



HHS Public Access

Author manuscript

J Autism Dev Disord. Author manuscript; available in PMC 2022 August 01.

Published in final edited form as:

J Autism Dev Disord. 2022 August ; 52(8): 3598–3611. doi:10.1007/s10803-021-05240-0.

“I don’t do much without researching things myself”: A mixed methods study exploring the role of parent health literacy in autism services use for young children

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Abstract

Little is known about how parent health literacy contributes to health-related outcomes for children with autism. This mixed-methods study included 82 U.S. parents of a child with autism 2–5 years-old and sought to describe (1) health literacy dimensions, (2) how health literacy influences services use, and (3) health literacy improvement strategies. Results showed: autism information was accessed from multiple sources; understanding autism information involved “doing your own

Conflict of interest

The authors have no relevant financial or non-financial interests to disclose.

Ethical Approval

This study was approved by the Partners Institutional Review Board. The authors certify that this study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments.

Informed Consent

Informed consent was obtained from all individual participants included in the study.

Disclaimer

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research”; autism information empowered decision-making; health literacy facilitated behavioral services use; health literacy influenced medication use; family and system characteristics also affected services use; autism education remains needed; services information is needed across the diagnostic odyssey; and greater scientific information accessibility would increase uptake. Findings demonstrate how parent health literacy affects services use.

INTRODUCTION

Autism spectrum disorder (autism) is a chronic condition that affects the health of many children and their families (Hirvikoski et al., 2016; Kuhlthau et al., 2018; Maenner et al., 2020). The use of evidence-based, autism services following timely diagnosis may optimize health for this population (Reichow et al., 2012; Weitlauf et al., 2014). Still, comprehensive knowledge of how parents decide to use certain autism services, particularly evidence-based services, for young children is limited.

Recent autism services research underscores the lack of knowledge about this topic: roughly 28 percent (Payakachat et al., 2018; Zuckerman et al., 2017) to 40 percent (Pringle et al., 2012) of young children with autism are estimated to use evidence-based services like applied behavioral analysis (ABA), while approximately 45 percent (Owen-Smith et al., 2015; Perrin et al., 2012) use complementary health approaches (e.g., special diets). Although most complementary health approaches have limited evidence supporting their efficacy and/or safety for autism (Hyman et al., 2020), parents of young children may pursue them as often if not more often than evidence-based services for myriad reasons. These reasons include high perceived effectiveness of complementary health approaches for autism or beliefs that these approaches are “natural” (Christon et al., 2010; Lindly et al., 2018). Relatedly, parents may be impeded in using evidence based autism services by well-established barriers to autism care (e.g., low services availability; Zuckerman et al., 2017) and by high unmet need for services more generally (Lindly et al., 2016; Zablotsky et al., 2015).

Parent health literacy may further contribute to autism services use for young children. Health literacy is an individual’s ability to access, understand, appraise, and use needed health information and services to make appropriate health decisions (Sørensen et al., 2012). More broadly, health literacy is conceptualized as a family capacity that can promote health across the lifespan (Mistry et al., 2012). Because children with autism are commonly diagnosed in early childhood (Zuckerman et al., 2015), they depend on their parents to make decisions for them about services use. Parents are, therefore, critical partners in the care of young children with autism, and their health literacy is germane to optimal autism services use.

Many U.S. adults (~ 80 million; Kutner et al., 2006) and more than one-quarter (~ 29%) of U.S. parents have limited health literacy (Yin et al., 2009). From a public health perspective, this is concerning because limited parent health literacy is associated with poor child health outcomes like nonstandard medication dosing, decreased medication adherence, increased hospitalization, and missed school days (DeWalt & Hink, 2009). Furthermore, greater understanding of health literacy in advancing population health—especially for groups likely

to experience adverse health outcomes such as individuals with autism—is a national health priority [U.S. Department of Health and Human Services (USDHHS), 2014].

Yet, little is known about parent health literacy and autism services use for young children (Lindly et al., 2020). Most health literacy research has primarily been on adult populations (Berkman et al., 2011) or on general pediatric populations (DeWalt & Hink, 2009), with some focus on children with asthma (Keim-Malpass et al., 2015; Yin et al., 2017). Within the context of persistent and marked health disparities experienced by individuals with autism, it is especially important to consider parent health literacy as a potentially modifiable factor that could advance health for this population, beginning in early childhood. Significant gaps exist in understanding health literacy particularly from parents' perspectives and how health literacy relates to autism services use. This information is vital for taking steps to address health literacy in better supporting children with autism and their families to access services that optimize health.

Study Aims and Conceptual Framework

This study aimed to (1) describe key health literacy dimensions, (2) examine how health literacy influences autism services use for young children, and (3) identify health literacy improvement strategies related to autism services use from the perspectives of parents whose young children have autism. To guide the study's methodology addressing these aims, we adapted the integrated conceptual model of health literacy (Sørensen et al., 2012). We focused on the shaded constructs in Fig. 1. Sample indicators are bulleted in each construct. For each aim, the following four health literacy components were included (Sørensen et al., 2012; Connelly & Turner, 2017): (1) access, (2) understanding, (3) evaluation (appraisal), and (4) use of health information and services for health decisions. We integrated health literacy antecedents with predisposing, reinforcing, and enabling factors from the PRECEDE-PROCEED model (Green et al., 1980). For Aims 2 and 3, we included educational or behavioral interventions, psychotropic medication, complementary health approaches, and family support services as the main autism services types. Other outcomes in the framework, but not focused on in this study, are health promoting behaviors (e.g., physical activity) and more distal health outcomes (e.g., quality of life).

METHODS

Design

Pragmatism served as the overarching theoretical paradigm guiding this study (Jacobsen, 2021). We supposed that reality may be interpreted differently and is situational among parents of young children with autism (Jacobsen, 2021). For these reasons, we employed a convergent mixed methods design in which we concurrently gathered survey data and focus group data to synergistically address the study's three aims (Creswell & Plano Clark, 2018). The Partners Institutional Review Board approved this study.

Recruitment and Sample

From November 2018 to June 2019, we recruited parents of one or more child with autism ages 2–5 years enrolled in the Simons Powering Autism Research for Knowledge

(SPARK) study. SPARK is a large genetic study of autism funded by Simons Foundation Autism Research Initiative. SPARK is a national collaboration with 31 academic medical centers that has enrolled more than 23,815 families in an online research cohort (SPARK Community, 2018). At the time of this study, SPARK had enrolled approximately 5,311 children with autism ages 2–5 years. SPARK used the following inclusion criteria: a professional autism spectrum disorder diagnosis that if based on the prior DSM-IV-TR criteria must have included Asperger’s syndrome, autism/autistic disorder, or pervasive developmental disorder-not otherwise specified (parent-reported); family members are biological parents or are the non-biological guardian of the individual with autism; U.S. residency; and the ability to understand English (Simons Foundation Autism Research Initiative, 2017).

We sampled individuals from each major U.S. region (Midwest, Northeast, South, West), targeting recruitment to the ten states with the lowest adult high school graduation rates per the 2018 American Community Survey. We further sampled individuals based on the cities or towns with the lowest adult high school graduation rates in each state. Because low parent educational attainment (e.g., less than high school or a high school diploma or equivalent degree) has been associated with limited parent health literacy (Yin et al., 2009), we used this approach to oversample individuals who were likely to have limited health literacy. Most participants were recruited from Texas, New York, and Ohio (Supplemental Table 1).

SPARK staff initially contacted eligible SPARK participants to obtain their permission to be contacted for study recruitment. SPARK then provided contact information for interested individuals to our research team. Three research team members proceeded to contact these individuals by telephone and/or e-mail. If individuals confirmed their willingness to participate, we obtained verbal informed consent and scheduled participants to complete the survey and focus group or interview (hereinafter focus group).

Eighty-two parents completed the survey with 44 also completing a focus group. Table 1 summarizes the sample’s characteristics overall (i.e., those who completed a survey with or without a focus group) and by study component completed (i.e., survey only versus survey and focus group). Approximately 20 percent of the overall sample had limited health literacy, and significantly more participants with limited health literacy completed the survey only versus the survey and focus group (30.6% versus, 11.4%, $p = 0.049$).

Data Collection

To help ensure participant comprehension, the survey was verbally administered to participants over the telephone by a trained research team member. The survey took 15–45 min to complete. Research team members entered participants’ survey data using an electronic version of the questionnaire. Participants completed their focus group through the web-based video conference platform, Zoom, one to three week(s) following survey completion. For participants who did not have a Web camera for their computer, we mailed a camera for them to borrow. For participants without a computer and/or a reliable internet connection, telephone participation was permitted. Each focus group was 30–90 min. Eleven focus groups, with 2–6 participants, and four individual interviews were conducted. All

focus groups were audio recorded, and audio files were transcribed verbatim. A \$30 participant payment was provided.

Questionnaire—We developed a structured questionnaire that included items on parent and child sociodemographic characteristics, parent health literacy, autism services use, health information seeking, and understanding and using health insurance. Existing measures of parent and child sociodemographic characteristics (e.g., parent age, parent race and ethnicity) were adopted from the 2016–2017 National Survey of Children’s Health (The United States Census Bureau, Associate Director of Demographic Programs, 2017). The Newest Vital Sign (NVS) was used to assess parent health literacy because it is a widely used, brief health literacy screening instrument that measures prose, document, and quantitative health literacy, and identifies individuals with limited health literacy (Weiss et al., 2005). The NVS takes an average of 3–5 min for completion (Weiss, 2018). We adopted service use measures from the 2011 National Survey of Pathways to Diagnosis and Services (Centers for Disease Control & Prevention, 2012) and the 2016–2017 National Survey of Children’s Health (The United States Census Bureau, Associate Director of Demographic Programs, 2017). Autism service types included educational and/or behavioral interventions (e.g., speech and language therapy, ABA), prescription medication, complementary health approaches (e.g., special diets), and family support services (e.g., respite care). We also assessed if the child had a preventive medical care visit and any emergency department visit(s) during the past 12-months. Health information seeking items including sources (e.g., internet) that parents had gotten autism information from during the past 12-months, last autism information source accessed, and level of trust for each autism information source were adapted from the Looking for Health Information section of the Health Information National Trends Survey 5 Cycle 1. Items on understanding and using health insurance were adopted from the Urban Institute’s Health Reform Monitoring Survey. Items assessed participant understanding of premiums, deductibles, co-payments, co-insurance, maximum out-of-pocket spending, provider network, and covered services. Confidence with the following activities related to participants’ health plans were also assessed: finding a doctor/other healthcare provider in the health plan’s network, figuring out whether a service was covered by the plan, figuring out which prescription drugs were covered by the plan, figuring out how much a healthcare visit or service would cost, figuring out how much it would cost to visit an out-of-network provider, and figuring out what counts as preventive care under the health plan.

Focus Group Guide—The focus group guide contained unstructured questions and probes about parents’ perspectives on health literacy including barriers and facilitators to their health literacy, how their health literacy influenced autism services use, and health literacy improvement strategies for parents of young children with autism. Sample questions by study aim are shown in Supplemental Table 2. We conducted 10 cognitive interviews using think-aloud and verbal probing methods (Willis, 1999) with parents of children with autism to refine the guide before this study.

Analysis

Quantitative Data Analysis—To characterize the sample and determine variable properties from the survey data, we initially computed descriptive univariate statistics. We then computed bivariate statistics (e.g., cross-tabulated proportions, means, Wilcoxon rank sum tests, Fisher’s exact tests) to determine differences in the distribution of parent and child characteristics by study component completion (survey only versus survey and focus group) and parent health literacy (adequate versus limited). We also computed bivariate statistics to examine associations between parent health literacy and autism services use. All analyses were performed in Stata 16 (StataCorp, 2019).

Qualitative Data Analysis—A directed content analysis approach was used to analyze the focus group data (Hsieh & Shannon, 2005). This approach was intended to validate and extend the conceptual framework regarding parent health literacy for young children with autism. Elemental coding methods were primarily used including descriptive, in vivo, and structural coding (Saldaña, 2013).

Three research team members initially independently identified codes using data from two transcripts. They then met to discuss the codes identified and agreed on a set of codes to use in analyzing the remaining data. Two research team members met after coding each subsequent transcript. As new codes emerged, they communicated what these were and collectively decided whether to add them to the coding scheme. They resolved disagreements by conferring with a third research team member.

Sample structural codes relevant to data gathered through questions about key health literacy dimensions (Aim 1) included “Experiences Accessing Information” and “Approaches to Understanding and Evaluating Information,” as well as descriptive codes like “Hard to access information,” “Misinformation is abundant,” “Assessed child’s response to services,” and “Consulted partner.” These and other codes were used to distill themes related to the study aims. We selected exemplar quotes to help illustrate themes. Qualitative analyses were performed in QSR NVivo 12 (QSR International Pty Ltd., 2018).

Results Integration—To provide a more complete picture of parent health literacy and autism services use during early childhood, we integrated focus group and survey results by connecting certain findings (Creswell & Plano Clark, 2018). Quantitative results were primarily used to contextualize the qualitative results. For example, health information survey results helped to contextualize themes regarding key parent health literacy dimensions (Aim 1).

RESULTS

Results are described according to each study aim. The themes identified for each aim are first described. Nine themes were distilled in total (Fig. 2). Relevant survey results are interspersed to help contextualize the description of each theme.

Aim 1 Results: Key Parent Health Literacy Dimensions

For Aim 1, the following three themes were identified in relationship to the main health literacy dimensions: (1) autism services information is often accessed from multiple sources and varies in quality and utility (health literacy dimension = access to health information and services); (2) understanding information about the child's autism commonly involves "doing your own research," determining information credibility, and observing the child's response to a given service (health literacy dimension = understanding and evaluation of health information and services); and (3) autism services information may empower parents to pursue services intended to optimize their child's health (health literacy dimension = use of health information and services in making health decisions about child's autism). Most participants had adequate health literacy (overall = 80%, survey only = 69%, survey and focus group = 89%; Table 1). The only sociodemographic characteristics that were significantly correlated with parent health literacy level were parent age and race and ethnicity (Supplemental Table 3). Parents with limited health literacy were younger and less likely to be white and non-Hispanic than those with adequate health literacy.

Regarding the first theme, parents reported accessing information on autism services and the condition more generally from an array of sources. Internet, including specific websites (e.g., Autism Speaks), search engines (e.g., Google), and social media sites (e.g., Facebook), was most frequently used as a source of autism information. Parents also commonly mentioned word-of-mouth, parent groups, and the child's school as likely autism information sources. Survey results supported these qualitative results to some extent insofar as the highest percentage (93.9%) of parents indicated accessing the Internet as an autism information source during the past 12-months (Fig. 3). Focus group results further showed that parents either concurrently or sequentially accessed multiple information sources on autism. As one parent reported: "I mainly use the Internet but will also purchase books and consult with providers or other parents." Another parent explained "[My] initial info[rmation] comes from parents who have had successful experiences with these [services]. Research on the Internet is then done to find reliable sources that back up the experiences."

In discussing their experiences accessing autism information, parents also identified a lack of centralized information and information tailored to families' unique needs as common challenges. Additionally, parents often recounted struggles parsing high quality, evidence-based information from misinformation regarding their child's autism. As a parent summarized, "Yes, it's really hard to find the info[rmation] you're looking for. It's really easy to find information that's terrible. Really easy, actually."

The second theme related to the general process that many parents experienced trying to understand and evaluate information on autism services for their child. Parents often described this process as starting with "researching things myself" using a variety of sources either simultaneously or sequentially depending on their current situation, their child's needs, and their own information preferences related to their background (e.g., Facebook, PubMed). From there, participants explained how they would go about determining the legitimacy of information by "fact checking" one information source with another and/or interviewing other parents with relevant lived experience (e.g., another parent's experience

using ABA therapy for their child's autism) or searching for "personal references" (e.g., parent testimonials posted online about certain autism services). According to the survey results, parents indicated higher levels of trust for certain autism information sources. That is, on average, parents rated doctors and other healthcare providers as the most trustworthy autism information source ($M=3.4$, $SD=0.78$) followed by government organizations ($M=3.1$, $SD=0.86$) and the Internet ($M=2.8$, $SD=0.82$). The radio and religious organizations were rated as the least trustworthy autism information sources on average ($M=1.7$, $SD=0.84$; $M=1.8$, $SD=1.0$, respectively). At the final stage of the information understanding and evaluation process, most often after parents had decided to try a certain autism service for their child, parents explained how they would assess their child's response to a given service. A parent explained, "Once [...] you know this is what he needs, this is what—and then you can sit—look at a therapy and just after a couple sessions, you'll be like, 'Well, I can't see this being helpful for my kid'."

The third theme identified was about how parents can become empowered with autism services information to make decisions that they believe will optimize their child's health. In some cases, parents described how being empowered with information resulted in them better advocating for their child's autism service needs: "I try to educate myself based on information given by experts or sources backed by science to be the best advocate for my child and his individual needs," one parent succinctly stated. Parents additionally explained how accessing, understanding, and evaluating autism services information led them to pursue services delivered through the state (e.g., therapy services), work with the child's provider to pursue or maintain autism services, and/or waiting to see if the child needs a certain service.

Aim 2 Results: The Influence of Parent Health Literacy on Autism Services Use

For Aim 2, the following three themes emerged: (1) parent health literacy facilitated educational and behavioral services use for young children with autism; (2) parent health literacy was one factor influencing decisions to use psychotropic medication for young children with autism; (3) parent resources and health system characteristics (e.g., services availability) were other salient factors influencing autism services use for young children. Health literacy level did not, however, have statistically significant associations with autism services use per the survey results (Table 2). Additionally, there were no significant differences in preventive care or emergency department use by parent health literacy level for children with autism during the past 12-months.

Regarding the first theme, certain aspects of parent health literacy motivated educational and behavioral services use. Survey results showed that nearly all participants (98.8%) used some educational and/or behavioral services for their child's autism (Table 2). Information that parents processed through observing their child having a positive response to a given service and/or having professional (e.g., therapists, pediatricians) and non-professional (e.g., family, friends) networks to communicate with about the service to help access additional information and/or evaluate their information were both drivers of educational and/or behavioral services use. Some parents also mentioned how accessing, understanding,

evaluating, and using information on educational and/or behavioral services was facilitated by their child's early intervention program.

With respect to the second theme, many parents described how certain aspects of their health literacy had influenced their decision not to use prescription medication for their child's autism. Indeed, survey results showed only 4.9 percent of parents used prescription medication for their child's autism. Many parents discussed how their evaluation of the risks and benefits of medication for children, based on the information that they had, affected their decision. As one parent described, "I've taken psychology courses, and I know that the kid's brain is still growing. To me, that's scary to put them on a mental health medication [while] their brain is still developing." Parents also described conversations they had about medication with their child's provider.

In terms of the third theme, financial barriers (e.g., inadequate health insurance coverage) and limited provider availability (e.g., lack of providers in close geographic proximity, long wait-lists), in particular were noted by many parents as other factors substantially impeding autism services access. Parent understanding of health insurance may have contributed to perceived financial barriers. That is, survey results on understanding and using health insurance showed that participants reported the least confidence in understanding coinsurance ($M=3.1$, $SD=1.0$) and premiums ($M=3.3$, $SD=1.0$), as well as in figuring out the costs of care received through non-network providers ($M=2.4$, $SD=1.1$). Parents with limited health literacy were significantly more likely to be not at all confident about understanding maximum out-of-pocket expenses (9.4% versus 31.3%, $p=0.0468$) and figuring out what counts as preventive care under their current health plan (10.9% versus 18.8%, $p=0.0439$). Parents also frequently mentioned poor coordination including provider referrals and limited time to pursue services due to employment and/or other caregiving responsibilities as obstacles to using services for their child's autism. One parent elaborated, "Any type of training or meetings or anything like that or anything we need to do for our kids, it gets challenging with my oldest's busy schedule and then our full-time jobs and family time and stuff like that."

Aim 3 Results: Parent Health Literacy Improvement Strategies

For Aim 3, the following three themes were identified: (1) increased parent and clinician education on services and tools to facilitate holistic autism care are needed; (2) autism services information should be provided to parents throughout the diagnostic odyssey (i.e., before, during, and following diagnosis); and (3) easier accessibility to scientific autism services information may increase its uptake by parents. Regarding the first theme, many parents expressed the importance of increased education on autism and related services for clinicians, particularly pediatricians which were often parents' first point of contact in getting their child's autism diagnosis. One parent explained her frustration with this issue:

"It was frustrating for me in the beginning to find services because it's just—it's all over the place and you just have to do all this research, which seemed kind of weird for me. If my kid had cancer or something' it is not like you would have to do research to find places to treat your kid. Your doctor would just know all of the area places and that's not the case with autism, which is frustrating."

Parents additionally expressed how they themselves would like to become more educated about autism and related services using streamlined materials on main autism services and local providers or an online repository of credible autism information. Along these lines, some parents expressed how a semi-tailored “road map” with options for services based on their child’s autism symptoms, age, insurance type, and other characteristics affecting services use would be helpful. Several parents further described how having information on autism and related services that is positively framed with anecdotes from other families of children with autism could make parents more receptive. Assignment to a care coordinator or navigator who could help parents with autism information and services was another strategy to improve services use that parents often raised. In terms of the second theme, parents generally expressed that they would like to receive information on autism and related services at multiple time points, indicating the greatest need for information immediately following diagnosis. The third and final theme that emerged was to increase the accessibility of “science-based” autism information. Parents commonly mentioned making science-based information more readily available and easily understandable (e.g., free lay summaries of articles on new autism treatments). Parents also noted the importance of positively framing scientific autism information and balancing it with tangible anecdotes from real individuals living with autism. Several parents expressed how video delivery of scientific information might further help some parents to better understand it. Having information delivered by a professional and training parents on how to effectively do research were further mentioned as potential strategies to increase science-based autism information uptake.

DISCUSSION

This study provides new knowledge of how parent health literacy may influence services use for young children with autism. Though prior studies have examined associations of parent health literacy with health outcomes among children generally, none of these published studies have focused on children with autism (Lindly et al., 2020). Autism is an increasingly prevalent childhood condition (Maenner et al., 2020), and disparities in access to and quality of autism services are linked to poor health outcomes across the lifespan (Bishop-Fitzpatrick & Kind, 2017). Knowledge generated from this study may, therefore, be used to inform interventions targeting autism subgroups most likely to experience health disparities and ultimately advance the adoption of universal precautions for limited parent health literacy in the delivery of pediatric autism care. We discuss this study’s principal findings in terms of past research, implications, and future directions.

Related to Aim 1, the main dimensions of parent health literacy influencing autism services use that were identified suggest that many parents dynamically build their health literacy throughout the child’s diagnostic odyssey. During this process, parents described becoming increasingly savvy navigating the sea of autism information and deciding which services might be best for their child, often using multiple information sources. In turn, some parents were empowered to pursue the autism services that they believed would best optimize their child’s health, regardless of clinician and/or educator recommendations. Few prior studies have examined parent health literacy among children with autism. One qualitative study conducted by Cheung et al. (2016) with 14 Australian parents of children ages 3–6 years with developmental disabilities explored how mothers used information in home

therapy programs. This study similarly found that mothers go through a cyclical process of information acquisition, appraisal, use, and decision-making regarding their child's therapy services.

In relation to Aim 2, this study's findings further suggest that health literacy—especially processing and evaluating multiple information sources (e.g., child's response to services, community views on services)—may play the greatest role when parents are making decisions about educational and/or behavioral (e.g., speech and language therapy, ABA) versus other services (e.g., prescription medication) for their young child. Pre-existing parent attitudes, knowledge, and beliefs may be greater determinants than health literacy when choosing whether to use psychotropic medication. Family support services use may similarly be affected by the extent to which the parent perceives a need for these services, but also by local availability and quality of such services. Collectively, these factors along with the family's financial and time-related resources may interact with parent health literacy to determine the autism services used. Future research may, therefore, endeavor to further elucidate the interplay of parent health literacy with other personal and environmental factors in the use of specific services (e.g., ABA, psychotropic medication) for young children with autism. This information could, in turn, be integrated into decision aids and shared decision-making processes more broadly for commonly used autism services.

Taken together, our study's results suggest there is room for improvement in better guiding parents toward credible and useful information sources on autism services and by doing so, parent health literacy may be strengthened. Given clinical practice guidelines on developmental surveillance and screening, including autism screening, information on community resources and services along with potential referral could be provided as soon as a parent expresses initial concern about their child's development (Hyman et al., 2020). Brief guidance from the child's provider on how to decipher credible information sources including those online could also hold utility for parents. This could be as straightforward as directing parents to existing tools such as public web pages that certain National Institutes of Health agencies (e.g., the National Center for Complementary and Alternative Health) and universities have on finding and evaluating online resources and/or interactive tutorials such as those about evaluating internet health information. Of course, not all children may be routinely seen by a pediatric provider during their first years of life, in which case similar information on autism services may better reach some parents through early intervention and/or childcare programs. Future research may seek to examine whether providing autism services information to families early on (e.g., as part of developmental surveillance and screening)—potentially as a decision aid—along with basic training on how to determine credible information sources increases parent health literacy about autism services. Part of this future work may additionally involve developing a health literacy measure specific to autism.

Because a multitude of autism services exist for young children, the development and testing of decision aids specific to each main autism service type (e.g., educational and behavioral services) may be a promising next step to help parents build their health literacy and support their decision-making about autism services. Little research has investigated the effects of

autism specific decision aids on parent health literacy. One trial of a web-based, autism decision aid involving 71 Australian parents found that decisional conflict (i.e., the parent feeling conflicted and confused about intervention decisions) and parent confidence making treatment decisions did not significantly increase for the treatment versus control groups (Grant, 2016). Greater understanding of factors including health literacy that comprise the causal pathways by which parents of children with autism make services decisions remains needed, especially for those subgroups most likely to experience unmet need and ultimately health disparities. Some research has examined determinants of autism services disparities (e.g., parent stress with the diagnostic process, parent knowledge of autism; Zuckerman et al., 2017); however, parent health literacy has not been directly assessed in these studies (Bishop-Fitzpatrick & Kind, 2017; Dallman et al., 2020). For these reasons, future research should endeavor to determine the pathways by which parent health literacy may reduce health care disparities.

Findings related to Aim 3 further point to strategies to improve parent health literacy related to autism services for children. From parents' perspectives, greater education about autism services both for parents whose children may be identified as at-risk for DD—or autism more specifically—and pediatric clinicians serving families with young children is needed. For clinicians, increased education on autism services could be incentivized using continuing medical education opportunities and credits both within health care organizations and at larger professional conferences. In lower resourced environments, models like the adapted Project Extension for Community Healthcare Outcomes in Autism (ECHO Autism) may be used to both increase clinician autism knowledge and expedite the diagnostic process (Mazurek et al., 2018). Parents in this study also expressed the importance of educational opportunities and information on autism services at multiple time points and in response to their child's specific needs. Depending on a parent's circumstances, web-based tools and courses such as the Autism Navigator that have shown promising results could be recommended to parents for use (Autism Navigator, 2020). Extended family navigation programs tailored for autism may be another more interactive and longer-term way to increase parent health literacy and autism services access (Broder-Fingert et al., 2018; Crossman et al., 2020). In lower resourced settings, multi-session parent education and training programs that use community health workers or peer advocates (e.g., Parents Taking Action) through trusted community-based organizations may be more feasible and effective than self-directed, web-based training at increasing parent health literacy on autism services over time (Jamison et al., 2017; Magaña et al., 2020). The latter programs may have the additional benefit of building parent skills related to social communication and behavior management for their children with autism in the home environment. More generally, study findings demonstrated that increased accessibility (i.e., easy to find and read) of autism services information, particularly scientific evidence on services, may increase uptake and use by parents. This finding has been echoed in other studies (Grant, 2016), and may be addressed through the establishment of a centralized, web-based repository of scientific information in the form of lay summaries. Autism Speaks and other organizations have made strides in developing this type of resource for families; however, certain parents may be better reached if this kind of resource were to be part of a more neutral entity such as the National Institutes of Health. Wider spread adoption of universal precautions to ensure that

all autism services information provided by clinicians and/or educators is truly accessible to parents across health literacy levels (e.g., simplifying communication and confirming comprehension using teach back, making the office environment easier to navigate) may also help to increase information uptake (Brega et al., 2015).

Limitations

This study's findings should be interpreted with several limitations in mind. Foremost, this study was largely qualitative in nature and its external validity is, therefore, limited. Our sample was relatively small and self-selected being drawn from the SPARK cohort using an opt-in recruitment approach. Nevertheless, we attempted to increase the diversity of the sample by targeting recruitment to ten states with low high school graduation rates. Approximately 31 percent of the survey sample and 11 percent of the survey and focus group sample had limited health literacy, relative to 29 percent of parents previously found to have limited health literacy in one nationally-representative survey study (Yin et al., 2009). This comparison raises another critical limitation, which was that we were unable to gather both survey and focus group data from all participants. Moreover, participants who completed both survey and focus group components were significantly more likely than those who only completed the survey to have adequate health literacy. The survey sample may, therefore, be more representative with respect to the proportion of parents with limited health literacy than the survey and focus group sample. Also worth consideration is the use of the NVS to assess parent health literacy. The NVS' psychometric properties have primarily been established when it is administered in-person (Weiss et al., 2005). We were unable to administer the NVS in-person given the geographic scope of our study; however, we did verbally administer it to participants to ensure that their literacy did not impede their ability to complete the measure. Recent research suggests that the NVS has acceptable reliability (test-retest) when electronically self-administered using voice over versus being verbally administered in-person (Mansfield et al., 2018). In addition, the NVS was intended to be used as a brief screening assessment to identify limited health literacy and does not cover the full range of conceptual health literacy dimensions (e.g., interaction, navigation; Haun et al., 2014). Last, how we conducted focus groups—primarily using videoconferencing—should be accounted for. Using videoconferencing may have deterred certain parents from participating in this study component. Little is known about how the use of videoconferencing and/or telephone based qualitative data collection may affect information bias. Some research suggests that participants may say less but convey similar thematic meaning in online versus in-person focus groups (Woodyatt et al., 2016), and online versus in-person focus groups may be preferred and viewed as more confidential for harder to reach pediatric populations (e.g., parents of children with cancer; Tates et al., 2009).

Conclusion

This study is one of the first to explore how parent health literacy influences autism services use for young children. The mixed methods design allowed us to describe this experience more richly in a relatively diverse sample of U.S. parents whose young children have autism. Findings show the dynamic and multi-dimensional nature of parent health literacy and suggest that parent health literacy does indeed play a role in the complex process of

making decisions about autism services use for young children. However, this role may be highly variable depending on the family's circumstances and environment. Because educational and/or behavioral services are the most widely used for young children with autism, parent health literacy was the most salient in decision-making about this service type. Still, parents expressed a strong need for increased and easier to access information on all autism services types throughout their child's diagnostic odyssey along with increased clinician education about autism including services. Findings also reinforce the importance of health organizations taking a universal precautions approach to ensure clinicians and educators working with families of children with or at-risk for autism are meeting them at all health literacy levels. Ultimately, continued work in this area is imperative to improving health for children with autism and other chronic conditions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding

This research was supported by Autism Speaks and cooperative agreement UA3 MC11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. This work was conducted through the Autism Speaks Autism Treatment Network. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, the U.S. Government, or Autism Speaks. This work was conducted through the Autism Speaks Autism Treatment Network serving as the Autism Intervention Research Network on Physical Health. Dr. Lindly's effort was also supported by grant # T32HS000063 from the Agency for Healthcare Research and Quality and the Southwest Health Equity Research Collaborative at Northern Arizona University (Grant No. U54MD012388), which is sponsored by the National Institute on Minority Health and Health Disparities (NIMHD).

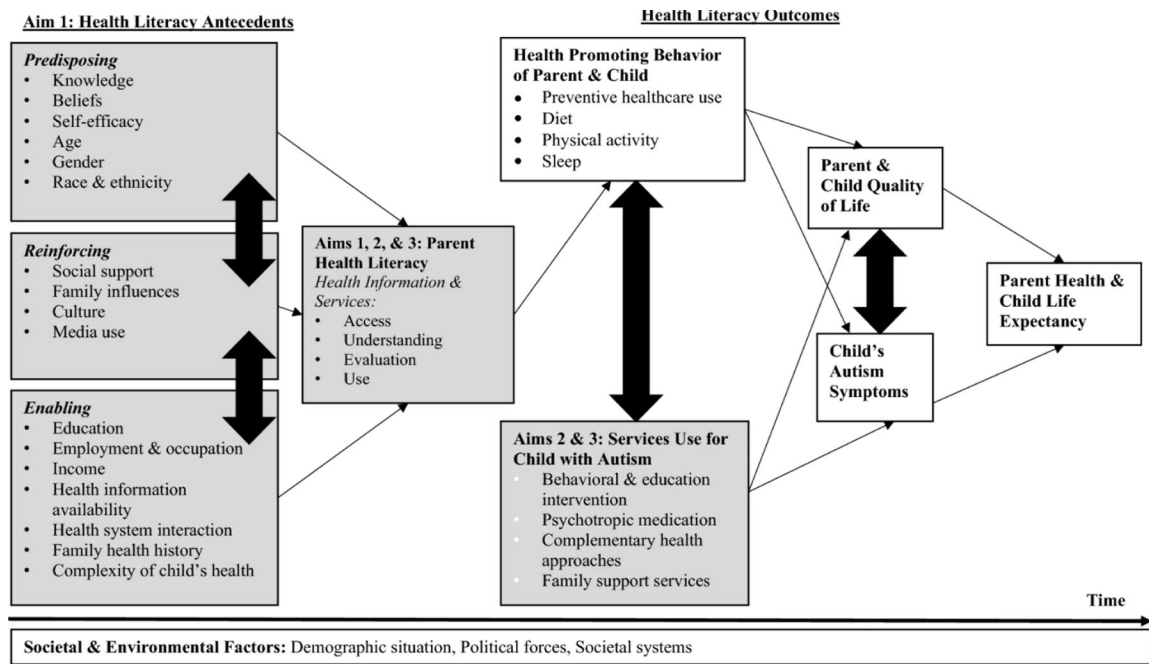
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Adapted from Sorensen et al. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health* 2012, 12:80.

Figure 1. Study conceptual framework of health literacy antecedents, key dimensions, and outcomes for parents and their young children with autism (The shaded constructs were assessed by the study's aims)

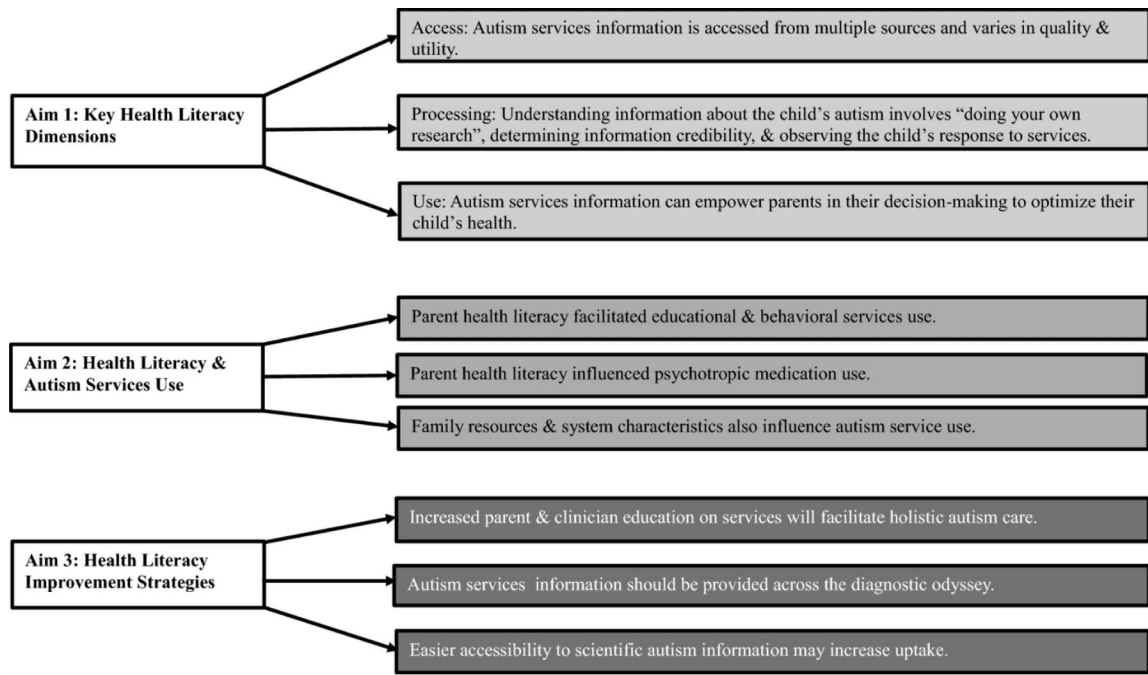


Figure 2.
Summary of main themes on parent health literacy and autism services use for young children by study aim

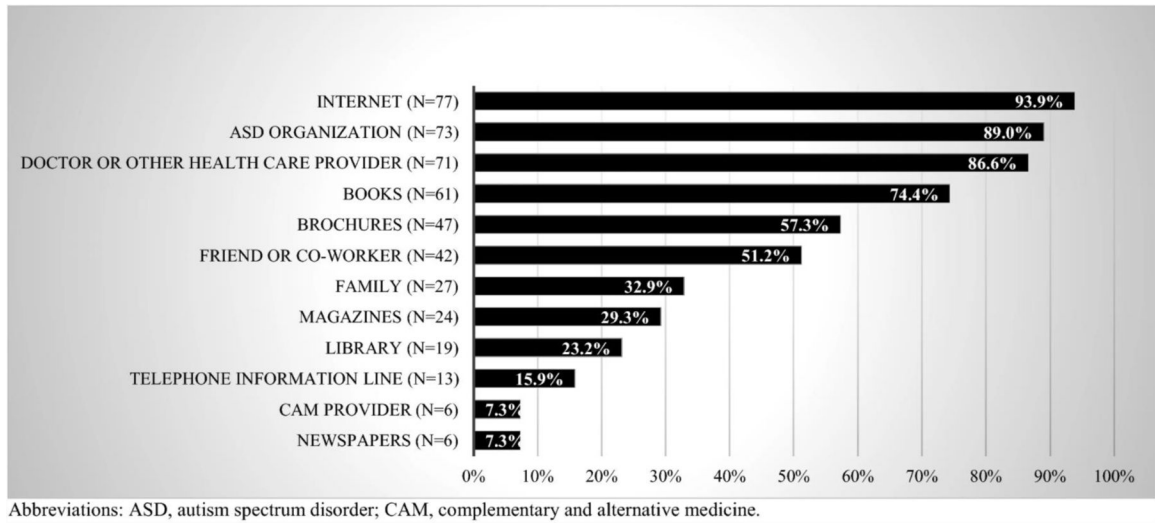


Figure 3. Percentage of participants overall who accessed each autism information source in past 12-months (N=82).

Table 1.

Sample Characteristics

Parent & child characteristics	Overall <i>n</i> (% or mean \pm SD)	Survey only <i>n</i> (% or mean \pm SD)	Survey and focus group <i>n</i> (% or mean \pm SD)	<i>p</i>
<i>Parent</i>	82 (100%)	38 (46.3%)	44 (53.7%)	–
<i>Health literacy</i>				
Limited	16 (20%)	11 (30.6%)	5 (11.4%)	0.049
Adequate	64 (80%)	25 (69.4%)	39 (88.6%)	
<i>Relationship</i>				
Biological or adoptive parent	78 (97.5%)	36 (97.3%)	42 (97.7%)	1.00
Grandparent	2	1 (2.7%)	1 (2.3%)	
Age, years	81 (35.0 \pm 6.5)	37 (35.4 \pm 6.2)	44 (34.7 \pm 6.9)	0.58
Range	23–67	26–56	23–67	
<i>Highest education</i>				
Some college or less	32 (40%)	15 (41.7%)	17 (38.6%)	0.82
College degree or higher	48 (60%)	21 (58.3%)	27 (61.4%)	
<i>Race and ethnicity</i>				
White and non-Hispanic	52 (64.2%)	22 (59.2%)	30 (68.2%)	0.29
Hispanic or Latinx	18 (22.2%)	8 (21.6%)	10 (22.7%)	
Black or African American	6 (7.4%)	5 (13.5%)	1 (2.3%)	
Other race	5 (6.2%)	2 (5.4%)	3 (6.8%)	
<i>Marital status</i>				
Married or living with partner	66 (80.5%)	28 (73.7%)	38 (86.4%)	0.17
Not married	16 (19.5%)	10 (26.3%)	6 (13.6%)	
<i>Employment status</i>				
No paid job	35 (43.2%)	14 (37.8%)	21 (47.7%)	
Paid job	46 (56.8%)	23 (62.2%)	23 (52.3%)	0.50
Number of other children	82 (1.3 \pm 1.3)	38 (1.5 \pm 1.6)	44 (1.2 \pm 1.1)	0.44
Had more than one child with autism	13 (15.9%)	8 (21.1%)	5 (11.4%)	0.36
<i>Child</i>				

Parent & child characteristics	Overall <i>n</i> (% or mean \pm SD)	Survey only <i>n</i> (% or mean \pm SD)	Survey and focus group <i>n</i> (% or mean \pm SD)	<i>p</i>
Age, years	82 (2.9 \pm 0.95)	38 (2.7 \pm 0.98)	44 (3.0 \pm 0.93)	0.24
Range	1–4	1–4	1–4	
Autism severity				
Moderate or severe	55 (67.1%)	30 (65.8%)	25 (68.2%)	0.83
Mild	27 (32.9%)	13 (34.2%)	14 (31.8%)	
Public health insurance	44 (53.7)	17 (44.7)	27 (61.4)	0.18

For parents of > 1 child with ASD ages 1–5 years, we used the age of the youngest child with autism. For binary variables, Fisher's exact test was used. For continuous variables, the Wilcoxon rank sum test was used. For nominal variables, a chi-square test was used

SD standard deviation

Table 2.

Autism services used, by parent health literacy level

	Educational and/or behavioral services	Applied behavioral analysis	Complementary health approaches	Prescription medication	Family support services
Survey					
Overall, <i>n</i> (%)	81 (98.8%)	41 (50.0%)	68 (82.9%)	4 (4.9%)	61 (74.4%)
Limited health literacy <i>n</i> (%)	16 (98.4%)	8 (50.0%)	13 (81.3%)	1 (6.3%)	11 (68.8%)
Adequate health literacy <i>n</i> (%)	63 (100%)	33 (51.6%)	54 (84.4%)	2 (3.2%)	49 (76.6%)
Survey and focus group					
Overall, <i>n</i> (%)	44 (100%)	24 (54.6%)	39 (82.9%)	1 (2.3%)	33 (75.0%)
Limited health literacy <i>n</i> (%)	n/a	4 (80.0%)	5 (100%)	0 (0)	5 (100%)
Adequate health literacy <i>n</i> (%)	n/a	20 (51.3%)	34 (87.2%)	1 (2.6%)	28 (71.8%)

No statistically significant ($p < 0.05$) differences in autism services use by health literacy level were found