Autism Spectrum Conditions, a report by Healthwatch Worcestershire, March 2018

Response to Recommendations from Worcestershire County Council (on behalf of both the Director of Adult Services and the Director of Children, Families and Communities)

1. Diagnosis, Information and Support

Diagnosis Pathways

Recommendations:

• Commissioners to continue to work with providers to monitor waiting times for diagnosis via the Umbrella Pathway and Adult Diagnosis Service and where possible identify opportunities to increase capacity to reduce waiting times.

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
For adults: Extra funding was allocated for the adult autism diagnosis and support service in 2017/18 in order to clear the waiting list and a plan agreed with the service provider to achieve this. These targets have been achieved. It was agreed in late 2017 that the service would no longer be commissioned by Worcestershire County Council. As from 1st	A new service specification and revised pathway have been developed and there was a published call by the CCGs for expressions of interest from potential providers to deliver the service from April 2018. The new contract is now in place with increased investment of £200,000 p.a. for 2 years. The pathway is as follows:
April 2018, the service is commissioned by the CCGs to ensure a direct relationship between the funding sources and service provision to allow the CCGs to allocate resources accordingly.	 Initial triage Support plan with clear outcomes Diagnosis if lower level support has not helped <u>and</u> there is a significant social disability <u>and</u> is clinically indicated.
	The provider has agreed to provide additional capacity to continue to reduce waiting times for both Initial and Diagnostic Assessments. Once the backlog is cleared, it is expected that there will be a reduction in Diagnostic Assessments, with greater emphasis being placed on support plans and working with generic

In relation to the autism assessment pathway for children (known as the Umbrella Pathway), commissioners receive a monthly dashboard with key performance indicators. Health and education commissioners and providers have quarterly monitoring meetings about I Imbrella Pathway, which	support services to make reasonable adjustments for people with Autistic Spectrum Disorders. The new contract commenced on 1st April 2018 with The Family Psychologist. Monthly performance monitoring will enable the CCG to ensure that the additional resource is used appropriately and the waiting times for access reduce in line with the agreed activity plan. Monitoring data and meetings will continue as before. Changes have been implemented to the referral pathway and the impact will continue to be monitored on an ongoing basis, using both the existing and additional key performance indicators
quarterly monitoring meetings about Umbrella Pathway, which include consideration of activity data related to the pathway from both the Health and Care Trust and Babcock Prime. Reports have been given and recommendations accepted about the Umbrella Pathway, with the aim of reducing time taken from referral to diagnosis - to the Integrated	indicators.
Commissioning Executive Officers' Group (ICEOG) in January 2018 and Overview and Scrutiny Performance Board in February 2018.	

• Consider how monitoring will be carried out to ensure that revised information about referral and diagnosis pathways and support available is passed on to individuals, carers and relevant health professionals e.g. GP practices.

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
In relation to the pathway for adults, the initial focus of communications for the CCG is with GP Practices. The effectiveness is monitored by the CCG Primary Care Team	There is communication plan for primary care to ensure they are aware of the revised service specification. As waiting times reduce the provider will support commissioners by publicising
through locality meetings and feedback from practices.	the service on a regular basis.

In relation to the pathway for children, revised information about the Umbrella Pathway has been distributed internally by WHCT to their staff; to all GP practices via the CCGs; and to all schools via the newsletter published by the Assistant Director Education and Skills.

Information leaflets about the diagnosis pathway and about support available were developed in 2017 by WHCT in conjunction with commissioners and with parental input coordinated by HWW. These are provided by WHCT to those going through the pathway and are also available on the Trust website: http://www.hacw.nhs.uk/our-services/childrens-community-health-services/umbrella-pathway/

There is a webpage on autism on the Worcestershire Your Life Your Choice website, with information, advice, signposting, details of support groups etc: https://ylyc.worcestershire.gov.uk/care-and-support/disabilities/autism/

Maintain liaison with primary care via direct contact with Local Medical Committee and the CCG Mental Health Clinical Commissioning Meetings.

Maintain monitoring of complaints, compliments and feedback via Friends & Family Test (this information is provided by the Trust to the CCG Clinical Quality Review Meetings). Assurance and feedback discussed at the quarterly meetings of commissioners and providers involved in the Umbrella Pathway.

Feedback and dialogue with other stakeholders including HWW and Families in Partnership and through ongoing engagement and consultation work in relation to the SEND agenda.

• Ensure that people with Autism Spectrum Conditions and carers are involved in giving feedback about their experiences of referral and diagnosis pathways, information received and future development.

What work is currently being done to address this?	What do commissioners plan to do in response to this
	recommendation?
The Autism Partnership Board will continue to be the key	The new specification for the adult autism diagnosis and support
forum for partnership working, including gathering feedback	service has a range of quality indicators that the provider is
about local services and developing future services.	required to report routinely to commissioners. This includes
Through our co-production with specialist groups in the	measure of patient experience.
voluntary sector we are specifically targeting minority groups	
to ensure inclusion of all members of the community who	

may be on the spectrum. New members have been and will continue to be recruited on an ongoing basis in order to widen the range of partners and knowledge.

For health services and the children's assessment pathway, we will maintain monitoring of complaints, compliments and feedback via Friends & Family Test (this information is provided by the Trust to the CCG Clinical Quality Review Meetings). For the children's pathway, we will also discuss assurance and feedback at the quarterly meetings of commissioners and providers involved in the Umbrella Pathway; and seek feedback and dialogue with other stakeholders including HWW and Families in Partnership and through ongoing engagement and consultation work in relation to the SEND agenda.

A number of feedback sessions with parent carers have been carried out since March 2017 to find out about services. From these discussions, a lack of support for children with or without an autism diagnosis was a key concern. Separate sessions have been set up because of this to enable discussions and feedback from parent carers around guick wins (improving information and advice) and longer term improvements needed (training and support, behaviour change within professionals etc). As well as attending groups (including specific support groups for parents with children on the autistic spectrum), questions have been asked on various social media groups to gather feedback and ideas from a range of parents around ASD. We are also working closely with Worcestershire's official parent carer forum, Families in Partnership (FiP) to enable feedback.

Feedback has also been gathered from children and young people although this has mostly been about groups and Families in Partnership is a developing forum and intend to do more to engage with a wider group of parent carers through a variety of channels including attending support groups, asking questions on social media and running surveys. Worcestershire County Council is supporting FiP to do this. activities rather than referral and diagnosis and only a very small number of young people have been spoken to.

Commissioned Parenting and Family Support providers have also been doing work with parent carers around what information and support is needed for children and young people with SEND, including autism. This has been done by attending support groups and carrying out surveys. The results of these have been shared with Worcestershire County Council and used in particular (along with the feedback WCC has gathered) to improve the information and advice available on the WCC website.

Accessing Information

Recommendations:

• Ensure that comprehensive and up to date information is available about the statutory and voluntary services and support available for people with Autism Spectrum Conditions and their carers.

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
For adults:	Your Life Your Choice will continue to hold a range of
People who contact the Council or The Family Psychologist	information about support and groups that can offer help. The
are signposted to local groups for information and guidance.	Family Psychologist will also continue to signpost adults and
The Worcestershire 'Transforming Care Plan' for patients	WHCT will continue to signpost children/parents/carers, to
currently in locked and secure inpatient facilities focuses on	appropriate groups/services etc.
admission avoidance and the continued development of	
sustainable community services for people with a learning	In line with the redevelopment of the Local Offer, the information
disability and/or autism, delivering a model of care that	about children will be reviewed with parents/carers to ensure it is
embeds the 9 overarching principles set out within Building	easy to understand and lists as many support services as
the Right Support (2015) (a national plan to develop	possible. This will be kept up to date by ensuring services are
community services and close inpatient facilities).	contacted regularly to check details and liaising with parent
	carers who might know of new groups and services. This
For children:	information is, and will continue to be, shared with professionals

Information leaflets about the diagnosis pathway and about support available have been developed by WHCT in conjunction with commissioners and with parental input coordinated by HWW. These are provided by WHCT to those going through the pathway and are also available on the Trust website: http://www.hacw.nhs.uk/our-services/childrens-community-health-services/umbrella-pathway

For both adults and children, there is a webpage on autism on the Worcestershire Your Life Your Choice website, with information, advice, signposting, details of support groups etc: https://ylyc.worcestershire.gov.uk/care-and-support/disabilities/autism/

Following feedback from parent carers, new information has been added, including what to do if a parent thinks their child might have autism and a range of support services available in Worcestershire. This includes groups and activities for children and young people as well as information websites, online forums and support groups for parent carers.

including parenting and family support providers so they are aware of where to signpost families to who need more information and support around autism. We will consider how this can also be better shared with social workers, schools and other local teams/organisations working with children and families.

• Consider use of a specific website or section of website to provide information about services and support.

What work is currently being done to address this?	What do commissioners plan to do in response to this
	recommendation?
For adults, generic wellbeing support is available through the CCG commissioned Worcestershire Healthy Minds and the Public Health commissioned Worcestershire Advice Network	Public Health are leading a programme of work to commission an Integrated Wellbeing Service for Worcestershire by April 2019. This will provide both generic and specialist support, and
websites.	support the expansion of social prescribing through a website with information about services and support.
For children and parents/carers, information leaflets about the diagnosis pathway and about support available have	

been developed by WHCT in conjunction with commissioners and with parental input coordinated by HWW. These are provided by WHCT to those going through the pathway and are also available on the Trust website: http://www.hacw.nhs.uk/our-services/childrens-communityhealth-services/umbrella-pathway

For both adults and children, there is a webpage on autism on the Worcestershire Your Life Your Choice website, with information, advice, signposting, details of support groups etc: https://ylyc.worcestershire.gov.uk/care-andsupport/disabilities/autism/

As detailed above, information will continue to be available and will be updated as appropriate. For children, this is linked in to the Local Offer redevelopment work and will be regularly reviewed to ensure it is up to date and relevant.

Consider use of social media e.g. specific Facebook and / or Twitter pages to promote information about services and support and where to find further information.

Worcestershire County Council already uses social media to promote information about services and support which includes information about autism. Different teams within Worcestershire County Council and commissioned Parenting and Family Support providers share information and links to services on social media pages. Families in Partnership regularly share information about services and

the Council link in to members to share information about

services that are promoted to FiP members.

What work is currently being done to address this?

What do commissioners plan to do in response to this recommendation?

The Autism Strategic Partnership Group has a priority of "Awareness raising and training" within the Autism Strategy and will continue to implement and monitor its plan to achieve this priority.

The Council will continue to use social media to promote information about services and support available to people with autism. It is acknowledged that more can be done on the County Council social media pages, and to link with Families in Partnership and other local social media groups to share information about services and the Local Offer. Following the redevelopment of the Local Offer, the Council will be engaging with parent carers, professionals and children and young people

to seek feedback on how easy it is to access information on the Local Offer and what information is missing or needs improving. Social media will be a key tool in doing this, to enable the Council to reach a number of people accessing different autism
pages.

- Consider if any of the following methods could also be used to promote information about services and support
 - Drop in information sessions
 - o Leaflets in health and community settings
 - o Leaflets in schools and colleges
 - o App for phones and tablets
 - Local telephone contact number

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
For adults with autism, contact details for The Family Psychologist and other support groups/services are available on Your Life Your Choice.	The Autism Strategic Partnership Group will consider what it would like to see developed/ available in future as part of its action plan for "Awareness raising and training".
For children, information is available on the Worcestershire Health and Care Trust website and Your Life Your Choice. Trust leaflets include a specific local telephone contact number for those on the Umbrella Pathway. The	Details of provision and support for people with autism will continue to be held on Your Life Your Choice and updated appropriately.
Kooth on-line platform has been commissioned for generic emotional wellbeing/mental health support for children and young people. Support and information is also available through commissioned voluntary sector organisations (e.g.	Following the redevelopment of the Local Offer, a communications plan will be put into place to promote the Local Offer, what it contains and how it can be accessed. Consideration will be given to various methods, which could include leaflets, assist media advertising and information.
Your Ideas in Matchborough, Redditch who have developed a specialism in engaging with and developing provision for young people with ASC) and umbrella / infrastructure organisations. The community capacity element of contractswith commissioned Parenting and Family Support	include leaflets, social media advertising and information sessions with support groups and in special schools.

providers, undertakes information sharing in localities,
including sharing information with a number of local
organisations.
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The MoMo (Mind of My Own) app is being launched in Worcestershire. This will provide young people with an instant, relevant and accessible way to express their views, wishes and feelings, and WCC with a smart way to respond, record and collate them in order that issues, needs and trends can be identified and taken in to account.

- Consider if further information can be made available about
 - Developing understanding of Autism Spectrum Conditions and strategies for support, in particular around sensory issues and developing social and communication skills
 - Support and advice for partners, families and siblings
 - Mental health support and other available therapies
 - o Gaining employment and employment support
 - Social activities and events

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
WCC provides training for front line staff working with both	Awareness raising and training is a priority of the Autism
children and adults about autism spectrum conditions, which	Strategy and will continue to be addressed by the Autism
focuses on how professionals can support people on the autism spectrum and their families to achieve improved	Strategic Partnership Group.
quality of life and better outcomes.	The Strategy is due to be refreshed in 2018 and all priorities will be considered and updated, taking into account the
An Autism and Employment Awareness event was held on 19th March 2018 hosted by The Autism Strategy Partnership	Government's 'Think Autism' Strategy governance refresh of March 2018.
Board in partnership with Fortis Living. This bought together	
local employers and people living with Autism to an open	We will work to ensure that up to date information and advice is
forum to discuss the benefits of employing people with	maintained on Your Life Your Choice and the Local Offer.
Autism and the importance of breaking down barriers. Over	

150 people attended the event and it provided valuable	We will offer further support to parenting providers around
feedback for the Strategy and the Partnership Board.	developing autism-specific parenting programmes as well as
	more local support groups.
Babcock Prime are commissioned to provide training and	
support to schools and education settings in relation to	
children with ASC and as an accredited Autism Education	
Trust trainer, can also offer AET autism awareness training.	
Commissioned parenting and family support providers have	
supported the development of specific parent carer support groups for parents of children with autism. Some providers	
are looking in to additional training to deliver autism-specific	
parenting programmes.	
parenting programmes.	
Conversations have been held and feedback received	
through engagement events about improving the training	
and support offer to parent carers to provide practical skills	
on managing behaviour and sensory needs etc. This is	
being discussed at a commissioning level to identify the	
need and existing evidence-based programmes that could	
be adopted locally.	

Support

Recommendations:

• Consider how to increase provision and access to Local Autism support groups for people with Autism Spectrum Conditions and carers across all areas of Worcestershire.

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
For adults with autism: The Council does not directly commission support groups for people with Autism Spectrum Conditions.	It is important that the services provided by community and voluntary groups are available across the county and that these services are accessed by those who need them. Information is available on Your Life Your Choice.

However, "Supporting community based organisations and groups" is a priority of the Autism Strategy and further development is therefore being progressed by the Autism Strategic Partnership Group.

Groups such as Aspie and Autism West Midlands help to provide a range of provision across Worcestershire.

For children:

Parenting providers are increasing their training to enable them to deliver autism-specific parenting programmes. Providers have also been focusing on developing community capacity by helping parent carer support groups to set up and become self-sustainable.

Some of the Council's commissioned Positive Activities providers (youth activities) already offer groups and activities for young people with autistic spectrum conditions.

The Autism Strategic Partnership Group has a standing agenda item on Your Life, Your Choice and has addressed access issues for service users with autism spectrum conditions and worked with the YLYC team to ensure that local organisations who offer services for children, young people and adults on the spectrum are able to register on the site.

Short breaks for children with disabilities are currently being recommissioned which includes year round and school holiday groups and activities. This is being done using a Dynamic Purchasing System (DPS) which aims to enable greater flexibility and more potential providers.. Market engagement activity has been carried out with a number of providers to enable thinking in to what they could do to extend their current offer of youth activities to those with a special educational need and/or disability. The new contracts will commence in September 2018 however providers can continue to be added to the DPS to allow the Council to advertise for specific groups to meet specific needs in the future – which could allow for groups specific to those with Autism Spectrum Condition if the need and funding is identified.

- Consider if there is scope to establish or increase provision and access for people with Autism Spectrum Conditions to
 - Drop in sessions for support and advice
 - One-to-one support with day to day tasks
 - Online support groups
 - One-to-one support with attending appointments e.g. GP practices, Hospitals
 - Support in education and planning for future education and training
 - Employment support
 - Support to develop social skills and access social opportunities
 - o A mentoring or buddy system.

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
The eight priorities of the Autism Strategy cover a wide range of issues including those listed.	The strategy is due to be refreshed in 2018 and the priorities will be updated as appropriate. The Autism Strategic Partnership Board will be involved with the refresh of the document.
The WCC learning and libraries offer includes support such as Autism friendly libraries and access to adult learning opportunities.	As discussed in section 1, extra investment will be available for the next 2 years via the CCG commissioned service for adults from The Family Psychologist. Individuals' support plans will
As discussed above, initiatives relating to children include maintaining existing support groups, parenting programmes,	identify needs and the appropriate level of support identified.
current online information, advice and guidance.	As mentioned above in terms of redevelopment of the Local Offer and further conversations around training and support for parent carers of people with Autism Spectrum Conditions.

- Consider if there is scope to establish or increase provision and access for Carers of people with Autism Spectrum Conditions to
 - o Drop in sessions for support and advice
 - Online support groups
 - o Advice about transition, adult services, employment and supporting with day to day tasks and life skills.

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
Worcestershire Association of Carers is commissioned by WCC to provide services for unpaid carers across the county. This includes carers of people with autism. Support is offered in a variety of ways, including: online (including web chats), telephone, one-to-one, training sessions.	Services for carers will continue to be provided with support services as described. If any specific needs are identified for carers of people with autism, they will be considered and appropriate support identified – e.g. training, signposting to community groups or other resources.

2. Understanding and awareness of Autism Spectrum Conditions

Recommendations:

• Ensure all health care providers in Worcestershire have an understanding and demonstrate a commitment to the vision of the All Age Autism Strategy.

What work is currently being done to address this?	What do commissioners plan to do in response to this recommendation?
A Guide for GPs and Professionals in Worcestershire is available in all GP practices which offers information and	The guide will continue to be available in all GP practices.
advice if a GP suspects undiagnosed autism.	Ensure appropriate senior representation of health commissioners and providers on the SEND Improvement Board.
Health care providers are represented on the All Age Autism Strategy Partnership Board. The Strategy is owned by Health and Wellbeing Board.	

- Review and adapt Autism: A Guide for GPs and Professionals in Worcestershire to include feedback from people with Autism Spectrum Conditions and carers and the recommendations reported in this report - Healthwatch Worcestershire Autism Spectrum Conditions Report March 2018.
- Following review and adaptation of Autism: A Guide for GPs and Professionals in Worcestershire, reissue to all GP practices in Worcestershire, to ensure they are aware of feedback and recommendations made in this report.
- Consider distribution of Autism: A Guide for GPs and Professionals in Worcestershire to other health services in Worcestershire, including Worcestershire Acute Hospital Trust, Worcestershire Health and Care Trust, Care UK and West Midlands Ambulance Service.

What work is currently being done to address the issues referred to in the 3 recommendations above?	What do commissioners plan to do in response to the 3 recommendations above?
As discussed above, the Guide for GPs and Professionals in Worcestershire is available.	Discuss at the Autism Strategic Partnership Group and consider a refresh of the document to include feedback from people with autism spectrum conditions and carers and the recommendations in the Healthwatch Worcestershire Autism

Spectrum Conditions Report March 2018. The document would then be re-launched and reissued to all GP practices. At the
same time, consideration will be given to the document being distributed to the wider health services in Worcestershire.

- Identify and promote training and awareness opportunities to GP practices, Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust.
- Consider how to encourage and gain commitment from GP practices, Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust to provide Autism Awareness training for staff.
- Consider identifying champions within GP practices and departments within Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust, with existing knowledge or willingness to undertake training to provide a point of contact for other staff when supporting patients with Autism Spectrum Conditions and their carers.

What work is currently being done to address the issues	What do commissioners plan to do in response to the 3
referred to in these 3 recommendations above?	recommendations above?
This recommendation is not aimed at WCC	

3. Access to health services

Recommendations

GP practices should consider:

- Ensuring all staff, including reception staff, have an updated knowledge of Autism Spectrum Conditions via access to training and appropriate information and resources.
- In particular, that staff have an understanding of the importance of using clear language, avoiding the use of jargon and figurative language and allowing time to process information and check understanding.
- Using a flagging system to enable staff to see that patients have a diagnosis of Autism so appropriate adjustments can be made.
- How to enable patients with Autism Spectrum Conditions to have appropriate support to attend appointments where possible. For example, booking appointments at a time a carer is available.
- Offering appointments at a guieter time of day.
- Offering longer appointment times.
- Offering a quiet place to wait.
- Providing patients with information about the expected waiting time for their appointment.

- Providing activities for a variety of age groups in the waiting area, if possible to include fiddle toys and sensory items.
- Providing patients with written and / or Easy Read information about visiting the practice and diagnosis, treatment and follow on care required.

Going to the Hospital:

Recommendations:

The Worcestershire Acute Hospital Trust and Worcestershire Health and Care Trust should consider -

- Ensuring all staff, including reception staff, have an updated knowledge of Autism Spectrum Conditions, via access to training and appropriate information and resources.
- In particular, that staff have an understanding of the importance of using clear language, avoiding the use of jargon and figurative language and allowing time to process information and check understanding.
- Flagging system to enable staff to see that patients have a diagnosis of Autism so appropriate adjustments can be made.
- How to enable patients with Autism Spectrum Conditions to have appropriate support to attend appointments where possible, for example, booking appointments at a time a carer is available.
- If reminders, such as a text message can be sent to patients prior to their appointment.
- Sending written and Easy Read information to patients in advance about the Hospital, the purpose of the visit and what will happen at the appointment.
- Offering appointments at a quieter time of day.
- Offering longer appointment times.
- Offering a quiet place to wait.
- Providing patients with information about the expected waiting time for their appointment.
- Providing activities for a variety of age groups in the waiting area, if possible to include fiddle toys and sensory items.
- Providing patients with written and / or Easy Read information about visiting the hospital and diagnosis, treatment, procedures and follow on care required.
- Providing visual resources to help aid communication during appointments.

Current work being done	Any future work planned?
This recommendation is not aimed at WCC	

Access to Mental Health Services

• Consider reviewing if there is currently adequate access to mental health support for people with Autism Spectrum Conditions and their Carers.

What work is currently being done to address this issue?	What do mental health commissioners plan to do in response to this recommendation?
The mental health and emotional wellbeing transformation plan for children and young people has been informed by consultation and engagement with the public/patients and services commissioned accordingly, some of which are available by self/parent referral. Kooth on-line platform now available, offering information and counselling by self access. Schools and colleges can now seek support from a named worker in the CAMHS CAST (consultation, advice, support and training) team who can signpost and facilitate referrals in to specialist CAMHS if appropriate. The service specifications for CAMHS and other community health services include a requirement to contribute to the Umbrella Pathway.	Monitor impact of new services for children and young people and ongoing feedback as part of service review and commissioning cycle. Following commencement of the contract for Adult Autism Assessment and Support Services, mental health Commissioners are to further develop the local pathway for adults, working with both The Family Psychologist and Worcestershire Health and Care Trust.
contribute to the offibrella r atriway.	