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What Resources, Toys, Appliances and Print Materials Would Parents of Autistic Children find on The Internet, in Libraries and Shops, and how many are Evidence-Based?

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Abstract

Background: The 2005-2006 US National Survey of Children With Special Health Care Needs found children with autism were less likely to receive specific health care, family support services or prompt family–centred care. Parents report more stress if their child has more severe symptoms but stress levels are lower if they find helpful readily available support.

Objectives: We wished to identify the types and costs of resources parents of children with autism could find if they searched, and how many are evidence-based.

Methodology: We searched for web-based or printed materials, computer applications and programs, videos, CDs and toys and visited children's stores. We checked whether resources corresponded to the NICE 2013 systematic review on autism recommendations.

Results: We identified 27 websites, 10 videos, 188 books, five occupational or play therapy programs and 78 computer applications/games. Only three websites provided information about interventions tested by an RCT: one for Picture Exchange Therapy (PECS) and two for Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), and two books that described TEACCH. Parents would not be able to use these resources as PECS is a training program for autism teachers and TEACCH is a training program for parents taught by autism therapists. No website used evidence-based assessment tools to assess biases in design, execution and data-analysis of the resources they advocated. Many contained advertisements to purchase books or other resources they had not assessed. The US Centers for Disease Control (CDC) website reports on autism prevalence rates are evidence-based but the remainder of its website is not.

Conclusions: Parents could use much time reading websites and spending money purchasing books and videos that are not evidence based. Parents need guidance from professionals who are up to date with systematic reviews of evidence-based literature, such as the NICE systematic review.

Keywords: Autism; Parents; Resources; Internet; Apps for computers; CDs; Videos; Printed materials; Toys

Introduction

The Centers for Disease Control and Prevention (CDC) estimates that the prevalence of Autism Spectrum Disorder (ASD) in the USA has risen over 75% in the past decade from 1 out of 150 in 2002 to 1 out of 88 in 2008, partly due to improvement in diagnosis and partly a true increase in prevalence [1]. The 2005-2006 US National Survey of Children With Special Health Care Needs estimated that 535,000 children have special health care needs. The survey assessed 38,373 children 3 to 17 years (2088 children with autism spectrum disorder (ASD), 9,534 with "other emotional, developmental, or behavioral problems," and 26,751 other children with special health care needs). Children with ASD were less likely to be receiving specific health care services, family support services, prompt and family–centred care and prompt referrals. Their families were more likely to have financial problems, spend > $1000 a year on care, need more income to provide medical care for the child, spend at least ten hours each week coordinating or providing care for the child, or family members had stopped work or reduced their hours of work to care for the child [2].

Parents of children with autism report more stress if their child has more severe symptoms and difficult behaviour issues [3-7]. Their stress level is lower if they can find helpful support which is readily available [7-12] and if they can learn to reframe their child's problems in a more favorable perspective [5,13]. A study of 217 parents of a child between 26 and 82 months old with ASD showed that higher stress scores on the Questionnaire on Resources and Stress (QRS–F) were significantly associated with higher Autism Diagnostic Observation Schedule (ADOS) scores for the child (i.e., their child had more behavior problems). They had lower stress scores if their child had higher Vineland Adaptive Behavior Scales (VABS) scores, the parents had social support that helped them cope, had more coping strategies, and were able to reframe their child's problems positively [14]. A study of a convenience sample of 55 parents (29% response rate to 188 questionnaires) from a US California Bay Area organization that supports families with special needs children found that parents' key informal source of support was their family's social network, that they also sought support from parents with similar problems, and used agencies for formal support [15].

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A key problem for parents with autism is the unpredictability of their child's behavior in public. Ryan argues that children's behavior in public is seen as reflecting on the perceived competence and moral character of parents, and that adult spectators may remind parents by glances, remarks and non-verbal behaviors that their child is not behaving according to public norms [16]. Ryan's study of 48 parents found that they fluctuated between strategies: avoiding going out in public, preparing their child to go out, confronting accusers, and explaining that their child was autistic. They perceived that their children's behavior is caused by difficulty dealing with new sensory issues and being overwhelmed by new settings (lights or darkness, unusual noises and smells, or crowds and queues). Parents said they could not find guidelines to learn how to manage these experiences. However, some had found a website where they could share their experiences [17].

A study of the mothers and teachers of 95 children with ASD found that maternal involvement at school and home in their child's education was strongly positively influenced by the encouragement of school staff and the opportunities they provided for involvement, and negatively affected by the severity of the child's behavioral problems [18]. Parents of children with ASD search for resources from family members, friends, the parents of other ASD children, organizations and websites.

Objective

We wished to find what resources parents might find to deal with the above issues if they looked on the web or visited children's bookstores. We wished to discover what help they could find for specific behavioral issues (e.g., behavior in public, or self-injurious behavior), to cope with food preferences, or aids or toys their children would accept (e.g., games to teach social skills), educational resources to help them learn, or how to reduce isolation by joining online communities, blogs, or focus/support groups.

Materials and Methods

To identify such resources we searched the Internet for printed materials, videos, CDs, physical aids, apps for computers/phones and toys and their costs using Google.ca and examined both online and in-person retail locations, including Amazon.ca, bookshops in the local area, and retail locations aimed at children and early education/development for children. We also searched MEDLINE and Embase from inception to 1 February 2015 using the terms autism, parents or family, and health resources. To assess whether the resources parents might find were evidence-based we assessed if they were included in the Summary of NICE 20013 recommendations (Table 1) (National Institute for Health and Care Excellence, 2013) [19] and if they were evaluated as evidence-based by the NICE 2013 systematic review (National Collaborating Centre for Mental Health, 2013) [20]. We excluded NICE recommendations directed to autism teams, assessment and pharmacological interventions.

Results

We identified no research articles assessing whether publicly available resources for parents such as on the Internet or in bookstores are evidence-based. We identified 27 websites, 10 videos, 188 books, five occupational or play therapy programs and 78 computer apps/computer games (Supplementary File).

1.3 Specific interventions for the core features of autism
Psychosocial interventions
1.3.1 Consider a specific social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. Strategies should:
● be adjusted to the child or young person's developmental level
● aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction
● include techniques of therapist modelling and video-interaction feedback
● include techniques to expand the child or young person's communication, interactive play and social routines. The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.
1.4 Interventions for behaviour that challenges
Anticipating and preventing behaviour that challenges
1.4.1 Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:
● impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes
● coexisting physical disorders, such as pain or gastrointestinal disorders
● coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD
● the physical environment, such as lighting and noise levels
● the social environment, including home, school and leisure activities
● changes to routines or personal circumstances
● developmental change, including puberty
● exploitation or abuse by others
● inadvertent reinforcement of behaviour that challenges
● the absence of predictability and structure.
1.5 Interventions for life skills
1.5.1 Offer children and young people with autism support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.
Autism
The management and support of children and young people on the autism spectrum
Issued: August 2013
NICE clinical guideline 170
guidance.nice.org.uk/cg170

Table 1: Summary of NICE 20013 recommendations relevant to searches for resources that parents might initiate.

Government websites: Government websites tend to list available services but do not evaluate them. The website of one of the Canadian provinces (Ontario) is one of the more comprehensive. It has a short Autism Parent Resource Kit with four brief sections (About Autism, Recognize the Signs, Learn More, and Find Help). In the Find Help section there are sections on Applied Behavior Analysis Service, Transition supports for adolescents, Respite services, School support services, and helping autistic children make the transition to school. None of the website sections are evidence-based [21].

The Centers for Disease Control website reports on autism prevalence rates assessed by the Autism and Developmental Disability Monitoring Network and provides a series of Milestones by age but the remainder of its website is not evidence-based. It lists one book (Amazing Me), one kit ("Go out and play") and one therapy (Autism Case Training (ACT) A developmental Behavioral Pediatrics Curriculum). Whether these resources are evidence-based is not assessed [22].

Other websites: The most useful website is the Math Resource for Autism, which provides math exercises from Junior Kindergarten to Grade 12 and shows how they fit with the mathematics curricula of each of the Canadian provinces. A search using the term autism brings this website up labelled as for autistic children but it is in fact generic [23]. The only website that made any evaluative comment is the Autism Web. A Parent's Guide to Autism Spectrum Disorder. It has sections on Reviews of Applied Behavior Analysis and Verbal Behavior, DIR/Floortime, Sensory Integration Therapy, TEACCH, and Relationship Development Intervention (RDI) without explaining why it chose these resources. It's comment on TEACCH is one phrase: "TEACCH has not published comprehensive long-term studies of its effectiveness in treating and educating children," which begs the question why TEACCH is on their website [24].

Most websites list resources without any evaluation to guide the reader. The Autism Canada Foundation lists videos of its past conferences 2009-2014 and only five books without explaining why it is selling only these (M. Herbert and K. Weintraub, The Autism Revolution; B. Jepson, Changing the Course of Autism; J. McCandless, Children with Starving Brains; J. Alderson, Challenging the Myths of Autism; and Autism Physician Handbook. Canadian Edition). It does not provide a list of the contents of the books or any evidence-based assessment [25]. The Autism Speaks website lists resources alphabetically from A (ASD vacations) to Z (ZocDoc, a listing of doctors and dentists) without any evaluation [26]. The Geneva Centre for Autism states that it has the most printed resources in Canada but advises that it is a non-lending library where visitors can only browse [27]. The Bumblebeekids website states that it provides "Unique DVD's that help Toddlers with autism start to talk" but provides no evidence [28]. The autism parent café website provides links to US and Worldwide autism organizations and other sites but no evaluations [29]. The website Autism Resources website merely lists Autism books ("lots of them, of all types") and Autism links ("a bunch of them, categorized") [30].

The commercially most explicit websites are Friendship Circle [31] and Autism...Learn: Educational Activities for Persons with Autism [32]. Friendship Circle: 15 Indispensable websites for Parents of Children with Autism includes the US National Autism Association, whose opening page has advertisements for foods, infrared heat and an "avatalker" app to encourage talking. On the Autism…Learn website the only activity is a shopping cart to purchase non-evidence based learning tools for the Alphabet, Colors, Countries, Direction, Graphing, Money, OT/Fine Motor, Seasons/Weather, Shapes, Sizes, Tabletop Activities, and Visual Discrimination); and Parent Coaching for Autism (an advertisement by Connie Hammer, owner of The Progressive Parent LLC, offering her coaching services to parents without any evidence-base). Other non-evidence based websites are sensory planet [33] which advocates Sensory Integration Therapy, and icdl.com [34] which is a web-based radio show. Only three of the websites provided information about interventions that had been tested by an RCT: one website for the Picture Exchange Therapy (PECS) [35] and two for the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) interventions. Two books described TEACCH [36]. However PECS is a training program for autism teachers and TEACCH is a training program for parents taught by autism specialist therapists and are thus not a resource parents are likely to be able to learn or adapt.

Books and videos: A wide range of videos (costs ranged from CDN$14.95 to $88.85) and books ($17.50 to $43.95) were advertised without any evidence-based assessment.

Applications: An example of an application is an iPod/iPad programs that says it can improve social skills using stories. It proposes using the logged behavior files to provide the child with a concrete understanding of the specific social skills using social learning sequences aimed at demonstrating the required social expectations in several situations. No evidence of effectiveness is provided.

Physical aids: Examples are an alarm placed inside the child's diaper to promote toilet-training [37], a "pressure sensory vest" (CAD$49.92) and a "toddler sensory table" CAD$149.95) (CAD $1.70 = £1.00). No evidence of effectiveness was provided. Some of the specialty online stores and the lists of websites' recommendations for purchase are long and quickly add up to be very expensive for parents.

Discussion

Extensive resources advertise interventions parents can provide to their autistic child, and an inexperienced parent could spend a considerable sum of money without much benefit. Only two out of 27 websites presented interventions tested in an RCT (PECS, TEACCH) and 2/188 books (both TEACCH). There are many books written by parents of autistic children which may be emotionally helpful to reduce feelings of isolation as a parent of an autistic child, but some of the advice could be inappropriate if not supervised by a physician or child psychiatrist (e.g., restrictive diets and physical restraints). Parents thus need to sort through a wide range of material that is neither evidence-based nor screened by professionals. Health care workers should caution parents and ensure they are using interventions tested only by RCTs at low risk of bias. None of the videos, occupational or play therapies, or computer apps/computer games had been tested in an RCT. PECS is a training program for autism teachers and TEACCH is a training program for parents taught by autism specialist therapists and are thus not a resource parents are likely to be able to learn or adapt. Professionals and parents should be cautious when purchasing or implementing parenting resources not assessed as evidence-based. They may benefit from information on the Internet about how to socialize with parents of other autistic children for support. If parents are educated that almost all resources are not RCT tested, then they can make better decisions about how to invest their time and money.

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