

Mile High Down Syndrome Association Health Care Partnership

Final Report of the Grant provided by Mountain States Genetics Regional Collaborative Center to the MHDSA Health Care Partnership

Synopsis of Project

The MHDSA Health Care Partnership was developed in 2004 in response to the concerns of our members that they had not received the information and support they needed at the time of their children's diagnosis. Many also indicated that their children's health care providers did not have the knowledge, skills and resources needed to provide the level of care they required. The Health Care Partnership Coordinator is both a pediatric care provider and a parent of a child with Down syndrome, and is therefore able to apply both the parent and the professional perspectives to educate and offer resources to health care providers regarding Down syndrome. The education is conducted through face-to-face meetings, inservices, presentations, guest lecturing at local universities, published articles, and the provision of practical resource material designed for health care providers.

The goals and objectives written for the grant application were based on the expectation that the grant period would be 18 months, but the actual period covered by the grant contract was 15 months. Despite the shorter period of time, the majority of the objectives exceeded their targets and great progress was made toward each of the goals. The geographic reach has also exceeded the planned target of the metro Denver area. Outreach has been done in Greeley, Fort Collins, Loveland, Boulder, Colorado Springs and Longmont. Additionally, further education and outreach has occurred from visits to the MHDSA website, www.mhdsa.org.

Progress Toward Goals and Objectives

1. New and expectant parents receiving the diagnosis of Down syndrome will be given accurate, current information about Down syndrome, will be treated with sensitivity, and will be given a referral to MHDSA for support.
- **80% of local newborn centers will be contacted directly with offer to provide education and resources within the 18 month grant period.**
 - Eleven sites were contacted during the 15 month grant period allowing contact with 245 providers including nurses, physicians, social workers and others. This number, added to those contacted prior to the grant period, equals nearly 85% of all newborn centers in the area.

- **Education regarding Down syndrome including tips for providing the diagnosis and information about MHDSA and other resources, will be provided to 400 students of health care professions within the 18 month grant period.**
 - Seven different university programs were served with 21 presentations reaching 759 students, 190% of the targeted number. The majority were nursing students, physician assistant students and human services students.
- **Education and resources will be given to 10 providers of prenatal screening and diagnosis within the 18 month grant period.**
 - Meetings occurred with several providers of high risk prenatal care and genetic counseling prior to the beginning of the grant period. 21 more were provided with updated information and resources during the grant period which is 210% of the targeted number.
- **Education and resources will be given to 60 providers of obstetric care within the 18 month grant period.**
 - 18 sites were visited or contacted during the grant period, reaching 179 providers of obstetric care, 298% of the targeted number. This category has some overlap with the 245 providers listed above at birth centers.

Progress Update: Tremendous progress has occurred toward this goal during the fifteen month period of the grant. Numbers can only tell part of the story. The ultimate impact is on the families of children with Down syndrome. We have had the good fortune to have heard directly from families who shared that when their health care providers told them their babies have Down syndrome, they also told them of having received recent education updates from the MHDSA Health Care Partnership. Parents have reported of hearing their babies' diagnoses in a balanced, supportive manner and being connected to community resources immediately. Additionally, the number of expectant parents with prenatal diagnoses of Down syndrome who have contacted MHDSA for information and support, increased significantly after the first 18 months of the Health Care Partnership.

2. New and expectant parents of infants and children with Down syndrome will have access to genetic information regarding Down syndrome.

- **500 families of children with Down syndrome will be given access to education regarding the genetics of Down syndrome and how to access additional, individualized genetic counseling within the 18 month grant period.**
 - During the 15 month grant period, MHDSA collaborated with other community agencies to provide 4 large educational programs regarding various health, developmental and learning aspects of Down syndrome. These programs had total attendance of 670 professionals and 670 parents, 134% of the targeted number.
- **90% of area genetic counselors practicing in prenatal diagnosis will receive education regarding MHDSA programs as a resource to expectant parents and**

an expert source of current Down syndrome information within the 18 month grant period.

- 21 providers of high risk prenatal care and genetic counselors have received updated information about Down syndrome and community resources during the 15 month grant period. Additionally, several area genetic counselors were contacted prior to the grant period putting the total number contacted at close to 90%.

Progress Update: The results of meeting with providers of prenatal care and genetic counseling have been demonstrated in the increase of expectant parents contacting MHDSA for information and support. Several genetic counselors shared that they had previously been aware of MHDSA as a source of information and support for expectant parents who had already decided to continue their pregnancies, but hadn't previously realized that MHDSA could be an expert source of non-directive information and support for those still undecided. After meeting and learning more about MHDSA's program, they expressed increased comfort with recommending MHDSA to expectant parents.

An important effort to increase understanding of the genetics of Down syndrome among parents of children with Down syndrome, is an article planned for the MHDSA newsletter, *Down's Update*, providing this information in lay terms. This article is in progress with a targeted completion date of August 2007.

3. Individuals with Down syndrome will receive health care that addresses the specific developmental and medical needs associated with Down syndrome and the best practices to address them.

- **40 outpatient pediatric care providers will receive education and resources regarding Down syndrome within the 18 month grant period.**
- **100 inpatient pediatric care providers will receive education and resources regarding Down syndrome within the 18 month grant period.**
 - Inpatient and outpatient providers of pediatric care were totaled jointly due to the high rate of overlap. During the 15 month grant period, 33 presentations or meetings occurred which reached 191 providers, 136% of the targeted number.
- **500 parents of children with Down syndrome will be given access to education regarding their children's health needs and access to needed resources within the 18 month grant period.**
 - Four large educational programs were offered in partnership with other community groups with a combined attendance of 670 parents.

Progress Update: Pediatric health care providers have been very receptive to the information and resources MHDSA's Health Care Partnership has been able to provide. However, the number of providers of pediatric care is huge so much work remains to be done in this area. A future focus in this area should be family medicine physicians.

Keys to Success

The MHDSA Health Care Partnership only began in 2004. At that time, there were few models of programs providing education to health care providers available from which to learn strategies, although the National Down Syndrome Society's Changing Lives Program was reviewed and provided some good tools and ideas. The MHDSA Health Care Partnership has met with great success in educating health care providers. Conclusions can be drawn about the keys to this success as well as the strategies which have proven less successful. These conclusions will be grouped into categories of Coordinator, Finding Contacts, and Strategies.

Coordinator

- The most important factor in the success of the MHDSA Health Care Partnership is that the coordinator is both a parent of a child with Down syndrome and a health care provider. Sometimes providers can dismiss the knowledge or credentials of parents but will respond to the credentials of a fellow provider when being asked to learn something new. The provider credentials often "open the door" and provide the opportunity to "speak the same language" while the parent experiences actually answer many of the provider questions.
- Public speaking skills are a great asset to the coordinator. Knowing the information is only part of the job. Conveying it in a way that engages people increases the learning of the audience. It also assists with gaining new contacts.

Contacts

- A very effective way to launch the program was for the coordinator to contact colleagues from previous health care positions in the community as well as at the university attended. Each of these colleagues facilitated initial meetings and presentations that then led to others elsewhere in the community.
- One method of reaching new contacts that proved to be quite ineffective is cold-calling providers. On the other hand, calling and requesting to speak with a specific provider by name and sharing the name of the person who provided the contact information led to a much higher rate of positive response. Several strategies for finding these contacts are suggested below.
- Asking fellow parents of children with Down syndrome to tell their child's providers about the MHDSA Health Care Partnership and to share the contact information for their providers with the coordinator increased the rate of positive response to offers of presentations.
- During every meeting or presentation with providers, the providers were asked if they knew of other providers who would also benefit from the information and resources shared. The vast majority of the time, they did provide additional contacts.
- Expressions of appreciation and compliments from providers are a great opportunity to ask for additional contacts.
- Mailings to lists of providers introducing the Health Care Partnership and offering education and resources have proven to be somewhat costly and not effective. The rate of response is very low.

Strategies

- Joining targeted professional organizations provides information about conferences, meetings, and publications, all of which present opportunities for speaking to groups, increasing contacts and increasing awareness of the organization and the program.
- Collaborating with other groups and agencies can greatly increase the outreach of the program but has also been more time and labor intensive than working independently.
- When preparing for meetings and presentations, being flexible about the content and the timeframes allowed for accommodation to the needs and interests of the audience. Often, meetings that began as ten minute meetings led to future inservices or conference opportunities.
- There is seasonality to this program. Providers are reluctant to schedule presentations, conferences or inservices during the holiday season or during the summer months when larger numbers of providers are away on vacations. These months provide good chances to work on program development, funding, surveys or writing articles for publication.
- The *Down Syndrome Information and Resources* notebook developed by the MHDSA Health Care Partnership Coordinator and offered free of charge to health care providers, has been a very practical way to provide materials and information to providers. This resource was well received and greatly appreciated. Additionally, offering “give-aways” such as the notebook and the Down Right Beautiful calendar to providers increased the rate of inservices scheduled and provided positive awareness tools that then may be seen and used by others as well.

Future Plans

Work is already underway on several additional projects within the Health Care Partnership. They include:

- Analysis of a Health Care Satisfaction Survey eliciting experiences and feedback from parents of children with Down syndrome. This will provide direction for the program and when compared to the results of an earlier survey, will provide an opportunity to measure changes.
- Further updates to the *Down Syndrome Information and Resources* notebooks for providers.
- Completion of an article on the genetics of Down syndrome in lay terms for the constituency of MHDSA.
- Web-based provider education about Down syndrome and community resources. MHDSA is developing a program called Virtual Visits which will put discussions about Down syndrome on the MHDSA website. Visitors can click on the “visit” of their choice. These will include visits with parents of children with Down syndrome, self-advocates, grandparents, and siblings, in addition to video interviews of the Health Care Partnership Coordinator speaking to providers. Several of these videos have been taped and are currently in the editing process.

- Development of an e-newsletter to be sent to health care providers with updates about Down syndrome and about the MHDSA Health Care Partnership.

The support of the Mountain States Genetics Regional Collaborative Center, both monetary and human in the form of ideas, contacts and encouragement, has assisted the MHDSA Health Care Partnership in meeting with great success. We are proud of our accomplishments and excited about the future of this program. We are equally proud and excited to have created a model from which to build other health care outreach programs. Thank you for all of your support. It has truly been an invaluable part of our success.