

## Autism Spectrum Conditions

### Questionnaire for Carers of people with an Autism Spectrum Condition

Healthwatch Worcestershire gathers feedback from patients and the public about health and social care services in Worcestershire. We use the information to tell those who run services what could be improved or developed in the future.

We want to find out what people with Autism Spectrum Conditions and their carers think about accessing health services.

We do not require names and the information you provide is confidential, except that anonymised quotes may be used.

- I understand the purpose of this survey and consent to the use of the data as described above

## Going to the Doctors

### Making an appointment

1. How easy do you find it to make an appointment at the Doctors for the person you care for?

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

2. What would make it easier for you to make an appointment? (Tick all that apply)

- Booking appointments online
- Being sent a text message with appointment information
- GP notes saying that they have Autism and I am their carer (*so the receptionist can see this when you are booking an appointment*)

Other -

## Waiting for appointment

3. How easy does the person you care for find waiting to see a Doctor or Nurse?

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

4. What would make waiting easier? (Tick all that apply)

- Having a quiet place to wait
- Having an appointment at a quieter time of day
- Something to read or do while they wait

Other -

## Communication

5. How easy does the person you care for find it to explain to the Doctor or Nurse about the reason for their visit?

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

6. What would help them to explain things to the Doctor or Nurse? (Tick all that apply)

- Having a longer appointment
- Pictures / visual aids e.g. show me where cards
- Someone to support them

Other -

**7. How easy do they find it to understand what they are told about treatment, medication or follow on care?**

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

**8. What would help them to understand what they are being told? (Tick all that apply)**

- Having a longer appointment
- If they used clearer language
- Being given written information
- Being given Easy Read information
- Someone to support them

Other -

**9. Is there anything else that you would like to tell us about going to the Doctors or things they could do to help people with an Autism Spectrum Condition or their carers?**

## Going to the Hospital

10. How easy would the person you care for find it to prepare for an appointment at the hospital?

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

11. What would help them to prepare for an appointment? (Tick all that apply)

- Their notes saying that they have Autism (*so they can see this when they send you information about the appointment*)
- Written information about what the appointment is for and what will happen
- Easy Read information about visiting the hospital
- Easy Read information about what the appointment is for and what will happen
- Leaflet with map of the hospital and photos
- Online map and photos / interactive mobile app

Other -

## Waiting for the appointment

12. How easy would the person you care for find waiting for their appointment?

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

**13. What would make waiting easier? (Tick all that apply)**

- Having a quiet place to wait
- Having an appointment at a quieter time of day
- Something to read or do while they wait

Other -

### **Communication**

**14. How easy does the person you care for find it to explain to the Doctor or Nurse about the reason for the visit?**

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

**15. What would help them to explain things to the Doctor or Nurse? (Tick all that apply)**

- Having a longer appointment
- Pictures / visual aids e.g. show me where cards
- Someone to support them

Other -

**16. How easy would they find it to understand what they are told about treatment, medication or follow on care?**

Very Easy

Fairly Easy

Not Easy

Very Difficult

- Why?

**17. What would help them to understand what they are being told? (Tick all that apply)**

- Having a longer appointment
- If they used clearer language
- Being given written information
- Being given Easy Read information
- Someone to support them

Other -

**18. Is there anything else that you would like to tell us about going to the hospital or things they could do to help people with an Autism Spectrum Condition or their carers?**

## Information

19. Do you feel you have enough information about support and other services and groups available for people with an Autism Spectrum Condition and their carers?

Yes

No

Unsure

20. What has been most valuable?

21. What other information would you find useful?

22. Which two of these would you find / have you found the most useful way to access information about support and other services for people with Autism Spectrum Conditions?

- Leaflets available at health and community settings
- Leaflets available in schools and colleges
- Website - specific section on local health service website
- Social media - e.g. specific page on Facebook or Twitter
- Local telephone contact number
- Drop in sessions for information
- An information App for your phone or tablet
- Other (please state) -

## Support

23. Overall, do you feel that the person you care for receives the support that they need related to their Autism Spectrum Condition?

Yes

No

Unsure

24. What support has been most valuable?

25. Which other support would they find useful?

- One-to-one support with day-to-day tasks at home
- One-to-one support with attending appointments e.g. Doctors and Hospital
- On line support group
- Drop in sessions for support and advice
- Local Autism specific support group
- Other (please state) -

26. Overall, as a carer, do you feel you receive the support that you need?

Yes

No

Unsure

27. What support has been most valuable?

28. What other support would you find useful?



## Getting a Diagnosis

**29. When did the person you care for receive an Autism Spectrum diagnosis?**

- Within the last year
- Within the last 1 - 2 years
- Within the last 2 - 3 years
- More than 3 years ago - please go to question 35

**30. Who referred them for a diagnosis?**

- GP
- Paediatrician
- Other (please state) -

**31. Please rate the information they gave you about what would happen next**

Excellent                      Good                      OK                      Poor                      Very Poor

Comments -

**32. Who gave them their diagnosis?**

- Umbrella Pathway - for children and young people
- Family Psychologist Service
- Private diagnosis
- Other (please state) -

Please rate -

**33. The time it took to get a diagnosis**

Excellent                      Good                      OK                      Poor                      Very Poor

Comments -

**34. The information and support you were given to understand the diagnosis**

Excellent                      Good                      OK                      Poor                      Very Poor

Comments -

**35. Do you have any other feedback about health and care services for people with Autism Spectrum Conditions and their carers and how they can be improved?**

**About You:**

Are you:    Male                       Female                       Other (e.g. Transgender)

How old are you:    13-18            19-24            25-50            51-64            65-74            75 or over

**About the person with ASD:**

Are they:    Male                       Female                       Other (e.g. Transgender)

How old are they:  
0-8    9 - 12            13-18            19-24            25-50            51-64            65-74            75or over

**Where do you live?**

Worcester City                       Redditch                       Bromsgrove  
 Wyre Forest                       Wychavon                       Malvern Hills

**How would you describe your Ethnic Group?**

<b>White</b>	<b>Mixed ethnic groups</b>	<b>Asian / Asian British</b>	<b>Black / Black British</b>
<input type="checkbox"/> British <input type="checkbox"/> Irish <input type="checkbox"/> Gypsy/Irish Traveller <input type="checkbox"/> White other: _____	<input type="checkbox"/> White and Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian <input type="checkbox"/> Any other mixed: _____	<input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian: _____	<input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black: _____ <input type="checkbox"/> Arab/any other group: _____

**Thank you for taking part!**

**Return to: FREEPOST RTEE-GKAT-SRLR Healthwatch Worcestershire,  
 Civic Centre, Queen Elizabeth Drive, Pershore, Worcestershire,  
 WR10 1PT**