and this should be followed up regularly by professionals supporting those families;
- County needs to plan ahead for housing and factor people's needs into equation

Car Park

- Outreach Support v. Supported Living: lack of understanding about the difference and clarity that they are even different
- Lack of clarity around difference between personal budgets and direct payments
- Query about telephone number for Fire Service on OCC website



Table Seven
**Navigating the Adult Social Care System and
finding the right help in Adult Social Care**

Do you know where to get the right support at the right time? Do you know what information and advice is available? Which person do you contact for what?

Finding your way round Adult Social Care can be tricky especially when you have been out of the system for a while. What would help you to navigate this better? What is working well now? What is not working well?



Do you know where to get the right support at the right time?

- Reviews are held at short notice
- There is no information about what questions are going to be asked.
- It takes time to get back to families after the reviews.
- Lack of named social worker – who should we contact?
- Frequency of reviews
- Difficult to reach the person you want to speak to.
- Carers do not know where to go for information – Live well website, OACP

- Difficult to find the phone number for Adult Social Care
- Phone number should be displayed in all GP surgeries
- Transitions
 - At 17 should have a contact for transition
 - Up to 25 – should have a named social worker
 - After 25 still should be reviewed annually
- What is the difference between a social worker and a care manager?

Do you know what information is available?

- Transition from children to adult services is like 'falling off a cliff'
- Sometimes good information about what meetings were about
- Provision – costs are driving placement
- McIntyre – parents not knowing what to expect
- Assessments – changing to strength based approach

What would help you navigate the system better?

- Websites are difficult for some – not everyone has good access to the internet and not everyone feels confident using it.
- Sometimes too much jargon
- Where do people go for information? Citizens Advice Bureau? Other parents (lots use this), GP's, Schools. GP's are very variable – some are not interested, you have to wait a long time for an appointment and they are very busy so don't want to take up their time with non-medical questions.
- Do we have specialist social workers? No.
- Generalist social workers do not know about the services available for people with learning disabilities.
- What happens in an emergency? Family carers do not know who to contact.
- Importance of knowing your way around the system – the system works for OCC but not necessarily for families.
- Older carers need to have paper copies of assessments etc.
- Need for information about where to go in a crisis
- Annual reviews – OCC tries to go annually to reviews but not enough staff to cover the numbers. Do try to go to the annual reviews for those out of county.
- How does OCC adult social care find out about the young people coming through? They try to identify those who will need support as adults from about the age of 14. There are approx. a 100 people coming through each year.
- Parents feel they are having to push for reviews. How do parents find out what they need to do?
- There needs to be a monitoring system to help predict who will need help.

- The front door telephone number for Adult Social Care needs to be more widely publicised.
- 'Parents have to drive everything'

Immediate takeaways.

- Promote ASC telephone number including a more obvious link on the website
- Visual pathway for Moving into Adulthood and one for everyone
- Put 'front door number' on GP annual health check
- Need clearer language on the ASC website – less jargon
- Needs to be a leaflet for those not on line
- Promote direct payments
- Needs to be closer contact with older carers
- Need to improve links with schools and colleges.

Table Eight Day Time Services

**Are there enough opportunities for your family member?
Are there any gaps that are not been covered?
What is working well? What could be done differently?
What opportunities would you like to see?**

Existing provision

- OCC Provision: Live Well Oxfordshire Website (bit like Wikipedia). Needs to be in the Local Offer
- How does this sit alongside the Local Offer/Family Information Service Directory?
- Reason for having both the Local Offer and Live Well is that it is a legal requirement for both Adult/Children Services to offer information. Could they be connected through their separate sites as sometimes there is lots of overlap particularly for disabled people.
- Friends groups attached to OCC services. Need to fundraise for the "extras".
- Information Directories; Care Choices: Smile: Home Farm Trust: Rebound – Bicester; Style Acre; Ice Centre: Guideposts e.g. Dig n Grow.

- OXSRAD (Oxford and District Sports and Recreation Association for the Disabled Ltd. (Cannot leave the child)
- Thomley Hall (cannot leave the child)
- Farmability
- Wheels 4 all
- Wallingford Gateway Club
- Ark T

Gaps In provision

- Daytime employment opportunities for people who are not literate e.g. About with Friends based in Norfolk.
<https://www.aboutwithfriends.co.uk>
- Buddying/1:1 support for people with profound and multiple learning disabilities.

What is Working Well?

- OCC Community Support Services: e.g. good, varied, support services in Abingdon for a 50 year old son.

What could be different/better?

- Better use of assistive technologies?
- Day centres are limited/less places for people in supported living at day centres
- EHCP's (Education Health and Care Plans). More information should be provided in these plans.
- Is Family Information Service linked to Facebook/social media?
- Ideal provision would be offered from 9.00 am until late.
- Weekends are as important as weekdays for provision.
- Information about opportunities. The onus is on the parents to find out – it would be great to be told something.
- Everyone should be added to the short breaks email.
- Not enough emphasis on Social Care in EHCP's – focus is too much on the academic side.
- Daytime support outside of school hours – thinking about impact on siblings.
- Daytime sessions are a mix of teenagers and older people
- Availability of social workers.

What Opportunities are needed?

- More support on cost implications for families
- Not all people are on social media. How to communicate effectively with them? Printed information is still needed.
- More drop in community centres.

6. Feedback From Attendees

Attended: 100
Feedback forms: 27

This is the second time we have run the Better Together event. We took on board the feedback from our first event and where possible made changes that people suggested – fewer questions and a longer time in which to discuss the issues. Feedback from this year's event was again very positive and it is clear that family carers and professionals value the opportunity to get together to discuss and share information.

What was the best thing about today and why?

- Stating your opinion & in one case learning how to go further with your problem. Good coverage of topics.
- Meeting people who are using OCC services and hearing feedback about the service and support we are offering.
- Hearing families stories and other professionals
- The chance to hear views of people who use services and who provide support and to ask 'Are we doing things the best way''
- Being able to share concerns
- Networking with people with LD/Autism , family carers and professionals. Hearing people's stories.
- Very constructive and hugely appreciated the discussions. Learnt a lot on Adult Social Care
- Much information given
- Great opportunity to talk about things that matter and to meet new and old friends. Good venue too....
- Meeting with parents/carers, young people and adults who use services and hear their views and needs. Stalls – resources – lunch!
- Being able to talk openly & share experiences with other parents (& professionals). Lovely venue and refreshments.
- Hearing from families and professionals – incredibly valuable learning
- Hearing the views and perspectives of family members; meeting and learning from different members of the inter-professional team; learning from each other; having group facilitators worked really well
- Getting an insight in to lots of different topics – world café style supported this well and also choice in what you wanted to learn
- Positive/negative feedback from families/professionals etc
- Hearing about people's experiences
- Mix of people and range of topics to discuss
- Networking with families and carers and professionals; hearing how things are in reality; good time for discussions
- Hearing from parents – got me thinking about a few different themes: open discussions
- Coming together of family carers and professionals; breaking down barriers and interactivity
- The best is that everyone joined in to pass on information and that is helpful

- Opportunity meeting other people and creating new networks
- People talking about what they like to do
- Meeting others in similar situations
- The green and red cards – would have been good if all tables used these; the facilitators; the amount of time at each table; the variation of professionals services and parent carers
- Information Sharing. Hannah (young ASD girl) sharing her experiences
- The topics on the tables were well chosen. The professionals were very informative and helpful

What was the least helpful thing and why?

- The feeling that although you have had 'your say' that is the end of it.
- Replication of other events I attend
- Not sure I can think of one.... It may have been hard to stay 'on topic' at tables but all that was shared was valuable
- Noisy, too bright, random phones ringing
- Nothing x 2
- After 2.00 pm many parents left so for the last world café discussion, there were no parents to input their views, perspectives and direct conversations
- Not being able to do all the sessions rather than just 4 out of 8, but would be difficult to fit in the time.
- Varied facilitators – some ignored signs people were holding up and did not step in when people dominated the conversation. Table 5 and 8 had strong facilitators.
- Struggling to hear at times due to the size of the room, so if possible tables spread out more
- Not enough time to attend all tables or to hear concerns/issues from all families/carers/professionals
- The people facilitating the tables seemed quite set on the negatives and highlighting bad services
- Lack of providers
- I wondered about the phrasing of some of the questions – it seemed more helpful when these were explorative rather than directing people to only discuss the negatives (eg CAHMS)
- How the programme is set is really helpful
- Table 2
- The environment could have been more autism friendly – too noisy, phones ringing, lots of rustling on tables e.g. sweets
- The tables at the venue

Any suggestions on how we could do things better?

- Consider the vast range age range of people we are talking about. Not all relevant.
- Maybe get those working stands to give a brief introduction and highlight professionals in the room to aid networking
- Less plastic in lunches
- A dedicated session on supported living process
- A dedicated session on supported living through the ages

- Information on law/policy and rights of people using services in an easy -to-understand document/leaflet
- Do them more often? Set up an online group for us to keep in touch.
- A shorter day – maybe only three sessions! Have a representative from each organisation on each table. OxFSN doing some teaching in universities.
- Further promote and advertise the event to more health care professionals and education providers as well as students who don't learn enough in university about autism and learning disabilities
- When arriving give information on what information tables are; smaller rooms; I would have liked to have attended all tables
- To involve more carers/families; really wanted to attend all table discussions
- Balance the discussions
- More family carers
- I wondered if there could be more involvement of professionals. I really wanted and valued hearing from families but also had feedback/discussion points which might have been shared with families – being more together
- More providers – weren't many represented!!
- Less plastic; more visual structure about what to discuss on tables to avoid going off topic
- Yearly conference, Information fairs
- A yearly get together is very helpful

Did you feel listened to today?

- Yes x 14
- Yes, I felt everybody had an opportunity to talk, and all points raised were valid.
- Yes felt valued and listened to on all topics
- Yes definitely x 2
- Yes and having the green and red cards was a good idea
- Yes, the I want to speak cards worked so well and included everyone and I felt I got to participate 100%
- Yes overall but as a 'professional' I was not felt as welcomed as parents
- Yes and suitably challenged
- Yes – I really valued the opportunity for family feedback but felt more room for open discussions about working together may have been helpful
- Yes felt very welcomed – excellent event
- Yes Absolutely. I had the chance to participate all the time

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

- Smooth, clear transition process
- Lobbying for funding. Improvement of transport services.
- More chances to build bridges and improve the lives for people and their carers.
- Better support for those with autism
- Signposting maybe
- Better signposting to services
- For changes to 'systems' to actually take place such as transport (SEN) – we know it's not great but nothing seems to change. Would also save OCC ££'s.
- That parent/carers experiences are taken seriously and worked on.

- Adult Social Care and National Health Trust implement these changes – the ones that will have impact upon people the most
- It would be amazing to be emailed typed copies of the feedback received
- Better shared communication, changes happening before a crisis. Health/ Professionals sharing already developed resources
- I think the overall event was great and for the right purpose to make it Better Together
- Better communication between teams and better information (simple and clear)
- Better communication and information sharing
- Open discussions – good event though
- Change in blame culture of funding although unfortunately always an issue – health and social care will always face these challenges and need to learn how to stretch resources more efficiently
- No comments
- Better clearer more accessible information available to people in digital and hard copies
- Things definitely taken on board
- Making Information more available e.g. a booklet when child is newly diagnosed. A free helpline for parents/carers with SEND children to give advice when needed.

Appendix

The following organisations/services supported this event

- Abingdon and Witney College
- Action For Carers
- Barnardo's
- Challenging Our Behaviours
- Community Glue
- Jigsaw
- KEEN
- McIntyre
- Oxford Brookes
- Oxfordshire County Council – Adult Social Care
- Oxfordshire County Council – Children's Services
- Oxfordshire County Council – Finance Department
- Oxfordshire County Council - SEND
- Oxford Health - CAMHS
- Oxford Health – Continuing Care
- Oxford Health – Intensive Support
- Oxford Health – Learning Disability Services
- Oxford Health – Patient Experience
- Oxfordshire Parent Carers Forum (OxPCF)
- OxFSN
- Sendiass
- Style Acre
- Yellow Submarine