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Development and evaluation of a novel caregiver-report tool to assess barriers to physical healthcare for people on the autism spectrum

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ARTICLE INFO

Keywords:
Autism spectrum disorder
Healthcare access
Reasonable adjustments
Healthcare equity
Healthcare disparities
Health

ABSTRACT

Introduction: People on the autism spectrum often experience poorer health than the general population despite higher engagement with the health services. This suggests a disparity in the accessibility of appropriate healthcare for autistic individuals. To improve access, barriers to healthcare first need to be identified. This paper aimed to: 1) develop and evaluate a caregiver-report tool; 2) identify barriers to physical healthcare for autistic individuals; and 3) identify potential contributing factors.

Methods: A previously established taxonomy of barriers to healthcare for autistic individuals informed the development of the tool; this was then distributed to caregivers of autistic adults and children. Exploratory factor analysis (EFA) assessed validity and reliability of the tool. Multiple Regressions were performed to identify predictors of barriers.

Results: In total, caregivers of 194 autistic children or adults participated in the study. The EFA produced four factors: 1) patient-level barriers; 2) healthcare provider-level (HCP) barriers; 3) healthcare system-level barriers; and 4) barriers related to managing healthcare. The greatest barriers included difficulties with identifying/reporting symptoms (endorsed by 62.4% of participants); difficulties handling the waiting area (60.3% of participants); and a lack of HCP knowledge regarding autism (52.1% of participants). Autism severity, general adjustment problems, anxiety, age and having unmet needs predicted the frequency and/or severity of barriers.

Conclusions: A tool that allows assessment of patient-, HCP-, and system-level barriers to healthcare was developed and evaluated. Patient-level barriers appear to occur frequently and pose substantial challenges. This tool will help identify areas most in need of intervention and support intervention evaluation.

1. Introduction

Individuals on the autism spectrum may require a greater degree of interaction with health services due to the multitude of medical comorbidities that often present alongside autism (e.g., gastrointestinal issues, psychiatric conditions, intellectual disabilities; Benevides, Carretta, Graves, & Sikka, 2020; Croen et al., 2015; Levy et al., 2010). Yet, despite the higher rates of contact with both
emergency and non-emergency healthcare (Weiss et al., 2018; Zerbo et al., 2019), autistic individuals tend to have poorer health outcomes (Cashin, Buckley, Trollor, & Lennox, 2016; Croen et al., 2015), engage less with preventative care (Cummings et al., 2016; Nicolaids et al., 2013), have lower health-related quality of life (Kuhlthau, McDonnell, Courey, Payakachat, & Macklin, 2018), and higher mortality rates (Hirvikoski et al., 2016; Woolfenden, Sarkozy, Ridley, Coory, & Williams, 2012) than others. This suggests that autistic individuals face significant inequities in healthcare.

A number of determinants of health inequities for people with learning and developmental disabilities have been outlined (Emerson & Baines, 2010). These include social determinants (e.g., poverty, unemployment); poorer communication and health literacy; poor health behaviours; and deficiencies in access to, and quality of, healthcare. Although research suggests that autistic individuals share many of these determinants of health inequities, this particular population may face additional, unique challenges as the lack of a ‘visible disability’ may lead to a misperception that they experience less barriers and therefore require less support in healthcare settings (Nicolaids et al., 2013; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). Improving access to healthcare may be one way to improve health equity for autistic individuals. Healthcare access is a complex issue for which a number of conceptualisations exist (Derose, Gresenz, & Ringel, 2011). According to Penchansky and Thomas (1981), access should be viewed as the ‘fit’ between the patient’s needs and the health service’s ability to meet those needs. This requires consideration of the availability, accessibility, accommodation, affordability and acceptability of healthcare services. Shengelia, Murray, and Adams (2003), conceptualised access as the likelihood of receiving a healthcare service when it is needed (coverage), and the quantity of healthcare services and procedures used (utilisation). Similarly, Levesque, Harris, and Russell (2013) describe access as the ability to identify healthcare needs, seek services, reach resources, obtain or use services, and be offered services appropriate to needs. Although various conceptualisations of access exist, there appears to be a fundamental commonality that access requires both getting into a service and receiving the appropriate and necessary care, when it is needed.

Disparities in access to healthcare can lead to delays in, or non-receipt of, appropriate care (Lindly, Zuckerman, & Kuhlthau, 2019); higher financial burden on the patient (Drainoni et al., 2006); increased use of emergency care (Broussau, Bergholte, & Gorelick, 2004); higher hospitalisation rates (Long, Coughlin, & Kendall, 2002); higher risk for, and poor management of, chronic illness or comorbid conditions (Bowles, Naylor, & Foust, 2002); greater risk of unmet needs (Coughlin, Long, & Kendall, 2002) and increased burden and cost on the healthcare system due to preventable disease exacerbations and premature deaths (Vecchio, Davies, & Rohde, 2018). Ready access to healthcare on the other hand, is linked to a variety of important outcomes including better health status (Nicolaids et al., 2013), higher patient satisfaction (Babataar, Dorjdagya, Luvsannym, Savino, & Amenta, 2017), lower hospitalisation rates (Ansari, Laditka, & Laditka, 2006), and reduced burden and cost on the healthcare system (Reid et al., 2010). Given the benefits of improved healthcare access to both the health services and the patient, it is important that access issues are examined and remedied among the groups for whom access is impaired.

A growing body of research has identified a complex array of access barriers for autistic people. In a previous taxonomy (Walsh, Lydon, O’Dowd, & O’Connor, 2020), barriers to physical healthcare which were reported/endorsed by autistic individuals, caregivers and HCPs, were categorised as occurring at the level of the patient (e.g., difficulties with social interactions and communication; Zweigenbaum et al., 2016), the HCP (e.g., a lack of physician knowledge about autism; Nicholas et al., 2016), and the healthcare system (e.g., a lack of support for autistic individuals and their families; Unigwe et al., 2017). Other literature has observed similar results (Bradshaw, Pellicano, van Driel, & Urbanowicz, 2019; Mason et al., 2019). Addressing these complex barriers to accessing healthcare requires an understanding of the specific issues that impact on the ability of patients to access the appropriate care in their services. It is therefore important that measurement tools designed to assess barriers to accessing healthcare consider barriers across the healthcare system. A recent systematic review (Walsh et al., 2020) indicated that few caregiver-report tools consider the barriers across the healthcare system (i.e., patient, HCP, and systems levels). Although Raymaker et al. (2016) have developed a thorough self-report tool for autistic adults, not all autistic individuals can self-report on their experiences due to factors such as age or comorbid intellectual disabilities. Therefore, it is important to provide caregiver-report tools that ensure good measurement of potentially diverse barriers. Such tools will enable the identification and evaluation of initiatives that aim to reduce barriers and improve healthcare access or experiences.

1.1. Study aims

The aims of this study were to: 1) develop a valid caregiver-report tool to measure barriers to healthcare for autistic individuals; 2) use the newly developed tool to examine the barriers to care endorsed by caregivers; and 3) identify potential contributing factors such as autism severity, comorbid psychopathologies, or having unmet needs.

2. Methods

2.1. Participants

Eligible participants were: 1) the primary caregivers to an autistic child or adult; 2) over the age of 18; and 3) living in the Republic of Ireland.

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1 Many autistic individuals and their supporters prefer the use of identity-first language (i.e., autistic person) as opposed to person first language (i.e., person with autism; Kenny et al., 2016). Accordingly, this article mainly uses identity first language.
2.2. Measures

2.2.1. Survey instrument

The survey instrument administered to participants consisted of six sections: 1) demographics; 2) barriers to healthcare; 3) frequency of contact with the health services; 4) perceived unmet healthcare needs; 5) autism severity; and 6) presence of co-occurring psychopathology.

2.2.2. Demographics

Caregivers were asked to provide information on both themselves (i.e., age, gender, location, and highest level of education, relationship to the autistic person), and the autistic individual for whom they care (i.e., age, gender, health status).

2.2.3. Barriers to Healthcare tool

2.2.3.1. Literature review. A systematic literature review on barriers to healthcare was conducted and is described in detail elsewhere (Walsh et al., 2020). Individual barriers reported by autistic adults, caregivers and HCPs in the included studies were categorised into a taxonomy of barriers containing 4 themes (autism-related characteristics; other patient-related barriers; HCP-level barriers; system-level barriers). These themes informed the item construction of the tool.

2.2.3.2. Item construction. An iterative method was used to construct the items of the questionnaire, following best practice (Rattray & Jones, 2007). This involved two consensus building meetings between three members of the research team (CW, SL, & POC). The specific items from existing questionnaires were deliberately not reviewed as part of this process as the team wanted to work from the themes within the previous taxonomy (Walsh et al., 2020). It is acknowledged, however, that because there are a finite number of ways to ask about a particular barrier, similarities with items in existing measures may arise through convergence as part of the development process. In the first meeting, questionnaire items \( n = 57 \) were constructed to address the four themes in the taxonomy. During the subsequent meeting, these items were reviewed, refined and condensed into 42 items, each representing a different barrier. Respondents were asked to indicate: 1) the frequency with which that barrier had occurred in the past 12 months on a Likert scale ranging from 0 (never) to 4 (very often); and 2) the severity with which that barrier was experienced on a Likert scale ranging from 1 (slight) to 3 (severe). The response options were adapted from the Behaviour Problems Inventory (Mascitto et al., 2015).

2.2.4. Frequency of contact with the healthcare services

To indicate the frequency of contact with the healthcare services, participants provided information in response to the following three items: 1) number of general practice (GP) visits in the past 12 months; 2) number of emergency department (ED) visits in the past 12 months; and 3) number of hospital visits in the past 12 months.

2.2.5. Unmet needs

Participants were asked to indicate whether unmet healthcare needs had occurred in the last 12 months from GP, hospital, emergency care, mental healthcare service, or ‘other’ services. This item was adapted from (Nicolaidis et al., 2013). For the purpose of analysis, this variable was collapsed into two categories, (i.e., whether they had experienced an unmet need, or not).

2.2.6. Autism severity

The Social Responsiveness Scale-2 was included in the questionnaire as a measure of autism severity. This is a 65-item validated scale (SRS-2; Constantino & Gruber, 2012) that has previously demonstrated high internal consistency (Cronbach’s alpha = .95; Bruni, 2014). There are four versions of the SRS which are intended to allow autism severity to be measured across all age groups: 1) caregiver report: pre-school children, 2.5–4.5 years; 2) caregiver report: school age children, 4.5–18 years; 3) caregiver report: autistic adults, 18+ years; 4) autistic adults self-report. Across all versions, the items, which describe the autistic person’s behaviour over the past 6 months, are similar but worded as appropriate for the respondent (i.e. caregiver/self-report) and developmental stage (child/adult). Each item is scored on a Likert scale ranging from 0 (not true) to 4 (almost always true).

2.2.7. Anxiety, depression, obsessive compulsive disorder, general adjustment problems

The Psychopathology in Autism Checklist (Helverschou, Bakken, & Martinsen, 2009) was used as a measure of comorbid psychopathological issues that may be experienced by autistic individuals. The tool consists of 42 items which correspond to one of four psychiatric disorders: Anxiety (6 items), Depression (7 items), Obsessive Compulsive Disorder (OCD; 7 items), Psychosis (10 items); and General Adjustment Problems (GAP; e.g., sleep disturbances, self-harm, challenging behaviour; 12 items). Four subscales (Anxiety, Depression, OCD, General Adjustment Problems) which have previously demonstrated good internal consistency (Helverschou et al., 2009) were used in the current analysis. Each item is rated on a Likert scale ranging from 1 (not a problem) to 4 (severe problem). The average score per item per subscale is used in analysis.
2.3. Procedures

2.3.1. Recruitment and data collection

A variety of non-probability sampling methods and recruitment strategies were employed in an effort to recruit as wide a sample as possible including: 1) sending letters of invitation with a recruitment flyer to primary and secondary schools (n = 395) which had an ASD unit or special needs class, and to special schools (n = 80) in the Republic of Ireland. Principals were asked to disseminate information on the study and/or distribute questionnaires to the parents of their students; 2) autism parent support groups and autism and intellectual disability support services/organisations were contacted and asked to share information about the study and/or distribute questionnaire packs to their members; and 3) advertisements were placed in local and national newspapers, on local radio, and were posted on social media. Snowballing methods were also employed whereby participants were asked to share information about the study with others. Potential participants were asked to contact the primary author to access further information about the study or to request a survey pack which was either sent to the participant by post with a stamped return envelope, or could be accessed online. Participants were offered the opportunity to enter a prize draw to win one of four €50 gift vouchers as an incentive to participate.

2.4. Ethical approval

Ethical approval for this study was granted by the NUIG Research Ethics Committee (Ref: 17-Nov-20). Informed written or electronic consent was obtained for each participant.

2.5. Statistical analysis

All analyses were performed using IBM SPSS Statistics 24. Significance levels for all analyses were set as $p < .05$.

2.6. Initial data screening

Little’s test for Missing Completely at Random was conducted to ensure the missing data were randomly distributed. Missing Data Analysis in SPSS was also used to assess the missing data. Preliminary analyses were performed to ensure no violations of the assumptions of normality, multicollinearity and homoscedasticity. The reliability of the predictor variable scales (Anxiety; Depression; OCD; GAP; Autism Severity) was assessed by calculating Cronbach’s alphas.

2.7. Addressing aim 1: development of a valid and reliable caregiver-report Barriers to Healthcare tool

2.7.1. Construct validity

Construct validity is concerned with whether the items in the subscale reflect the same construct (Lavrakas, 2008). A way to assess this assertion is to use exploratory factor analysis (EFA; Trevor & Fox, 2001) The approach to EFA outlined by Costello and Osborne (2005) was undertaken.

2.7.2. Step 1: adequacy of the correlation matrix

The suitability of the data for use within an EFA was assessed by considering the sample size, factorability of the constructs (correlation matrix), examination of the Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy and Bartlett’s Test for Sphericity.

2.7.3. Step 2. Factor extraction, retention and interpretation

Principal Axis Factoring was chosen as the factor extraction method as this focuses explicitly on latent factors (Costello & Osborne, 2005). Factor extraction was determined by considering Kaiser’s criteria (Eigenvalue >1), the scree plot, and a parallel analysis (PA; via an online PA engine; Vivek, Surendra, Singh, & Donovan, 2017). Oblique (Promax) rotation was used as the data cannot be assumed to be completely independent of each other. This is considered most accurate for research involving human participants (Costello & Osborne, 2005). Items with factor loadings of greater than 0.4 was chosen as a cut off for factor retention in the current dataset (Stevens, 2012). The pattern matrix guided interpretation and naming of the factors by the research team (Field, 2018; Stevens, 2012).

2.7.4. Step 3. Internal consistency

Internal consistency (the extent to which items within a construct are inter-correlated; Revicki, 2014) was assessed by calculating Cronbach’s alpha for each construct produced by the EFA.

2.8. Aim 2. Examine the barriers to care endorsed by caregivers

2.8.1. Examining barriers endorsed by respondents in terms of frequency

A total Frequency of Barriers scale score was calculated by summing all items that remained after the EFA. Subscale scores were then calculated for each of the extracted factors after the EFA.
2.8.2. Examining the barriers endorsed by respondents in terms of severity

A total Severity of Barriers scale score was calculated by summing all items. No subscale scores were calculated as no EFA was conducted due to insufficient data.

2.9. Aim 3: identify related variables

2.9.1. Identifying variables related to frequency of barriers

A series of five hierarchical multiple regressions was performed to assess whether the frequency of barriers could be predicted by the following variables: 1) age; 2) gender; 3) health status; 4) perceived unmet needs; 5) Autism Severity; 6) Anxiety; 7) Depression; 8) OCD; or 9) General Adjustment Problems. Frequency of contact with the healthcare services was controlled for because it is likely that individuals who have a higher frequency of contact with the healthcare services are more likely to report a higher frequency of barriers. The same method was used for each of the five regressions with just the criterion variable changing each time. These variables were selected on the basis of a systematic review examining barriers to healthcare (Walsh et al., 2020).

2.9.2. Step 1

In each regression, frequency of contact with the health services (i.e., number of GP, ED, and hospital visits in the past 12 months)

Table 1

| Caregiver Characteristics | N(%) |
|---------------------------|------|
| **Age**: M (SD), Range     |      |
| 42.26 (8.15); 23–63years  |      |
| **Gender**                |      |
| Female                    | 162(83.1) |
| Male                      | 33(16.9)  |
| **Education**             |      |
| Primary                   | 2(1)  |
| Secondary                 | 41(21) |
| Third level (Undergraduate)| 66(33.8)|
| Third level (Postgraduate) | 68(34.9)|
| Diploma/certificate trade  | 17(8.76)|
| **Location**              |      |
| Rural                     | 73(37.6) |
| Village                   | 25(12.9) |
| Town                      | 67(34.5)|
| City                      | 29(14.9) |
| **Relationship to autistic individual** | |
| Mother                    | 145(74.7)|
| Father                    | 24(12.4)|
| Other relative            | 1(0.5)  |
| Care worker               | 24(12.4)|
| **Characteristics of Autistic Individuals (N = 194)** | |
| **Age M (SD); Range**     |      |
| 12.47 years (8.89); 2–64 years | |
| < 10                      | 92(47.4)|
| 10–20 years               | 74(38.1)|
| 21–30 years               | 18(9.3) |
| 31–40 years               | 6(3.1)  |
| >40 years                 | 4(2.1)  |
| **Gender**                |      |
| Female                    | 39(20.1)|
| Male                      | 155(79.9)|
| **Health status**         |      |
| Excellent                 | 74(38.1)|
| Good                      | 96(49.5)|
| Fair                      | 20(10.3)|
| Poor                      | 4(2.1)  |
| **Unmet need during past 12 months** | |
| GP                        | 22(11.3)|
| Routine hospital care     | 57(29.4)|
| Emergency care            | 10(5.2) |
| Mental healthcare         | 77(39.7)|
| Other                     | 53(27.3)|
| **Contact with health services during past 12 months** | M (SD); Range |
| GP                        | 3.9(4.12); 0–24 |
| Routine hospital care     | 2.97(5.07); 0–41 |
| Emergency care            | 5.2(1.29); 0–12 |

GP = General practitioner.
were controlled for by entering them in the first step.

2.9.3. Step 2
Age, gender and health status (good/poor) of the autistic individual; perceived unmet healthcare needs (yes/no); Depression; Anxiety; OCD; General Adjustment Problems; and Autism Severity were all entered in the second step. The five criterion variables were: 1) the overall frequency of barriers endorsed; 2) the frequency of barriers endorsed at the patient level; 3) the frequency of barriers endorsed at the healthcare provider level; 4) the frequency of barriers endorsed at the systems level; and 5) the frequency of barriers endorsed relating to managing healthcare.

2.9.4. Predicting severity of barriers
A multiple regression was performed to assess the predictive values of all predictor variables on the perceived severity of barriers. In this analysis, the criterion variable was the total score for perceived severity of barriers and the predictor variables were: age, gender, health status (good/poor), Autism Severity; unmet need (yes/no), contact with health services (i.e., number of GP, ED, and hospital visits in the past 12 months), Anxiety; Depression; OCD; and General Adjustment Problems.

3. Results

3.1. Response rate
Due to the various recruitment methods (i.e., advertising and distributing information leaflets), it is not possible to provide an accurate response rate. A total of 403 surveys were sent, and 194 were returned – an estimated response rate of 48.14 %.

3.2. Participants
Caregivers of 194 autistic children/adults participated in the study. Descriptive statistics indicated that the mean age of caregiver respondents was 42.26 years ($SD = 8.15$, range $23–63$ years). Respondents were mostly female ($n = 162; 83\%$) and were mostly mothers of the autistic individual ($n = 145, 74.7\%$). The majority of autistic individuals about whom the survey was completed were male ($n = 155; 79.9\%$) and had a mean age of $12.47$ years ($SD = 8.89$, range: $2–64$ years). Table 1 provides more detail on sample characteristics.

Table 1
| Scores on Barriers Scales | $N$ | M(SD) | Range | Scores on Predictor Variable Scales | $N$ | M(SD) | Range | $\geq$ cut-off point N(%) |
|---------------------------|-----|-------|-------|------------------------------------|-----|-------|-------|---------------------------|
| Total frequency of barriers; | 194 | 54.8  
(23.06) | 5–119 | Depression | 187 | 1.94 (.60) | 1–3.71 | n/a |
| Frequency of patient-level barriers; | 194 | 23.63  
(8.94) | 1–40 | Anxiety | 187 | 1.69 (.56) | 1–3.83 | n/a |
| Frequency of HCP-level barriers; | 194 | 12.16  
(6.28) | 0–24 | OCD | 187 | 1.78 (.61) | 1–3.57 | n/a |
| Frequency of system-level barriers; | 194 | 14.02  
(9.90) | 0–40 | General Adjustment Problems | 187 | 2.26 (.57) | 1–3.92 | n/a |
| Frequency of barriers related to managing healthcare; | 194 | 5.27 (3.78) | 0–16 | Autism Severity | 187 | 108.61 (26.44) | 50–182 | 171 (91.44) |
| Total severity of barriers; | 121 | 37.45  
(15.95) | 5–80 |

HCP=Healthcare provider; OCD = Obsessive Compulsive Disorder.
3.3.2. Construct validity

3.3.2.1. Step 1. Suitability of the data to an EFA. No pairs of items were highly correlated (>0.8), suggesting that the correlation matrix was adequate, and multicollinearity was unlikely to be an issue (Field, 2018). Bartlett’s test of sphericity indicated the correlation matrix was not an identity matrix ($\chi^2 = 4389.062, df = 861, p < .001$). The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy also indicated that the matrix was suitable for EFA (KMO = 0.89). Examination of the Measures of Sampling Adequacy (MSAs) along the principal diagonal of the anti-image correlation matrix indicated that all variables were suitable for inclusion in the EFA as all had a value greater than 0.8 and off diagonal values were small (<0.3; Tabachnick & Fidell, 2014).

3.3.2.2. Step 2. Factor extraction, retention and interpretation. All 194 participants were included in the EFA. In the current dataset the Eigenvalues >1 rule extracted 10 factors; however, this method has a tendency to over extract factors and so is not generally recommended (Tabachnick & Fidell, 2014). The scree plot suggested retaining three factors. However, since the sample size was <200, it is not advisable to rely on the scree plot alone (Stevens, 2012). To determine the number of factors more rigorously, Parallel Analysis (PA; Horn, 1965) was conducted. The PA suggested retaining four factors as the Eigenvalues for the first four components exceeded the corresponding Eigenvalues generated by random data at the 95th percentile (Appendix 1). Correlations between the factors were observed in the factor matrix suggesting an oblique rotation (Promax) be maintained (Field, 2018).

The four-factor solution cumulatively explained 43.88% of the variance. Nine items did not meet the loading criterion of >0.4 (Stevens, 2012), so were discarded from the model.

On the next iteration all items loaded above 0.4. However, three items loaded with a difference of <2 onto more than one factor. The EFA was run again with these items removed. On the next iteration, all items had a factor loading of >0.4; one item cross loaded onto two variables with a difference of less than 2, so was discarded. On the next iteration, another item did not have a loading of >0.4 on any factor, so was deleted. In the following iteration one item cross loaded onto two factors with a difference of less than 2, so was discarded. On the final iteration, all remaining items had factor loadings greater than 0.4; any evident cross loadings showed a greater difference than 2. This final model explained 50.82% of the variance. Table 3 presents the four extracted factors with the corresponding items, factor loadings, and the amount of variance explained by each factor. The items which had been observed as Kurtosed earlier were discarded during the EFA process (see Appendix 2 for item deletion process). The final Barriers to Healthcare tool contained 27 items and requires approximately 10 minutes to complete (See Appendix 3).

3.3.2.3. Step 3. Internal consistency. As shown in Table 3, Cronbach’s alphas indicated that all four factors showed good internal

| Table 3 |
| Factor Loadings of Items After EFA with Reliability Scores and Variance Explained. |
|---|
| Item | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
| Factor 1: Patient-level barriers (Cronbach’s α = .889; 32.9% variance explained) | | | | |
| Child/adult finds appointments overwhelming; | .841 | | | |
| Child/adult finds it difficult to tolerate medical procedures; | .725 | | | |
| Child/adult finds it difficult to handle the waiting area; | .697 | | | |
| Child/adult dislikes doctors; | .674 | | | |
| Healthcare facilities cause child/adult sensory discomfort; | .624 | | | |
| Caregiver worries that stress of interacting with the healthcare system will cause child/adult distress; | .601 | | | |
| Caregiver is afraid to take child to the doctor; | .586 | | | |
| Caregiver finds healthcare appointments overwhelming; | .584 | | | |
| Child/adult has difficulty identifying/reporting pain and other symptoms; | .582 | | | |
| Child/adult has difficulty communicating their thoughts, wants or needs; | .537 | | | |
| Factor 2: System-level barriers (Cronbach’s α = .865; 8.86% variance explained) | | | | |
| Insurance impacts access to healthcare; | .825 | | | |
| Cost of care impacts access to healthcare; | .759 | | | |
| Insurance does not cover the care we need; | .727 | | | |
| Transport costs too much; | .692 | | | |
| There are other transportation problems; | .562 | | | |
| Inadequate caregiver/family support; | .513 | | | |
| Caregiver does not know where to go; | .454 | | | |
| Factor 3: HCP-Level barriers (Cronbach’s α = .876; 5.07% variance explained) | | | | |
| HCPs do not listen; | .825 | | | |
| Child/s/adult’s behaviours are misinterpreted by HCPs; | .810 | | | |
| HCPs have inadequate knowledge/education for treating autistic people; | .722 | | | |
| Caregiver does not like how HCPs have treated child/adult in the past; | .705 | | | |
| Finding a HCP who will accommodate child/s/adult’s needs can be difficult; | .635 | | | |
| I know others who have had negative healthcare encounters; | .614 | | | |
| Factor 4: Managing healthcare (Cronbach’s α = .753; 4.03% variance explained) | | | | |
| Medical recommendations given to child/adult can be hard to follow; | .697 | | | |
| The treatment plan given to child/adult can be hard to follow; | .582 | | | |
| Caregiver finds it difficult to remember to attend appointments; | .556 | | | |
| Following up on child/s/adult’s care can be difficult; | .530 | | | |

HCP=Healthcare provider; Factor loadings <0.4 are not shown.
consistency as per conventional standards of interpretation (DeVellis, 2016).

3.4. Aim 2: examine the barriers to care endorsed by caregivers

3.4.1. Frequency scores

All 194 participants were included in this analysis. Regarding patient level barriers, more than half of respondents indicated that difficulty identifying/reporting pain/symptoms (62%), finding it hard to handle the waiting area (60%) and being unable to communicate thoughts, wants or needs (53%) were ‘frequent’/‘very frequent’ barriers. Regarding HCP-level barriers, a lack of HCP knowledge was reported by over half of respondents (52%) as a ‘frequent’/‘very frequent’ barrier. At the systems level, almost half of respondents (46%) indicated that a lack of support was a ‘frequent’/‘very frequent’ barrier. For full details of barriers endorsed, see Table 4.

3.4.2. Severity scores

The missing data were found to be randomly distributed for the Severity of Barriers scale. However, a large number of items had a relatively high percentage of missing data (range: 4.6%–11.9%). On closer inspection, it was inferred that data were missing due to misinterpretation of the scale due to its presentation in the questionnaire (see Appendix 3). Participants were asked to choose two responses for each item to indicate: 1) frequency, and 2) severity. However, many participants responded to the frequency scale alone. Therefore, simple mean imputation was not deemed suitable, listwise deletion was used instead. Cronbach’s alpha indicated good internal consistency (α = .925).

Difficulty identifying/reporting pain/symptoms was endorsed as severe by 40% (n = 78) of respondents. This was followed by the autistic individual not being able to communicate their thoughts, wants or needs (36%; n = 70). A lack of HCP knowledge was endorsed as severe by 33% (n = 64) of respondents. See Table 4 for further details. As listwise deletion was used, the sample size for each item varies, the percentages provided reflect the number of participants who responded to that item.

Table 4
Endorsement Rates of Barriers as ‘Very Frequent’/‘Frequent’ and ‘Severe’.

| 1. Patient-level barriers                                                                 | Very frequent/ frequent N (%) | Severe N (%) |
|------------------------------------------------------------------------------------------|-------------------------------|--------------|
| Child/adult finds appointments overwhelming;                                              | 79 (40.7)                     | 40 (20.6)    |
| Child/adult finds it difficult to tolerate medical procedures;                           | 95 (49.0)                     | 39 (20.1)    |
| Child/adult finds it difficult to handle the waiting area;                               | 117 (60.3)                    | 69 (35.6)    |
| Child/adult dislikes doctors;                                                            | 61 (31.4)                     | 35 (18.0)    |
| Healthcare facilities cause child/adult sensory discomfort;                              | 87 (44.8)                     | 50 (25.8)    |
| Caregiver worries that the stress of interacting with the healthcare system will cause child/adult distress; | 92 (47.4)                     | 39 (20.1)    |
| Caregiver is afraid to take child/adult to the doctor;                                   | 36 (18.5)                     | 16 (8.2)     |
| Caregiver finds healthcare appointments overwhelming;                                     | 59 (30.4)                     | 25 (12.9)    |
| Child/adult has difficulty identifying/reporting pain or other symptoms;                 | 121 (62.4)                    | 78 (40.2)    |
| Child/adult has difficulty communicating their thoughts, wants or needs;                  | 103 (53.1)                    | 70 (36.1)    |
| 2. System-level barriers                                                                  |                               |              |
| Insurance impacts access to healthcare;                                                  | 65 (33.5)                     | 38 (19.6)    |
| Cost of care impacts access to healthcare;                                               | 66 (34)                       | 38 (19.6)    |
| Insurance does not cover the care we need;                                               | 67 (34.5)                     | 43 (22.2)    |
| Transport costs too much;                                                                | 41 (21.2)                     | 17 (8.8)     |
| There are other transportation problems;                                                 | 24 (12.4)                     | 12 (6.2)     |
| Inadequate caregiver/family support;                                                     | 90 (46.4)                     | 53 (27.3)    |
| Caregiver does not know where to go;                                                     | 21 (10.8)                     | 10 (5.2)     |
| 3. HCP-Level barriers                                                                    |                               |              |
| HCPs do not listen;                                                                     | 56 (28.8)                     | 31 (16.0)    |
| Child/s’adult’s behaviours are misinterpreted by HCPs;                                   | 63 (32.5)                     | 29 (14.9)    |
| HCPs have inadequate knowledge/education for treating autistic people;                   | 101 (52.1)                    | 64 (33.0)    |
| Caregiver does not like how HCPs have treated child/adult in the past;                   | 45 (23.2)                     | 31 (16.0)    |
| Finding a HCP who will accommodate child/s’adult’s needs can be difficult;               | 77 (39.7)                     | 39 (20.1)    |
| Caregiver knows others who have had negative healthcare encounters;                      | 89 (45.9)                     | 48 (24.7)    |
| 4. Barriers related to managing healthcare                                               |                               |              |
| Medical recommendations given to child/adult can be hard to follow;                       | 42 (21.6)                     | 15 (7.7)     |
| The treatment plan given to child/adult can be hard to follow;                          | 41 (21.2)                     | 18 (9.3)     |
| Caregiver finds it difficult to remember to attend appointments;                         | 23 (11.8)                     | 10 (5.2)     |
| Following up on child/s’adult’s care can be difficult;                                   | 45 (23.2)                     | 11 (5.7)     |

Note: The sample size for each item of the severity scale varied due to listwise deletion. The percentage reflects the number of participants who responded to that item.

HCP = Healthcare provider.
### Table 5
Summary of Regression Analyses.

| Variable                      | Beta  | SE   | F change  | B      | R²   | A R²  |
|-------------------------------|-------|------|-----------|--------|------|-------|
| **Predictors of total frequency of barriers** |       |      |           |        |      |       |
| 1. GP visits                  | .945  | .452 | 5.789**   | .159*  | .087 | .72   |
| Hospital appointments         | .536  | .358 | .108      |        |      |       |
| ED visits                     | 3.022 | 1.507| .151      |        |      |       |
| 2. Autism severity            | .195  | .069 | 14.810*** | .206*  | .483 | .447  |
| Anxiety                       | 1.439 | 3.921| .032      |        |      |       |
| Depression                    | 1.615 | 3.514| .039      |        |      |       |
| OCD                           | −2.670| 2.904| −.066     |        |      |       |
| General adjustment problems   | 17.434| 4.409| .396***   |        |      |       |
| Unmet needs                   | 7.030 | 2.903| .140*     |        |      |       |
| Health status                 | −4.179| 4.728| −.054     |        |      |       |
| Age                           | −5.86 | .157 | −.210**   |        |      |       |
| Gender                        | −1.794| 3.549| −.029     |        |      |       |
| **Predictors of frequency of patient-level barriers** |       |      |           |        |      |       |
| 1. GP visits                  | .102  | .169 | 2.385     | .047   | .038 | .022  |
| Hospital appointments         | .080  | .134 | .044      |        |      |       |
| ED visits                     | .161  | .562 | .160      |        |      |       |
| 2. Autism severity            | .113  | .026 | 14.177*** | .330***| .445 | .406  |
| Anxiety                       | −.697 | 1.476| −.043     |        |      |       |
| Depression                    | −.189 | 1.323| −.013     |        |      |       |
| OCD                           | −1.949| 1.093| −.132     |        |      |       |
| General adjustment problems   | 7.856 | 1.524| .492***   |        |      |       |
| Unmet needs                   | −.540 | 1.093| −.030     |        |      |       |
| Health status                 | 1.704 | 1.780| .061      |        |      |       |
| Age                           | −.118 | .059 | −.116     |        |      |       |
| Gender                        | −.397 | 1.336| −.018     |        |      |       |
| **Predictors of frequency of HCP-level barriers** |       |      |           |        |      |       |
| 1. GP visits                  | .175  | .117 | 3.013*    | .116   | .047 | .031  |
| Hospital appointments         | .141  | .093 | .112      |        |      |       |
| ED visits                     | .424  | .389 | .084      |        |      |       |
| 2. Autism severity            | .032  | .021 | 5.900***  | .132   | .270 | .220  |
| Anxiety                       | −.430 | 1.179| −.038     |        |      |       |
| Depression                    | .438  | 1.056| .042      |        |      |       |
| OCD                           | −1.032| .873 | −.100     |        |      |       |
| General adjustment problems   | 3.602 | 1.217| .324**    |        |      |       |
| Unmet needs                   | 2.208 | .873 | .174*     |        |      |       |
| Health status                 | −.177 | 1.421| −.091     |        |      |       |
| Age                           | −.100 | .047 | −.142*    |        |      |       |
| Gender                        | −.923 | 1.067| −.059     |        |      |       |
| **Predictors of frequency of healthcare system-level barriers** |       |      |           |        |      |       |
| 1. GP visits                  | .479  | .182 | 5.507**   | .201** | .083 | .068  |
| Hospital appointments         | .201  | .144 | .101      |        |      |       |
| ED visits                     | .775  | .606 | .097      |        |      |       |
| 2. Autism severity            | .032  | .031 | 8.366***  | .083   | .360 | .316  |
| Anxiety                       | 3.898 | 1.751| .218*     |        |      |       |
| Depression                    | −.286 | 1.569| −.017     |        |      |       |
| OCD                           | −.003 | 1.297| .000      |        |      |       |
| General adjustment problems   | 3.444 | 1.808| .195      |        |      |       |
| Unmet needs                   | 3.701 | 1.296| .184**    |        |      |       |
| Health status                 | −2.711| 2.111| −.088     |        |      |       |
| Age                           | −.329 | .070 | −.205**   |        |      |       |
| Gender                        | .113  | 1.585| .005      |        |      |       |
| **Predictors of frequency of barriers related to management of healthcare** |       |      |           |        |      |       |
| 1. GP visits                  | .121  | .070 | 3.419*    | .134   | .053 | .038  |
| Hospital appointments         | .074  | .055 | .099      |        |      |       |
| ED visits                     | .290  | .233 | .096      |        |      |       |
| 2. Autism severity            | .015  | .013 | 4.370***  | .108   | .228 | .174  |
| Anxiety                       | −1.198| .726 | −.177     |        |      |       |
| Depression                    | .888  | .651 | .142      |        |      |       |
| OCD                           | .311  | .538 | .050      |        |      |       |
| General adjustment problems   | 1.596 | .750 | .239*     |        |      |       |
| Unmet needs                   | .381  | .538 | .050      |        |      |       |
| Health status                 | −1.260| .876 | −.108     |        |      |       |
| Age                           | −.076 | .029 | −.179*    |        |      |       |
| Gender                        | .417  | .657 | −.045     |        |      |       |
| **Predictors of overall severity of barriers** |       |      |           |        |      |       |
| 1. GP visits                  | .388  | .326 | .094      |        |      |       |
| Hospital appointments         | .254  | .210 | .088      |        |      |       |

(continued on next page)
To view the full text, please use a compatible PDF viewer.
from previously developed tools (e.g., Bultas, McMillin, & Zand, 2016; Lum, Garnett, & O’Connor, 2014; Raymaker et al., 2016). This is unsurprising as there are a finite number of ways to ask about a particular barrier, as evidenced by the convergence observed across tools included in the previous systematic review (Walsh et al., 2020; e.g., I don’t have insurance coverage - Raymaker et al., 2016; Insurance benefits never/always cover child’s needs - Ahmedani & Hock, 2012; Difficulties related to insurance coverage - Kuhlthau et al., 2016; no insurance – Chiri & Warfield, 2012). Since these studies, among others, informed the taxonomy upon which the tool was based, some level of convergence is to be expected. Fifteen of the original items were removed as part of the development of the tool, a common practice in survey tool development (DeVellis, 2016). The EFA indicated that the latent constructs underlying our tool did indeed corresponded to patient, HCP and systems-level barriers. An additional factor also emerged, which does not fall easily onto any one of the three levels: barriers related to managing healthcare (e.g., finding it difficult to follow up on care). It is possible that this occurred as the tool was developed based on barriers identified/endorsed by caregivers, autistic individuals and HCPs. For autistic individuals, difficulty on following up on care may be related to patient level factors such as issues with executive function (Raymaker et al., 2016). For caregivers, this may reflect systemic issues (e.g., being unable to get referrals; Chiri & Warfield, 2012), or HCP-level barriers (e.g., poor communication between the HCP and caregiver; Lake, Milovanov, Sawyer, & Lunsky, 2014). Future research could investigate this more thoroughly.

4.2. Identification of barriers

The second aim of this paper was to examine the barriers that were endorsed by participants. The findings that barriers occur at the patient, HCP and systems levels echo previous research (Bradshaw et al., 2019; Mason et al., 2019; Nicolaidis et al., 2015). Difficulty reporting/identifying pain/symptoms is the barrier which was most often endorsed and echoes previous qualitative studies with autistic individuals, caregivers and HCPs (Muskat et al., 2014; Nicolaidis et al., 2015; Van Cleave et al., 2018). Difficulty communicating/interpreting symptoms is a serious issue as misinterpretation can lead to diagnostic overshadowing, misdiagnosis, or delayed or non-receipt of care (Allely, 2013; Nicolaidis et al., 2015; Scarpinato et al., 2010). To facilitate effective communication and interpretation of pain/symptoms, it is likely that a variety of interactive methods and observations are required (Ely, Chen-Lim, Carpenter, Wallhauser, & Friedlaender, 2016). Choosing appropriate methods will depend on the autistic individual’s specific needs and preferences but may include the use of electronic devices or rating scales such as the Wong-Baker FACES scale (Ely et al., 2016; Eufemia, 2009).

More than half of caregivers reported a lack of HCP knowledge and training as a frequent barrier with over a third of caregivers identifying this a severe issue. A lack of provider knowledge regarding autism has been widely reported by HCPs, caregivers and autistic individuals, indicating the need for improved autism training for HCPs (McCormack, Dillon, Healy, Walsh, & Lydon, 2019; Golnik, Ireland, & Borowsky, 2009; Zerbo, Massolo, Qian, & Croen, 2015). Autistic standardised patients (SPs) are a novel method of incorporating autism training into the medical curriculum and encouraging results have been observed with nursing students when combined with classroom instruction (McIntosh & Thomas, 2020; McIntosh, Thomas, Allen, & Edwards, 2015). Research should continue to investigate the conditions under which such simulations are most effective and assess their feasibility with other healthcare professionals.

4.3. Predictors of barriers

The third aim of the paper was to examine the potential predictors of the frequency and severity of the endorsed barriers. Two of the key predictors were General Adjustment Problems and having experienced unmet needs in the past 12 months. General Adjustment Problems (e.g., aggression towards self/others) can hinder the delivery of care (Bultas, 2012; Bultas et al., 2016). Such behaviours can be a response to feeling fearful or overwhelmed during a healthcare encounter but advanced preparation, use of rewards or reinforcement, and distraction or structured activities have been identified as helpful strategies for reducing the occurrence of such behavioural challenges in healthcare contexts (Johnson, Bekhet, Robinson, & Rodriguez, 2014; Johnson, Bree, et al., 2014). Efforts should, therefore, be made to examine which strategies might work best for different individuals in preparation for a healthcare visit.

Similar to the current study, unmet needs have previously been linked to HCP-level barriers such as being unable to find HCPs who can adequately accommodate autistic patients (Chiri & Warfield, 2012). Providing training to HCPs which encompasses identifying and implementing accommodations could, therefore, reduce the occurrence of unmet needs. It is important to not only focus on HCP training, however. Altering the delivery of care may also reduce unmet needs. A growing body of research has indicated that access to a medical home (a team-based model of primary care which offers comprehensive and continuous, patient/family-centred care; American Academy of Family Physicians, n.d.) can reduce unmet needs and improve satisfaction with care (Golnik, Maccabee-Ryaboy, Scal, Wey, & Gaillard, 2012. Since 2012, the Primary Care Centre (PCC) model has been developing in Ireland which is similar to the medical home model in the United States. PCCs aim to provide multidisciplinary, first-point of care which includes physician care, occupational therapy, speech and language therapy, and psychological services in one setting (Department of Health, 2019). The current tool could be used as a pre/post assessment to evaluate whether PCCs can reduce unmet needs and barriers to care for autistic individuals and their families in Ireland.

4.4. Limitations

There a number of limitations to this study which need to be considered. First, despite sampling efforts, and although caregivers of autistic adults did participate, this group remained underrepresented and so the results of the study are likely more reflective of autistic
children. Much of our recruitment was done through schools and online support groups which may be more likely to have younger parents as members. Future research could use the tool to compare barriers experienced by caregivers of autistic adults and children to assess whether separate tools would be more beneficial. Second, our sample of autistic individuals was predominantly male, but this is consistent with autism prevalence rates (Loomes, Hull, & Mandy, 2017), future research may want to use the tool to compare barriers experienced by different genders. Third, autism diagnosis was caregiver-reported however, the use of the SRS-2 supported this, as over 90% of the sample scored above the cut-off score for indication of autism diagnosis (Hus, Bishop, Gotham, Huerta, & Lord, 2013) and those who did not, fell just marginally below it. Fourth, due to the correlational nature of regression analyses, only associations can be determined between the predictor and criterion variables without causal inference. Fifth, although the tool was informed by previous research with autistic participants, their supporters and HCPs, it would have benefitted from direct community involvement; unfortunately, this was not possible in the current project due to time and resource constraints. The authors support the need to engage in co-creation of tools and interventions with the autism community to ensure that research priorities are aligned, appropriate and acceptable (Chown et al., 2017) and recommend that future research conduct validation work on this tool with autistic self-advocates and their supporters. Sixth, although health insurance was listed as a barrier in the tool, it is unknown how many participants in the current sample had private health insurance. In two-tiered healthcare systems, such as in Ireland, private health insurance can be linked to higher socio-economic status, which can be linked to improved access to care (Martin, Siciliani, & Smith, 2020; Sundmacher & Kopetsch, 2013). Future research may wish to use the current tool to compare barriers experienced by families who have private health insurance and those who do not. Seventh, no comparison group was included in the study; future research may want to use the current tool to compare barriers experienced by caregivers of autistic and non-autistic individuals. Finally, a high percentage of data were missing from the Severity of Barriers scale which was likely an unfortunate result of the presentation of the scale in the questionnaire. As a result of the missing data, the sample size was small for this particular scale so analysis of this data should be considered with caution.

4.5. Future research

It is important to acknowledge that this paper only describes the initial development of the tool and so further validation research is required to examine: reproducibility (does the same factor structure result from the analysis of another sample of responses?); responsiveness (is the tool sensitive to changes?); and interpretability (can qualitative meaning be assigned to the quantitative scores?; Rattray & Jones, 2007). Future research could also further refine the tool and assess whether adaptations are required to suit different sub-groups (e.g., individuals with intellectual disabilities). Cognitive interviewing with autistic individuals and their caregivers may be beneficial for this.

We recommend that this tool be used to assess the barriers which might exist in healthcare facilities. Previous work has highlighted that although HCPs are aware that accommodations are required, they often struggle with knowing what accommodations are needed and how to implement them (Tuffrey-Wijne & Hollins, 2014). HCPs could ask caregivers of their autistic patients to complete the current tool so that they can identify what barriers exist for that patient in their specific healthcare setting. This may facilitate conversations between the HCP, the caregiver and the autistic person around what accommodations might be helpful and how these might be implemented; for example, allowing the patient to wait outside until their consultation if they are unable to tolerate the waiting area. Future research might also consider using the tool to collect data across different services to identify service-specific barriers. This knowledge could help raise HCPs’ awareness of barriers they may be more likely to encounter in their own contexts and help them identify the required accommodations. This could also help determine whether tailored tools or subscales for different settings and medical professions would be beneficial.

The current tool could also be used to compare barriers experienced by different subgroups of the autism community. Autism severity was a significant predictor of barriers in the current study which suggests a need to examine how different subgroups (e.g., those with co-occurring psychopathology, different intellectual abilities, different abilities in daily living skills) within the autism community experience barriers to healthcare. Knowing whether some barriers and their associated accommodations are more common for different subgroups could help HCPs better prepare for visits with different patients. More research representing autistic adults who may not be able to self-report is also needed. This group is under-represented in research in general (Russell et al., 2019). In the current study, autistic adults accounted for just 16.5% of the sample, despite recruitment efforts and it is unknown how many were capable of self-reporting. Consideration of ways to better engage caregivers of autistic adults who can and cannot self-report is recommended.

The current Covid-19 pandemic has exacerbated the inequities faced by autistic individuals, compounding the need to highlight and overcome barriers to care (Ne’eman, 2020; Pellicano & Stears, 2020; The National Autistic Society, 2020). The increased social isolation has had disproportionate adverse effects on the mental health of autistic individuals (The National Autistic Society, 2020) and although many services have moved online, many people do not have access to, or the ability to use, the internet, so are not getting needed support (The National Autistic Society, 2020). Many autistic people have underlying medical conditions, placing them at a higher risk of complications if they contract the virus; yet those living in residential care, or as inpatients in mental healthcare facilities, may be more at risk of becoming sick due to living in close quarters with others (Ne’eman, 2020). Those who do become sick may face additional challenges. Communication issues, for example, may cause particular difficulties for an autistic person who is hospitalised if they cannot be accompanied by a supporter under coronavirus restrictions (Ne’eman, 2020). The pandemic has also demonstrated how accommodations to services are possible, however. Changes in service delivery, such as the move to online/telephone healthcare consultations, or waiting in the car outside a healthcare facility rather than in the waiting area, are examples of accommodations that the autism community have long been asking for, which have become the norm as a result of the pandemic (Cassidy et al., 2020). Future research should monitor the effects of such changes on the accessibility of healthcare for autistic individuals and examine how
these changes may be maintained in the long term for those who need them.

4.6. Conclusions

Caregivers of autistic individuals indicate that a range of barriers are experienced by people on the autism spectrum when attempting to access healthcare, and that these barriers occur at the level of the patient, healthcare provider and system. As a result, the autistic community experiences disparities in healthcare and unmet healthcare needs. In order to improve access, initiatives which aim to make healthcare more inclusive for individuals on the autism spectrum, such as improved autism training for healthcare professionals, are required. It is hoped this tool will help to identify areas most in need of attention and guide intervention development and evaluation.

Author contributions

CW, POC and SL proposed and designed the study. CW and AH collected the data. CW analysed the data and drafted the manuscript. CW, SL, and POC contributed to the manuscript. All authors have read, commented on and approved the final manuscript.

Declaration of Competing Interest

The authors declare they have no conflicts of interest.

Acknowledgements

This study was funded by the Irish Research Council (funding reference: GOIPG/2017/1356) and the School of Medicine National University of Ireland Galway as part of a PhD scholarship programme. The funders had no part in study design, data collection, data analysis or interpretation, writing of the report or decision to submit the article for publication.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:10.1016/j.rasd.2020.101680.

References

Ahmedani, B. K., & Hock, R. M. (2012). Health care access and treatment for children with co-morbid autism and psychiatric conditions. *Social Psychiatry and Psychiatric Epidemiology, 47*(11), 1807–1814. https://doi.org/10.1007/s00127-012-0482-0.

Alleye, C. S. (2013). Pain sensitivity and observer perception of pain in individuals with autistic spectrum disorder. *The Scientific World Journal, 2013*. https://doi.org/10.1155/2013/916178.

American Association of Family Physicians (n.d.). Medical Home. https://www.aafp.org/about/policies/all/medical-home.html.

Ansari, Z., Laditka, J. N., & Laditka, S. B. (2006). Access to health care and hospitalization for ambulatory care sensitive conditions. *Medical Care Research and Review, 63*(6), 719–741. https://doi.org/10.1177/1077558706293637.

Batbaatar, E., Dorjdagva, J., Luvsannyam, A., Savino, M. M., & Amenta, P. (2017). Determinants of patient satisfaction: A systematic review. *Perspectives in Public Health, 137*(2), 89–101. https://doi.org/10.1177/175791916634136.

Benevides, T. W., Carretta, H. J., Graves, K. Y., & Sikka, V. (2020). Emergency department use among young adult Medicare beneficiaries with autism and intellectual disabilities. *Research in Autism Spectrum Disorders, 70*. Article 101470. https://doi.org/10.1016/j.rasd.2019.101470.

Bowles, K. H., Naylor, M. D., & Foust, J. B. (2002). Patient characteristics at hospital discharge and a comparison of home care referral decisions. *Journal of the American Geriatrics Society, 50*(2), 336–342. https://doi.org/10.1046/j.1532-5415.2002.50067.x.

Bradshaw, P., Pellicano, E., van Driel, M., & Urbanowicz, A. (2019). How can we support the healthcare needs of autistic adults without intellectual disability? *Current Developmental Disorders Reports, 6*(2), 45–56. https://doi.org/10.1007/s40474-019-00159-9.

Brousseau, D. C., Bergholte, J., & Gorelick, M. H. (2004). The effect of prior interactions with a primary care provider on nonurgent pediatric emergency department use. *Archives of Pediatrics & Adolescent Medicine, 158*(1), 78–82. https://doi.org/10.1001/archpedi.158.1.78.

Bruni, T. P. (2014). Test review: Social responsiveness scale–Second edition (SRS-2). *Journal of Psychoeducational Assessment, 32*(4), 365–369. https://doi.org/10.1177/0734292913517525.

Bultas, W. (2012). The health care experiences of the preschool child with autism. *Journal of Pediatric Nursing, 27*(5), 460–470. https://doi.org/10.1016/j.jped.2011.05.005.

Bultas, M. W., McMillin, S. E., & Zand, D. H. (2016). Reducing barriers to care in the office-based health care setting for children with autism. *Journal of Pediatric Health Care, 30*(1), 5–14. https://doi.org/10.1016/j.pedhc.2015.08.007.

Cashin, A., Buckley, T., Trolor, J. N., & Lennox, N. (2016). A scoping review of what is known of the physical health of adults with autism spectrum disorder. *Journal of Intellectual Disabilities, 22*(1), 96–108. https://doi.org/10.1177/1744629516655242.

Cassidy, S. A., Nicolaidis, C., Davies, B., Rosa, S. R. D., Eisenman, D., O’niwu, M. G., … Waisman, T. C. (2020). An expert discussion on autism in the COVID-19 pandemic. *Autism in Adulthood Knowledge Practice and Policy*.

Chini, G., & Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with Autism Spectrum disorder. *Maternal and Child Health Journal, 16*(5), 1081–1091. https://doi.org/10.1007/s10995-011-0833-6.

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., & MacGregor, D. (2017). Improving research about us, with us: A draft framework for inclusive autism research. *Disability & Society, 32*(5), 720–734. https://doi.org/10.1080/09687599.2017.1320273.

Constantino, J. N., & Gruber, C. P. (2012). Social responsiveness scale second edition (SRS-2): Manual. Western Psychological Services (WPS).
