

Overcoming barriers to autistic health care:

towards autism-friendly practices

Rates of autism diagnosis have increased over the past 20 years,¹ reflecting increased awareness and recognition both by patients and by GPs. Indeed, many GPs are discovering autistic traits in themselves² mirroring the shift towards increased diagnosis among those without co-occurring intellectual disability. While a fall in referrals for autism assessment occurred early in the pandemic, high profile celebrity revelations, media coverage, and perhaps the pandemic itself, continue to track with climbing numbers of referrals [Table 1].³ In fact, the number of referrals in the first quarter of 2021/2022 were more than double that of the corresponding period in 2019/2020.

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AUTISTIC HEALTH CARE — BEYOND DIAGNOSIS

The needs of autistic patients do not end at diagnosis. Links between autism and poor health outcomes are well known. Higher rates of both physical⁴ and mental ill-health, with up to 30 years shorter life expectancy,⁵ spurred the Royal College of General Practitioners to make autism a clinical priority from 2014–2017. Indeed, a growing body of evidence connects autism and joint hypermobility. In turn this evidence conjoins autism to interoceptive differences,⁶ meaning that bodily experiences, such as illness, pain, puberty, menarche, and menopause, can be challenging for autistic patients.⁷ Given the interoceptive differences and consequent overwhelm, this can, for example, affect an autistic person's ability to communicate when in pain — including non-verbal cues such as facial expressiveness. Consequently, health professionals may not adequately account for autistic patients' distress.⁸

GPs have limited training on autism⁹ and only a minority feel confident when treating autistic patients.¹⁰ Two recently published

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articles^{11,12} from the authors explore this further and offer practical, reasonable adjustments to meet the needs of these patients.

REMOTE CONSULTING — TELEPHONE ASSESSMENT CHALLENGES

Telephone triage has long been part of primary care delivery. The proportion of consultations offered by telephone increased markedly during the pandemic and continues to play a significant role in the delivery of health care. This can be challenging for autistic patients and affect access to care.¹² Indeed, with the loss of subtle cues experienced face-to-face, many doctors themselves feel ill at ease consulting by telephone.

Offering alternatives to telephone may enable autistic patients to access care equitably. This includes interactions with a surgery that enable direct care provision, such as appointment booking or prescription requests, where a suitable alternative may be reasonably offered.

BARRIERS TO PRIMARY HEALTH CARE — PREDICTABILITY, COMMUNICATION, AND SENSORY PROCESSING

Autistic adults report that barriers to primary care lead to poorer health outcomes, identifying predictability, sensory processing, and communication as key domains under which such barriers fall.¹¹ Alongside discrete domains of difficulty, there is a consistent sense that the poor overall understanding of what autism is by all staff affects their care. This aligns with findings of the 2019 'Right to be heard' report,¹³ which led to the Oliver

McGowan Mandatory Training.¹⁴

AUTISM-FRIENDLY PRACTISES AND PRACTICES

Combining these facts, we may surmise that there is more at stake for autistic patients than non-autistic comparisons in terms of finding their GP practice, and its practises, suited to them. This extends beyond encountering kind, empathic staff — though the importance placed on this component has been found to be significant¹¹ — to practical steps that any practice may take.

Predictability. By reducing elements of uncertainty in any situation, we may allay patients' anxiety and thus ameliorate this barrier. Examples of adjustments might include prior notification of precisely what will happen during a cervical screening examination, or appointments with a preferred physician.

Sensory processing. Many autistic people experience sensory processing differences. They may require quiet waiting areas or subdued lighting. Others may not need different sound or lighting adjustments but may need more time to process information during their appointment, for example, does this hurt when I press here? Indeed, during physical examinations it may be helpful to ask the patient to tell you if it hurts rather than relying on facial cues.

Communication. It is good practice to use clear, unambiguous language and to provide written follow-up information. The challenges accompanying the telephone may mean that using electronic or written means of communication is helpful, as indeed are electronic appointment booking systems.¹¹

CONCLUSION

As we settle into the 'new normal' we may consider how we shape general practice to be a more accommodating space for autistic patients and colleagues. Though the adjustments described may be seen

Table 1. Summary of Autism Statistics Quarter 1 (April to June) 2019–20 to Quarter 1 (April to June) 2021–2022³

| Year | 2019/2020 | | | | 2020/2021 | | | | 2021/2022 |
|---------------------|-----------|------|--------|--------|-----------|--------|--------|--------|-----------|
| Quarter | Q1 | Q2 | Q3 | Q4 | Q1 | Q2 | Q3 | Q4 | Q1 |
| Providers, <i>n</i> | 63 | 68 | 70 | 74 | 72 | 78 | 84 | 83 | 91 |
| Referrals, <i>n</i> | 8146 | 9055 | 11 775 | 10 858 | 7750 | 10 162 | 13 988 | 14 319 | 16 991 |

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as simply ‘good practice’ or ‘nice to have’, without these autistic people may suffer adverse health outcomes.

We are beginning to understand that our role as primary healthcare providers goes beyond recognition of autistic traits and onwards referral, but extends through the entire life and all aspects of health. Through the consideration of possible adjustments, together we can support better accessibility to primary care and so improve general health outcomes in autistic patients.

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