

GPAST Research Project – Summary of Results

Introduction

Autism and related developmental disorders have attracted national attention in the past years. Increasing prevalence has led to campaigns, legislation and calls to action. As the number of individuals affected with this disorder rise, families and professionals are calling for increased infrastructure and services to address needs.

National data suggest that the prevalence of autism is about 1 in 150 children (CDC, 2007). The rate for ND school-age children is 1 in 238 (Askvig, 2008); and the numbers have risen more than five fold in the last 10 years.

In 2008, the North Dakota Center for Persons with Disabilities (NDCPD) conducted a three month process of discussions, data analysis and fact-finding on autism in North Dakota (ND). Findings suggested that ND has multiple systems issues that must be addressed including a dramatic increase in prevalence, astounding financial impact, inaccessibility and availability of services, a lack of qualified staff, lagging early screening and early intervention supports, and perhaps most importantly, the lack of a clearly defined strategy or infrastructure for addressing the current and future needs of these children.

As the numbers of children continue to rise, so does the financial impact of autism. The estimated lifetime cost of autism is \$3.2 million per individual (Ganz, 2007). Using Ganz' cost rate and ND's current child count data, autism will cost ND \$1.4 billion in health care, services, and lost productivity. This does not include children with a diagnosis of Asperger's, or children served in our birth to three Part C programs. Thus, the true financial impact to our state is likely greater. Couple this with the fact that nearly 1 in 3 ND families are left to pay for services with

their own personal funds or through their private health insurance (Haarstad, 2008).

Unfortunately, ND does not have legislation supporting insurance to fund many autism treatments and parents cannot afford to pay out of pocket.

In addition, ND's low population density makes delivering general human services, and autism services in particular, extremely difficult. It is not uncommon for families to drive 100 miles one way every day to receive autism-specific therapies.

There are no specific program planning or treatment services available across the state. ND has no statewide strategic plan for addressing current and future autism initiatives. Autism services are fragmented and reactive rather than coordinated and proactive in nature. Several organizations are trying to piece together services, training, diagnoses, and other supports for children and youth with autism but there is no systematic communication between those entities.

It has become obvious that these ND families are under a great deal of stress; from the child's problematic behavior to financial burdens and/or inaccessibility of services (Interactive Autism Network, 2009).

Thus far, long distance telehealth technologies have yielded promising results; including reduced time and distance in accessing appropriate services (Miller, Bruce, Long, Mazonac & Moder, 2006). The implementation of software technology, enabling long distance interventions, may be the answer to ND's heavy financial burdens and inaccessibility of services for families.

The Great Plains Autism Spectrum Disorders Treatment Program (GPAST) set out to answer this question by conducting a study with rural families in ND who have children with or suspected of having an ASD. More specifically, GPAST staff utilized long distance telehealth technologies as a primary service delivery method; enabling parents and to access information without having to travel long distances.

It was hypothesized that through involvement with various GPAST activities, using long distance telehealth technologies as a primary delivery method, the families of the pilot study would experience increased ability to handle stress, and would incur less monthly expenses.

Method

Measures

Pre/Post Questionnaires: Prior to and upon completion of the project, information was gathered about family demographics, ability to handle stress, and financial impact of ASD on the household income.

Monthly Questionnaires: Monthly data was collected to determine ongoing ability to handle stress and financial impact. This information was quantitative in nature.

Weekly Questionnaires: Weekly, the GPAST team contacted the families to a) talk about their child’s week in an open-ended format and b) rate the parent’s week through quantitative information. For an overview, see Table 1.

Information Gathered	Frequency of data collection	Person(s) responsible
Family Demographics	Pre/Post	GPAST staff
Family stress	Pre/Post, Monthly, and Weekly	GPAST staff
Family financial issues	Pre/Post and Monthly	GPAST staff

Table1. Overview questionnaires

The stress questionnaires were based on a (2009) national study conducted by the Interactive Autism Network (IAN) that looked at parental depression in families raising a child with ASD. The questionnaires inquired about ability to handle stress in seven different areas:

ability to handle child's behavior at home, ability to handle child's behavior in social settings, ability to access appropriate services, impact of services on child's progress, relationship with spouse, ability to socialize with friends and in the community and finally the ability to get adequate sleep. A 5-point Likert scale was used (1=low/poor, 5=high/good) to determine stress levels.

The finance questionnaires were based on a national study conducted by the American Academy of Pediatrics (2008), investigating the relation between raising a child with ASD and the loss of family income. The questionnaires focused on monthly expenses in the following areas: *prescription drugs, dietary supplements, insurance co-pays and recommended services.* Answer options varied from \$0 to +\$1000 dollars.

Participants

Six families were selected to participate in the study. The selected families were representative of rural communities across ND who have children diagnosed with or suspected to have an autism spectrum disorder. The selection criteria were as follows:

1. Resident of rural community (population of 5,000 or less)
2. Representative of a variety of ages (3-21)
3. Representative of a variety of service needs

Due to personal reasons one family withdrew before the data collection period started, which left five.

The children's ages varied from four to seven. All had a diagnosis of Autistic Disorder. Two children had additional diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and Pervasive Developmental Disorder (PDD).

The Pre questionnaires indicated that approximate annual household income ranged from \$15,999 to + \$70,000 for the twelve months prior to GPAST participation. Post questionnaires showed that two of the families had an annual household income decrease of respectively 30,000-34,999 to 25,000-25,999 and 20,000-24,999 to 15,000-19,999 during their involvement in the GPAST project.

Prior to participation in the GPAST study four families had to reduce hours of work (N=248) and four parents stopped working all together.

Outcome assessment

Responses were entered into “Survey Monkey,” an online survey tool. A Secure Sockets Layer (SSL) encryption was used to ensure private transmission of information over the internet. Pre- and post results were compared. This allowed for the examination of differences in parental stress and monthly expenses at the beginning and end of the data collection period. In addition, trends in time were examined by analyzing the results of the weekly and monthly interviews. Families were assigned a number varying from 100 to 500 to ensure confidentiality.

Equipment

GPAST staff implemented technology using different hardware, software and internet connectivity. The systems installed in family locations included the following:

Hardware

- Dell Vostro laptop with integrated camera
- Global Media’s “ClearMic Duo” echo-cancelling microphone and speaker combo
- Network switch, when system was additional to existing desktop unit

Software

- Windows XP Operating system
- Polycom PVX; video conferencing technology
- TeachTown ©: Basics, (Whalen, 2009); computer-based intervention program for children with ASD and language disorders.
- RelateNow; platform using web based technology to connect parents to professionals.
- Flipvideo; a handheld video camera device.

Network

- Families were set up on public internet connections.

In addition, a higher-end videoconferencing system was used to communicate with families and other institutions, primarily when larger groups were involved. This system was compatible with the desktop solutions set up for GPAST families.

Procedures

NDCPD implemented an application process by which individuals applied to receive intensive training, technical assistance, evaluations, or consultations. The application was provided to Special Education Unit Directors, Developmental Disabilities Case Managers and Family Voices of ND who were then asked to pass along to families of children with ASD. The application included a cover letter inviting individuals to apply and a four-page application.

Thirteen families applied to participate in the research study. Committee members reviewed all applications, including video tapes that were submitted. Three families were

eliminated as they did not meet the criteria for living in a rural area of 5,000 people or less. Of the remaining ten families, six families were selected based on the following criteria:

1. Resident of rural community (population of 5,000 or less)
2. Representative of a variety of ages (3-21)
3. Representative of a variety of service needs

In order to be able to implement the previously described technology; laptops containing the relevant software, hardware and connectivity and the flip video cameras were delivered to the families.

For the duration of the data collection period pre/post, monthly and weekly interviews were conducted. The pre/post and monthly interviews were conducted over the phone by five Minot State University (MSU) school psychology graduate students. The weekly interviews were initially conducted by GPAST staff members, but after some time most families preferred to fill them out online.

During a nine month data collection period, the families received various on and/or off site services based on individual needs. These services included on sight and distance consultation. On sight consultation involved various GPAST team members observing a child at school or home, attending IEP meetings and providing recommendations and feedback on skill acquisition and behavioral deceleration programming. Distant consultation involved various GPAST members, including a Board Certified Behavior Analyst, interacting with parents/teachers via email and phone, offering recommendations and feedback on programming and reviewing child progress via video uploads.

In addition, a variety of long distance technologies was pilot tested; Teach Town: Basics, Relate Now and PVX. GPAST program impact on ability to handle stress and monthly expenses were measured.

Results

Pre/Post questionnaires:

Ability to handle stress. A paired samples *t* test was conducted to evaluate whether families experienced increased ability to handle stress after nine months of GPAST participation. Assessments on two different occasions (pre and post GPAST participation) were compared according to a repeated-measures design. The results indicated that the mean for ability to handle stress pre ($M = 3.71, SD = .60$) was greater than the mean for ability to handle stress post ($M = 3.54, SD = .75$). This implies the families estimated their ability to handle stressful situations higher pre than post GPAST participation. However, the difference was not significant, $t(4) = .305, p > .05$. Figure 1 shows average general ability to handle stress, pre and post GPAST participation.

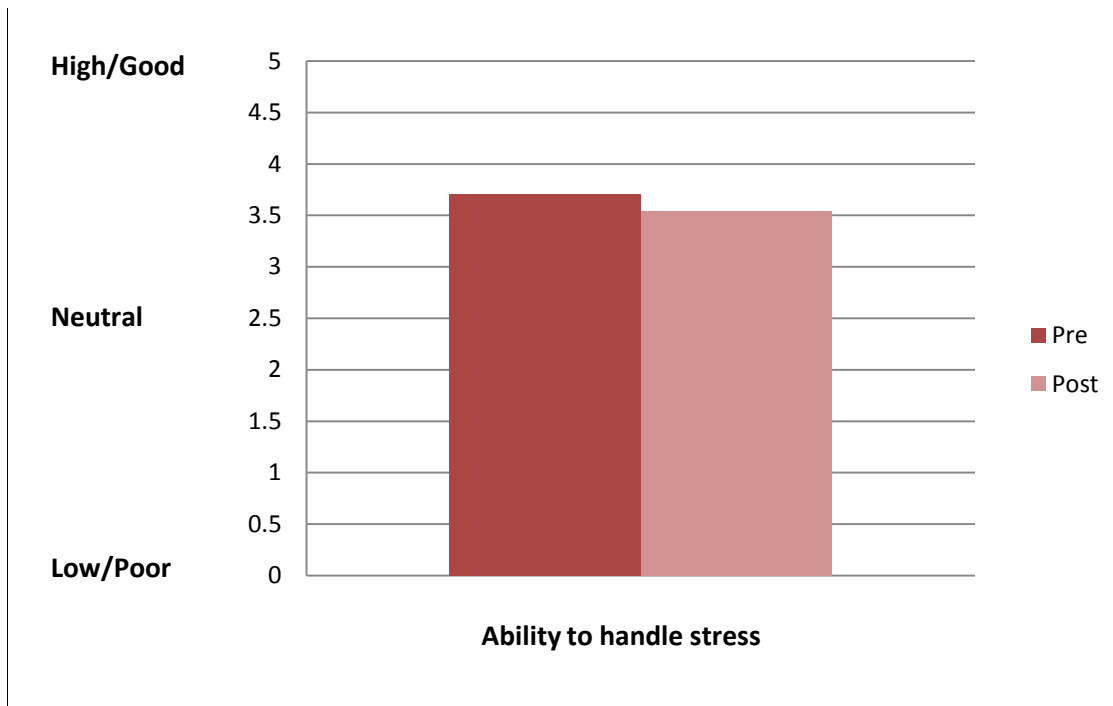


Figure 1. Ability to handle stress pre/post

Additional analysis of pre/post differences per question and per family where conducted.

Significant differences were not found. Figure 2 shows ability to handle stress per question and

Figure 3 shows ability to handle stress per family.

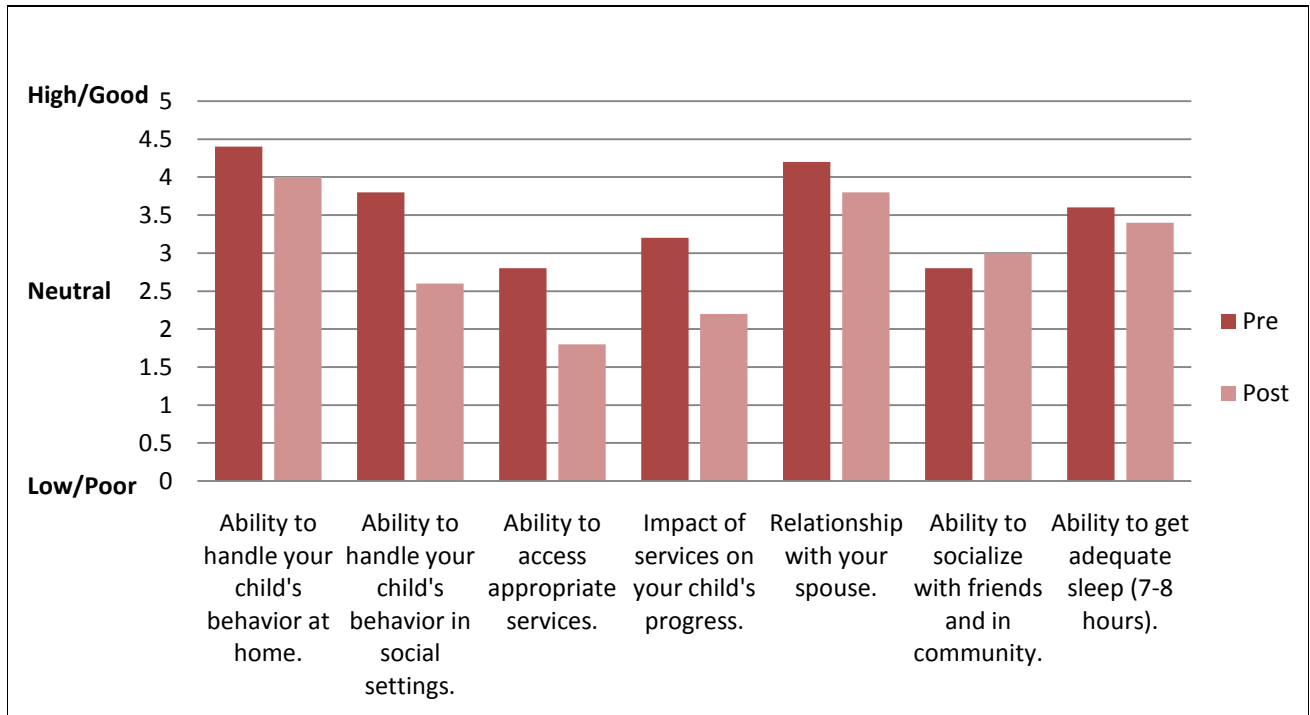


Figure 2. Ability to handle stress pre/post per question

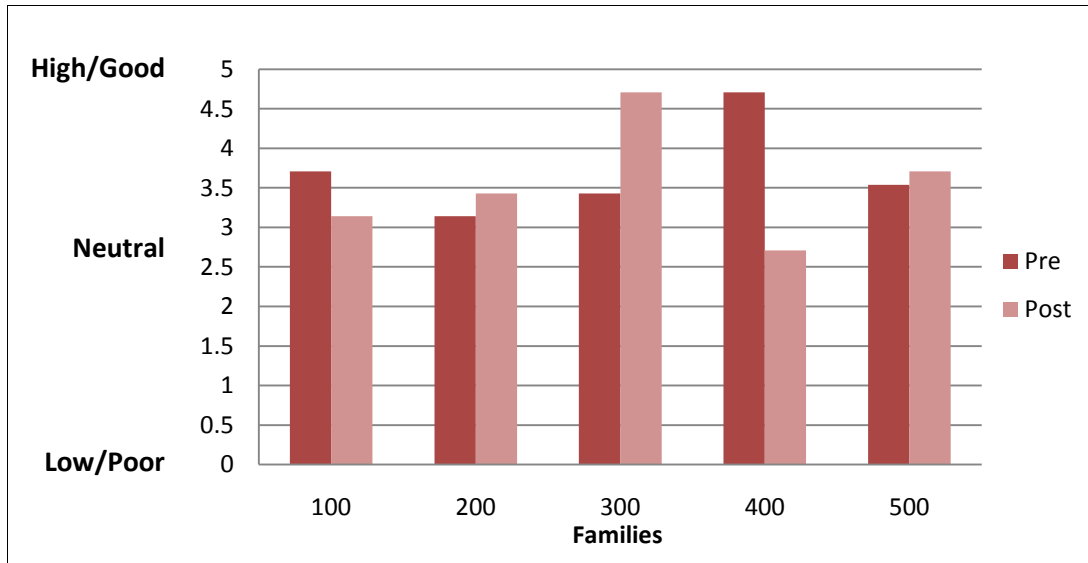


Figure 3. Ability to handle stress pre/post per family

Expenses. A paired samples *t* test was conducted to evaluate whether families experienced decreased monthly expenses after nine months of GPAST participation. Assessments on two different occasions (pre and post GPAST participation) were compared according to a repeated-measures design. The results indicated the mean for monthly financial expenses pre ($M = 3.75$, $SD = 3.04$) was higher compared to post ($M = 3.15$, $SD = 1.32$). This implies average monthly expenses were lower post than pre GPAST participation. However the difference was not significant, $t(4) = .62$, $p > .05$. Figure 4 shows average monthly expenses pre and post GPAST participation.

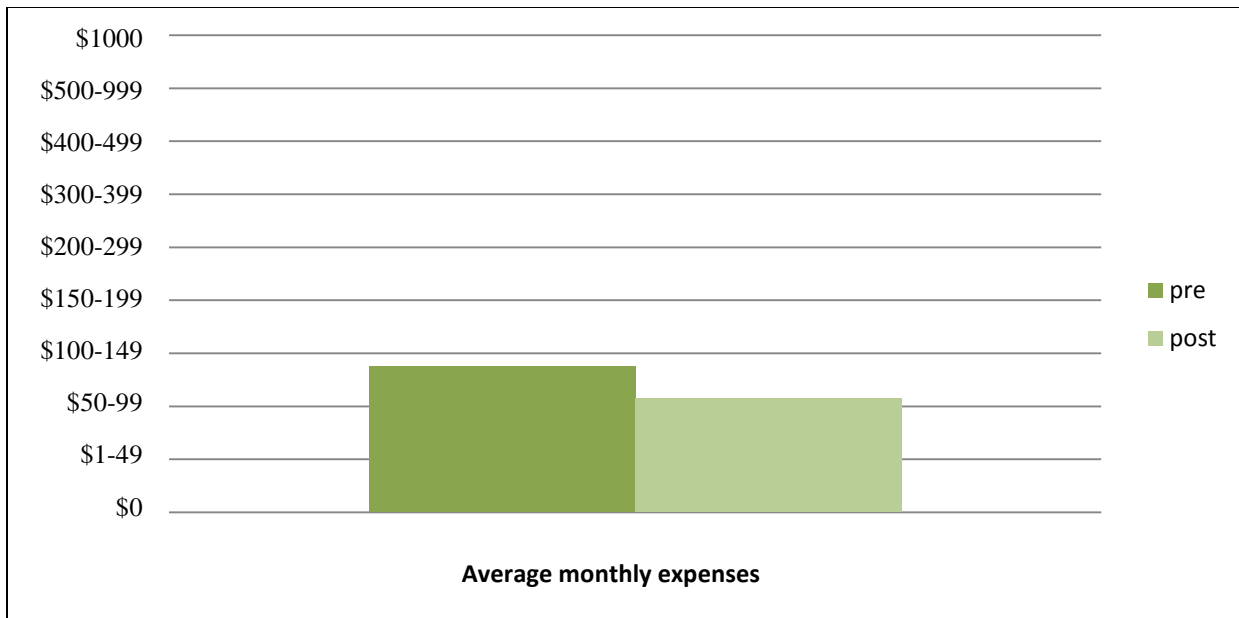


Figure 4. Average monthly expenses pre/post

Additional analysis of pre/post differences per expenditure and per family where conducted. Significant differences were not found. Figure 5 shows average monthly expenditures per expenditure and Figure 6 shows average monthly expenses per family.

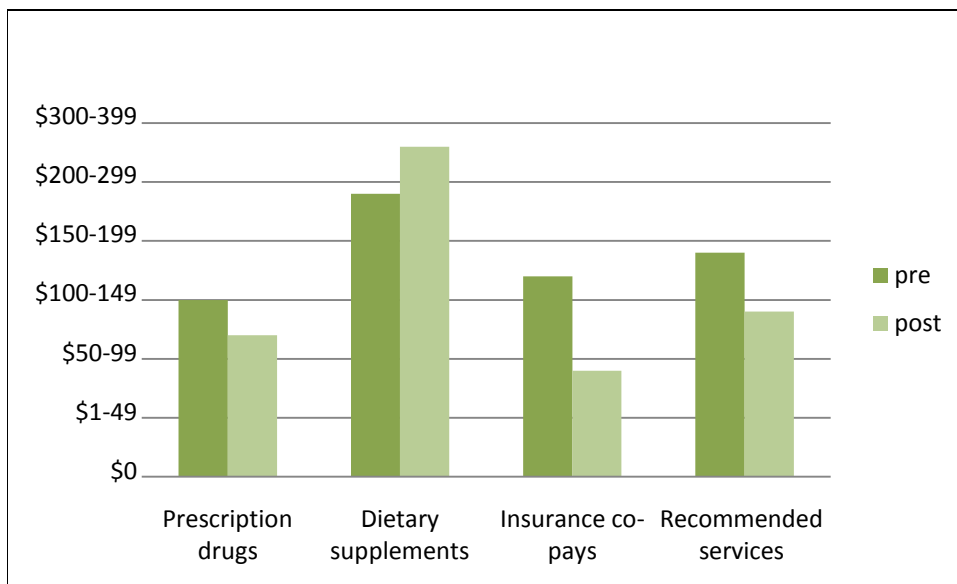


Figure 5. Average monthly expenses pre/post per expenditure

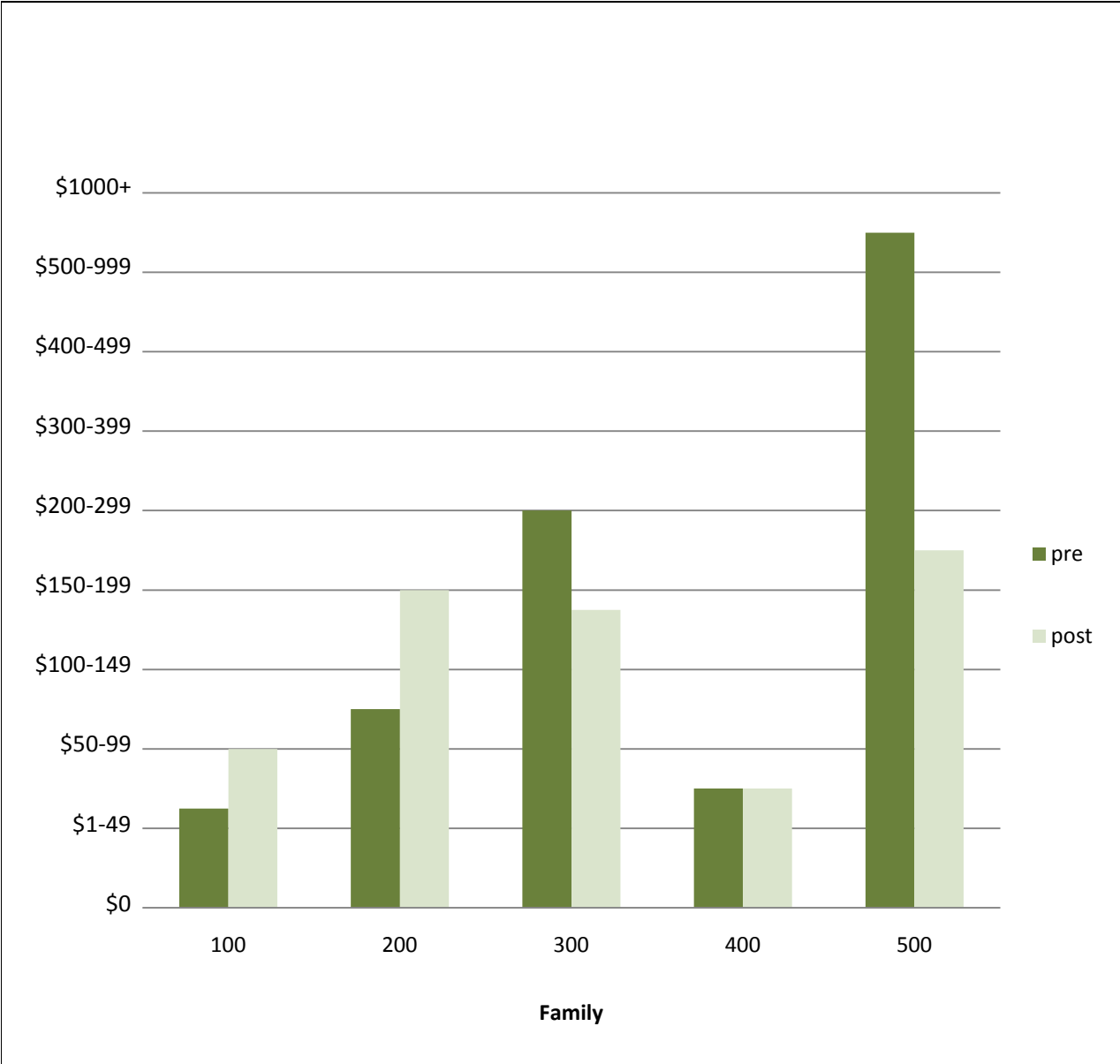


Figure 6. Average monthly expenses pre/post per family

Monthly questionnaires:

Ability to handle stress. A linear regression was conducted to evaluate whether GPAST participation would result in improved ability to handle stress. Data from the monthly interviews was used. Results indeed indicated that longer GPAST participation led to better ability to handle

stress. However, a significant association was not found, $F(1,33) = 1.07, p > .05$. Figure 7 shows the association between GPAST participation (months) and ability to handle stress.

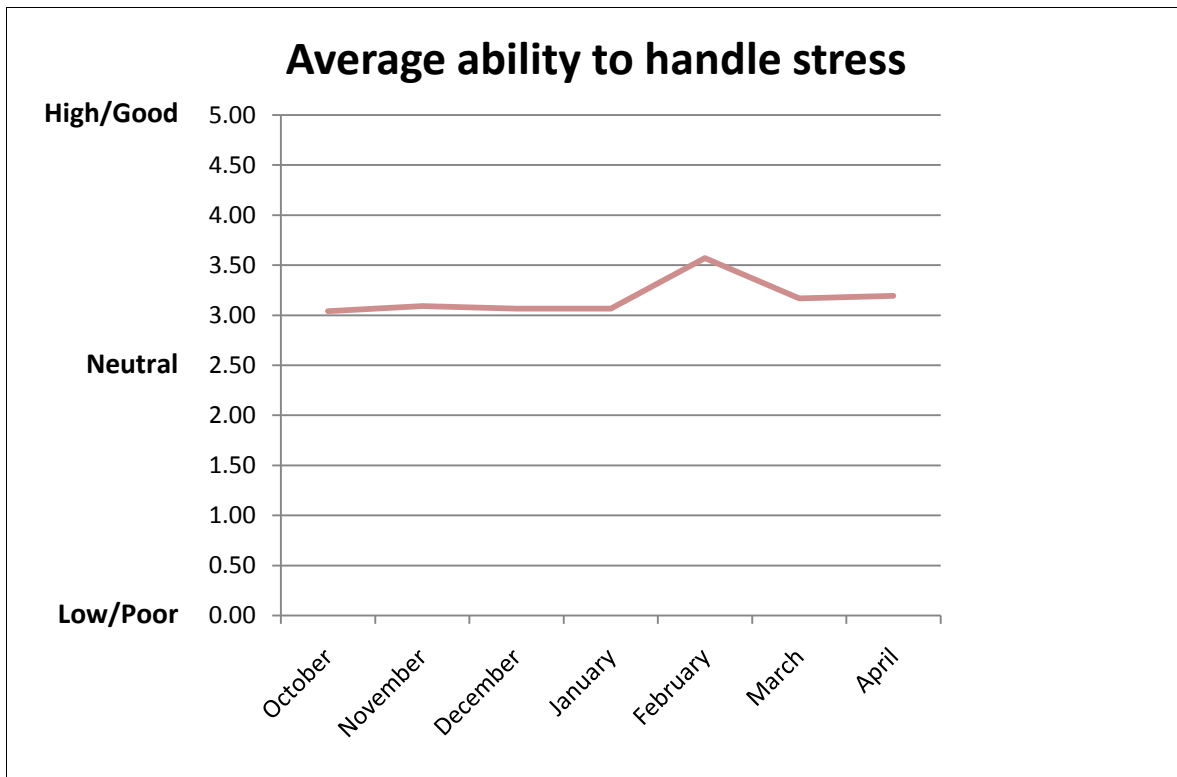


Figure 7. Ability to handle stress

Additional analysis of associations between ability to handle stress and the different questions and families were conducted. Significant associations were not found. Figure 8 shows ability to handle stress per question. Figure 9 shows ability to handle stress per family.

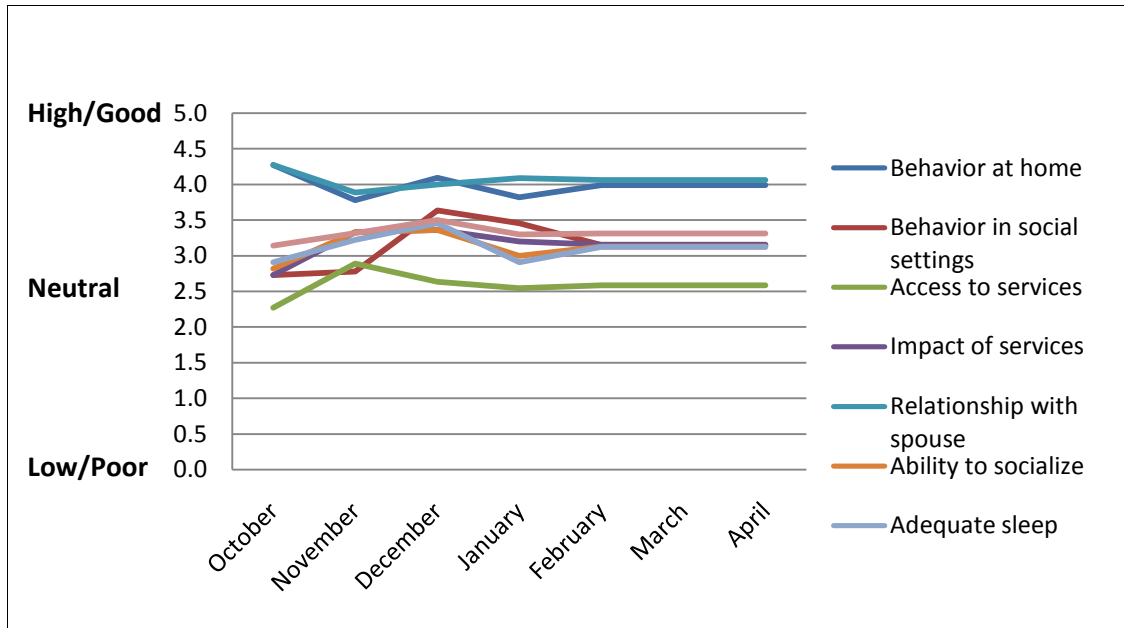


Figure 8. Ability to handle stress per question

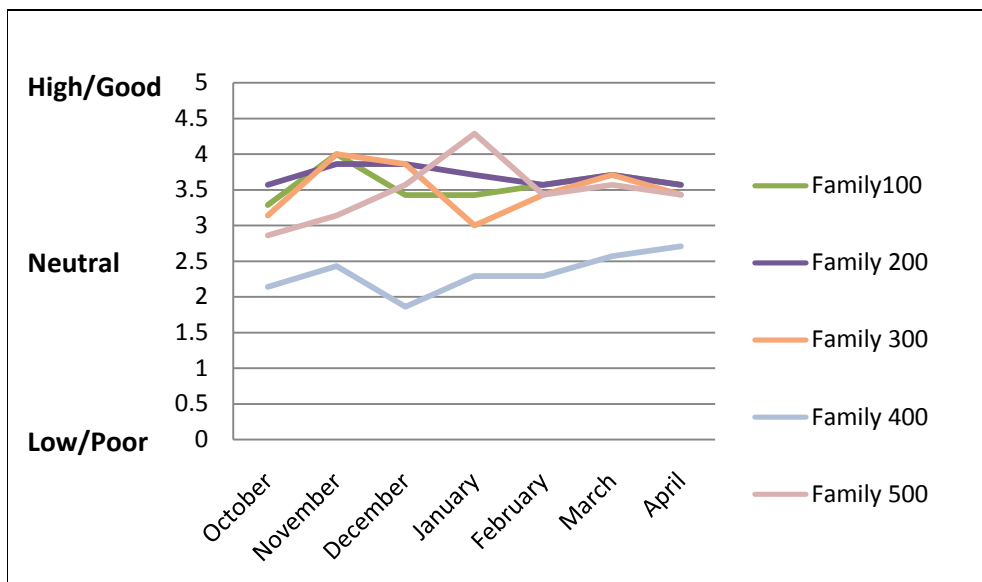


Figure 9. Ability to handle stress per family

Monthly expenses: A linear regression was conducted to evaluate whether GPAST participation resulted in lower average monthly expenses. The results indicated that longer GPAST participation indeed led to decreased average monthly expenses. However, a significant relation

was not found, $F(1,33) = .921, p > .05$. Figure 10 shows the association between GPAST participation (months) and monthly expenses.

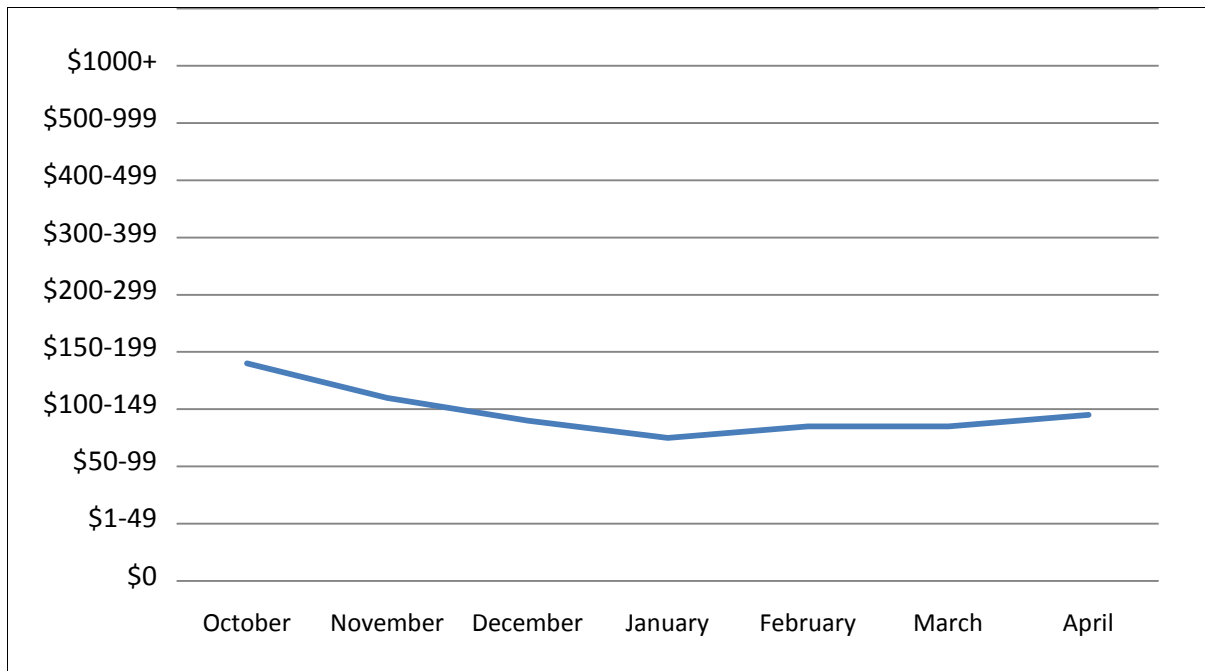


Figure 10. Average expenses per month

Additional analysis of associations per question and per family was conducted. A significant relation was found for one family, family 500, $F(1,5) = 22.82, p < .01$. This implies that for this family GPAST participation predicted a significant reduction in costs. Figure 11 shows average monthly expenses per expenditure. Figure 12 shows average monthly expenses per family.

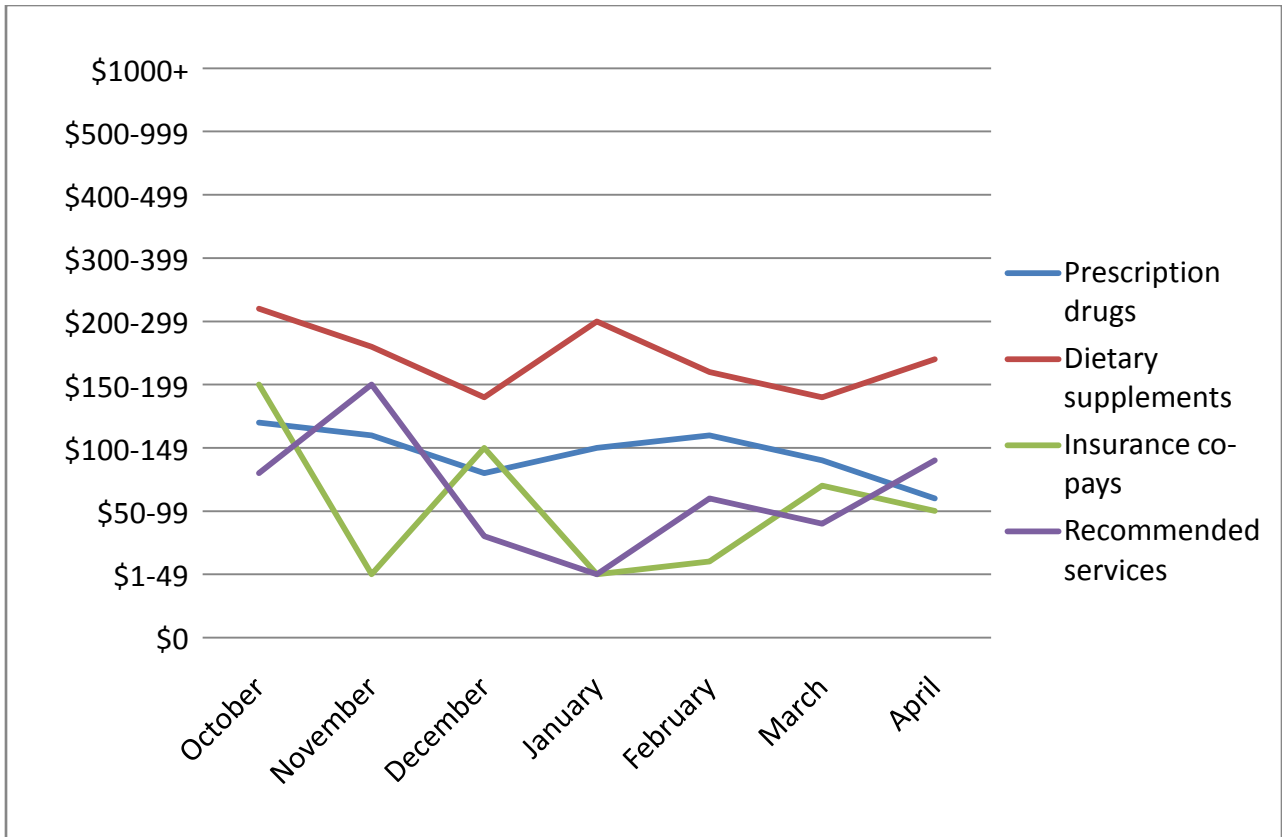


Figure 11. Monthly expenses per expenditure

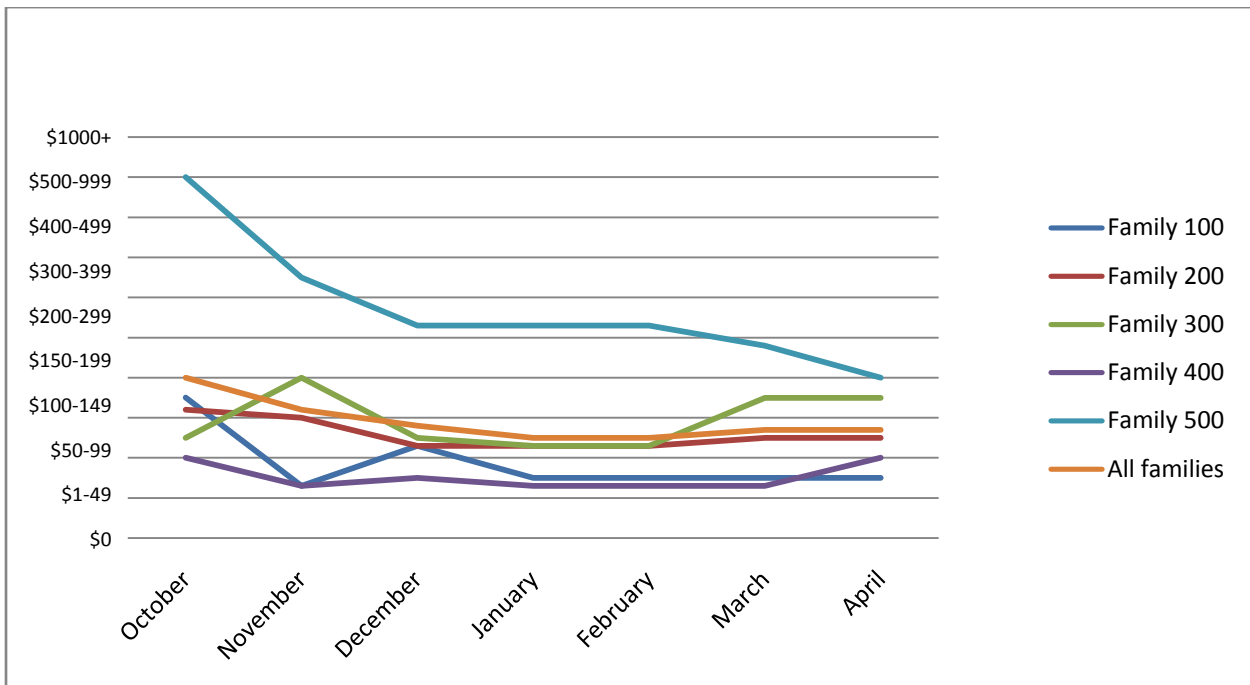


Figure 12. Monthly expenses per family

Discussion

As reported, ND has multiple ASD related system issues that need to be addressed: astounding financial impact as well as unavailability and inaccessibility of services for rural families.

This report presents the results of a program evaluation study, which studied the effectiveness of various on and off site services, including long-distance technologies, with rural families in ND who have a child with ASD. Individual families were asked to participate in the study to measure program impact. It was hypothesized that through involvement in a variety of GPAST activities; the families would increase their ability to handle stress and would incur less monthly expenses.

Results show that family ability to handle stress and monthly expenses indeed decreased during the nine month data collection period (with the exception of *general stress levels pre/post*, *dietary supplements* and *the ability to socialize with friends and in the community*). However, significant results, confirming the influence of GPAST participation on family ability to handle stress and financial impact, were not found. Various explanations can be offered.

First, the study sample sizes were very small (n=5). Small sample sizes limit the power to detect significant results, even if they do exist. A closer look at the study's effect sizes indicate that future studies, using larger samples, may find more significance.

Second, the GPAST family selection process failed to take into consideration pre-existing abilities to handle stress and monthly expenses. As a consequence, the majority of the families did not report notable inability to handle stress and/or high monthly expenses in the Pre Questionnaires. Since base levels were not high to begin with, it was nearly impossible for program impact to be remarkable. Future studies may want to consider incorporating inability to handle stress and high monthly expenses as a selection criterion.

A lack of significant findings in the areas of ability to handle stress and monthly expenses does not indicate statistically significant decreases did not take place. The questionnaires, used in the study, placed a specific focus on certain target areas, like; *insurance co-pays, recommended services, ability to handle your child's behavior at home* etc. A decrease may have taken place in other non discussed areas. Future studies should include additional questions, possibly in a more open ended format; informing if there was an effect and if so, in what area.

Finally, despite the reported lack in statistically significant findings, parent reports indicated effects in other areas, more specifically; child progress and general satisfaction with GPAST activities were considered beneficial especially in the areas of collaboration with service providers and consultations (both distant and face-to-face) as demonstrated by the program evaluation. (See attached) Future studies may want to change the variables to be measured.

References:

- Center for Disease Control and Prevention (CDC). *Center for Disease Control and Prevention Homepage*. Retrieved on November 15, 2008 from http://www.cdc.gov/ncbddd/autism/faq_prevalence.htm.
- Ganz, M. (2007). Lifetime Distribution of the Incremental Societal Cost of Autism. *Archives of Pediatrics and Adolescent Medicine*, 161, 343-349.
- Halterman, Jill S., & Montes, Guillermo. (2008). Association of Childhood Autism Spectrum Disorders and Loss of Family Income. *PEDIATRICS*, 121, e821-e826.
- Interactive Autism Network (IAN), Interactive Autism Network homepage. Retrieved on June 5, 2009 from http://www.iancommunity.org/cs/ian_research_reports/ian_research_report_april_2009.
- Miller, T.W, Bruce, E, Long, K, Mazonac, C., & Moder, M. (2006). Telehealth home health applications for adults with developmental disabilities. *Telemedicine and E-health*, 12, (2) 137-145.
- Whalen, C., Cernich, S., Vaupel, M. & Moss, D. (2009). Analysis of usage of Teach Town: Basics© computer assisted program in urban school district. Poster presented at the International Council for Exceptional Children conference, April 1-4, 2009.