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Editorial comment

Advances in software technology provide the means to take complex knowledge and design a comprehensive system to guide decisions. AutismPro was created to do this for the field of autism (see www.autismpro.com). It is a new online software tool developed in Canada by international educators in the field of autism. It follows 'best practice' to guide intervention decisions and activities. Parents and professionals who subscribe to AutismPro are able to:

- make informed choices about methods
- design and implement a quality, individualised plan
- evaluate the plan with progress data

This paper presents data from a survey of 28 parents who have used AutismPro.

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Introduction

Children with autism and other developmental disorders benefit from educational intervention as early as possible. Early intensive intervention has been shown to be very effective especially when parents become central to decision-making and are active participants in the intervention. In many early intervention models, professionals serve primarily as trainers and demonstrators, assigning daily activities to the parents and educators to conduct with young children. With recent advances in software, there has been a trend in using technology as a means of coaching and guiding people and enabling them to 'act like experts'.

There are important reasons to explore the use of technology to assist the delivery of autism intervention. First, more and more children are being diagnosed with autism and requiring treatment with recent estimates being at 1 in 150 young children (Center for Disease Control, 2000). Secondly, the demand for services is far greater than their adequate supply due to cost, turnover/burnout (Stempien and Loeb, 2002) and human resource issues. Thirdly, social trends mean that parents often go to the internet to research solutions and are currently overwhelmed by both legitimate and bogus treatment options. Fourthly, children with autism and other developmental disorders require

complex, tailored intervention from specially trained individuals in scarce supply (Perry, 2002). The therapy is complex since it may cross disciplines - such as speech and language, psychology and occupational therapy - and may borrow from one or more approaches with a confusing array of acronyms such as ABA, DIR, PEGS, RDI, SCERTS and TEACCH. Both parents and professionals require a means of integrating and making sense of a multitude of elements in order to help the child immediately and effectively.

The expense and time-consuming nature of the current service delivery model for autism is crippling the education systems and is having a profound impact on the health care systems of the United States and Canada. The Department of Education in Massachusetts (data from 2001-2002 school year) estimates the annual cost for education, per child aged 3-5 years, to be \$55,000 and similar costs are reported in other states and in Canada. The consequences for health and educational services are staggering.

United States Federal law (94-142) requires comprehensive, appropriate education and treatment from the age of 3 to 22 years. Most provinces in Canada have incorporated intensive autism programs as part

of their mandates. Clearly, the growing number of children, families and educators in need of information and support cannot be addressed by the current pattern of service delivery.

Hundreds of research papers exist, providing a very large information database concerning methods of autism treatment. However, the challenge is to use this large body of knowledge to select the most effective treatment approaches for the wide range of individuals with autism spectrum disorders (Lord, 2000).

'Treatments that are dramatically effective for one person with autism may be ineffective or even contraindicated for others.'

(Whiteford, 2000, p83)

In addition, a single child may receive a mixture of treatment strategies. All these choices mean difficult decision-making for both parents and professionals (Sheinkopf and Siegel, 1998).

In addition to a myriad methods, there are hundreds of potential treatment goals to choose from when designing an intensive early therapy program. Typical preschool autism programs contain approximately 500 treatment objectives and continue for 2 to 3 years at an intensity of 20-40 hours per week. Furthermore, research is continuing to find new evidence that some of these goals are more pivotal and important than others. Knowledge of which goals are of higher priority than others is critical if children are to be treated in a time- and cost-efficient manner (Koegel, Koegel and McNeerney, 2001).

The complexity of the disorder and the treatment choices mean that clinicians and educators need to develop logistically feasible and effective treatment programs. Furthermore, there is an additional requirement continually to monitor the effectiveness of the program and both modify and update the goals, methods and activities (McConnell, 2002). These changes arise from measures of how well or poorly the child is responding and how quickly they are mastering skills. In addition, there is a need to keep up with new research providing recommendations to enhance clinical practices.

Technology such as intelligent software, the internet and multimedia e-learning is uniquely able to assist in performing the functions of knowledge integration, group communication, distance education and data analysis. There appears to be a wide variety of 'expert system' applications using computer communication networks in the medical field. For example, expert

software systems have been developed to assist in diagnosing patient cases (Huettig et al, 2004; Kuznetsova et al, 2003). However, despite the increasingly common use of decision-support software for diagnosis and education in the medical field, virtually nothing has existed to support complex intervention requirements in the fields of special education and educational intervention.

The objective of this research project is to answer the question: Can technology be applied to help solve the service delivery dilemma in the field of autism at the same time as enabling parents to become active participants in the intervention process?

The technologies to be explored include a comprehensive package of software technologies (artificial intelligence, client management) supporting decision-making, client management and monitoring processes, with internet technologies and e-learning technologies (video vignettes, etc.) addressing the accessibility to expertise issue.

The particular challenge is the existence of different levels of knowledge and training among potential end user target groups, whether they be parents, educators or professionals, some of whom will have little or no knowledge of autism and autism intervention. The concern would be that given the diversity within the autism spectrum, the numbers of differentiated methods and strategies for intervention and the level of expertise required to navigate this information appropriately it would be extremely difficult to create expert system software that would allow a novice to autism to design and implement an individualised intervention program for a child.

The goal of this research therefore was to assess whether or not an intelligent software system can fulfil its goal of coaching and guiding parents to facilitate their child's early intervention despite the user having little or no knowledge of the field and little or no access to human expertise.

Method

Participants

Participants included 46 families across Ontario, including 63 adult care providers and 52 children aged 2 to 9 years. These children had all received a diagnosis of autism from a physician or psychologist using DSM-IV-TR criteria (American Psychiatric Association, 2000). All participants were recruited through parent-list invitations by autism organisations in Ontario.

Design

An online survey was designed and distributed to families for anonymous completion within approximately four months of using AutismPro. Of the 46 parents requested to complete the survey, 28 responded (57 per cent). This response rate is fairly typical of other studies that use questionnaires.

Software

AutismPro online software helps ensure best practices are followed by its users when treating the child with autism. The software includes a comprehensive curriculum of eight developmental areas including social, emotional, communication, academics, language, understanding, self-care and motor skills. It educates users around choices and makes treatment recommendations based on answers to questions. It provides multimedia training in practical chunks according to the child's needs and the user's place in the learning process. It provides video demonstrations of strategies and step-by-step activity procedures to follow with the child. The software evolves the plan to next steps as the user marks the child's progress. Although clinical supervision of AutismPro would be useful, the software can be used independently by parents as is the case when parents use paper-based curriculum programs.

An expert advisory board of key educators in autism helped produce and/or review the content and logic behind AutismPro during the years of its development. Their names are given in Table 1.

Measures

The survey was designed to measure the product's usability, usefulness and perceived value for parents.

Results: navigability

Usability was measured with questions about user navigation and content design (see Table 2). All users either agreed or strongly agreed that the software was

Table 1: Consultants involved in developing AutismPro

Name	Place of work
Michael Cameron	Simmons College
Theo Peeters	Center for Training in Autism, Antwerp
Cathy Pratt	Indiana University
Kathleen Quill	Autism Institute, Essex
Brenda Smith-Myles	Kansas State University
Diane Twachtman-Cullen	Editor of Autism Spectrum Quarterly
Pamela Wolfberg	San Francisco State University

Table 2: Ratings on user-friendliness and navigability

	Strongly agree	Agree
Navigational design		
Users will easily understand what to do in AutismPro to receive guidance	43%	57%
Users will understand where to go in AutismPro to access different types of guidance (ie objectives, strategies, supports, activities, FAQs)	46%	54%
Content design		
Users will easily understand the recommended objectives	37%	63%
Users will easily understand and be able to follow recommended activities	44%	52%
Users will easily understand recommended supports	29%	64%
Users will easily understand recommended strategies	35%	62%

designed well enough so that users clearly understand where to go and what to do to receive guidance within the program. All users unanimously agreed or strongly agreed that the software's recommendations on treatment objectives, activities, strategies and supports were easily understood.

Results: usefulness

Usefulness was measured with questions about how well the software functions to guide and support the users' decisions and, secondly, to manage the complex requirements of autism intervention (see Table 3). Most users agreed AutismPro helped them decide on methods, goals, supports and teaching strategies. Most users also agreed that AutismPro helped them schedule, co-ordinate, evolve and prioritise their efforts with their children.

Results: perceived value

Perceived value was measured with questions about how well the software was able to guide and support the users' decisions; to manage the complex requirements of autism intervention; to reduce costs; and to increase the quality of intervention (see Table 4). Users all agreed that AutismPro was a valuable tool to support intervention decisions, guide intervention and manage intervention. Most users also agreed that costs of intervention would be reduced and quality of intervention would be enhanced through use of AutismPro. All users agreed that they would recommend AutismPro to other parents.

Table 3: Ratings on the usefulness of AutismPro

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Decision support and guidance functionality					
AutismPro helps users decide on a treatment method	31%	58%	12%		
AutismPro helps users decide on treatment goals (Objectives)	33%	59%	4%	4%	
AutismPro helps users implement positive behavioural supports	15%	73%	12%		
AutismPro helps users implement teaching strategies	17%	83%			
Management functionality					
AutismPro helps users manage scheduling of activities	27%	54%	15%	4%	
AutismPro helps users prioritise objectives and manage those priorities	23%	65%	12%		
AutismPro helps users update and evolve a plan in response to a child’s changing needs	28%	60%	8%	4%	
AutismPro helps users co-ordinate team efforts	8%	64%	20%	8%	
AutismPro helps users understand when they need to try something new	8%	58%	25%	8%	

In ranking the major outcomes from AutismPro, users ranked *empowers parents* as the top benefit (Table 5).

Discussion

This survey demonstrated that parents of children with autism were able to use a technology-based tool, AutismPro, to receive guidance on how to intervene and teach developmental skills with their young children with autism. This approach is consistent with other studies that point to active parent participation as key to successful intervention outcomes for children with autism and other developmental disabilities.

The concern that parents are not capable of using an intervention guidance tool independently from an

autism professional is not supported by the results. In fact, all users reported that the tool was useful, meaning they could easily follow its recommendations and found them to be practical for their needs. In addition, although half of the parents in the study reported no professional involvement in intervention, they responded as positively to the tool’s effects as those parents whose child was in a professionally supervised intervention program.

The concern that the tool had too much content (10,000 pages) and covered so many different elements of intervention that it would be too difficult to navigate it and find what was needed was not supported by the results. In fact, all users reported

Table 4: Perceived value of AutismPro by parents

	Strongly agree	Agree	Neither agree nor disagree
AutismPro is a valuable decision-support and guidance tool for parents	36%	60%	4%
AutismPro is a valuable management tool for parents	32%	64%	4%
	Significantly	Not significantly	Not at all
Do you believe the cost per family for clinical consulting will be reduced by the use of AutismPro?	71%	24%	
Do you believe cost per family for travel will be reduced by the user of this program?	75%	17%	8%
Do you believe the cost per family for curriculum development will be reduced by the use of this program?	82%	14%	5%
Do you believe the relevance and quality of educational therapy plans will be enhanced by the use of this program?	86%	14%	
	Yes	No	
Would you recommend AutismPro to other parents?	100%		

Table 5: Top benefits of AutismPro as rated by parents

Top benefit	Group ranking
Empowers parents	1
Saves time	2
Saves money	2
All of the above	2
Improves therapy	2
Improves accessibility	3
Improves speed of care	3
Empowers teachers	3

positively to questions measuring the tool’s usability, meaning they could easily navigate within the software to find what they wanted.

Concluding comments

The idea that AutismPro’s greatest perceived benefit would be its ability to give immediate advice following diagnosis and reduce the associated costs was not supported by the results. Indeed, it was quite evident from the objective data as well as verbal and written comments of users that the tool had its most significant impact on parent well-being, increasing a sense of empowerment, control and reducing the opposite feelings of powerlessness, lack of control and direction and associated stress.

Only half the parents who took part in the trial responded to the evaluation questionnaire and so the

results reported here may not be representative of all the parents in the trial. It would be interesting to follow up some of the parents who did not reply - in a different way (eg face-to-face interview) to gain their views. Not all parents and professionals will enjoy or access information effectively via computer, so it is important that different ways of providing information and advice are available.

To conclude, AutismPro software-based guidance appears to be a promising option for parents to receive immediate, cost-effective guidance and support for treating and managing autism and autism intervention with their children. The global use of computers and the internet in homes means that it is a potentially valuable medium for helping address the supply-demand gap in autism services and special needs services in general.

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