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552 Sessions*

*including groups, one-to-one, phone and online survey



This has helped us reach

1160 voices!



Information and Support





Information is often offered at the time of diagnosis, but it can be "too much, too soon." It can then be difficult to gain further information and advice when it's really needed. More support is needed at all stages of the dementia journey, ideally from a specialist nurse or other support worker – "Don't give up on us, we're not getting any better." More advice is needed on the side effects of drugs, healthy living, claiming benefits and form filling, as well as reminders for repeat prescriptions and annual health checks. Information is available online but many struggle to find it and some have no online access. More printed information and personal support (face to face or telephone advice) would be better.

Buckinghamshire County Council is working on a 'digital front door' to make information easier to access.

our Voice

The Dementia Community Engagement
Group meetings will continue to discuss
communication methods and how
support groups can more pro-actively
contact people post-diagnosis. The
Council is working on improving
communication, ensuring people living
with dementia receive timely
information. They are also looking to
raise awareness of dementia among
young people and professional groups
(GP practices in particular).

GPs

GPs and GP surgeries don't know enough to give advice or signpost where to go for the help needed.

GP surgeries are appointing Social Prescribers who will offer information about wellbeing and prevention approaches, and introduce people to relevant community groups, activities and statutory services.



Mental Health



Buses

You said

Most buses arrive on time and take you where you need to go, but the inability to use a bus pass until 9:00am (although many still believe they cannot be used until 9.30am) can make it difficult to attend morning medical appointments and day care centres.

Mental health illness is a hidden disability which allows some to sit in priority seats on buses, but when you do you can become a target of abuse. Other issues with buses, which can create anxiety, are: crowded buses, especially at school times; lack of information about bus times and bus stops; route changes, and incorrect signage on bus routes.

Annual Health Checks

Annual health checks (when experienced) are appreciated, but few are aware of their availability or benefits; and many are reluctant to go to yet another GP appointment.

Perinatal Mental Health Service

There has been a lack of mental health midwives.

Recovery College

Many (but not all) feel the quality of the courses and the teaching at the Recovery College has declined. There are not enough new courses and the focus needs to revert to recovery.

What's happening?

The Council arranged a meeting between Talkback and Arriva where all the bus travel issues were raised. It is hoped that similar meetings will take place with other bus providers.

The Council will work with the Clinical Commissioning Group to promote annual health checks for people with serious mental illness. Resource packs are being developed and will be sent to every GP surgery to include letter templates, leaflets for signposting, text message services etc.

The Perinatal Mental Health service has been expanded, from two clinical people to 12.

Buckinghamshire County Council will work with Oxford Health, and both users and non-users of the Recovery College, to review the provision offered. They will look to return to a more recovery based model.

Learning Disability



You said

Transport

In many areas the local transport services work well. Dial-a-Ride (Chiltern and Wycombe) is popular and is able to transport wheelchair users (and others) to their daily activity, some taxi drivers are friendly and helpful, and most buses work according to schedule. Some taxis can create a lot of anxiety. People worry if the seat belts are not working (or not worn), if they turn up late without warning, if the driver takes a different route to normal, and if they overcharge. Travelling by bus can create anxiety if they are running late with no updates, if the route changes mid journey, and if the bus drivers don't wait for people to be seated before setting off.

Buckinghamshire Online Directory

Most were unaware of the Buckinghamshire
Online Directory and its purpose. People said it
is better to find out about activities from people
you know and trust.

You want to know that any new activity would cater for your interests and needs. The Online Directory does not allow you to search by specific activity e.g. badminton; or by need e.g. activity for someone with a learning disability. Many don't have internet to access the Directory.

GP appointments

People with learning disabilities can struggle to make GP appointments via the automated telephone answering systems. The lack of internet access means the online appointment booking service is not a solution for all.

What's happening?

Buckinghamshire County Council recently held a meeting with Arriva and Talkback to discuss the issues raised by people with a learning disability when travelling by bus.

The Council will raise the issue of overcharging by taxis with Trading Standards and taxi providers.

There will soon be a two year funded 'Train the Trainer' programme provided by The Council to form a small team of independent travel advisors, who will support people to access the community, look at travel options and stay safe.

Buckinghamshire County Council is recreating its webpages, including the Online Directory, to make them easier for all to use. It will also create paper versions. The Council will seek feedback from the community on the changes.



The Council and the Clinical Commissioning Group (CCG) are looking at Health Passports for people with learning disabilities, and improving access to GP appointments.

The Council is working with GPs to make information more accessible and in Easy Read format.

Physical and Sensory Disabilities



You said

Buses

Buses can work well, and Arriva buses now have more space for wheelchairs. However wheelchair users report being left at bus stops when the wheelchair spaces have already been taken (by other wheelchair users or parents with pushchairs), or when the driver "can't be bothered" to lower the ramp. Others have had problems when buses are cancelled or routes are changed without notice or consultation.

Taxis

Some taxis provide an excellent service and look after their passengers well.

But wheelchair users can struggle to find taxis large enough to take their wheelchairs.

Taxi drivers often charge wheelchair users more than other passengers.

Those with a visual impairment can struggle to find the taxi without support, whilst those with a speech impairment can struggle to speak to drivers.

Dial-a-Ride

Dial-a-Ride provides a highly valued door to door transport service to many with restricted mobility in the Chiltern and Wycombe districts. With no Dial-a-Ride option in Aylesbury Vale some struggle to find suitable transport.

What's happening?

The Council will ask bus providers to consult with the community before any changes to bus routes take place and to review the number of designated spaces for wheelchairs on buses and access to ramps.

A meeting between the Council, Arriva and Talkback has taken place to discuss all the issues raised. It is hoped that meetings with other bus providers will follow.

Buckinghamshire County Council plans to address the discrepancy in taxi costs by escalating the issue to Trading Standards and taxi providers.



The Council will consider using the fleet maintenance programme to help a Dial-a-Ride type service succeed in Aylesbury Vale.

Autism



You Said

GPs and Hospitals

Medical staff can lack an understanding of the needs of those with autism or are too busy to adapt health services staff in the next six months. The their services to fit them. That can leave people with autism feeling anxious and agitated about going to the GP or hospital.

When going to hospital, some have received excellent support from the Learning Disability nurses, but more specialist autism support at all times of the day and night would be welcomed. Some GP surgeries and some outpatient departments offer appointments at quiet times and/or offer quiet (waiting) rooms, but most don't. It can be hard to see the same GP, and it's frustrating to have to explain the autism diagnosis at every visit.

Some GPs didn't diagnose autism early enough, resulting in considerable childhood trauma.

Social support

More autism peer support social groups that offer social events, cooking and other activities are needed.

Mental health services

More autism-specific mental health services are needed. Being categorised as either autism or mental health causes additional frustration as often support is needed for both.

What's happening?

Autism training is due to be rolled out for front line Council will be looking at ways to include a person's autism diagnosis on their medical records, to improve support and access.

The new digital My Care Record (health and social care) could have an autism diagnosis recorded on the front page, and any communication/sensory issues clearly flagged. An autism Alert Card to raise awareness will be considered as part of the autism strategy.

The Council is looking to support voluntary sector partners with a bid for lottery funding to support the growth of peer support schemes.

The Council is working with mental health services to improve the diagnosis wait time for children and young people. Additional funds have been agreed this year to reduce adult waiting times for diagnosis. The Council is committed to improving training for mental health professionals, including staff delivering individual and group Cognitive Behavioural Therapy (CBT) interventions so they are tailored to the needs of the individuals. This will be addressed as part of the autism strategy later in the year.

Carers



You Said

Carers assessments

Carers Assessments continue to be an issue, with many feeling they have to fight to be assessed for care (as well as other services). Carer's assessment forms are long and difficult to complete; it can be a long time before any feedback is received.

Blue Badges

Some have had issues completing Blue Badge forms and re-applying feels like an unnecessary burden, particularly when nothing has changed, or deteriorated. Blue Badge applications have been particularly difficult for those caring for people with hidden disabilities.

Information and support

It can be confusing knowing where to go for help. While some struggle on unaided, others are helped by the support groups they attend. A single point of access for all information and support would be ideal.

Respite care

Respite care is difficult and expensive to source. It lacks the flexibility to cater for individual needs. This means many choose not to go away or have a break which impacts health and wellbeing. There is a shortage of day care facilities to provide one day a week respite care, especially in the north of the county.

Whats happening?

The Council is working with Carers Bucks to improve Carer's assessment forms.



The Council will examine how to offer more support with Blue Badge applications and renewals for all those eligible, including those with hidden disabilities.

Buckinghamshire County Council has confirmed that Carers Bucks will be the single point of access for Carers. They are redesigning their website to reflect this. Regular follow-up and wellbeing calls to Carers is part of their new contract.

More work is being done to encourage GPs to become more Carer aware and improve support. Carers Bucks are taking part in a pilot project within a few schools to help new educational health teams to identify young carers.

A Carers' support group for Council staff is being launched in September 2019.

The Council is working with Carers Bucks to understand respite care needs within Buckinghamshire, with a view to developing more relevant services.

Gallery











Over the coming months we will continue our outreach and gather more voices

If you don't like coming to meetings, struggle with transport, or can't make the times and dates, let us know. We would still love to hear your voice!

We will continue to work with our strategic partners and other providers in the community to strengthen the voice that we share with Buckinghamshire County Council.

AND finally...

Let us know how we are doing, what we could do better or if you have any suggestions, please tell us! We are here to represent the community, so your input is greatly valued.

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