

Treatments and Services for Neurodevelopmental Disorders on Advocacy Websites: Information or Evaluation?

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Abstract The Internet has quickly gained popularity as a major source of health-related information, but its impact is unclear. Here, we investigate the extent to which advocacy websites for three neurodevelopmental disorders—cerebral palsy (CP), autism spectrum disorder (ASD) and fetal alcohol spectrum disorder (FASD)—inform stakeholders about treatment options, and discuss the ethical challenges inherent in providing such information online. We identified major advocacy websites for each disorder and assessed website accountability, the number, attributes, and accessibility of treatments described, and the valence of treatment information. With the exception of FASD websites, we found that advocacy websites provide a plethora of information about a wide variety of

readily available products and services. Treatment information is primarily targeted at families and is overwhelmingly encouraging, regardless of the type or conventionality of treatments. Many websites acknowledge corporate sponsors. While the majority do not overtly advertise or endorse specific brands, they also do not prominently display disclaimers about the nature and intent of treatment information. Thus, while advocacy websites are organized to serve as information clearinghouses, they implicitly appear to provide endorsement of selected treatments and services. We conclude with recommendations for new partnerships between government-funded health organizations, advocacy and investigators to make more transparent the role of online information in informing treatment options and improving the evaluation of information.

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Introduction

The role of the Internet in healthcare is ‘as broad as medicine itself’ [1]. Websites provide information about medical conditions and treatments, discussion of educational approaches, contact with healthcare practitioners, community support, and advocacy [2–4]. Here we specifically examine information on advocacy websites about treatment products and services for three neurodevelopmental disorders (NDDs): cerebral

palsy (CP), autism spectrum disorder (ASD) and fetal alcohol spectrum disorder (FASD), which together affect more than one million children in North America. At present, there is no single accepted treatment option or educational approach for any of these disorders, and information supplied by advocacy organizations, which are assumed to represent the interests of those affected [5], is thus highly potent. Indeed, the Internet is now the second most used and preferred source of health information for parents after their health-care providers [6–9]. We studied treatment products and services presented on advocacy websites, and examined techniques to promote or caution their use. For all three neurodevelopmental disorders, the question of ‘treatment’ can overlap with the question of ‘education’ as treatments often address practical, cognitive, or emotional barriers to learning. We therefore also consider a broad group of products and services that include those targeted at educators as well. We discuss the ethical issues associated with the role of advocacy websites as ‘information conduit’, and consider possible strategies for improving the services they provide to parents, teachers, and medical practitioners.

Disorders of Neurodevelopment, Intervention and Personalized Healthcare

The three neurodevelopmental conditions we consider are the foci of research for a new Network of Centres of Excellence (NCE), NeuroDevNet, a Canada-wide initiative to study children’s brain development from both basic and clinical perspectives. The work reported here is part of the neuroethics component of the initiative. Below we summarize key features of ASD, CP, and FASD and their advocacy contexts, and survey key ethical issues surrounding online information about treatment products and services.

Autism is characterized by problems with social interaction, communication, and by narrow interests and repetitive behaviours [10]. There is substantial controversy about the cause of ASD, and treatments range from behavioral therapies to diets and supplements. Advocacy organizations for this disorder play an important role in debates about how autism should be understood and treated. Recently, some members of the autism community have begun to question the disease model that underlies calls for research into a ‘cure’, embracing instead a concept of “neurodiversity”; the

idea that people with ASD have brains that are *different* rather than *disordered* [11]. Concepts of diversity have a complex relationship to disability rights discourse [12], with important implications for the education and treatment of children with ASD, as well as for the allocation of research funding and resources. Advocacy groups play a vocal role in this debate, and they themselves generate substantial research income. CP is an umbrella term for a range of non-progressive disorders of motor and sensory development. There is less controversy about the causes of CP and treatment possibilities, but it also carries important advocacy and financial issues surrounding the integration of children with challenges of mobility into educational and social settings. FASD applies to a range of developmental deficits and behavioral problems associated with maternal consumption of alcohol. These problems include physical abnormalities and cognitive disabilities such as poor memory, attention deficits and impulse control [13]. Diagnosis can lead to guilt and shame, and as a disorder where prevention has been the primary focus [14], and where the pattern of deficits is so diverse, there is relatively little research on intervention and treatment approaches.

The Role of Advocacy?

The risks and benefits of online access to treatment information are much debated, for pediatric conditions as well as for adults [e.g. 3–9]. For example, increased ‘consumer choice’ for treatments implies increased responsibility for the choices made, which can add to the psychological burden of parents charged with securing the wellbeing of their child [15]. This is particularly problematic when there is a high volume of information, and when this information is difficult to evaluate [16–18]. For CP, ASD, and FASD, uncertainty surrounding treatment options and educational approaches is accompanied by a demand for information about cutting edge, unconventional, or unproven therapies, from families often frustrated with conventional medicine [19]. In addition, given the lack of consensus over educational approaches, and the paucity of in-school resources, decisions about behavioural/educational approaches are often made by parents as part of a broader approach to ‘treatment’. This configures the advocacy organization as a potential conduit of information that might otherwise be hidden or unavailable, and raises important

ethical questions. Is the role of such a conduit to collect available treatment options, to evaluate, or to promote them? Do websites make their intentions clear? If treatments or services are sold direct-to-consumer, what responsibility does a host have for evaluating the efficacy of products and the quality of information? In the role of ‘broker’ between buyer and seller, what kind of authority and expertise is implied by, and reflected in, their information practices?

In addressing these questions it is important to attend to the particular disorder at stake, as the nature of the condition, the aims of treatments and services, and the advocacy environment shape the unique relationship between treatment providers, practitioners, educator, and patients. In asking what kind of information advocacy organizations provide through their websites, we aimed to provide insight into the strengths and gaps of information on websites that reach the greatest numbers of stakeholders, and explore broader ethical implications of the presentation of information in the context of advocacy debates.

Methods

The primary aim of the analysis was to understand what treatment products and services are being offered to stakeholders on major advocacy websites representing three neurodevelopmental disorders. To achieve this goal, we elected to conduct an in-depth descriptive analysis of a sample group of websites documented to have the greatest reach in terms of number of visitors. This approach allowed us to individuate products and attend to trends that might be lost in a more superficial analysis of a larger sample. We also consider relevant features such as the tone of messages surrounding treatment information, purchase information and target audience to ascertain the particular role they play in advocacy contexts.

Selection of Websites

Inclusion Criteria We selected three top advocacy websites for each of the three neurodevelopmental conditions of interest. Advocacy websites were defined as webpages containing content that describes a cause, opinion, or idea of a particular group or association that may or may not be sponsored by or

affiliated with organizations (e.g., community, academic, or government) or businesses. We triangulated Internet traffic ranking scores (see Table 1) from three independent web analytic companies (Alexa Internet Inc, Compete Inc, and Quantcast Corporation) to inform the selection of websites and analysis pool. We selected nine final sites for analysis—three per condition—based on the highest combination of average daily visitors and page views over the 3 months between May–July 2010 and that met our other inclusion criteria.

Expert Opinion Four experts—the NeuroDevNet Principal Investigator and each of the Project Leaders for ASD, CP and FASD—confirmed the website selection results. One raised concerns that two of the top CP advocacy websites identified by ranking scores are sponsored by legal services. Given that sites sponsored by businesses meet our inclusion criteria, and that legal sponsorship is a prominent feature of CP advocacy [20], we accepted these sites for analysis. As Freeman et al. [20] noted, legal sponsorship is consistent with the high level of financial resources required to care for children with CP and with the possibility, however little pursued, for litigation against medical practitioners involved in obstetric care.

Content Extraction

Website Accountability We characterized the accountability and agenda of the host organization as expressed on each site. Follow the methods of Silberg et al. [21], we documented the presence or absence of: a mission statement of the website or organization; a list of website contributors and their credentials; a list of the Board of Directors; Website administrator contact information; financial disclosures; legal disclaimers; advertisements; corporate sponsorship; and domain type (e.g., government agency [.gov], academic institution [.edu], or non-profit organization [.org]).

Content Analysis We methodically searched each website for content relating to both free and commercially available treatment information by scanning all pages and by using the sitemap website search engine (if available, if not using the browser’s ‘find’ function) to locate passages containing the following text strings: “treat*”, “purchas*”, or “buy”. The

Table 1 Websites selected for analysis with their respective traffic ranking scores

URL	Alexa rank	Quantcast rank	Compete rank	Links	DOB (dd/mm/yyyy)	Country
autismspeaks.org	57274	11225	12095	1643	14/12/2004	USA
autism-society.org	169703	19949	18911	2013	29/03/1996	USA
autism.com	246071	70277	50915	313	14/07/2002	USA
ucp.org	457992	69493	91284	791	24/02/1996	USA
cerebralpalsy.org	1178384	96354	140191	65	03/12/1999	USA
originsofcerebralpalsy.com	1505475	261220	696915	67	19/03/2004	USA
nofas.org	1168482	203597	297645	317	29/07/1996	USA
fasworld.com	2077338	n/a	472087	47	15/07/1999	Canada
faslink.org	4260697	338235	317195	42	01/01/1999	Canada

boundaries of the website were defined as any information present in the text of the website, or as a download located on the website's server. We noted if a product was accessible to purchase or otherwise acquire via a direct link to a supplier website, but longer chains of links were disregarded as being beyond the boundaries of the website.

We defined treatment as any item, activity, or program intended to cure or improve a child's underlying condition, alleviate symptoms, cope with difficulties arising from the disorder, or facilitate learning or integration into educational settings. We excluded: 1) diagnostic products or techniques, including those used to assess treatment efficacy, 2) information about the symptoms, progression, or biological basis of the disease, and 3) any product aimed at parents' wellbeing, such as relaxation techniques or supportive anecdotes.

The path taken through the website was recorded at the start of each excised text section. Text for all nine websites was extracted within a 2 week period between 7/7/10-7/22/10 and date of access and most recent date of website update noted.

Single treatments formed the units of analysis (henceforth referred to as 'cases'), and were defined at the greatest level of specificity included on the website. For example, one website might include only general information on 'diets', which would form a single case (i.e., Diet) whereas another might mention specific types of diet (e.g., Gluten Free Diet, Sugar Free Diet, Feingold Diet), each of which would be treated as a separate case. Any text pertaining to a particular treatment was extracted and included in the appropriate case file, with URLs and site-map location

listed for each entry. To verify the consistency and reliability of the data extraction, two independent coders checked the cases against the master text file, noting and resolving any points of disagreement about case identification, case omissions, redundancy or overlap.

Coding

All coding and content analysis was conducted using NVivo 8 qualitative research software from QSR International Pty Ltd. An initial coding scheme was developed through detailed exploration of the website with the highest traffic ranking for each disorder, guided by the descriptive hypothesis. Discussion of disagreements in the application by two coders (ND and LW) of the initial coding scheme was then used to refine a final version. Some codes were mutually exclusive, such that only one could be applied to each case. These included codes for product type, accessibility, conventionality, product information placement, purchase information, and message valence. In contrast, multiple codes could be applied to each case for target audience and caution statements, with a default code applied to the case only if no other code was assigned.

Objective features of product attributes and information accessibility were coded by one author (ND), and checked for any errors or inconsistencies by a second author (LW). Message valence for each product was independently double-coded (ND and LW) and inter-coder reliability calculated using Krippendorff's alpha as a conservative measure of

the agreement [22]. Any remaining disagreements were resolved through discussion.

Treatment Product Attributes

Type We assigned codes for type of treatment and service as follows: diet/supplement (DS), pharmaceutical (PH), medical/surgical (MED), behavioral (BEH), educational (EDU), mind-body (MB), body-based therapies including massage and physiotherapy (BT), technological (TECH) and other (OTH).

Conventionality We coded treatments and services as conventional (CON) if they are practiced by holders of M.D. (medical doctor) and D.O. (doctor of osteopathy) degrees and by allied health professionals, such as physical therapists, psychologists, and registered nurses [23]. These included behavioral and educational techniques (e.g., ABA, TEACCH, Floortime, PECS, speech therapy) and prescription drugs (e.g., Risperdol, Ritalin) that are FDA approved to treat the disorder under consideration in our study. In addition, we included sensory therapies (e.g., art, dance, music, sensory integration) under this category, because they are offered as part of regular school services [24]. We coded all other treatments, as well as off-label use of pharmaceuticals, as complementary and alternative medicine (CAM). We followed the definition developed by Hansen et al. [24] in the ASD context, adapted to encompass the range of products and services we consider for CP and FASD, to distinguish conventional from complementary or alternative treatments.

Accessibility We assigned three different codes for product accessibility: Direct to consumer (DTC)—advertised directly to patients and families even if the treatment has to be obtained through a prescription from a physician; Clinical trial—available through a clinical trial (CT); and Readily available—available in the open market or over-the-counter (OTC).

Placement We assigned three different codes for placement of treatment information: appearing as a dedicated page or subsection requiring a click on a link, button, or tab whose title refers to treatments in general, or a particular class or type of treatment (DED); embedded on a page or section whose title does not indicate a focus on treatments or their purchase (EMB), or requiring downloading to be

viewed (DLD). The DLD code included information about treatments and software or media products that are themselves downloadable.

Purchase Information Instances in which purchase information was provided (i.e., a telephone number, company name and address, or link to external site that sells the treatment) were coded as Purchase Information (PI). This did not include links to pages that provide additional information about the product or a further list of suppliers. If purchase information was absent, we assigned the code (NPI). Treatments that could be purchased directly from the website, were developed and sold exclusively by the website organization, on sale from an embedded shop, or provided for free download (e.g., educational books, films, manuals) on the website were coded as Purchase from Website (PFW).

Target Audience We coded for products explicitly or implicitly directed at parents and families (FAM); directed at children or suggesting that a child's opinion be sought (CHD); or directed to physicians (PHYS), allied health professionals (AH), and educators (SCH). When a target audience could not be identified, a default code was applied (UNCLEAR).

Message Valence We coded the description of each product or service for overall tone, selecting one out of the following four codes: Encouraging—focusing on positive outcomes or debunking fears about side effects or efficacy (ENC); Fearful—citing negative outcome if the treatment is not used or is stopped (FRF); Discouraging—including warnings against the particular treatment, or presenting substantive doubt about its efficacy or safety (DSC); or Neutral: no valence (NEU). In addition to these four message valences, any substantive reference to a lack of evidence for efficacy, or concerning potential negative side effects and safety concerns, was coded as cautious (CAU).

Data Analysis

Statistical Analysis Coding results were exported from NVivo8 to Excel to generate descriptive statistics of codes used across all websites ($n=9$) and grouped by disorder ($n=3$ websites for each disorder).

Mann-Whitney Tests were used to compare a single sample against a hypothesized median for the data across all nine websites. For smaller sample sizes, binomial tests were used to test comparisons between the means of two possible code assignments (e.g., the number of CAM vs. CON treatments on ASD websites). We used the nonparametric Kruskal–Wallis one-way analysis of variance statistic to compare two or more code assignments across all websites sampled (e.g., DTC vs. OTC vs. CT). When the Kruskal-Wallis test was significant, Dunn’s multiple comparison tests were used for post-hoc pairwise analysis. All percentages are provided to 2 significant figures.

Results

Websites

Selection The websites selected for analysis are shown in Table 1.

Accountability All websites provided mission statements and website administrator contact information. Although ASD and FASD websites sometimes provided author information at the end of content displayed on their pages or in downloaded documents, none of the websites provided a stand-alone list of website contributors with their credentials. Eight out of nine websites solicited for donations (with the exception of www.originsofcerebralpalsy.org), and all reported financial support from corporate sponsors; two of the three CP advocacy websites were created and sponsored by legal firms with an interest in advocating for insurance coverage of treatment products. Four out of nine websites provided financial disclosures or a list of members on Executive Committee Boards. Banner advertisements were not present on any of the websites, however corporate sponsor logos were prominent on donor acknowledgement pages. No sites featured brand name products when describing treatment options. Seven of nine websites provided legal disclaimers about the accuracy and nature of the content present, variously stating that it may be subject to change, is for reference or informational purposes only, does not substitute for medical advice from a medical professional, or a combination of the three.

Treatment Attributes

Frequency and Type Figure 1a displays the 146 products and services identified across the nine websites. CP sites referred to the largest number (see

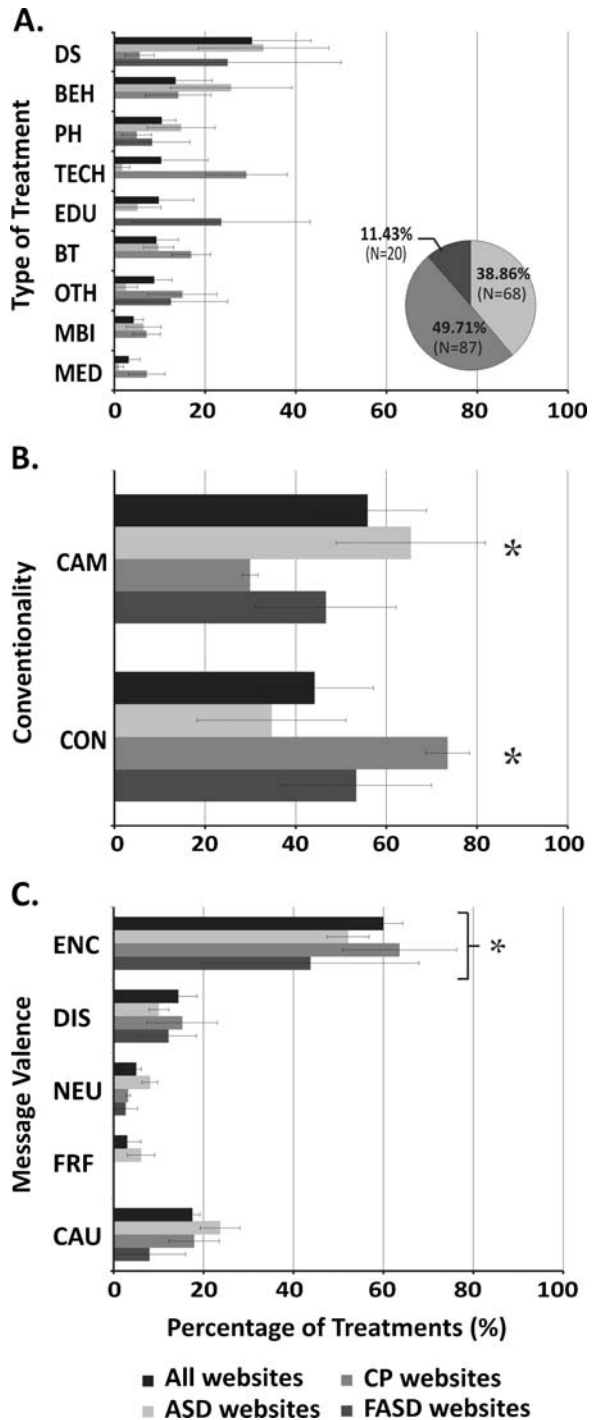


Fig. 1a, inset): $n=87$ (50%); ASD sites: $n=68$ products (39%), and FASD sites: $n=20$ products (11%). Technological devices for improving mobility, such as wheelchairs and adaptive sports equipment, or computer software to aid with communication account for the largest percentage of products on the CP sites ($n=27$, $29\pm 9\%$). The majority of treatment products and services on the ASD sites involved diets or supplements ($n=24$, $33\pm 14\%$) and behavioral therapies ($n=19$, $26\pm 13\%$). Of the limited amount of information on FASD websites, diets or supplements ($n=9$, $26\pm 24\%$) and educational tools that aimed to assist with learning or educate teachers about learning needs ($n=5$, $24\pm 19\%$) were the focus. One advocacy website for FASD contained no information on treatment products or services at all. It is important to note the large standard errors here; not all advocacy websites are the same.

Conventionality Table 2 lists examples of CON and CAM treatments on advocacy websites for each product or service type. Overall, the numbers of CAM and CON treatments did not differ across websites (Mann–Whitney $U=30$, $n_1=99$, $n_2=76$, $p=0.87$). Binomial analysis of conventionality for each disorder, however, revealed that ASD sites contained more information about CAM ($n=43$) than CON ($n=25$) treatments ($p<0.001$), whereas CP sites showed the opposite trend (CAM; $n=66$, CON; $n=21$, $p<0.001$) and the number of CON and CAM treatments referred to on FASD sites did not significantly differ (CAM; $n=6$, CON; $n=4$, $p=0.25$) (Fig. 1b).

Accessibility Significant differences in treatment accessibility were obtained across websites ($H(2)=$

◀ **Fig. 1** Mean percentages (\pm SEM) across all websites and by websites for each disorder for: **a**) *Product Types*; Diet/supplement (DS), pharmaceutical (PH), medical/surgical (MED), behavioral (BEH), educational (EDU), mind-body (MB), body-based therapies (BT), technological (TECH) and other (OTH). **Inset**; Percentage and number (n) of treatments referred to on ASD, CP, and FASD advocacy websites. **b**) *Conventionality*; ASD sites contained more information about complementary and alternative medicines (CAM) than conventional (CON) treatments, whereas CP sites showed the opposite trend. **c**) *Message Valence*; significantly more encouraging (ENC) messages about treatments and services were observed compared to discouraging (DIS), fearful (FRF), or neutral (NEU) messages. We note that 17.5% of treatment cases overall contained statements that cautioned (CAU) either about the safety or efficacy of treatments. * indicates significance of $p<0.001$

17.59 , $p=0.0002$). Post-hoc pairwise tests indicated that there were significantly more OTC treatments compared to DTC ($p<0.05$) or CT treatments ($p<0.001$). Binomial tests further revealed that ASD websites ($p<0.0001$) referred to a greater number of OTC than DTC treatments and that CP websites featured more OTC than DTC and CT treatments combined ($p<0.0001$). This comparison was not significant for FASD sites ($p=0.25$). Treatments in clinical trials were stem cell therapy and voice synthesizer technology for patients with CP. We note here that in their mission statements (but not on individual product pages), five of the nine websites indicated that references to commercial products or services did not constitute an endorsement, and six advised that all treatment decisions be discussed with a physician first.

Placement Across the eight websites that referred to treatments, significant differences ($H(2)=7.416$, $p=0.02$) were observed for how treatment information was displayed. Post-hoc pairwise comparisons revealed that significantly more information was embedded on pages that also referred to other treatments or types of information, as opposed to located on a dedicated treatment page or via downloadable document ($p<0.05$). Binomial tests revealed that this comparison was significant only for ASD sites ($p=0.02$), but not for CP and FASD.

Purchase Information Significant differences between the types of purchase information available across all websites were obtained ($H(2)=11.84$, $p=0.003$). Pairwise comparisons revealed that fewer treatments could be purchased directly from websites (PFW; $p<0.01$) than from external organizations for which contact information was provided ($p<0.05$), or than where no purchase information was given ($p<0.01$). However, there was no significant difference between the numbers of products for which contact information for purchasing the product was present or absent. Over all websites, information about TECH-type products such as wheelchairs, walkers, and adaptive sports equipment was the most likely to include purchase information (17%), followed by OTH-type products such as toys, service animals and adaptive clothing (13%). The type of treatment for which purchase information was least often provided was DS-type products, such as vitamins and supplements (14%).

Table 2 Examples of conventional and complementary and alternative medicine treatments for each treatment type

Product Type (Code)	Conventional	Complementary and Alternative Medicine
Pharmaceutical (PH)	Antipsychotics, anticonvulsants, SSRI	Diflucan, Dilantin, MB12, Secretin
Diet/Supplements (DS)	Nutritionist	Chelation, glutathione, gluten free diet
Medical (MED)	Surgery	Hyperbaric oxygen therapy
Behavioural (BEH)	Applied behavioural analysis (ABA), speech therapy, occupational therapy	Auditory and sensory integration therapy, holding therapy
Educational (EDU)	DVDs, manuals	N/A
Mind-body Intervention (MBI)	N/A	Biofeedback, magnets, BioSET
Body-based Therapy (BT)	Aquatherapy, physical therapy	Craniosacral therapy, hippotherapy
Other (OTH)	Adaptive clothing, orthotics	Homeopathy
Technological (TECH)	Wheelchairs, sensors, communication devices	Virtual technology

Finally, the only treatments that could be purchased or downloaded directly from advocacy websites (PFW) were EDU-type products such as educational DVDs, software, and manuals found on FASD and ASD sites.

Target Audience Overall, there were significant differences in the assignment of target audience codes ($H(5)=22.59$, $p=0.0004$). Post-hoc pairwise comparisons revealed that the majority of treatment information was targeted at families as compared to allied health practitioners ($p<0.001$), educators ($p<0.05$), or children ($p<0.01$). Examples of messages targeted at parents include: “*The Autism Treasure Chest offers educational toys, therapy aids, GFCF food, furniture and books to help make a positive impact on your child’s life*” (www.autismspeaks.org) and “*Parents wishing to pursue a gluten/casein free diet should consult a gastroenterologist or nutritionist, who can help ensure proper nutrition*” (www.autism-society.org).

Message Valence Overall, there were significant differences in the number of treatments assigned each valence code ($H(3)=19.65$, $p=0.0002$). Post-hoc pairwise comparisons tests indicated that significantly more messages were encouraging ($p<0.001$) (e.g., “*Botox, for us, is a miracle drug...*”, www.cerebralpalsy.org) than fearful (e.g., “*You must keep the diet 100%... Even one bite of normal bread or a gluten-containing cookie can send the child into wailing tantrums or aggressive biting for a week or two.*”, www.faslink.org) or ‘discouraging’ ($p<0.001$) (e.g., “*...we do not recommend the use of chlorella.*”; www.autism.com). Binomial tests revealed that websites used significantly more encouraging messages about treatments and

services for each disorder ($p<0.001$) compared to all other message valences (Fig. 1c). There was no significant difference between the proportions of encouraging valence assignments for CON vs. CAM treatments.

No ‘discouraging’ codes were assigned to any CP or FASD website. Statements coded as discouraging on ASD sites focused on DS-type (e.g., “*These fat-soluble vitamins should not be taken in high dosage, as they can be toxic in excess.*” www.faslink.org) or BEH-type (e.g., “*This technique assumes that by supporting a nonverbal child’s arms and fingers so that he can type on a keyboard, the child will be able to type out his or her inner thoughts... studies have shown that the typed messages actually reflect the thoughts of the person providing the support.*” www.austimspeaks.org) treatments. We note that 17.5% of treatment cases contained statements that cautioned either about the efficacy of treatments (e.g., “*There is no scientific evidence to support these claims.*” www.autismspeaks.org) or potential negative side-effects (e.g., “*A serious concern with alpha-lipoic acid it is readily consumed by yeast, and its usage can often exacerbate intestinal yeast overgrowth.*” www.autism.com).

Discussion

This study assessed the nature of information about treatment products and services provided by a sample of the nine most popular advocacy websites for CP, ASD and FASD. We assessed website accountability, message valences, accessibility and type of treatment products and services featured on

these websites and found that while advocacy websites serve as information clearinghouses, generally consistent with their stated objectives, they implicitly appear to provide endorsement of selected treatments and services.

Selection of Treatments and Sources of Information Within the Context of Advocacy

Accountability data are an important source of information about website credibility. As Sonnenberg [1] notes, most people are not well equipped to evaluate medical information themselves and so rely on the expertise of the information provider. We found that most websites included legal disclaimers and contact information, but few provided lists of contributors or executive committee members. While we cannot comment on how parents actually use these websites, it is important to recognise that people do not generally read web pages in a thorough or linear way. It has been reported that users tend to piece together information from different sites: instead of checking the source, they evaluate information by comparing it with other pieces of information [25] or by its position in search engine results [26]. It is also important to situate advocacy websites within the social movements and controversies that surround them, as this may shape how information on these websites is seen and used. For instance, the autism websites examined here predominantly endorse the view that autism is a disease that needs to be cured rather than accepted. This is a stance that clashes with proponents of the neurodiversity movement who advocate instead for societal accommodations to people with different kinds of brains [27]. Moreover, even among organizations that espouse the disease model of ASD there remains disagreement over the causes of the disorder and hence the best course of intervention. For example, the Autism Research Institute and its Defeat Autism Now program primarily views autism in biomedical terms and has been criticized for challenging the findings of established science [27] and for advocating for treatments for purported heavy metal poisoning that are supported by the anti-vaccine movement [28]. In addition, websites that were not created by medical professionals, as is the case with over half of cerebral palsy websites [29], and which are sponsored by lawyers who stand

to gain from successful lawsuits against obstetricians, may be viewed with skepticism by consumers. In the case of FASD websites, the lack of information about treatment products and services must be put into the context of the primarily preventive stance of advocacy groups.

Here, no website included banner advertisements or explicit promotion of particular brands, and seven of the nine websites included legal disclaimers about the accuracy and nature of their content. Arguably, websites are thus meeting stated goals of providing health-related information for informational or educational purposes, but leaving users to evaluate products for themselves. However, disclaimers were hard to find, non-specific, and were usually separated from the overwhelmingly positive statements about the treatment products and services described. This risks giving an overall impression of independent endorsement rather than unbiased information. Given assumptions about the primacy of stakeholder interests, and about the experience and expertise of advocacy sites, the paucity of explicit discussion about how treatments and services are selected and evaluated is an important gap. In attempting to make the stance of advocacy websites more transparent, we therefore argue that information and evaluation policies should be prominently included in all discussion of treatment products and services.

Greater Choice or Greater Burden?

The websites provide a plethora of information about treatments and services that are readily available in the open marketplace, targeted mainly at parents. Whether exposure to large amounts of online treatment information will lead to better and more tailored treatment and service decisions for children affected by neurodevelopmental disorders remains an unanswered question. While there is relatively little research on the impact of the Internet on practitioner-patient interactions, surveys suggest that practitioners increasingly encounter patients who have gathered information or even ordered treatment products online [15, 30]. On the one hand, high volumes of treatment information might empower patients and families to take control of their care, and guide a more effective relationship with the practitioner. On the other, it might be distracting or harmful, providing poorly evaluated information from sources often erroneously assumed to carry authority or

expertise. Consumers may experience confusion and anxiety over the vast amount of information made available online, which is often poorly organized and varies in quality and relevance [31–33]. It has long been shown that increases in choice and information can lead consumers to make poorer decisions, even when given objective information about products [34, 35]. This potentially negative impact on medical decision-making is compounded for NDDs by the vulnerability of parents who are often frustrated with a lack of progress, dealing with a lack of resources and consistency within educational systems, and desperate to improve the wellbeing of their child and the impact of the disorder on the entire family [36, 37]. The shift towards greater choice thus places a greater burden of responsibility on patients; some have questioned whether this is what people really want [15]. Further work is necessary to understand this dilemma in the NDD context; a desire for increased choice and the responsibility that comes along with it may in fact be present amongst parents, but may also relate to a perceived stagnation in treatment within the mainstream healthcare system [19]. Indeed, concerns that online health information will reduce trust in practitioners [32] are especially salient in the context of messages of hope from advocacy websites about the cure and treatment of NDDs.

Disparities in the Dissemination of Information

In examining the differences between the three conditions, we note the relative paucity of treatment and service information on FASD advocacy sites. This finding may reflect differences in government funding into research for treatments for FASD. According to data from the Canadian Institutes of Health Research Funded Research Database [38], FASD research currently receives approximately \$10.5 M in funding as compared to \$51 M for ASD. However, we note that funding for CP research is also relatively low at approximately \$10 M and that CP websites nevertheless referred to the greatest number of treatment products and services. Hence, we posit that other factors may account for this discrepancy. For example, the lack of FASD treatment information online may instead reflect the digital divide that excludes those without access to the internet from developments in online healthcare. Low socioeconomic status and older age are both factors that have

been linked to lower internet access, and to FASD. Maternal risk factors for FASD include low socioeconomic status [39], and many FASD children with alcoholic parents are placed into the custody of extended family members including grandparents [40]. The focus of advocacy groups on prevention and awareness rather than on treatment is also an important factor, and is of course likely to reflect the fact that FASD is fully preventable: in fact, mission statements for FASD websites highlight prevention as their key objective. However, it is also important to recognize the impact of parental resources on advocacy for treatments, and the potential role of social perceptions, lack of understanding, and the desire to protect children from discrimination by limiting public discussion and advocacy for FASD treatment products and services.

Online Initiatives to Inform Treatment Decisions

Despite the challenges of providing information that is complete, authoritative and balanced identified here and by others [1, 15, 18], online health information can be beneficial to families and patients who value the convenience, anonymity, and diversity of the internet [41, 42]. The use of advocacy websites has significant potential to inform health-care decisions and management, improve patient well-being, assist with effective education provision, and bring stakeholder voices into the development of research. Whether this potential is realized intrinsically depends on how information is presented and used, raising the question of how information practices could be improved. Currently, online evidence-based resources for informing treatment decisions and improving patient care exist through initiatives such as the Cochrane Library (www.cochrane.org) that provides an up-to-date digital archive of research on the effectiveness of healthcare treatments and interventions, as well as reviews and summaries of research articles by panels of medical experts to facilitate the dissemination health information. In addition to expert reviews, the Cochrane Consumer Network aims to make evidence-based health care accessible to people by allowing consumers to submit comments or contribute to reviews and lay summaries of findings, pending approval from a Cochrane Library review committee. Currently, these services are available free of charge only in some countries or

local states that fund them; otherwise access requires membership and fees that can run into the hundreds of dollars. We suggest that a database similar to the Cochrane Library be created for neurodevelopmental disorders, funded by public agencies, so that advocacy websites can provide users with links to access these resources. Benefits could also be more effectively realized if advocacy groups were connected to the faculties and web-based resources (i.e., library resources) of colleges and universities. The development of regional teams responsible for reviewing the literature and making summaries available to others could also be developed either centrally or provincially by the Centre of Excellence for Child and Youth Mental Health [43] and other similar agencies.

The implementation of these suggestions would constitute a move away from the ‘information clearinghouse’ approach represented by the websites examined here, which risks obscuring hidden selection procedures or attitudes to treatment. A more explicit division of labour between advocacy websites that select items judged relevant to their audience, and the sources of evaluation about these products, would also recognize the challenges inherent in evaluating new forms of online expertise. Partnership with existing organizations whose ethical status as information evaluators is linked to their institutional credentials is an important avenue for patient-focused organizations to avoid misinformation and deal with the burden of evaluation. However, it is also important to recognize that novel forms of expertise, support, and lay knowledge about what are often unproven or complex treatments do have a potential role to play in improving outcomes for children with NDDs. It is a significant challenge, and one that reaches far beyond the case we consider here, to integrate such forms of advocacy with ‘conventional’ treatment approaches, and in doing so to account for live debate about underlying concepts of disorder, difference, and disability.

Implications for Neuroeducation

Our findings indicate that advocacy websites generally do not target educators when providing information on treatment products and services. Moreover, little information on educational products or services were provided that could benefit schools, such as teaching materials to facilitate learning in the class-

room or instructional videos and manuals to inform teachers about NDDs and effective teaching strategies. Indeed, of the 15 treatments targeted at educators only four included educational materials (e.g. DVDs and teaching manuals); the remainder consisted of brief descriptions about behavioral-type treatments (ABA, music therapy, SCERTS, floortime, RDI, PECS, OT, speech therapy) or treatments classified as “Other” (e.g. toys and recreational activities). Research has shown that early intervention may be critical for helping children with NDDs to thrive [44] and that some of the most promising and effective treatments involve intensive behavioral therapies that are often administered in the home by families or by certified therapists [45]. In addition, children may make large gains with intensive behavioral treatment implemented in school settings [46]. Thus, it is important for school staff to be aware of interventions being used by families and medical practitioners to ensure that school curricula are as congruent as possible with behavioural therapies. Indeed, parents are increasingly asking public school teachers to incorporate behavioral therapies into classroom instruction [47]. Unfortunately, teachers who are not specialized to teach children with NDDs receive relatively little, if any, formal instruction in evidence-based practices for children with disabilities [48]. With this in mind, there is a clear need for neuroeducation initiatives that inform educators about the best teaching strategies for children with disabilities. Advocacy websites could potentially provide a platform for these initiatives by helping to disseminate free teaching aids, assist educators in evaluating teaching strategies, and provide a platform for discussion about specialized instruction on NDDs to public school teachers.

Conclusion

In this paper, we suggest that statements about evaluation should be prominently displayed with all treatment product and service information rather than relegated to hard-to-find disclaimers. We further urge investments in initiatives that would improve the ability of consumers to critically assess the quality of online health information, both by addressing the presentation of information and through explicit techniques and guides to help users with particular needs to navigate and critically assess website

information. We also suggest that government-funded investigators such as those from NeuroDevNet Inc. could collaborate on better processes for evaluating the educational information made available to users, as well as on monitoring commercialized developments. New online information projects led by high profile, trusted government organizations may constitute a particularly effective response to the rising demand for personalized health care [33] in our western society and the successful empowerment of families and children.

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