

## Providing Family Help at Home

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### Abstract

*A web based system is described for the delivery of evidence-based behavioral interventions in the home for a variety of mental health problems in children. The goal of the interventions is to teach parents and/or children new skills to enable them to better manage their problems without having to drive into the clinic for face-to-face therapy sessions. The first web based problem module, Disruptive Behavior, includes video clips, interactive modules, web based communication and communication with a human coach on a regular basis using the telephone. The preliminary findings of the first pilot test with 22 families are also discussed.*

### 1. Introduction

Pediatric mental health problems are very common and inflict a heavy burden on the individual, the family and society if untreated. There are both immediate and future impacts on the daily functioning and quality of life for the child and the family. Access to mental health treatment is of concern because about 80% of children with diagnosable mental health problems are not seen by mental health professionals [8]. Barriers to care include lack of mental health professionals due to limited resources and the current system in Canada that treats only children with severe problems results in long wait lists for children with mild to moderate problems.

For the 20% who receive care, it is often very difficult for families with children to commit to their treatment plan with the specialist, especially if they live outside of the major centers. The travel required by the family to accommodate the face-to-face appointment with the specialist results in a significant cost burden. Parents have to take time off work, pay for transportation costs, meals and babysitting services for other children. About 45% of families drop-out before completing the treatment

[5]. The stigma associated with receiving mental health services is also a contributing factor. When specialist care is received, the treatment plan is often not evidence-based even though such intervention programs have been proven to be effective. Consequently, those who receive mental health care may not receive the most effective treatment, resulting in poor health outcomes.

In order to increase access to effective mental health care, we have been developing and testing evidence-based distance treatment programs for mental health problems in children. The goal of treatment is to teach parents and/or children new skills to enable them to better manage their problems. These programs engage the parents, and in some cases the children, in treatment using our web based materials that include embedded videos and a trained coach, available by telephone or e-mail, who is supervised by a psychologist. The coach monitors progress, identifies problems, and is on call to problem solve on a continuing basis. Treatment is delivered from a distance with no face-to-face contact.

A variety of treatment delivery methods have been explored for disorders for which treatment relies on the learning of new skills. These delivery methods include self-help books, therapist-reduced treatment, para-professional delivered treatment and videotape-administered treatment. Scogin et al., [9] conducted a meta-analysis of 40 studies of self-administered behavioral mental health treatment. They found that self-administered treatments were superior to no treatment and not different from the more traditional modes of therapy delivered by a specialist therapist. Similar effectiveness has been found for computer-based treatments [4, 7 & 10]. Work with child psychological and behavior problems, although limited, has similar results. Webster-Stratton [11, 12 & 13], in a series of parent-training studies that used videotape modeling of parenting skills as the primary treatment, reported clinically significant improvement in child behavior. Follow up at one year showed that these gains were maintained. Similarly,

McGrath et al. [6] found that treatment delivered primarily by means of a manual, audio-tape and telephone calls was as effective as the same treatment delivered in the more traditional way by a therapist and it was superior to a placebo treatment. We recently reviewed the evidence for these non-traditional ways of delivering care [3].

Two modes or channels of delivery have been designed for these new distance treatment programs. The first generation was designed to be delivered by means of handbooks complemented by videotapes and reinforced through weekly telephone sessions with a coach. The purpose of the weekly telephone sessions is to review the chapter content with the participant, problem-solve, recommend solutions, and evaluate whether there was effective implementation of the learned skill. Each participant is assigned a primary coach at the beginning of treatment to ensure consistency of the treatment plan that is customized to meet the participant's needs. The first generation program modules included interventions for Disruptive Behavior Disorder, Attention Deficit/Hyperactivity Disorder, Enuresis, Recurrent Abdominal and Headache Pain, and Anxiety. We are currently testing these five modules using randomized control trials.

The second generation design uses the Web as the mode of delivery grounded by weekly telephone sessions with a human coach and the option of using e-mail as a means of communicating between sessions. The Web version provides a higher level of interaction, video clips, audio, electronic communication with other parents and the coach by means of a discussion board, direct contact with their coach via e-mail and finer level of data collection. To date, 22 families have used the first web based module for Disruptive Behavior Disorder (DBD) over a 3 month period as a pilot study with no control group. The results are very encouraging as the families enthusiastically supported this intervention mode. Using feedback from this initial study, we have developed a common shared architecture that supports a wide range of such interventions including those currently using printed handbooks (Attention Deficit/Hyperactivity Disorder, Enuresis, Recurrent Abdominal and Headache Pain, and Anxiety) as well as new modules for Inflammatory Bowel Disease, sleep disorders and post-partum depression.

## 2. Web-based Clinical Series

The first generation program used printed home-based learning modules developed by the Family Help group in conjunction with telephone based coaches with success in Nova Scotia. The objective of the second generation treatment delivery system was to: transform the content and develop a web based platform that would support a variety of such treatments, facilitate monitoring of engagement in the program by parents, as well as

generate evidence for analysis of effectiveness on outcomes in the families.

The goal of the initial web based clinical series, for the Disruptive Behavior Disorder (DBD), was to provide families with 24 hours a day, 7 days a week access to an evidence-based behavioral intervention program in their homes. By providing treatment to families in the comfort and privacy of their own homes by means of the Internet, we can increase the interactivity and involvement of the families, track activities of parents, reduce costs and increase access to treatments. Our longer term goals are to increase the scope of our programs to cover more problem areas and to expand the reach to families within the province and at the national level.

### Treatment Program Description

This behavioral intervention program was adapted from the COPE Program designed and proven to be effective by Dr. Charles Cunningham, [1 & 2]. Cunningham's approach involves trained leaders who provide weekly information sessions in a parental group setting with the expectation that the parent will successfully practice and implement the learned skill with their child during the following week. These weekly sessions include a video component that illustrate 2-3 scenarios of ineffective ways to deal with specific behaviors followed by a scenario that demonstrates successful implementation of the learned skill to deal with the same behavior. Consistent use of these parenting skills such as paying attention to good behavior, ignoring whining and complaining, and time out have proven to produce positive behavioral changes in children 3-7 years of age. The Family Help Program approach has adapted the COPE skill-based concepts and video component, but modified the treatment program to be delivered from a distance, one-on-one (parent/telephone coach) with no face-to-face contact.

The Web-based Disruptive Behavior Disorder treatment program has ten evidence-based, skill-focused lessons. The opening page is shown in Figure 1. On the average, the lessons take approximately one week to complete. Parents access the secure web site to learn the skills by means of the written material, the case-based videos and the homework assignments. Questions based on the video clips enable the coach to evaluate the level of parental understanding of the skills. The data from the weekly homework assignment, the "Tryout Page", is used to determine if the parent has been successful in implementing the new skill with their child. Parents can review the lesson content at any time by interacting online or they may download sections to work offline at a leisurely pace. Working offline eliminates the issue of a busy phone line for the user with dial-up service.

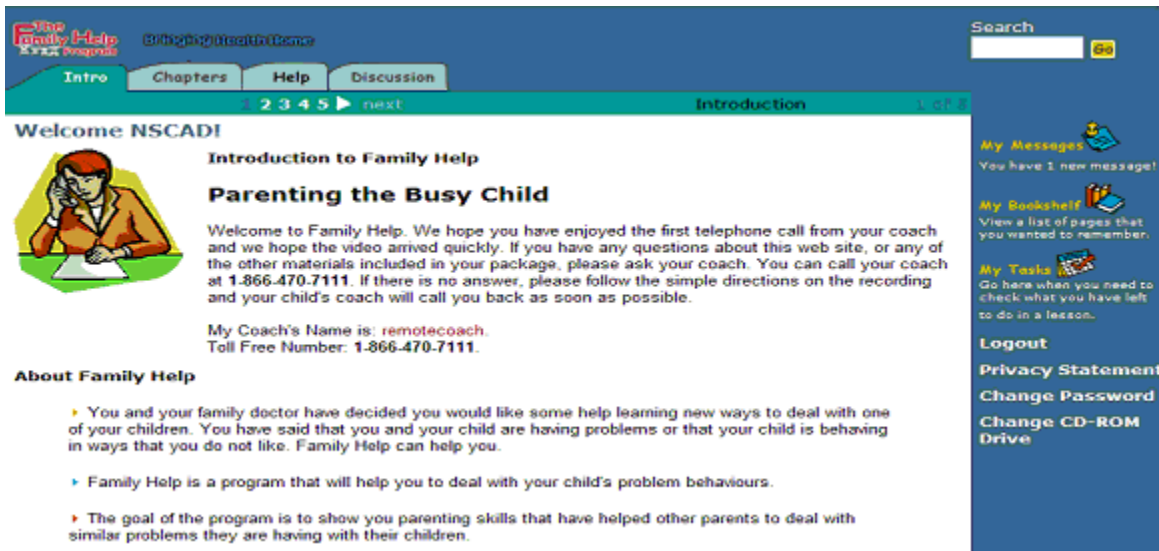


Figure 1. Opening page of Family Help for Disruptive Behavior Module

The table of contents page, shown in Figure 2, is a dashboard design providing access to all of the program chapters. Notice that the sections of the chapter that the parent has already completed are shaded. There is no restriction on the order that parents access the chapters imposed by the system. A chapter is, however, only considered complete when the parent has completed the

exercises associated with that chapter. A context for self directed interaction is provided where the parent can check discussion boards and emails, parents can bookmark content for quick reference in their own Bookshelf, as well as create and monitor their own “To Do” reminders.

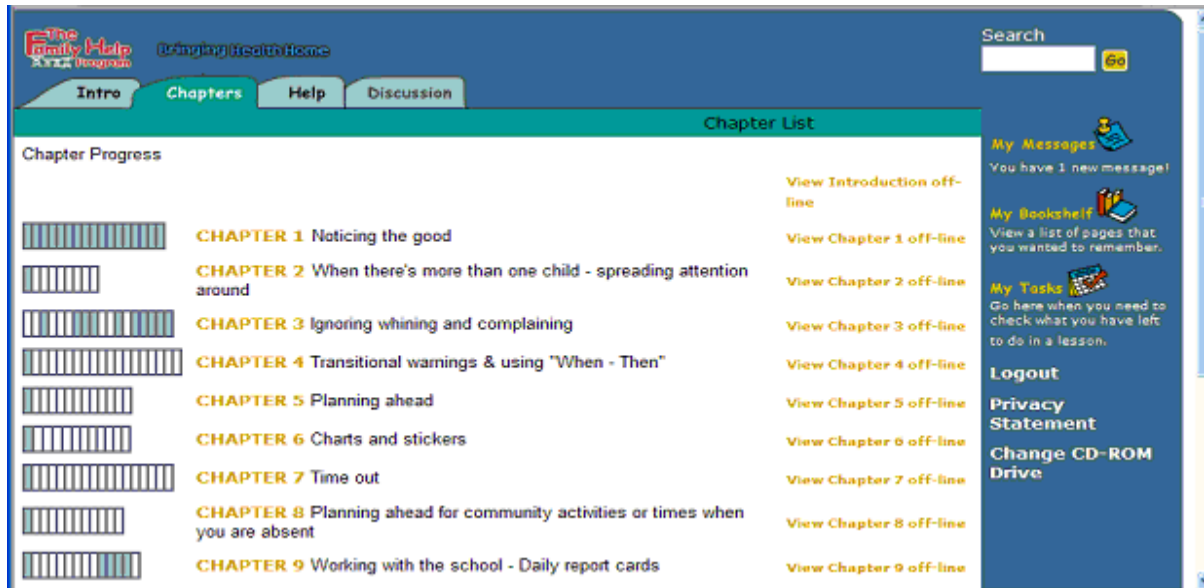


Figure 2. Module Table of Contents and Progress Page

A typical lesson would consist of explanatory text, charts, video scenarios, and work sheet style questions for the parent to practice the new skills as well as provide a

basis for discussion with the coach. Figure 3 presents typical skill practice questions.

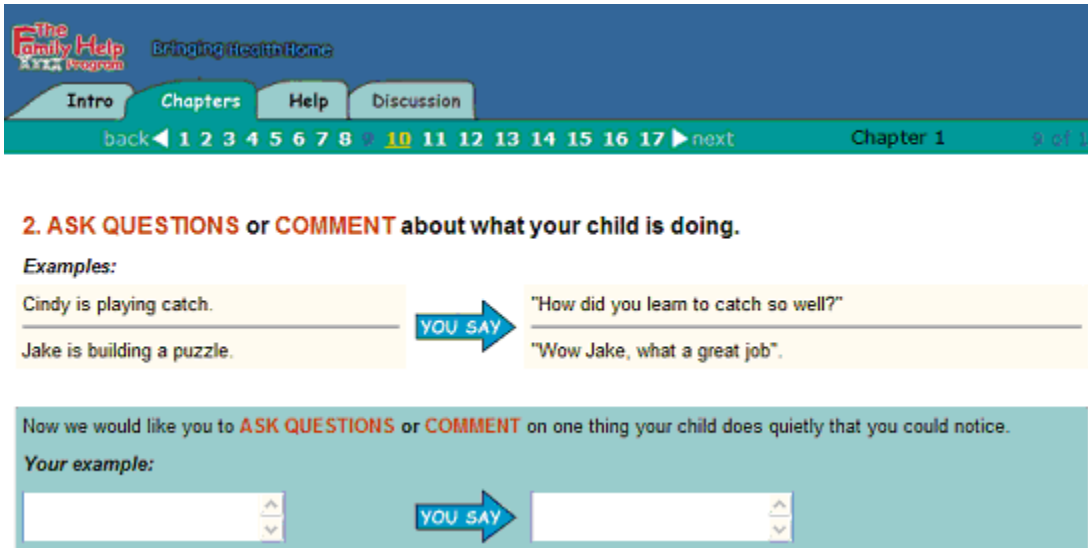


Figure 3. Sample interaction page.

A suite of approximately 44 video scenarios has been developed for this program using real families as the actors. As described earlier, each video scenario has several components, each related to the text of the lesson and with its own skill assessment interactions for the parent. For example, in chapter 1 "Notice the Good", one

such clip shows a busy father asking his son to pick up his crayons and Figure 4 shows part of the ensuing interaction that the parent completes. During the weekly telephone session, the coach will review the parental responses to the video segments and determine if the parent understood the importance of acknowledging the times that their child is well behaved.

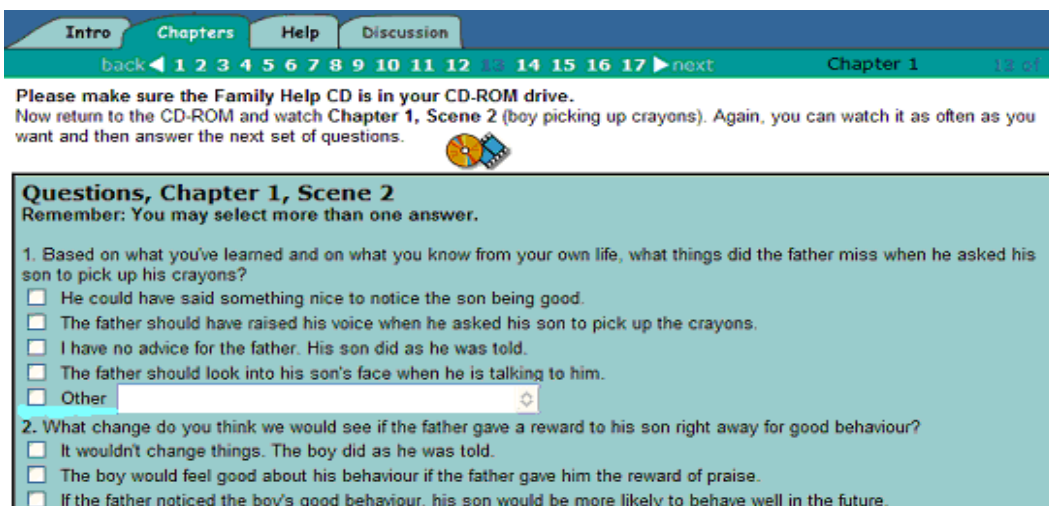


Figure 4. Interaction related to video clip.

The role of the telephone coach is to reinforce the main concepts presented in the lesson, problem-solve with the parent, motivate and pace them through the program as well as customize the service to meet the needs of the family. The coach and family interact by telephone, e-mail and via an asynchronous discussion board. For each treatment call, the coach also logs on and accesses the parent performance information, using a split-screen designed for this purpose. This split-screen concept,

shown in Figure 5, enables the coach to follow a protocol script for the specific lesson, review data submitted by the parent and enter responses from the parent during the treatment session. The working offline feature, mentioned previously, enables the parents with dial-up connections to view the content and their responses while talking on the phone with their coach.

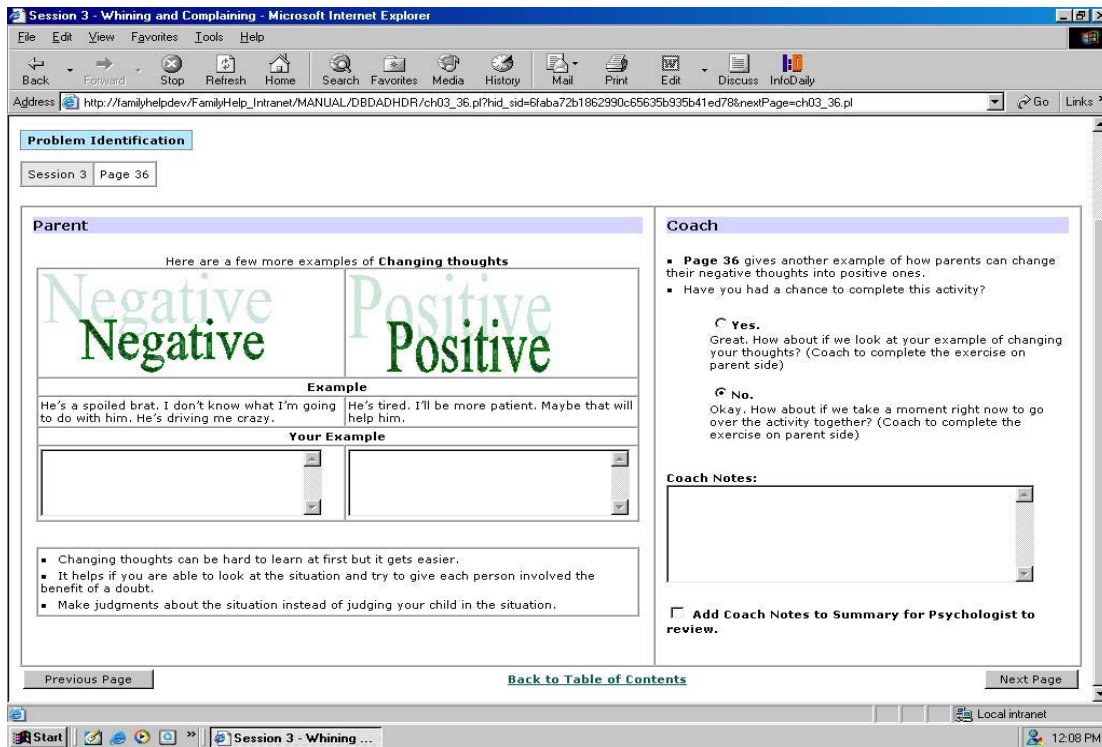


Figure 5. Split screen for Coach.

### 3. Architecture and Security Issues

Using the web as our platform for delivery offers several advantages over the first generation model of printed material with video tapes. The most obvious advantage is the richness of media that can be easily incorporated, such as video, animation, sound, high quality images, and hypertext links. Second, interaction can be initiated at many points in every lesson and the interactions may generate immediate feedback or be sent immediately to the coach for analysis. This real-time data entry on the part of the participant enables the coach to track treatment progress. The coach can view the information entered by the participant and engage in direct discussion either via e-mail or discussion board.

Additionally, they can send prompts and reminders to personalized for the user with dynamic composition of lessons, bookshelves, bookmarks, chat groups, diaries, and discussion board capabilities. Our ability to update material, add supplementary material, replace examples, provide responses from a specialist, and update frequently asked questions provides a more stable, long term process for maintaining the quality of the content and enhancing positive health outcomes. Finally, once developed, the web-based system is less expensive to deliver to the families as there is a very low per unit cost of materials (compared to color printing costs for manuals in the first generation model) and less coaching time is needed.

## Content

The content of the lesson material came from the written materials used in the earlier handbooks. The content was segmented and stored in a database from which Web pages are dynamically generated as needed using Active Server Pages and PERL. The bandwidth in some rural areas of Nova Scotia does not support high quality video interactions. Therefore, in order to ensure that the video segments ran seamlessly on as low as a 56K line, the video clips were compressed and burned to cd-rom. Access to the video clips is transparent to the user and is initiated by a hyperlink in the Web page itself.

## Architecture

The architecture was designed to provide web-based

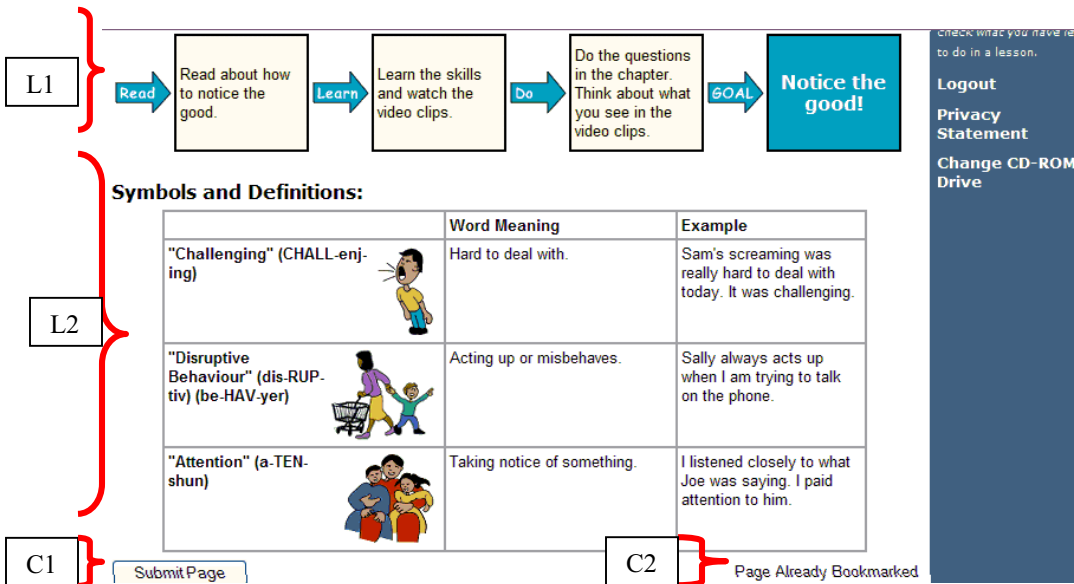


Figure 6. Sample Modular Composition of Lesson Page

A three layer architecture was developed, as shown in Figure 7. Two logical databases are used. One to store the lesson components and one to store user input data and user navigational data. Users include study participants, coaches, and management staff. User input records all intentional input from the user, such as answers to questions, notes, e-mails to the coach and discussions. The system records navigational activities of the user, such as Web page access, video showing, and help. This data is for use in analysis of the use of features post hoc. Algorithms have been programmed to score aspects of the outcome measure assessments to facilitate interviewing and evaluation processes.

Security issues are a high priority for all user data, including the users' input and navigational data. These are

access to learning modules for a wide variety of psycho-social treatments.

The principles of the design are as follows: content components common to other problem modules should be reusable, Web-site control components such as submit and bookmark, should be reusable, and user navigational data should be collected at all levels. Consequently, we designed the online learning lessons as composites of fine grained components for maximum reuse and lesson configuration. The user is afforded control of the actual navigation pattern through the site and many of the user activities were tracked for analysis purposes for future studies and system improvements. For example, in Figure 6 there are two learning components consisting of lesson content (L1 and L2) and two control components (C1 and C2) used to create the lesson presented.

kept in a secure physical location and behind the hospital firewall. In addition, a digital certificate from Verisign® ensures that all communications to and from the user are encrypted at the SSL (Secure Socket Layer) protocol level. Access to the site is secure and only available by assigned rights to eligible participants. The Web-page content data is accessible to the participant by a unique user name and password. The data for coach and management access only is logically located in the hospital intranet and inaccessible from the outside. All data entered in forms on Web pages is automatically dumped to the back-end database server.

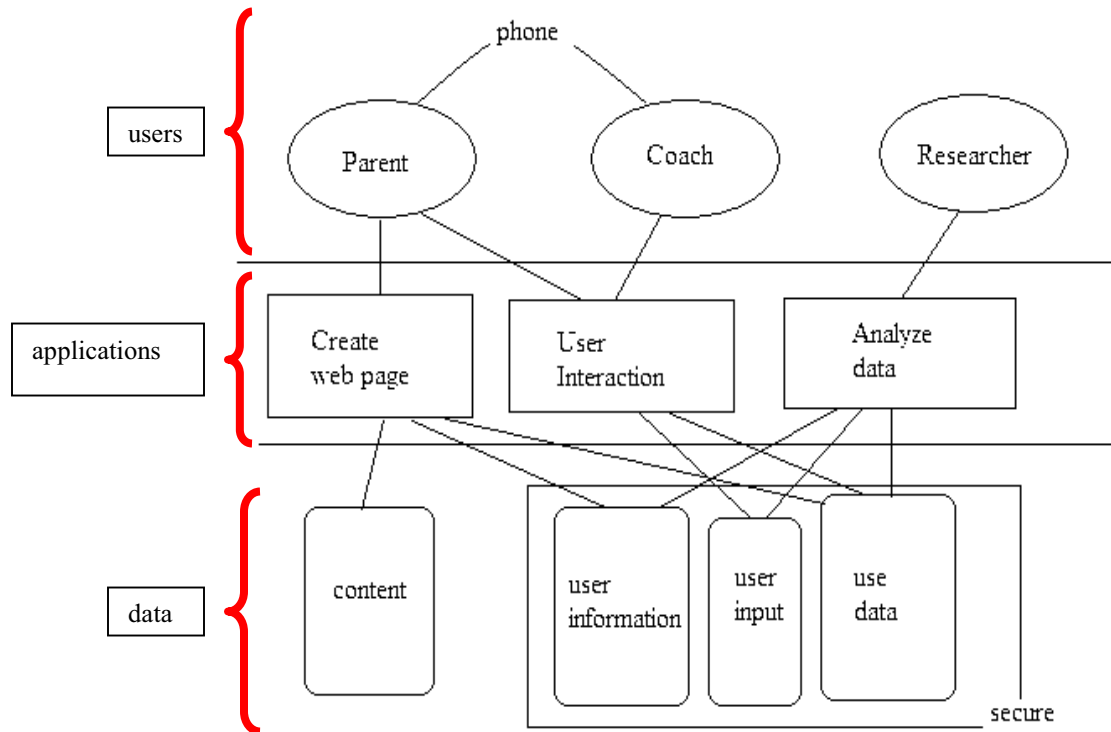


Figure 7. Three Layer Architecture

#### 4. Initial Study and Preliminary Findings

For the initial study, physicians who practiced in Nova Scotia District Health Authorities 4, 5, & 6, a rural area of Nova Scotia, could refer families to the Family Help Web-based DBD pilot study if they had a child between 3-7 years of age with mild or moderate symptoms of Disruptive Behavior Disorder. A total of 27 children from rural Nova Scotia were enrolled, with signed parental consent. Of these, 5 were withdrawn, 16 have completed treatment, and 6 are in active treatment. For families who did not have the necessary computer or Internet access, these were provided for the duration of the treatment program. Human Resources Development Canada and Nova Scotia District Health Authorities 4, 5, & 6 funded this trial.

Of the 16 who have completed treatment to date, approximately 88% of the participants were supplied a computer and 81% required dial-up internet connections in order to gain access to the program. Program funding covered internet services costs.

Prior to shipping the computers, the systems were tailored with the installation of the Family Help software, internet explorer, the internet service provider and a multimedia player. The shipment included a user manual illustrating computer set-up and how to access/navigate the Family Help internet site. Technical support was available by phone or on-site at the patient's home as necessary.

Using well-known, validated scales, health outcomes were measured at four timepoints throughout the program: baseline, end of treatment, 6 and 12 months later. These measures were administered to the parent by phone and included a detailed diagnostic interview; a child health questionnaire; a parenting scale and scales specific to behavior disorder. The outcome data generated from these interviews is in the process of being analyzed, therefore the results are not yet available.

A participant satisfaction questionnaire was completed at the end of treatment. The table below summarizes preliminary results of the satisfaction questionnaire completed by the 16 parents, who have completed the program to date:

Questions	Ratings				
	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
Website content was helpful	12	3	1	0	0
Videos were helpful	10	3	3	0	0
E-mail to coach was helpful	5	3	7	1	0
Discussion Board was helpful	3	3	9	1	0
Would encourage others to use Family Help	14	2	0	0	0
		<b>Yes</b>	<b>No</b>		
Website was easy to use		15	1		

Results from the Customer Satisfaction Questionnaire, shown above, indicate that the majority of the parents who completed the treatment program (primarily mothers) strongly agreed that the Family Help DBD website was easy to use, the content and videos were helpful, and they would recommend the program to other parents.

The opinions of the e-mail system and the discussion board were not as remarkable. About half of the participants had neutral feelings regarding the helpfulness of these functions. However, only 2 of the 7 parents who reported neutral feelings regarding the e-mail helpfulness actually used this function suggesting that they had no opinion. In fact, utilization reports indicate that over half of the parents e-mailed their coach at least once. This finding is quite promising when considering the primary and most immediate mode of contact with the coach for this pilot study was by telephone. The coach was always available by means of a toll-free phone number that triggered a pager for the coach to respond to the call.

The majority of these rural-based parents required a computer and access indicating that their technical and typing abilities may have been limited. New users may have found it challenging to learn how to use the basic computer functions, review the online text and videos, implementing the learned skills with their challenging child and enter the data online in preparation for their next coach session telephone call. Another limiting factor to consider are the restriction of a dial-up service such as difficulties logging-on due to a busy signal, connection issues and the fact that while on-line the parent's home phone line would be unavailable. Concluding that it would be much easier to leave a voice message for the coach than take the time to type an e-mail and check for the response.

One parent who e-mailed her coach 30 times during treatment reported an issue with the inability to save the

sent e-mails, whereas another who e-mailed 23 times reported that she liked this function because she was a very technical person. Another parent found that many participants did not utilize the discussion board. The coaches had used e-mail at least once for 69% of the 16 participants. Once the pilot study is completed, these findings will be reviewed more closely in the final analysis in order to plan for future improvements in these areas.

Many of the parents who had completed the module provided comments about their experience. One mother commented that "As a family, we have benefited so much from this program." Another mother reported to the coach that she liked "the fact that you can do it on your own time, you don't have to take time off of work to travel to Halifax." With the PC in her home, she could work on the program whenever she wanted. She was able to adapt to having a regular time and it worked for her despite the fact that she says she normally does not like having to be in a certain place at a certain time. Another mother reported that she liked the fact that it was on her own time; web and phone contact was great; it fit her needs. A different mother found it very helpful and loved the fact that it was in her home. She said that it was very helpful for the father as well and that her child's behavior had changed a lot. The coaches also report positive behavioral changes compared to the baseline condition.

The coaches who worked with parents in both treatment delivery systems (first generation paper manual/video compared to web/cd-rom) found that they liked the ability to check the progress of the web participants enabling them to send e-mail prompts or make telephone calls to keep them on track. Early indications suggest that there may be better retention and treatment completion rates in the web-based program that will require further investigation to determine the rationale for these findings.

## 5. Conclusion

Family Help Disruptive Behavior Program was designed based on an evidence-based group therapy behavioral intervention model. The goal was to develop a remote, family based model that would address the issues of access to care and effectively meet the needs of the individual family. Testing of two modes of delivery (web based and paper based systems both complimented with videos and telephone treatment sessions) will be analyzed in the near future to determine if the intervention was successful in producing positive health outcomes. Currently, the web-based system is under review to identify particular characteristics and functions that provide most benefit to the user.

Successful implementation of the Web-DBD clinical series has lead to architectural improvements. The new web design is a layered concept with hyperlinks to supplemental information. Additional navigational data collection will be implemented to capture all key-strokes, time spent on specific pages, and the number of times a video clip is reviewed. In addition, parents will be able to save e-mails sent to the coach and customization of treatment delivery will be provided. Consideration will be given to ways to increase remote user socialization. Some ideas include adding a live chat room, enabling the participants to e-mail one another and encouraging the use of electronic communications with the coach. Systematic improvements are focused on the development of: e-mail alerts to supervisors of treatment or data issues, participant tracking to ensure that treatment progresses in a timely manner, and the use of games as reinforcement of core issues for children.

We are currently working on expanding the reach of the program across Nova Scotia and Canada and extending the scope to include problem modules for Inflammatory Bowel Disease, post-partum depression, child obesity, sleep disorders, pediatric leukemia and adolescent depression.

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