

Online Dissemination of Resources and Services for Parents of Children with Autism Spectrum Disorders (ASDs): a Systematic Review of Evidence

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Abstract As autism spectrum disorder (ASD) diagnoses continue to rise, traditional support services are unable to meet the demand. Parents are increasingly turning to online resources, which vary across a continuum of interactivity from passive online information seeking to highly interactive eHealth models, allowing engagement for parents in innovative ways. Although online resources may provide necessary opportunities for information dissemination, outreach, intervention, and support systems, there is cause for reservation. The current study summarizes results of a systematic review ($N=27$ articles) of the evidence surrounding parent use of online resources. Recommendations for researchers to better leverage online tools for the advancement of service provision and child outcomes are discussed.

Keywords Online parent resources · ASDs · Technology-assisted intervention delivery

Autism spectrum disorders (ASDs) are increasingly identified in children, with prevalence rates for ASD in school settings increasing 331 % between 2000 and 2010 (Polyak, Kubina, and Girirajan 2015). A diagnosis of an ASD can create a ripple effect across an entire family system requiring a new set of skills to adjust, cope, advocate for one's child, and seek appropriate services. It has been well established that parents of children with an ASD experience significant stress, even compared to parents of children with other developmental disabilities (Schieve, Blumberg, Rice, Visser, and Boyle 2007). Increased stress is common in families of children with ASDs, and families consistently struggle to gain access to proper care, referrals, and support services that meet their children's needs (Kogan et al. 2008). Accessing appropriate resources is especially difficult for ethnic minority families and for those living in rural areas (Thomas, Ellis, McLaurin, Daniels, and Morrissey 2007).

The burgeoning increase in identification and diagnosis along with continued trends in limits to care and support create a significant problem for parents trying to find solutions and support for their child (or children) on the autism spectrum. These challenges may explain why online information and supports for parents of children with disabilities have increased substantially (Jones et al. 2013; Pagliari et al. 2005). As the rates of diagnosis and the available online resources rise, the internet has become the most commonly used resource for parents to gain more information related to life-altering and family-altering diagnoses such as an ASD or other developmental disorders (Chowdhury, Drummond, Fleming, and Neitfeld 2002; Mackintosh, Myers, and Goin-Kochel 2005). Although the availability of cost-effective, publicly accessible resources may be a benefit to parents who have limited or no access to professionals who can guide them to reputable resources, there are questions related to the evidence supporting their use (Hall, Culler, and Frank-Webb 2016). The present systematic review examines the current

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research on online resources for parents of children with ASDs and seeks to highlight promising findings, current limitations, and avenues for future research.

Evolving Landscape of “The Web”

There is little doubt that as the internet has evolved from a “pamphlet on a screen” to an interactive, user-created environment (termed “Web 2.0”; Anderson 2007), it has created the capacity to support the dissemination of evidence-based interventions and access to current information. Web 2.0 also provides new opportunities for researchers as they can disseminate findings, access potential research participants, and conduct research in new ways without requiring high levels of technical skill (e.g., little to no programming skills) or technical support (e.g., hiring programmers or web designers). Despite this evolution and the enormous potential, many questions have arisen about how the internet may be used to specifically support parent education and assist with the spread of evidence-based interventions (Hall and Bierman 2015). A recent review of early childhood parenting interventions and supports indicated that technology-assisted delivery of evidence-based interventions shows promise, yet there is a need for more methodologically rigorous research, and more research related to how user factors, such as demographics and other characteristics like motivation, may have an impact on the uptake and use of internet information and technology-assisted intervention delivery (Hall and Bierman 2015).

The terms “technology-assisted” or “technology-based” delivery may have different meanings depending on the application. There are new, cutting edge technology applications that include the use of artificial intelligence interfaces (Ondersma, Svikis, Thacker, Beatty, and Lockhart 2014), tablet and ebook technologies (Huang, Liang, Su, and Chen 2012), and the use of serious gaming (Malykhina 2014) in order to support parents and children

with a variety of needs. Although these up-and-coming tools represent important emerging trends, research has struggled to keep the pace as the internet and associated mobile technologies are much more widely integrated into the daily lives of parents and professionals. This rapid dispersion has given way to a marked increase in access to the internet through smartphones and other mobile devices (e.g., tablets), which has begun to close what has been termed the “digital divide” (Smith 2013). Although there are still concerns about internet reliability and potential lack of internet access for minority, remote, and impoverished populations, overall access has been increasing. It may seem unreasonable that researchers could keep up with the exponential development of tools and delivery mechanisms, yet research may be able to examine the effectiveness of internet delivery on a spectrum of interactivity that may help to elucidate what kinds of tools may be the most beneficial for parents in regard to information seeking, finding peer support, and finding access to intervention services.

Parent Resources and Interactivity

The internet has evolved such that it can be used in a variety of ways that promote a range of passive to active participation by parents. In an attempt to conceptualize how the internet may be used for this spectrum of parent needs, it is useful to think about a continuum of internet use platforms, such as information seeking, eLearning, blogging and virtual journals, social media and support groups, and eHealth relative to their capability to support interaction (see Fig. 1).

On one end of the continuum, parents may seek online information related to a specific disability, such as attempting to connect with local medical, behavioral, or educational services through a virtually hosted encyclopedia or phone book. Moving away from primarily one-sided use (“book on a screen”), parents may engage in eLearning platforms, which include massive open

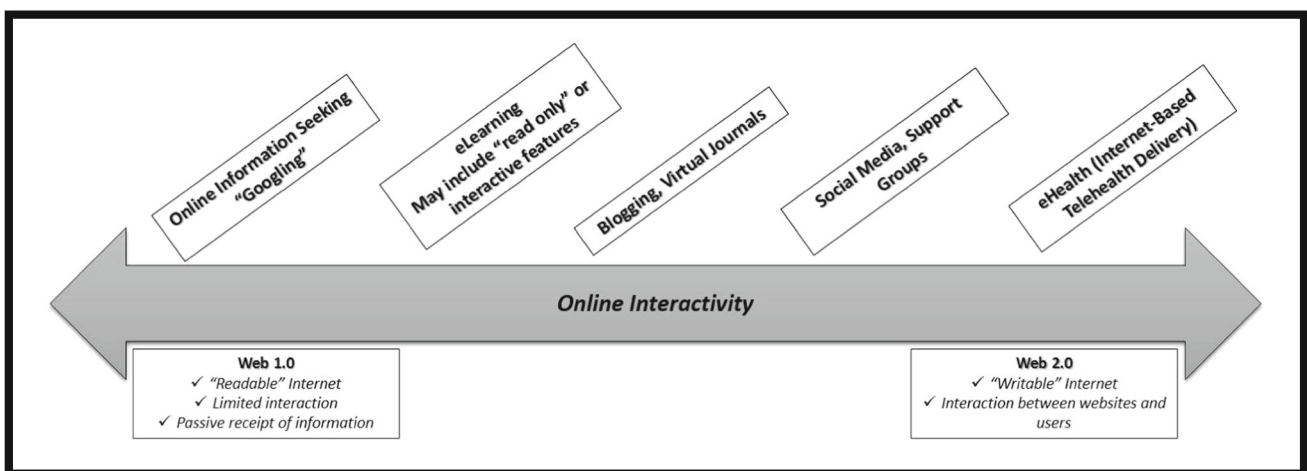


Fig. 1 Online interactivity continuum by application

online courses (MOOCs) or even university-hosted or agency-hosted online learning. ELearning platforms vary greatly, including read-only content or interactive features such as video, audio, and discussion platforms that may require a more active learning and participation component. Next, parents may use the internet to read or create blogs or virtual journals and may anticipate varying levels of participation from, or connection with, others. Level of interactivity or participation may vary as online blogging or virtual journals may include participation as a reader, commenter, or author. Further distinctions occur as readers may or may not decide to comment on or connect with authors just as authors may not opt to connect with their readers past their initial post or entry.

Moving toward even more interaction, popular social media platforms (e.g., Facebook, Twitter) or dedicated support group websites include an assumption on the part of the user that participation will lead to social support and discussion, even if not in real time (like video chat or instant message). On the primarily interactive end of the continuum, the use of internet-delivered interventions and consultation through eHealth platforms constitutes the most interactive level of online engagement as parents connect with professional assistance, often using real-time communication like video chatting. Although the boundaries between and among these uses of the internet are not exclusive or exhaustive, the consideration of the ways in which parents may utilize the internet and for what potential benefits is one way to conceptualize online tools relative to user needs and interactivity.

Present Study

Given the various ways in which the internet may be used by parents to cope, find information, or seek treatment, it is important to understand the current landscape of research in these areas to meaningfully inform how online tools may be developed for the improvement of service provision, child outcomes, and family functioning in the face of an ASD diagnosis. The current systematic review describes the literature related to online resources and supports for parents who have a child diagnosed with an ASD. Prior research has tended to focus on either broad examinations of technology-assisted delivery (Hall and Bierman 2015) or on the application of technology for other subpopulations such as child maltreatment (Self-Brown and Whitaker 2008) or parent management training (Breitenstein et al. 2014; Jones et al. 2013). To expand on the current literature that examines technology-assisted intervention delivery and online information seeking, the present review addressed unanswered questions about online resources and intervention for parents of children with ASDs.

Specifically, the review sought to investigate what peer-reviewed research was available across the

continuum of internet interactivity by searching terms that related directly to this continuum. Second, the review was designed to examine the methodology and measurement used to evaluate the efficacy of online tools for parents of children with ASDs. Finally, the review pursued an understanding of current trends in order to make recommendations to researchers about what is promising and what is yet unknown about leveraging online delivery of information, support, and interventions for parents.

Method

The present review included separate searches of ERIC, PsychINFO, and PubMed, including the search terms *parent* or *parents* and *autism spectrum disorders* both paired with the terms *online support*, *social media*, *discussion boards*, *massive open online courses*, *web-based learning*, *e-Health*, *telemedicine*, and *telehealth*. Initial search results included 459 total hits. Duplicate entries across initial searches were not calculated. Articles were selected for inclusion if they met the following inclusion criteria:

1. Published in a peer-reviewed journal (dissertations, white papers, gray papers, and technical reports were excluded),
2. Published in 2005 to November 2015,
3. Published in English,
4. Included parents of children with an ASD as the population of study (and may have included child outcome measures but was not required), and
5. When more than one published article resulted from the same research study, the primary outcome paper was described.

Snowball sampling to cross-check for missed references included hand inspection of references of relevant articles and search for articles that included the target article in their citations (using Google Scholar). A total of 268 studies were found from the snowball sample. Of those, 240 did not meet inclusion criteria, 20 were already included in the sample from the search engine search, and 8 were new to the sample and subsequently included (Grant, Rodger, and Hoffman 2015a, b; Ingersoll and Berger 2015; Reichow et al. 2012a; Reinke and Solheim 2015; Wainer and Ingersoll 2015; Whitney and Smith 2015; Zeman, Swanke, and Doktor 2011b). Many of the studies not included from the snowball search were excluded due to not being relevant for the population of interest, not having a technology focus, or not being published in a peer-reviewed journal. The final count for studies included in the present review is 27. Please see Table 1 for a complete summary of all articles included.

Table 1 Summary of technology and measurement characteristics of reviewed articles

Citation	Technology characteristics					Measurement					
	IS	B/OJ	OSG	ELP	EH	F/D	CA	V	PS/F	OPC	OCC
Clifford and Minnes 2013a			X						X		
Clifford and Minnes 2013b			X						X		
Di Pietro, Whiteley, Mizgalewicz, and Illes 2013	X							X			
Ferdig et al. 2009				X		X					
Fleischmann 2005		X					X				
Grant, Rodger, and Hoffman 2015a	X							X			
Grant, Rodger, and Hoffman 2015b									X		
Hamad, Serna, Morrison, and Fleming 2010				X					X		
Heitzman-Powell, Buzhardt, Rusinko, and Miller 2014						X			X	X	
Ingersoll and Berger 2015						X				X	
Jang et al. 2012				X					X		
Kobak et al. 2011				X					X		
Powell and McCauley 2012		X				X					
Reichow et al. 2012a, b	X										
Reichow, Gelbar, Mouradjian, Shefcyk, and Smith 2014	X						X				
Reichow et al. 2012b	X						X				
Reichow, Shefcyk, and Bruder 2013	X							X			
Reinke and Solheim 2015	X	X	X				X				
Stephenson, Carter, and Kemp 2012	X							X			
Suess et al. 2014						X				X	X
Vismara, McCormick, Young, Nadhan, and Monlux 2013						X				X	X
Vismara, Young, and Rogers 2012						X				X	X
Wainer and Ingersoll 2013				X						X	X
Wainer and Ingersoll 2015						X				X	X
Whitney and Smith 2015		X								X	
Zeman, Swanke, and Doktor 2011a		X					X				
Zeman, Swanke, and Doktor 2011b		X					X				

IS information seeking, B/OJ blogs and online journaling, OSG online support groups, ELP eLearning for parents, EH eHealth or telehealth, F/D feasibility or descriptive only, CA qualitative content analysis (including search engine consistency and user-posted content), V content vetting (coding and analysis of the quality of information), PS/F parent satisfaction and functioning, OPC observed parent change, OCC observed child changes

Please see Table 2 for basic participant characteristics for reviewed articles.

the internet may be used in different ways to support parents of children with ASDs.

Results

Results of the systematic search were organized into application-based topic areas. Specifically, results from the search revealed five themes to include (1) online information seeking by parents, (2) blogs and online journaling, (3) online support groups for parents, (4) eLearning for parents, and, finally, (5) eHealth or telehealth applications (via the internet) for parents. Results were organized in the manner of application-based topics to capture the breadth of information, support, and services for parents utilizing the internet and how

Online Information Seeking

The search revealed a total of eight studies related to online information seeking for parents of children with ASDs, which included using search engines to identify information about disability-specific issues, identification of disability-specific websites, associations, and organizations, and vetting the quality of disability-specific information available online. Specifically, these studies have addressed variability in internet search results (Reichow, Gelbar, Mouradjian, Shefcyk, and Smith 2014; Reichow et al. 2012b), the quality of information on websites for intervention and the nature of the disorder (Di Pietro,

Table 2 Summary of participant characteristics for reviewed studies

Citation	<i>N</i>	Gender composition ^a	Minority representation ^b
Clifford and Minnes 2013a	45	95.6 %	NR
Clifford and Minnes 2013b	149	96 %	NR
Di Pietro, Whiteley, Mizgalewicz, and Illes 2013	146	NA	NA
Ferdig et al. 2009	34	0 %	NR
Fleischmann 2005	33	UK	UK
Grant, Rodger, and Hoffman 2015a	20	NA	NA
Grant, Rodger, and Hoffman 2015b	23	95.6 %	NR
Hamad, Serna, Morrison, and Fleming 2010	51	92 %	9 %
Heitzman-Powell, Buzhardt, Rusinko, and Miller 2014	7	NR	NR
Ingersoll and Berger 2015	27	96 %	22 %
Jang et al. 2012	28	92.9 %	NR
Kobak et al. 2011	23	NR	26 %
Powell and McCauley 2012	NR	NR	NR
Reichow et al. 2012a, b	Study 1 <i>N</i> = 100 Study 2 <i>N</i> = 299	Study 1 = NA Study 2 = NR	Study 1 = NA Study 2 = NR
Reichow, Gelbar, Mouradjian, Shefcyk, and Smith 2014	300	NA	NA
Reichow et al. 2012b	100	NA	NA
Reichow, Shefcyk, and Bruder 2013	208	NA	NA
Reinke and Solheim 2015	14	100 %	NR
Stephenson, Carter, and Kemp 2012	NR	NA	NA
Suess et al. 2014	3	NR	NR
Vismara, McCormick, Young, Nadhan, and Monlux 2013	8	NR	NR
Vismara, Young, and Rogers 2012	9	77.8 %	88.9 %
Wainer and Ingersoll 2013	9	100 %	NR
Wainer and Ingersoll 2015	5	NR	80 %
Whitney and Smith 2015	120	100 %	91 %
Zeman, Swanke, and Doktor 2011a	24	100 %	UK
Zeman, Swanke, and Doktor 2011b	24	100 %	UK

NR not reported, NA not applicable, UK unknown

^a Gender composition is noted in the percentage of female participants in the study (e.g., mothers, female caregivers)

^b Minority representation is noted in the percentage of non-White participants in the study

Whiteley, Mizgalewicz, and Illes 2013; Grant, Rodger, and Hoffman 2015b; Reichow et al. 2012a; Reichow, Shefcyk, and Bruder 2013; Stephenson, Carter, and Kemp 2012), and how parents utilize the internet for information and decision-making (Grant, Rodger, and Hoffman 2015a).

Two studies examined content results users might encounter when searching for or “googling” information online about neurodevelopmental or developmental disabilities. Reichow, Halpern, and colleagues (2012a) analyzed the top ten search engine results across Google, Yahoo, and Bing search engines for three consecutive years and studied lists of recommended websites for autism. The initial study demonstrated that over time, there is significant turnover in web materials when the term autism was searched with other terms (up to 56 % turnover), meaning that parents may not encounter consistent information from year to year. Some websites are not available over time as links no longer

work or sites are not updated. Further, changes in the algorithms for different search engines and user geographic location may have an impact on results presented to individuals. In a subsequent study of search results for neurodevelopmental disorders (e.g., autism, ADHD, Down syndrome, learning disability, and intellectual disability) across international search engines, Reichow and colleagues (2014) found that searches in different geographic locations like Australia, Canada, the USA, and the UK yielded some important similarities and differences. Often, websites included information about the disorder and treatment but used differing vernacular terminology. Also, there were differences across countries related to the extent to which personal content or information about residential programs, schools, or camps were shown. Further, there were differences in whether or not sites hosted in one country would appear in searches that occurred in other countries.

The second set of studies examined the quality of national association websites (Stephenson et al. 2012), compared the quality of websites for developmental disabilities (Reichow et al. 2013) and ASDs (Grant et al. 2015a; Reichow et al. 2012b), and vetted information on advocacy websites for neurodevelopmental disorders (Di Pietro et al. 2013). Examination of national association websites, which may seem like a quality source for information for parents, were discouraging given that websites had limited information about evidence-based interventions (Stephenson et al. 2012) and over 50 % of the reviewed sites listed weak interventions (e.g., facilitated communication, music integration therapy). Similarly, only 13 % of sampled websites for neurodevelopmental disorders included links to peer-reviewed publications, and 20 % of those references included were irrelevant or incorrect references (Di Pietro et al. 2013). In a review of 208 websites, Reichow and colleagues (2013) found that the highest quality websites were those that had less sponsored content (i.e., advertisements) and were .gov or .org, which may be difficult for parents to locate given that individuals generally scan only the first few search results (Eysenbach and Köhler 2002) and search engines' algorithms may highlight those resources that provide financial incentives. Other studies generally support these findings in that they demonstrate problems with readability of quality websites, that quality websites have less sponsored content (Reichow et al. 2012a) and overall mediocre quality ratings of content (Grant et al. 2015a).

Concerns about quality control of online content for parents seeking information about ASDs and treatment options are at the forefront when also considering how this information may be used for decision-making purposes. Grant and colleagues (2015b) conducted a qualitative study of parents in order to better understand their information seeking and decision-making after their child's ASD diagnosis. Parent interviews ($N=23$) demonstrated a theme of using the internet as a primary source of information. Only one parent in the sample reported an understanding of research evidence, and all others relied on professionals and "mainstream" interventions as being effective. Although it is not surprising that most parents are not savvy consumers of empirical research, it does call to attention that if internet resources are problematic and parents are relying on anecdotes, testimonials, and standard practice (Grant et al. 2015b), it may be difficult to view the internet as a good way to help parents make informed choices for their children.

The current literature regarding online information for ASDs indicates that parents continue to require assistance from experts on how to find reliable information online about autism given the challenges with web search engines and the quality of available information (Reichow et al. 2012a). The results of this review of online information seeking indicate that there are established problems with the consistency

(Reichow et al. 2012a, 2014), quality (Grant et al. 2015a; Reichow et al. 2013; Stephenson et al. 2012), and readability (Di Pietro et al. 2013) of online information for parents.

Blogs and Virtual Journals

Blogs or online virtual journals (<http://blogbasics.com/what-is-a-blog/>) have risen in popularity due to the ability for individuals to create their own webpages without programming skills. Web 2.0 (or interactive, user-generated web interfaces; Anderson 2007), allows bloggers to post content, share updates via interactive social media platforms, and receive comments from readers on their posts creating a reciprocal interaction capability in virtual journaling. Although there is some overlap between studies of online support and analysis of blogs (Zeman, Swanke, and Doktor 2011a, b) this review differentiates between those studies that examined content and impact (on parent stress or functioning) of online blog content from studies that more specifically examined how parents actively seek support or participate in support groups.

To date, the majority of research on blogs for parents of children with autism (three out of the four articles found for this review) have been largely qualitative (Fleischmann 2005; Zeman et al. 2011a, b) or descriptive commentaries (Powell and McCauley 2012), but these studies have begun to examine how online journaling may benefit parents of children with autism. Fleischmann (2005) qualitatively coded online narratives produced by parents of children with autism. Findings from this grounded theory analysis revealed information about how parents view themselves relative to their child's condition and commonalities in their experiences. Specifically, Fleischmann found that parents were able to better resolve and recognize the condition through diagnosis and then after readjustment, would begin to take action on behalf of their child. Zeman and colleagues (2011a) examined blogs of mothers of children with autism and found that primary content themes included risks for their children at school, ways to interact and collaborate with the school, and how they could support their child experiencing these risks. The findings of Zeman and colleagues (2011a) were focused on the more specific, practical ways that content is shared for parents whereas the Fleischmann (2005) analysis explored the ways in which content from parents examined the broader, longitudinal arc of experiences with resolving their feelings about the ASD diagnosis.

Zeman and colleagues in a separate study (2011b) qualitatively analyzed 24 blogs of mothers of children on the autism spectrum and noted themes associated with role strain (e.g., overlapping roles of parent, advocate, therapist) and isolation from potentially supportive peers experiencing the same challenges. Further, their analysis examined how mothers

described supportive relationships including friendships, family and marital relationships, and support gained from blogging itself. The study did not, however, examine any commentary or exchange between bloggers and commenters or readers. More structured and monitored versions of blogging and online journaling may provide additional supports to parents. The commentary from Powell and McCauley (2012) suggest that there are schools utilizing blogs as a way to facilitate home-school communication and collaboration, but there is a lack of formal or systematic study of outcomes.

Only one study (Whitney and Smith 2015) was found during this review that examined the impact of online journaling for parents of children with ASDs. In a randomized trial, mothers were assigned to an online journaling condition or a waitlist control condition. The journaling entries were analyzed qualitatively for emotional content, and mothers responded to measures of maternal stress at baseline and after the intervention. Qualitative results of the study indicated that mothers who participated in the online journaling “vented” their emotions. Quantitative results indicated that journaling reduced mothers’ overall stress post-intervention. However, only about a third of mothers completed all eight journaling sessions (37 %) suggesting that attrition or completion may be a concern given that this protocol did not include any moderator feedback or coaching.

The qualitative research to date can be viewed as a small window into the experiences of parents of children with autism. Broadly, the blogging and online journal research found in this review represent how the practice may serve to support the blogger or writer rather than a reader. However, it is possible that there are additional cathartic or social support benefits to being a regular follower or commenter on a blog, although current research in this area is lacking. Given the findings of the qualitative studies to date (Fleischmann 2005; Zeman, et al. 2011a, b), blogs and online journals focused on others’ experiences (e.g., messages of hope, resolution of grief) or practical tips or advice (e.g., how to deal with the school, teacher complaints) may result in various kinds of coping support for various readers.

Online Support

The present search revealed three peer-reviewed journal publications examining the impact of online support for parents of children with autism (Clifford and Minnes 2013a, b; Reinke and Solheim 2015). These online supports (e.g., online support groups and online discussion forms) provide opportunities for parents who have a child with an ASD to meet and interact with one another in a virtual environment. The study by Reinke and Solheim (2015) was the only study in the present review that included semi-structured and qualitative

analysis across several areas including online information seeking, reports about reading and gaining support from blogs or community posts, and the use of online discussion or other supportive groups. In interviews with 14 mothers, qualitative analysis revealed consistent findings with other studies (Grant et al. 2015b) in that the internet served as their primary resource for information seeking. Further, results of interviews indicated that mothers found support online including both providing support to other mothers and receiving support from persons online. Specifically, this study revealed that for some mothers ($N = 3$), the internet is the only place where they can interact with other mothers of children with an ASD.

A survey regarding characteristics of parents who might participate in support groups revealed that about 31 % of parents reported that they had participated in an online support group at one time (Clifford and Minnes 2013b). The sample for the survey was highly educated (over 90 % had some college education), demonstrated few internalizing symptoms, and overall reported effective coping strategy use. Although it was revealed that parents who were currently participating in support groups viewed support groups more positively than those who had never participated or who had participated in the past, no information was gathered about why participants did not continue to participate or why they never began participation in a support group.

Clifford and Minnes (2013a) analyzed the difference in parent stress, internalizing symptoms, and perceptions for those participating in an online support group (with scheduled chat sessions) and a control group. Although parents who participated in the online chats reported that they were useful, there were no differences between support group participants and controls on parent stress and symptom outcomes. Instead, parent stress was significantly related to parent reports of child problem behavior. A limitation of this study is that it did not examine potential differences between extent of participation and user characteristics, such as comfort level with technology or overall well-being or functioning.

Studies of online support groups and how parents seek, receive, and provide support online appear limited at the present time. Despite the limited number of studies, themes include descriptions of parent stress that are primarily explained by level of child behavior problems (Clifford and Minnes 2013b), differences between parents who participate in online support groups and those that do not (Clifford and Minnes 2013a), and mothers’ acknowledgement that the internet is an important resource for both gathering information and finding support (Reinke and Solheim 2015).

eLearning

Online learning is a growing field that has included a spectrum of formalized (e.g., university-sponsored and administered

online learning courses for credit) to less formal or grassroots learning materials (e.g., YouTube tutorials, MOOCs) for a variety of topics. Online learning materials can include a variety of features including voiceover narration, interactive screen activities, navigation bars for self-directed learning, embedded quizzes and games, video, and other features. However, computer-based learning materials that do not require an internet connection to access content (e.g., DVD programs) or materials that do not require participant interactions (e.g., clicking “next”) were not categorized as online learning materials. Quality and sophistication of online learning materials may vary widely. The present review focuses on six articles of online learning materials for parents of children with autism. Studies that included online learning and continuing education targeted for professionals were excluded (e.g., Fisher, Luczynski, Hood, Lesser, Machado, and Piazza 2014).

Earlier pilot work examining the usability, parent satisfaction, and knowledge associated with an online learning course revealed that parents demonstrated increases in knowledge and satisfaction with the program (Kobak et al. 2011). Subsequent studies of online learning include a randomized trial training parents in applied behavior analysis principles (Jang et al. 2012) and an extended trial for both parents and professionals regarding early intervention practices (Hamad, Serna, Morrison, and Fleming 2010). Jang and colleagues developed a rigorous online training program for parents and conducted a waitlist control pre-post design study. The training was time-intensive and took parents over 30 h to complete on average. Change score analysis demonstrated that parents in the online learning condition outperformed controls on knowledge quizzes. Hamad and colleagues (2010) created online learning materials for a variety of users including parents, paraprofessionals, and professionals. Results indicated that increases in knowledge were consistent regardless of participant education level and high participant satisfaction. These studies, while demonstrating important feasibility and proof of concept, did not include direct observations of behavior change or report on reasons for or amount of attrition in their samples.

In a multiple baseline single-subject experimental study, Wainer and Ingersoll (2013) studied the impact of an online learning program for parents and professionals regarding reciprocal imitation training for children with autism. The study found that parents who received the training increased both their knowledge and actual use of techniques taught as observed by coded video interaction. Children of parents who completed the online training also increased their imitation rates. Although this study uses a small sample design, its methodological rigor is clear as it examines observed behavioral outcomes (rather than simply relying on self-report of implementation) for both parents and children.

In contrast to stand-alone eLearning resources, some online learning may serve as a supplement or scaffold for home-

visiting or clinic-based services. In a description of a preliminary study, Ferdig and colleagues (2009) outline the development of an online portal for the Autism Family Training project in which fathers receive a log in to receive access to interactive training materials and a calendar that includes upcoming home visits and phone calls with their service provider. No specific study results were reported as the research was in progress at the time of the publication. However, the integration of web-based and face-to-face interactions could potentially make online supports more accessible to individuals with limited comfort with technology.

A recent study more specifically studied how the integration of coaching from a therapist may increase engagement with online learning materials (Ingersoll and Berger 2015). In a random assignment of parents to a self-directed or therapist-assisted online learning series, results indicated that there was more parent engagement with online learning materials for parents that received coaching and therapist assistance including more than double the number of log ins and higher completion rates (increase of 31 %). Results also demonstrated that therapist assistance and program completion both made unique contributions to parent knowledge outcomes (controlling for baseline knowledge). Results of this study are promising in that they indicate that parent engagement may be facilitated by coaching or technical assistance that may have a positive impact on knowledge.

To date, eLearning studies seem to demonstrate promising findings that indicate that parents find materials engaging, useful, and helpful to increase knowledge. In one study (Wainer and Ingersoll 2013), parents even demonstrated increases in strategy implementation through behavioral observation. Results from eLearning studies also indicate that coaching or technical assistance opportunities may have additional positive impact on parent knowledge and skills.

eHealth and Telehealth

Telemedicine was once restricted to video teleconferencing that occurred in regional centers that had the required equipment to conduct such remote sessions. Currently, video teleconferencing and other synchronous communication with medical, behavioral, or educational professionals can be conducted in the same way in the comfort of an individual’s home via personal internet connections. eHealth and telemedicine have the capability to connect families to service providers through live video chat and may include other features like online learning components, phone calls, and online discussion boards. Researchers have been using the terms *telehealth*, *telepractice*, *telemedicine*, and *eHealth* almost interchangeably. The present review included only those studies that examined the use of internet-based telemedicine or eHealth practice, not dedicated telemedicine in which families would have to travel to a clinic or medical center

for services (e.g., Gibbs and Toth-Cohen 2011; Wacker et al. 2013). The search revealed five studies that were focused on eHealth interventions for parents of children with autism (Heitzman-Powell, Buzhardt, Rusinko, and Miller 2014; Suess et al. 2014; Vismara, Young, and Rogers 2012; Vismara, McCormick, Young, Nadhan, and Monlux 2013; Wainer and Ingersoll 2015).

Two studies examined the feasibility and impact of eHealth programming for the Early Start Denver Model (ESDM) being delivered via the internet. In their first published study, Vismara, Young, and Rogers (2012) conducted a multiple baseline study for nine families including DVD-based instruction, synchronous online video sessions with a therapist, and live coaching of taught skills. Findings included increased fidelity of parent implementation, increases in child social behavior, and high parent satisfaction. In a follow-up study, a web portal was developed for delivering learning materials online, message boards, file sharing (parents could upload text, pictures, or video files to share with the therapist), and parent resources on the web (Vismara et al. 2013) in addition to the online coaching sessions and contact with the therapist. Findings from the follow-up study were similar in that parents utilized the new skills more and reported high satisfaction. Further, children showed improvement in behavior over time. This study also tracked parent log ins and use of online materials; however, no baseline statistics for online engagement are currently available for comparing behaviors.

In addition to remote delivery efforts for ESDM, other researchers are adapting well-researched face-to-face models such as applied behavior analysis (ABA) and functional communication training (FCT) for internet-based delivery. Heitzman-Powell and colleagues (2014) created an online system for delivering parent training and live coaching for ABA called Online and Applied System for Intervention Skills (OASIS). A small sample was examined for this study (ten parents from six families), and parent satisfaction, knowledge gains, and self-reported implementation of learned techniques were measured. Across participants, parents increased their knowledge of ABA techniques and reported overall satisfaction. The authors reported that the use of OASIS saved parents over 9000 driving miles. Although this study demonstrated promising results, the program was time-intensive (requiring 30–40 h to complete), did not include a comparison group, and did not measure direct observations of implementation of parent or child behaviors.

In a single-subject multi-element experimental design study, three children and their parents participated in FCT via eHealth (Suess et al. 2014). Families participated in remote, online sessions, and researchers observed and coached independent trials of using intervention techniques with children. Children demonstrated significant decreases in problem behavior, and parents were able to deliver trials with good fidelity and errors that did not have a negative impact on

overall child outcomes. In another single-subject experimental design study of telehealth-delivered imitation training (Wainer and Ingersoll 2015), five children (and their parents) demonstrated increases in children's imitation behaviors and good fidelity by parents in the study. Parents reported that the program was acceptable and user-friendly.

Results from initial studies of eHealth interventions delivered through remote consultative, coaching, or therapeutic sessions demonstrate positive outcomes. Specifically, parents gain knowledge and are satisfied with the process. Further, when behavioral observations are included in the evaluation, both child and parent interactions improve and parent fidelity is high.

Discussion

Resources on the web have the potential to fill in gaps for underserved families, provide a virtual community of support for parents, and allow for cost savings in service delivery for families of children with ASDs. The present review examined the breadth of research to date on online information, support, and service provision in a systematic search of the literature. The findings broadly reveal that much of the research on these areas for families of children with ASDs is in its early stages, yet shows important promise. That researchers are attempting to keep the pace with the rapidly growing base of internet information, and activity is laudable given that the “moving target” of the internet content and communications capability is difficult to study.

Information Seeking and Support

Although the internet provides a vehicle for information dissemination, outreach, and connection, the reviewed studies also demonstrate cause for reservation. Parents report that the internet is one of their main sources of information and support (Grant et al. 2015a, b; Reinke and Solheim 2015), yet the quality of the information they find may be less than ideal. The fact that websites have high turnover (Reichow et al. 2012b), are low in evidence-based information and quality references (Di Pietro et al. 2013; Reichow et al. 2013; Stephenson et al. 2012), and search results are inconsistent (Reichow et al. 2012b), it is no wonder why parents may stumble on poor or misleading information and why professionals may caution googling any topic of importance. Quality resources seem to be from .gov or .org websites (Reichow et al. 2013); however, there are some findings that suggest that in other fields of information seeking, diverse or disadvantaged parents may avoid such websites as they may be viewed as too complicated or confusing to be helpful (Mackert, Kahlor, Tyler, and Gustafson 2009). It may be

important for researchers to consider increasing ease of readability and increasing the use of video applications and audio narration for low literacy parents and locating and vetting websites that have accurate information that are accessible to all parents. Resources for medical websites such as Health on the Net Foundation (HON) have attempted to provide guidance for quality control on the Web, yet efforts such as these are labor-intensive and require web developers and publishers to seek out HON certification.

Blogs and virtual journals may seem like a one-directional way for parents to “vent” their experiences and feelings to an online audience; however, given the capacity for readers to add comments to these posts, they represent another way in which parents may find a sense of community online. Qualitative studies seem to dominate the research on blogging for parents of children with autism to date (e.g., Fleischmann 2004; Zeman et al. 2011a, b) and reveal emerging themes related to parents building narratives and sharing strategies and lessons learned online. One study in the review examined parent stress in a randomized trial of an online journal (Whitney and Smith 2015), but there are other remaining questions about the use of blogs from the authorship and readership sides. It is possible that parents who blog find the experience helpful as a way to process their experiences, or conversely, parents may experience burnout from pressures associated with updating blogs while managing daily life stressors related to parenting a child with a disability. In addition, parents may struggle as they experience online bullying or harassment in the form of “trolls” (Phillips 2011). Questions also arise related to the impact of blogging on readers. Readers may find blogs helpful or inspiring. Readers may also struggle with misinformation on blogs or find that reading some blogs increases their feelings of stress. If more is known about the impact of blogging and factors contributing to blog quality, perceived helpfulness, and perceived stress, it is possible that blogs may become a part of advocacy and other supportive practices for families.

Online support groups have received very limited study (Clifford and Minnes 2013a, b; Reinke and Solheim 2015). The research to date does attempt to better understand the user characteristics and coping skills that may relate to the utilization and perception of online support as helpful, yet it has a few limitations. Online support has not been systematically studied for existing social media platforms (e.g., Facebook groups) nor has there been study of the characteristics of those who do not participate. It may be possible that those who participate in online support groups are in need of support, yet high functioning enough that they are able to seek such support. For those that are in more distress or dealing with other risks, online support may be irrelevant or overwhelming. Other concerns include the impact of social media on general mood as demonstrated by recent a study on mood contagion on Facebook (Kramer et al. 2014). There may be

circumstances in which online support may be better indicated for some families more so than others depending on their overall mood and ability to cope.

Online Learning and Professional Intervention

Studies of eLearning for parents for children with ASDs generally showed increases in knowledge and high levels of parent satisfaction (e.g., Hamad et al. 2010; Jang et al. 2012; Kobak et al. 2011). Of the five studies reviewed, only two studies included direct observation of parent and child behavior outcomes as a result of training (Heitzman-Powell et al. 2014; Wainer and Ingersoll 2013) and only one study included the use of eLearning as part of a more comprehensive face-to-face intervention, yet this was still in its preliminary stages (Ferdig et al. 2009). There is work in other fields to suggest that MOOCs tend to have very high attrition rates (Gooding, Klaas, Yager, and Kanchanaraksa 2013; Liyanagunawardena, Adams, and Williams 2013; Ossebaard et al. 2010). Similarly, attrition has been a concern in other technology-assisted parent interventions (Hall and Bierman 2015). Research in this area indicates that eLearning may be a way to scaffold other interventions and provide psychoeducation to parents, yet questions remain about how learning in this context translates to parent or child behavior change.

eHealth (or internet-based telehealth) studies have largely examined the adaptation of existing empirically based interventions for remote delivery (e.g., ESDM, ABA, FCT) and have used rigorous single-subject experimental designs (Heitzman-Powell et al. 2014; Suess et al. 2014; Vismara et al. 2012, 2013). Although promising evidence for effectiveness has been demonstrated in many of these studies, questions remain around broader applications of eHealth delivery such as how eHealth delivery may work for diverse populations of families and how delivery may be sustainable and scalable with larger groups. In larger groups, patterns and challenges may emerge such as what sorts of parents are best suited to remote service delivery (e.g., motivation, stress levels, coping skills), actual use in the field, and attrition rates. A better understanding of these implementation factors will be important for researchers and practitioners alike.

Limitations and Future Directions

The current review has important limitations to consider. Although the review was systematic in nature, it did not sample technical reports, white or gray papers, or examine other private studies of the use of technology for parents of children with autism. Given the rapid pace of growth and the increased commercial interests, these sources of information may have offered a different, more broad or practical, perspective on

current trends in internet-based tools for parents. Further, this review did not examine the use of online resources for teachers, intervention specialists, or other professional development considerations. The use of computer-based training, online technical support, and online learning for providers is a burgeoning field that may have important implications for those practices that may be useful for families as well.

Several important implications for future research were identified as a result of the present review. Researchers who currently are not interested in or trained in utilizing online vehicles for dissemination may view eHealth, eLearning, and other online tools as being outside of their scope of expertise. Now that the creation of simple websites, online support groups through existing social media (e.g., Facebook), and other tools (e.g., video chatting, online learning) no longer requires technical know-how and populations of interest can be more easily targeted by social media and online advertising, researchers may decide to employ their own online presence to support the dissemination of quality, accurate information and to reach a different population than they had previously.

Future research may focus on a few lines of inquiry. First, more information is needed regarding parent or caregiver characteristics that contribute to (or detract from) optimum uptake and use of internet-based tools. Previous studies have indicated that socio-economic status and readability factors may be important factors related to internet information seeking (Di Pietro et al. 2013; Mackert et al. 2009). The present review revealed that many studies failed to collect or report information (40 %) about demographics, specifically ethnicity, which may be important to consider. Further, the overwhelming majority of studies included mostly mothers, which may reflect typical caregiving patterns but may also exclude fathers as playing an important role in supports for their children. Parents may demonstrate different levels of comfort with internet use or various levels of trust in online resources, which may help researchers and practitioners to better understand for whom internet resources may be the most acceptable. Second, more research regarding the impact of those who read, comment on, or otherwise utilize the online posts of other parents may be useful to understand the reciprocity of online supportive gestures. Third, considerations of access and adequate bandwidth abound as some parents may fall through the digital divide and not be able to utilize internet-based service delivery or online information. Recent research by the Pew Foundation (Smith 2013) found that the digital divide is closing as more adults have gained internet access with the advent of the smartphone. More information is needed about how concerns about access may have an impact on parents of children with ASDs.

Relatedly, it may be important to understand how online tools may help to bolster face-to-face or traditional delivery models. Examples of “hybrid” models may include the use of

video chatting for between-session coaching, use of instant messaging or video chatting for technical assistance, and the use of online learning tools to standardize instruction delivery and utilize face-to-face sessions for coaching, practice, and remediation. All of these possibilities bear the remaining question of how well they may assist with adding value to outcomes, decreasing costs of delivery, or standardizing certain aspects of delivery. Rigorous trials of how components may bolster engagement and outcomes including more direct examination of parent behavior change (and possibly child symptom abatement) will be an important step in advancing our knowledge of utilizing internet technology to bolster information dissemination, family support, and access to services for parents of children with ASDs.

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