

# **Twin Cities Zambia Disability Connection**

### Final Report • 2009

#### **Project partners**

Institute on Community Integration, University of Minnesota Arc Greater Twin Cities Opportunity Partners Fraser, Inc.

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### Introduction

Sandy Beddor, a long-time disability advocate, independent consultant, and family member, was working in Zambia on a leadership training program for Catholic priests and sisters. While there, she observed an acute need to develop more community services and supports for people with disabilities. The Twin Cities Zambia Disability Connection was created to meet this need and is a collaborative effort among several key partners. These include the University of Minnesota's Institute on Community Integration (ICI), Arc Greater Twin Cities (GTC), Opportunity Partners, Fraser, Inc., and several disability and community organizations in Zambia.

During the first two years, the Twin Cities Zambia Disability Connection has utilized a three-tiered training model and an actionoriented needs assessment strategy to build collaborations that bridge continents. The initiative has gained greater focus, while also taking action that will help to improve the lives of people with disabilities in Zambia.

This report provides an overview of the program, outlines preliminary outcomes, and identifies ongoing needs for individuals with disabilities in Zambia, which may provide the focus for future work.



### **Disability leadership training model**

The Disability Leadership Training Model was initially developed by a team led by Sandy Beddor. It was then adapted by ICI staff into an integrated training model that incorporates constructs from the business of development model. It is specifically designed to provide training and education that is culturally relevant, participant-guided, and based on explicitly defined needs. The target audience for this model is people with a stake in the development of disability services, advocacy, and policy.

This model integrates three components to promote successful leadership development and sustainable results. This includes improved community services and family supports for individuals with disabilities and their families. The three components include —

- Training based on promising practices in education and services for persons with disabilities. Training is focused on non-governmental organizations' (NGO) capacity building strategies.
- A tiered learning process that provides an opportunity for increased numbers of people to learn the same material. The learning process builds capacity for Zambians to become leaders and trainers

in progressive, inclusive disability services and supports.

3. A methodology comprised of core values. These include relationship building, transparency, inclusiveness, flexibility, team building, and experiential learning.

#### **Capacity building**

The initial project was designed to address gaps in the education and skill sets of Zambians that work in education, support, or advocacy services. This includes those working with children and adults with disabilities, their families, and their communities. This project builds capacity related to skill development, supporting infrastructure development, and fostering collaborative partnerships.

Skills and topical areas specifically targeted in this project include —

- Promising practices in special education, community human services, and family support.
- Program assessments, development of strategic plans, and creation of work plans.
- Collaboration and development of partnerships across and within service sectors.

#### **Tiered learning**

Tiered learning is a process in which each step of training and technical assistance is built upon the activities of the previous tier. In this model of learning, the number of participants exposed to the training increases at each tier and incorporates training from participants in the previous tier. This partnership and tiered learning program is —

- interactive;
- flexible;
- built upon and inclusive of personal experiences; and
- adapted based upon feedback from participants and changing circumstances.

#### **Core values**

This training methodology is based upon the core values of self-determination, normalization, social role valorization, and community inclusion. These core values currently guide the field of intellectual and developmental disabilities in the U.S.

- *Self-determination:* means a person has access to opportunity and resources to make decisions in his or her own life.
- Socially valued roles: This is the belief that an individual with a disability will be included in the community when he or she is recognized as having value or as being a contributing participant. Having a socially valued role(s) leads to further inclusion within a person's community.
- *Normalization:* This is the principle that people with disabilities should live their lives with the typical rhythms of the day, month, week and year.









### **Organizing partners**

#### **U.S.** partners

#### Institute on Community Integration

The Institute on Community Integration (ICI) is a federally designated University Center for Excellence in Developmental Disabilities (UCEDD). It is part of a national network of similar programs in major universities and teaching hospitals across the country. As a UCEDD, ICI is funded under the provisions of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 by the Administration on Developmental Disabilities in the Department of Health and Human Services. ICI believes that all persons with developmental and other disabilities should live as valued members of local communities. ICI seeks to make this possible through improving the services and social supports available to individuals with disabilities and their families. Their mission is realized, in collaboration with others across the U.S. and abroad, through research, professional training, technical assistance, and publishing activities.

ICI conducts the following core activities —

 Interdisciplinary pre-service training: Offering support in initial career training for paraprofessionals, professionals, and leadership personnel seeking to better serve persons with developmental disabilities and their families.

- Interdisciplinary continuing education: Offering professional and personal development workshops and presentations for educators, community service providers, families, and individuals with disabilities.
- *Technical assistance:* Offering consultation and program evaluation services to enhance the capacity of existing agencies and services.
- Improving policies and services: Policies and services affecting individuals with developmental disabilities and their families are improved through applied research conducted in collaboration with organizations, agencies, colleges, and universities around the country.
- *Dissemination:* Sharing information generated by Institute projects and collaborators through newsletters, curricula, training materials, resource guides, reports, brochures, journal articles, books, Web sites, videotapes, and other multimedia materials.

ICI contributions include the following —

- Assisted in the selection of the Zambian team.
- Created the instructional design for the Tier Two leadership training held in the U.S.
- Organized and delivered the training, both in the U.S. and Zambia.
- Funded the majority of costs to develop and deliver the leadership training program.
- Funded travel to and from Zambia to identify and select the Zambian disability team and to deliver follow-up training.

#### Arc Greater Twin Cities

The mission of Arc Greater Twin Cities (GTC) is to "secure for all people with intellectual and developmental disabilities and their families the opportunity to realize their goals of where and how they live, learn, work and play." Arc GTC does this by changing attitudes, changing policies and changing lives.

Arc GTC conducts the following activities —

- Individual advocacy services that help people solve the problems being faced.
- Provides support to families through education, training, and support groups.
- Advocates strongly for new policies and better options for people with disabilities and their families in Minnesota.

Arc GTC contributions include the following —

- Instrumental in securing host families for the Zambian delegation
- Provided the press with information about the program and its activities.
- Organized and delivered training.
- Supported the training that occurred in Zambia.

• Funded many of the Zambian disability professionals that came to the U.S. Assisted with funding the training program that was delivered in the U.S.

#### **Opportunity Partners**

Opportunity Partners supports individuals with disabilities and other special needs in their effort to improve self-sufficiency at work, at home, and in the community.

Opportunity Partners conducts the following core activities —

 Provides personalized employment, housing, and education services to more than 1,300 individuals with disabilities in the Twin Cities.

Opportunity Partners contributions include the following —

- Assisted with delivering the training to the Zambian team.
- Provided community based learning experiences that exposed the Zambian team to contemporary practices in American disability services.

#### Fraser, Inc.

Fraser, Inc. supports children and adults with special needs through comprehensive education, healthcare, and housing services. The Fraser vision is a world where all people have equal opportunity and choice to realize their dreams to live, work, learn, and play as members of our community.

Fraser, Inc. conducts the following core activities across the life span —

- Diagnostic evaluations.
- Comprehensive mental health services, including individual and group therapy
- Rehabilitation services including physical, occupational, speech-language, and music therapy.

- Child care and education for children with typical needs and special needs.
- Housing for adults and children with developmental disabilities.
- Workshops and seminars for parents, caregivers, and professionals.

Fraser, Inc.'s contributions include the following —

 Participated in providing education to the Zambian team on the wide range of services provided to people with disabilities in the community.

#### Zambia partners

The Zambian partners included a number of NGOs, one governmental agency, and a number of faith-based organizations. In Zambia much of the social service system is organized and delivered through church organizations. Programs affiliated with religion are central to the services provided to people with disabilities. The organizations listed below have an important stake in this collaborative effort, as they are all working to improve the lives of people with disabilities in Zambia.

The organizations offered varying levels of support to this effort. They participated in the planning, promotion, hosting, and implementation of training workshops in Zambia. They arranged for and accompanied the U.S. team members to informational and networking meetings with various organizations. Last but certainly not least, the friars and sisters provided the U.S. team with lodging and meals. The broad range of support activities provided by the Zambian partners was instrumental to the success of the activities by the U.S. team in Zambia, and most importantly to the overall outcomes currently being achieved in Zambia.

#### Zambia Ministry of Education

The Ministry of Education is responsible for approving education programs and for authorizing teachers paid by the government to work at specific schools. The Ministry of Education is responsible for policy and practices related to special education services for children with disabilities.

#### Bauleni Street Kids

Bauleni Street Kids is a multi-service program, funded primarily by missionary organizations located in France and Ireland. It is managed by the religious organization, Sacred Heart Sisters of Jesus and Mary, located in England. This organization offers community education to approximately 650 children in grades 1 to 9 and has 7 special education classrooms for approximately 220 children ranging in age from 3 to 18. It also provides home-based education to families in the local compound that have children with special needs. In addition, Bauleni has an on-site vocational and transition program designed to teach adults basic employment skills. Examples of these programs include a bakery, making cement building blocks, a piggery, farming to grow vegetables and raise chickens, and a catering company. It also includes on-site programs that are economically self-sustaining and offer young adults with disabilities the opportunity to gain experience in employment. Bauleni Street Kids raises about 50% of their operating budget from these projects.



#### Missionary Sisters of St Francis of Assisi

This international missionary organization's congregation is located in Assisi, Italy. Missionaries have been located in Zambia since 1960. The missionaries in Zambia build schools and hospitals, work with people who have disabilities, feed and care for orphans, run child care centers, and work farms.

## *Little Sisters of St Francis from the Diocese of Livingston*

This local religious congregation is in charge of running Cheshire Homes. Cheshire Homes is a special education and rehabilitation program for children with disabilities. They also provide home-based education for children with disabilities.

#### Hidden Voice School

This is a newly developed special education program for children with disabilities. It evolved through advocacy and support from a parent association and with support from partners in Ireland and the U.S. Hidden Voice School has just purchased property to house its first permanent program. It is located in one of the poorest compounds in Lusaka.

#### Parents Partnership Association

This is one of the few parent support organizations in Zambia. It is a grassroots organization that is designed to provide information, referral, and support to families that have children with disabilities. This organization is making a significant attempt to count the number of families that have children with disabilities in the nation's capital. The Parent Partnership Association currently has representation in 8 of more than 25 compounds in Lusaka.

#### The Religious Sisters of Charity

This religious order began in 1816 in England. The charism of the Sisters of Charity is "service to the poor" and the sisters take this statement as their 4<sup>th</sup> vow. The congregation in Zambia is growing and specializes in education of young girls and women. In Zambia, the congregation serves families with disabilities and special needs through their social and pastoral ministries. They identify families that are in need, assist them with resources in schools, and provide opportunities for spiritually through the Catholic Church Sacramental preparations.

#### *The Conventual Franciscan Friars of the Proto-Martyr — Province of Zambia*

This religious congregation of the Catholic Church, is officially recognized as Order of Friars Minor Conventual (OFM Conv). The 'Friars', as the members are known, are composed of priests and brothers. They are located on all continents of the world. In Africa, their first presence was in Zambia where the first missionaries arrived in 1931 and helped establish the Church. This is especially true in the Copperbelt and Northwestern Provinces. Besides preaching of the faith, they also carried on the Franciscan charism of identifying with poor and promoting their dignity. These pioneers, and missionaries that came later, engaged in a number of social activities including the education and health of the most vulnerable populations of society.

#### Makeni Formation Program

This program is designed to provide education and training opportunities to young men that are studying to be priests and brothers. The formation program provided by brothers and priests, teaches them philosophy and theology. They are faced with supporting individuals with disabilities and their families, often with little training regarding how to support families that have a member with a disability.







### Leadership training program

The leadership training program is comprised of a three-tiered training process implemented with members of the Twin Cities–Zambia Disability Connection in both Zambia and the U.S. Each training tier builds upon the previous tier. This provides more in-depth information to training participants, while also expanding the breadth of participant involvement.

#### Tier one

#### Planning

The first stage of planning involved initial conceptualization of the work to be completed in both the U.S. and Zambia. This was based largely on the observations of Ms. Beddor while working within the religious community in Zambia. It was also based on her extensive knowledge of the disability service system in the U.S., as both an advocate and a family member of a person with an intellectual disability. Based on the training and education model design, an interactive, dynamic, and fluid training development process was implemented. The composition of stakeholders in both the U.S. and Zambia was then determined. In Zambia, partnering across disability programs is extremely rare. This first tier was designed to bring professionals from various disciplines together to work toward the common goal of improving lives for people with disabilities in Zambian communities. This project brought together members of the community, missionaries, NGO staff, and government officials to focus on the improvement and development of supports for individuals with disabilities.

## Team building and leadership training in Zambia

The first tier of the training occurred in January, 2008. Staff from the University of Minnesota traveled to Zambia with Ms. Beddor to visit programs that serve people with disabilities. This provided an opportunity to meet disability professionals, learn about what services were being delivered, identify gaps in service provision, and begin identifying a potential team to attend the leadership training program in the U.S.

This observational trip enabled program staff to better understand the context of disability services in Zambia. It is important to understand that these services are delivered in a country that is consistently identified as one of the poorest in the world in terms of per capita Gross Domestic Product (GDP), as measured by the World Bank and International Monetary Fund. Pervasive community poverty, short life expectancies, an AIDS epidemic, and scarce resources for individuals and families all





contribute to the social and cultural context of disability services in Zambia. Nearly all programs for people with disabilities are institutional in nature. Residential schools and special education classrooms and programs are few and available only in urban centers. Many of the programs provide services during the week and the children and adults who attend these programs usually return to their homes on the weekend and holidays. Overwhelmingly, children and adults with disabilities remain at home with no services. Most with severe disabilities die at or soon after birth. Those individuals that do receive services appear to have physical disabilities, congenital abnormalities, learning disabilities, or other mild disabilities.

The Zambian disability rights movement is in early stages. The Zambia Federation of the Disabled (ZAFOD) is a national policy advocacy group that is active in ensuring that laws and policies provide equal rights and protections for persons with disabilities. Zambia has national policies that promote full inclusion and opportunities for people with disabilities in school and communities. Zambia was an early signatory of the United Nations (UN) Declaration of Rights for Persons with Disabilities. ZAFOD plays an instrumental role in advocating for policy change and is beginning to support litigation related to protecting the rights promoted by the UN Declaration.

Family advocacy groups are also in early stages of development. These tend to be informal networking groups that share ideas and support one another. Currently very few networking groups exist. Those groups that do exist, constantly struggle to find resources to support their activities. There is also an evolving self-advocacy movement. One Zambian selfadvocate testified before the UN regarding the Declaration of Human Rights.

After observing these organizations and meeting many disability professionals throughout Zambia, a group of approximately 20 disability professionals were invited to attend a one day information and training session in Lusaka. This meeting also served as an opportunity for this group of professionals to discuss their interest in participating in a training exchange with disability professionals in the U.S. Initial training included teambuilding exercises, the opportunity for representatives to share with others what services they provide to people with disabilities, and the challenges and successes of their work. For most of these individuals, it was the first time they learned about other disabilityrelated services in their own country. Even organizations that were a part of the same umbrella organization (i.e., Cheshire Homes) had never met or learned about other service programs from other parts of the country.

#### **Tier two**

Tier two of the leadership training program was designed to bring advocates and disability professionals identified in tier one to the U.S. to receive training on policy affecting people with disabilities and observe the wide range of community-based services that stem from these policies.

#### Planning

ICI took a lead on developing the U.S.-based leadership training program, in collaboration with project partners. The training was derived from needs identified by ICI staff during the Tier One training activities in Zambia. All partners felt it was critical for the Zambian team to be able to see, feel, touch, and experience services for people with disabilities in the U.S. The training design included halfday community experiences as part of each of 10 training days while in Minnesota. It was also important that the training be recognized and supported by academia in the U.S. The College of Education and Human Development at the University of Minnesota formally approved the training plan and recognized completion of the training with a two-week intensive Certificate of Completion. Many instructors from the University of Minnesota served as faculty for the Zambian leadership training program.

In Zambia, faith-based organizations deliver the majority of services to individuals with disabilities. Project partners felt it was important to provide the Zambian team with opportunities to engage with and learn from various faith based groups in the U.S. Efforts were made to share information about the contemporary and historical roles the church and faith-based organizations have played in the U.S. regarding supports to people with disabilities and their families.

In designing the curriculum, it was also important that the broad areas of policy, advocacy, and practice be central and that the curriculum have applicability across the lifespan. Partners wanted to make sure that the Zambian team got a picture of how services that support all aspects of life work in the U.S. for children and adults with disabilities. This includes such things as early intervention, education, transition, residential, employment, family support, art, recreation and leisure, and health.

ICI offers a core graduate level course called Contemporary Services and Policies for Persons with Disabilities. This course met most of the instructional aspirations for the Zambian disability leadership training program and therefore a modified version of this course was developed and offered. The added component





of the community based observations and experiences were added to the basic course structure.

## *Implementing the leadership training program in the U.S.*

The second tier of training occurred in April, 2008. This tier of training brought a team of nine Zambian disability professionals to the U.S. to increase their understanding of the different service models used in the U.S. for people with disabilities. Participants received a two week intensive training program through ICI, in collaboration with community partners. This intensive training program reviewed the history of disability services in the U.S., provided an overview of contemporary best practices, reviewed disability policy, and identified how services and supports for people in the U.S. are funded. The training included experiential learning and involved information sharing with community members, advocates, academics, religious organizations, NGOs, and state and local government officials. Community partners, the ICI staff, individuals with disabilities, and families delivered the instruction. The training also provided handson experiences within community services for people with disabilities in Minnesota.

This intensive training program encompassed a number of instructional goals. These included —

- Provide information about the nature of disabilities, with a focus on intellectual and other developmental disabilities, including causes, incidence, personal characteristics and abilities, and the array of services and supports available to individuals and their families.
- Present an overview of the history and progressive inclusion of individuals with disabilities into regular community life.
- Introduce key legislation and court decisions that affect the lives of people with disabilities.
- Provide an overview of the disability rights movement.
- Introduce guiding principles of service provision for individuals with disabilities, including, normalization, integration, inclusion, family-centered approach, collaborative teamwork, age-appropriate and functional skills development, personcentered planning, circles of support, and social networks.
- Present the "big picture" perspective about the organization and function of

service systems and agencies designed to assist individuals with disabilities and their families including national, state and local agencies, and consumer-controlled organizations.

- Provide an overview of systems, services, and policies that exist in Minnesota to support individuals with intellectual and other developmental disabilities in integrated community, school, work, and recreation environments.
- Provide examples of state-of-the-art early intervention, school age, transition, adult, and aging services in Minnesota.
- Introduce issues of choice, consumeradvocacy, and self-determination through interactions with individuals that have disabilities.
- Provide an opportunity for interdisciplinary learning about disability service provision.
- Address the issue of providing culturally sensitive services to people with disabilities and their families from diverse backgrounds.
- Discuss critical current issues, ethical questions, and future trends pertaining to the provision of services and supports for individuals to live, work, and play in regular community life.

#### Instructional topics

Instructional topics included the following ----

- History of services and supports to people with disabilities in Western countries.
- Core principles and values that guide services in the U.S.
- Family support and early intervention.
- The five goals of enhancing quality of life for all families.

- Putting the pieces together: Family support services.
- Inclusion in faith, arts, and recreation communities.
- Collaboration, leadership, and policy development.
- National goals and promises to people with intellectual and developmental disabilities.
- Civic engagement to realize goals.
- The importance of partnerships for changing service systems.
- Non-profit financial planning and accountability.
- Building a case for financial support.
- Donor's and grantor's perspectives.
- Leadership: Developing leaders, building solidarity and expanding the circle.
- Leadership Institute for Ministry Excellence.
- Special education in the U.S.
- Vocational training and residential.
- Basics of the child welfare system.
- Children with special health care needs.

#### Community observations and discussions

Zambian team members spent each afternoon in the community. These visits were offered so that team members could see and experience how services are delivered in the U.S. Often, the Zambian team was split up in the afternoons and members went to different organizations. At the end of the day, they were asked to share and discuss their experiences and observations. This is a list of the programs and places that encompassed the community learning experiences —

• Arc GTC: Participants attended parent education and support groups, and met with administrators, advocates, financial staff, and others to learn how this program operates.

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- *Opportunity Partners:* Participants visited both a residential home and employment sites.
- *St. David's:* Participants observed an autism therapy program and physical therapy activities.
- Dreamland Arts: Participants observed a theater performance and reading performed by an individual with a disability. A post-performance discussion was held regarding the stereotypes about people with disabilities.
- *Metropolitan Center for Independent Living:* Participants interacted with staff and learned about the role of Centers for Independent Living in the U.S.
- *Fraser Autism Program:* Participants observed a classroom that serves children with autism.
- *Fraser Academy:* Participants observed an early intervention program for children with disabilities.
- Home of Katy and Scott Thuleen and son, Zach: Participants met with this family to learn about the services they receive and how their family is supported within the community.
- Home of Troy and Betsy Auth: Participants met with this family to learn about the services they receive and how their family is supported within the community.
- *St. Stephen's Church:* Participants observed and took part in a program designed for adults with intellectual and developmental disabilities that is sponsored by the church.
- Institute on Community Integration (ICI) at the University of Minnesota: Participants attended an evening interdisciplinary class and participated in discussion with students in the class.

- Interact Visual and Performing Arts Center: Participants attended a play performed by an inclusive theater.
- *Minnesota capitol tour by State Senate Chaplain Father McDonough:* Participants learned how the Minnesota legislature works and were able to attend a health and human services committee hearing.
- Consortium for Citizens with Disabilities: Participants attended a strategy session at the Minnesota Legislature about how to address potential funding cuts.
- *New Directions:* Participants observed how people with disabilities are supported in the community through person centered planning.
- *Gillette Lifetime Specialty Healthcare:* Participants learned how assistive technology supports people with disabilities.

#### Host families and social networking

Families in the Twin Cities metropolitan area hosted Zambian team members for the duration of their stay in the Twin City area. Most of the host families had two individuals from Zambia stay with them for one week. All of the host families either had a family member with disabilities or worked in the disability field. The host family model offered the opportunity for the Zambian team members to discuss what they had observed and learned each day from the training and field experiences. Conversations over mealtimes and observations of how family members with disabilities were integrated and included in family activities contributed to the overall learning experiences. Several opportunities for socializing and networking were included in the overall training plan. These activities were designed to teach the Zambian team about the importance of social networking and relationship building in the development of effective services and policies for people with disabilities in the U.S.

#### Zambian disability delegation training in Colorado

Five of the team members continued to receive two more weeks of intensive training in Colorado. In Denver, Colorado, half to full day trainings were conducted with legal advocates, schools working with blind children, and a health care system. While in Colorado, the team met with a number of programs dedicated to furthering the rights and education of people with disabilities. This provided the team with a broad perspective of disability services and policies in the U.S. It also provided the team with access to many groups and organizations and the various ways of assisting people with disabilities. The following organizations participated —

 The Legal Center for People with Disabilities and Older People: The Legal Center is an independent public interest non-profit specializing in civil rights and discrimination issues. They protect the human, civil and legal rights of people with mental and physical disabilities, people with HIV, and older people throughout Colorado. Team members were able to witness how state and federal policy guides service delivery design.

- The Community Resource Center (CRC): CRC, sponsored by The Colorado Health Foundation, extended an invitation to the Zambian group to attend training on program and service evaluation.
- Tri-County Health Department: Dr. Jana Smith from Tri-County Health Department, conducted training on "Reporting to Funders: How to write reports." Dr Smith expressed the importance of ongoing communication that occurs between grantors and grantees. She also discussed accountability and strategies to implement methods of accountability in-service delivery.
- The Anchor Center for Blind Children: This is a not-for-profit organization dedicated to providing early intervention and education to blind and visually impaired children throughout the state of Colorado. The team visited and participated in activities at Anchor Center for Blind Children.



#### **Tier three**

#### Planning

Upon the completion of tier two activities, the leading partners solicited feedback from the Zambian team regarding which aspects of the training were most interesting to them and held most potential for influencing change in Zambia. Based on this feedback, a proposed training schedule identifying content areas to be addressed was developed by the team. This proposal was reviewed by representatives of the Zambian team.

The training and support provided in the third tier of training was based on the areas of interest and needs as identified by the Zambian team immediately following the training they received in the U.S. The Zambian team identified advocacy and networking as areas in which they would like further training and support. These were chosen to most directly support their efforts to develop and implement activities within their communities. Speech therapy was also identified as a specific area of need for service-oriented training.

## Implementation of disability training in Zambia

Tier three activities consisted of disability training and workshops in Zambia in June and August, 2008. In addition, U.S. partners met with professionals across sectors that work for the rights of and services for people with disabilities.

#### June 2008

The first U.S. team arrived in June of 2008. Two weeks of intensive training in speech pathology were implemented at two different locations. The first week was held in Lusaka. Approximately 100 parents, teachers, student teachers, clergy, and administrators attended the training. Each day the participants learned new content and built upon existing skills. Particular focus was provided in the area of identification of speech anomalies and supporting children and adults with speech disorders.

The second week of training was held in the Copperbelt Region of Zambia in the small town of Kitwe. Approximately 75 people attended this training. The group's composition was primarily volunteer teachers who had not yet completed their education. Other attendees included faith based clergy and sisters, parents, and administrators. Training consisted of a mixture of lectures, video and interactive exercises.

#### August 2008

In August of 2008 a second team of trainers from ICI and Arc GTC traveled to Zambia and provided customized training to a wide audience and to evolve the skills of Zambian trainers. This provided the opportunity for the Zambian team to create a policy and training agenda with the support of the trainers. The August training consisted of the following components.

#### **Chawama Family Group**

Members of the team met directly with people with disabilities and their family members in the Chawama Compound. This was an opportunity to learn about their life experiences. It was also a way to gather information about the needs of people with disabilities to share with the parish leaders.

Approximately 85 people with disabilities, both adults and children, and their family members attended this impromptu meeting. The purpose of this meeting was to —

- Share information about the work of the Zambian disability team and their partners. It was explained that the Regina Pacis Catholic Church was interested in learning about the number of people with disabilities within their parish and how the parish could better support these individuals.
- Gather information from the community in order to advocate for people with disabilities to the parish leadership.

• Discuss the concept of self-advocacy and the strength of many people having a united voice.

Brother Joseph Ntumbila, a member of the Zambian disability team, served as the translator during this meeting. During this meeting it became evident that people with disabilities and their family members had very little opportunity to connect with one another or access resources. Many had never been asked by professionals to share their stories. One person noted that he had not been in a room together with others who had disabilities similar to his own. This person reported that he felt an immediate sense of community and belonging simply through the recognition that there were so many other people with disabilities living in the compound area. It was clear that people were feeling a sense of empowerment through the simple act of standing up and telling their story. The stigma associated with disability in Zambian society is pervasive. This public acknowledgement was perhaps a first step in joining voices to create a united effort.



#### Personal stories of support needs

**Joseph** is a six year old boy with significant physical and developmental disabilities, including medical conditions. He is very small, approximately the size of a 1-2 yr old and has a shunt in his head. This little boy had received initial medical care for his shunt, but at the time we met him, had not received any medical or in-home support for 3 years. He was unable to walk or hold himself up. A small umbrella stroller is used to support his mobility. At the time we met him, he was growing out of this stroller and his mother was having difficulty carrying him. She was also having difficulty providing general support to him. His mother cannot work because she needs to care for him and has no family members to assist her. His mother is seeking financial assistance and any help she can get for her son, including medical care, and help caring for him.

Lewis is a young boy that had been diagnosed with epilepsy and a speech impairment. His mother reported that she went to the doctor to ask for help because she would like him to be able to go to school. The doctor simply told her to provide speech therapy at home. He provided the mother with no instruction regarding speech therapy. This mother sought information from a library and works with her son at home to improve speech the best that she can. She is asking for help with speech therapy. Her goal is to be able to send her son to school.

**Silvia** has a daughter with intellectual and mild physical disabilities that affected her mobility. The daughter had been raped in her early teen years, became pregnant, and now has an infant. The grandmother provides care and support for her daughter and grandchild. The grandmother has nobody else living in the house and no support from extended family. The grandmother cannot work due to her care-taking responsibilities. She has trouble providing food to her daughter and granddaughter on a daily basis. She is seeking financial support. Her daughter does not have any school to attend and is not able to get a job.

**Emmanuel** is a fourth grade boy who was born healthy. He had been a healthy child in general. Recently, and quite suddenly he had became seriously ill. His illness left him unable to walk. He had been a good student, but could no longer attend school due to lack of accessibility of the school. He indicated that he spends his day sitting in a makeshift wheelchair. His mother is seeking a wheelchair, and wants him to be able to return to school.

**Richard** is a boy with a mild intellectual disability that attended school until second grade. At that time he was told not to come back because he could not keep up academically with his peers. The teachers reported they could not help him any further. His mother wants him to be able to go to a special school.

Members of the team facilitated a discussion on working together as a group to advocate for change. Presenters discussed the selfadvocacy movement in the U.S., and the underlying concepts that guide this movement. During this time, a number of attendees expressed their desire to continue to meet and to discuss how they could help one another, as well as strengthen their voices to seek recognition and support from the parish leadership and government officials. At the close of the meeting, it was agreed that the group would meet in one week to continue the process of learning about one another and working together. This was initiated by meeting attendees, and a number of volunteers identified themselves to take a lead in future meetings. Additionally, many of these volunteers attended the training sessions on disability advocacy and networking that occurred the following day.

Educational conversations with clergy Opportunities to discuss issues related to supporting children with disabilities and their families with clergy and young men training to be brothers and priests were plentiful. These

conversations often occurred informally over meals. Many of these individuals had not received any specific training on how churches and clergy could support people with disabilities and their families. U.S. team members engaged people in conversations about how the church and its leaders in the U.S. were instrumental in the evolution of supports and policies for citizens with disabilities. As a direct result of the informal conversations and exposure

to the self advocacy group at Chawama, one of the seminarian students, Brother James, has shown great interest and is continuing to work closely with Mikala and the selfadvocacy group. He is so interested, that he has requested additional special education teacher training.

### Networking and collaboration with Zambia disability team members

One goal of the follow up training and technical assistance that was delivered in the fall of 2008 was to get the Zambian disability team members connected to other disability related activities that the team members had learned about through the Internet, Zambian disability team members, or other contacts. U.S. team members accompanied members of the Zambian team to the following organizations.

• ZAFOD: This organization is a national disability rights organization. They are advocating for policy change and trying to ensure the rights of people with disabilities is integrated into the new Zambian constitution and other national





policies. Other organizations with a stake in disability-related policy and services are often ZAFOD members. They are beginning to conduct individual advocacy and have filed legal action in some situations. The Zambian team was able to hear from the ZAFOD leadership about what their role is and about their activities. One member of the Zambian disability team is now active in the ZAFOD organization and one of the parent organizations (Parent Partnership Resources) is now a member organization of ZAFOD.

• University of Zambia: The University of Zambia offers a research program and graduate level training for teachers who work with children with disabilities. They also have an on-site assessment clinic. Members of the U.S. team and the Zambian team met with the directors of this program to learn more about their education system for disability professionals. Discussion occurred around the concept of community development and organizing. The academic staff were interested in partnership and research based on a participatory action research methodology.

• ZAMISE: The Zambian Institute for Special Education is the only special education program in the country for teachers that go back to school for a certificate in special education. This educational institute emphasizes supporting children with sensory and physical disabilities, as well as some learning disabilities. The curriculum that is used is outdated by U.S. standards and many of the special education classrooms are not equipped to provide needed accommodations. There was interest in using the online curriculum called College of Direct Support. Since the ICI offered this curriculum to the Zambian team, at least one of the participants has completed the entire curriculum.

### Lusaka/Livingstone disability policy and advocacy training program

While in Zambia the U.S. and Zambia disability team coordinated and implemented two training programs designed for families, individuals with disabilities, policy makers, faith based organizations, church leaders, and educators. This program was entitled, "Promoting Inclusion for People with Disabilities in Zambia: A Workshop on Policy, Advocacy and Collaboration." The training program was held at Bauleni Street Kids in Lusaka and Cheshire Homes School in Livingstone. It was organized, advertised, and implemented through the leadership of the Zambian disability team. Approximately 105 – 120 people attended these training sessions. The learning content included the following —

- Key principles and values (inclusion, empowerment, normalization, valued social roles, dignity, and respect).
- The power of using non-labeling and non-possessive language.
- Personal stories about people with disabilities in the U.S.

- Laws and policies (international, national, province, district).
- Policy advocacy.
- Models of disability (medical, social).
- How policy helps.
- Advocacy (self-advocacy, parent advocacy).
- Person centered teams and planning.
- Developing community partnerships (networking, coordinating, cooperating, collaborating).

During both the disability policy and advocacy training and the many networking meetings that occurred, ICI was able to conduct a needs assessment to inform future activities.



### Needs assessment

ICI staff conducted in-depth interviews, observations, and focus groups to identify the overall status of disability policy and services in Zambia, as well as areas of need to enable more inclusive communities.

#### **Research questions**

- What indicators are present for success of a disability advocacy movement within communities in Zambia? Indicators for success will be assessed in the following areas: political, social, cultural, and economic.
- 2. What are the barriers that children with disabilities face in receiving education?
- 3. What are the barriers adults with disabilities face in being supported in the community?
- 4. What are the best sources of support for people with disabilities?
- 5. What strategies and activities will lead to more access to education and community inclusion for people with disabilities?

#### **Data collection**

Data was collected at two workshops held in Lusaka and Livingstone, Zambia in September of 2008. Participants at the workshops were teachers and school personnel, parents of children with disabilities, members of disability organizations, and members of the clergy. At the beginning of each workshop, before the first session began and before any information about disabilities in Zambia was provided, the workshop participants were split into groups. In Lusaka, the 75 workshop participants were split into 15 groups, each with approximately five members; while in Livingstone, the 30 participants were divided into four groups. Each group was asked to collaboratively answer four questions regarding disabilities in Zambia. These questions were —

- 1. What are the barriers that children with disabilities face in receiving education?
- 2. What are the barriers adults with disabilities face in being supported in the community?
- 3. What are the best sources of support for people with disabilities?
- 4. What strategies and activities will lead to more access to education and community inclusion for people with disabilities?

Each group chose a recorder, who wrote down their collective answers to each question.

After the workshops were completed, the data from each workshop was transcribed into a single document. Two members of the research team independently coded the data. The codes were then reconciled and final themes were identified. The findings from this research activity are identified in the following section.

#### Findings

## Identification of barriers for special education access and participation

A number of challenges and barriers exist for children with special needs that would like to attend school. Participants focused on the following as the most significant.

• Mobility and transportation: Schools are often quite a long distance from the communities in which children with special needs live. There is not transportation to schools and the distances are so great that it is difficult and at times impossible for families to provide this transportation. Even when children are transported, there are often challenges to gaining access to the physical buildings because they are not handicap accessible and many students cannot get inside them or move around once they are in the building.

• Stigmatization and societal attitudes: Many parents believe that their children cannot learn and that they should be hidden. These attitudes often are reinforced in communities and cultural beliefs. Children with disabilities and their families are often stigmatized in society. These beliefs limit opportunities for children with disabilities to reach their full potential and result in limited expenditures of resources on special education. Their peers often ridicule them and when they are included in schools, they can be in classrooms with 50+ children and receive little to no attention when compared to the general education students.

supplied. Specialized equipment such as hearing aids, wheelchairs, prosthetics, crutches, Braille books, books on tape, and general supplies are not available to teachers for use.

- Lack of information provided to families: Often families are not connected to information about special education and programs for people with disabilities and their families. There is an extremely limited family network and advocacy is also lacking in Zambia. Additionally there are not enough assessment centers to determine eligibility and to diagnose disabilities.
- Lack of trained special education teachers and continuing education: There is only one special education training program in the country. This school is located in Lusaka but does not have the capacity to train enough special education teachers to meet the national needs. The government

 Lack of schools and supplies: Not all children in Zambia have access to school because there simply are not enough schools for all of the children. Children with disabilities have even fewer options, though by policy they are entitled to a free and appropriate education. Often special schools are very far away and it is impossible for the children to get to school. When special education schools or classrooms do exist. they are typically under



controls the training and dispatch of special education teachers. Additionally there is not enough access to ongoing education and training for teachers who were trained many years ago. Teachers receive limited exposure to how to support children with special needs and the overwhelming majority of their training is focused on sensory and physical disabilities. Teachers need more training on working with children with severe intellectual and developmental disabilities such as autism.

- Lack of transition and post education options: While there is a growing number of special education classrooms and schools throughout the country, Zambia has only a few vocational training and transition programs to support the workforce readiness needs of individuals with disabilities. Once a child reaches their final year of special education, there are few if any other programs and services. The curriculum these children are taught does not result in learning a skill that will enable them to earn a living post school.
- Limited specialization of programs and curriculum: The national curriculum for children in government-funded special education programs is the same curriculum used for general education programs. Teachers are not adequately trained on how to modify this curriculum or to provide accommodations to students with disabilities. In addition, the special education programs are often not specialized so that children with all different types of disabilities are in the same school or program. Teachers do not receive specialized training based on

various types of disabilities (e.g., deaf-blind, deaf or hard of hearing, learning disability, autism).

- Concern for safety and security: Many participants expressed that children with disabilities are not safe en route to and from school and that there is no security to ensure their safety. This lack of safety prevents many parents from being willing to have their children with disabilities go to school.
- Family poverty: Most families in Zambia experience extreme poverty. Families are often concerned about how to feed, clothe, and shelter their children. Providing school and inclusive opportunities to children with disabilities is often not a top priority. In addition, many families are faced with choosing to educate and provide for their children without disabilities or their children with disabilities when they are unable to provide for both.

## *Identification of barriers for community participation and inclusion*

Many of the barriers expressed related to community inclusion were similar to those identified for schools. These included —

- *Self-esteem:* Individuals with disabilities often have limited self-confidence and self-esteem. They are ridiculed and have limited opportunities. This limits their opportunities to participate and to be included in their communities.
- Lack of employment and skills: Having meaningful employment and being able to financially contribute to the family is a critical aspect of family and community life in Zambia. People with disabilities usually do not have education and skill training that results in gainful employment. Because



they are not working in the community, this limits their exposure and interaction with community members.

- Stigma, beliefs, exclusion, and discrimination: For many reasons, people with disabilities are stigmatized and discriminated against by Zambian society. These individuals are often not allowed to vote, are not given opportunities to participate in organized activities and work, or to obtain positions of leadership in their communities. More often than not, they do not marry nor do they have families. However, these are things that bring social status to individuals in this culture.
- Individual and family poverty: Most people with disabilities do not work or contribute financially to their families and communities. Because families are often living in poverty, it is difficult for them to provide opportunities for their family members with disabilities. These individuals often go without healthcare, social supports, or skill training due to the fact that they simply do not have the personal resources to pay for such things. The government is not responsible for

providing services and supports to adults with disabilities or to families of children with disabilities.

 Inaccessible communities: It is rare that buildings within the community are accessible. Community members do not have the training or skills to use sign language or other adaptive accommodations to support members with disabilities. This is true of many churches, community centers, stores, government buildings, sidewalks, roads, and other community areas in Zambia. Because of this, most people with disabilities simply stay at home.

## Most valuable resources for people with disabilities and their families

There was significant consistency across all of the groups regarding the most important resources for Zambians with disabilities and their families. This includes the following —

• *NGOs:* Non-governmental organizations provide various social service, education and sustenance support to individuals with disabilities and their families. These programs often are faith-based and many are Zambian-developed or have an

international influence.

- *Churches:* The church is of significant value to most Zambian families. The church is a central component of their value system and community life. Many Zambians are active members in their churches and belong to social groups within their church organizations. The church provides social support as well as health, wellness, and other resources.
- Families: Currently in Zambia, family members provide most of the services and supports provided to people with disabilities. Zambians rely on family to provide social, emotional, financial, and other types of support.
- Government: The government provides educational services and other types of social services, including some healthcare. There are laws and policies that are designed to protect the rights of children and adults with disabilities. While these laws are not enforced and few people with disabilities or families know about them, they do serve as a vital resource for advocacy and support.

## Greatest needs to promote community inclusion

There were many great ideas expressed about how to improve access to education and inclusion of people with disabilities in Zambia. Common themes included —

• Create an advocacy system: In Zambia there is a small but growing advocacy movement. Increasing the opportunity for people with disabilities to learn how to advocate on their own behalf is essential to creating change. Providing these individuals with the opportunity to become part of a disability group and teaching them basic advocacy skills will also be important. Creating a network of parent and family groups throughout the country that are designed to support one another and create a common message of need and rights is important.

- *Improve accessibility:* In order to be a part of the community, individuals must be able to get to the community and move around in the community once there. Efforts need to be made in Zambia to ensure new roads, sidewalks, buildings, public transportation, and other built environments become accessible.
- Increase opportunities for networking: When individuals and families are isolated from one another, they often do not see the possibilities for themselves or their children. Increasing opportunities for children and adults with disabilities to come together and network will have a strong influence on improving community life and opportunities for people with disabilities. One of the most powerful advocacy tools is parent-to-parent networks and selfadvocacy networks.
- Enforce policies and laws that are already in place: Zambia is a leader in disability policy. Their education law and disability rights law very clearly indicates the need for inclusive opportunities and communities. Zambia was one of the early signers of the United Nations Declaration of Rights. Unfortunately, there are wide gaps between policy and reality for most Zambians with disabilities and their families. Strong self-advocacy and parent advocacy can push systems in Zambia to increase allocations of resources and to uphold promises made in policy.

- Increase awareness of individual and community needs: The general public in Zambia does not see or interact with many citizens with disabilities, whose skills and needs remain largely unknown. Community inclusion could be increased by providing the public with more information and facts about the life experiences, valued social roles, and contributions made by people with disabilities in Zambia. Radio, print, television, and other popular media venues is one way to increase social status and community awareness of people with disabilities and their support needs.
- Improve funding and availability of education and specialized skill training: People with disabilities will be included in society and their communities when they are working. A good education and skill training is needed in order to get good jobs. These programs need to be developed, increase in numbers, and be made available to all citizens with disabilities in Zambia. When a person is an active worker, earns a living, and contributes to the local economy, they bring value to their communities. Education and skill training programs will enable this to develop.

### Initial outcomes of the Twin Cities-Zambia Disability Connection

- At the Chawama parish, the first selfadvocacy trainings for families with children with disabilities have begun. It is a collaborative effort with parish priests, students, and members from the Special Needs Team. The self-advocacy group at Regina Pacis Catholic Church in Chawama, is the first and only self-advocacy group with special needs in operation in that particular compound, which holds a very high density population of well over 50,000. The group now meets once a month for members to support and share information with each other. With the assistance of two of the Zambian disability team members (Mikela Mukongolwa and Sr. Namangolwa Lamunga ), negotiations are now taking place in order to find suitable classroom facilities for the first classroom for children with disabilities in the Chawama area. Grace Banda, a disability team member, is working closely with them to find a location and secure special education teachers that can be paid by the government. Through the continuation of this program and the leadership provided by the Zambian disability team members, conversations are happening for the first time, networks are being created, infrastructure is being identified, and the short and long term results are beginning to emerge. Families are hopeful and encouraged by this level of activity.
- Both U.S. teams benefited from their travel to Zambia as they witnessed and experienced the challenges and barriers facing this country, its leaders, parents, educators, and faith-based organizations. Experiencing the many different cultural and social stigmas helped the team to formulate and problem-solve existing barriers.
- Ms. Beddor returned to Zambia in January of 2009 and noted how much change had already occurred. Ms. Beddor attended one of the advocacy group meetings at Chawama Parish. She shared her family's story with over 75 people who were attending and participating in the meeting.
- At Hidden Voice School, the first building has been renovated and students are just beginning classes. There are approximately 20 new students enrolled and attending. Hidden Voice School currently has only one teacher. She is not paid by the government as most teachers are in Zambia. The school is the process of becoming registered with the government. This will allow the teachers to receive pay for their services. It is the hope that this school will be grantaided and more teachers will come as the school grows.
- The Franciscan Conventual friars have completed their Chapter elections, which occur every four years. The newly elected Provincial, the leader of the Province, is Fr. Patrick Chisanga. He has been influential in the development of the Chawama Special Needs Advocacy group.

- Many of the programs today operate in the most impoverished areas of Zambia. Through pastoral ministries in 12 parishes, work has begun to identify and provide assistance to families with disabilities. This new vision and awareness of how to work with families with disabilities is a significant development in the parish community.
- Access to technology is difficult in all parts of Zambia. Three of the nine Zambian team members have now begun accessing the on-line training modules that are offered through the College of Direct Support.

### **Recommendations for the future**

There is much work to be done to improve the lives of people with disabilities in Zambia and it is difficult to know where to begin. The Zambian and U.S. partners have identified the following recommendations.

#### Support schools and education

- Provide the Zambian team and project partners access to the College of Direct Support on-line training program.
- Provide training and education for teacher development (both regular education and special education).
- Create an autism program or model classroom with sensory integration and inclusionary opportunities, including teacher training program.
- Address the need for early intervention services for young children with disabilities.
- Support the infrastructure, training, and classroom development of Hidden Voices School.

#### Promote self-advocacy

- Provide technical assistance, training, and materials to build a family and selfadvocacy movement throughout Zambia.
- Provide support, technical assistance, and resources to the Chawama self-advocacy and parent advocacy group.
- Continue to learn more about the parents groups that already exist, including the Association of People with Disabilities (ADD), Community Based Interventions (CBI), Jesuits, and the hospital program of assessment. Ensure that the Zambian disability team is aware and connected to these associations and organizations.

 Create a short disability awareness and rights DVD, with the active participation and endorsement of ZAFOD, and parents groups.

#### **Build community and infrastructure**

- Provide access to the internet, where possible, to families in their local communities.
- Create a short top ten list around accessibility and inclusion of people with disabilities in the churches. Introduce this to interfaith groups in Zambia.
- Build a partnership with University of Zambia on a research agenda that involves community building and empowerment of families and people with disabilities.
   Provide College of Direct Support access for students learning about special education and community rehabilitation at the University of Zambia and ZAMISE.
- Encourage a research agenda that involves collaboration between ZAFOD and University of Zambia.
- Create an infrastructure to support the development of an employment and skill building programs for youth in transition and adults. Exchange ideas and information related to skill building and employment within micro-enterprises.
- Use parish councils as a venue for training on inclusion of people with disabilities.
- Continue to inform the formation training of church leaders so that disability and human rights issues are recognized within the responsibility of the church.
- Maintain Twin City Zambia Disability Connection blog.

### Appendix

#### Instructors/faculty

- Angela Amado, Ph.D., ICI, University of Minnesota
- Amy Hewitt, Ph.D., ICI, University of Minnesota
- Marijo McBride, ICI, University of Minnesota
- Jerry Smith, ICI, University of Minnesota
- Chris Johnstone, Ph.D., ICI, University of Minnesota
- Diane Halpin, ICI, University of Minnesota
- Matt Ziegler, ICI, University of Minnesota
- Julie Apaloo and Cliff Poetz, St. Stephens Catholic Church Faith Inclusion Program
- Greg Lais, Wilderness Inquiry
- Beth Metzler, St David's School
- Beth Amlicke, artist from Hammer
- Janet and Evan Salo, parent and son
- Fred Segron, Faith and Light
- Pat and Meredith Salmi, mother and daughter
- Antonietta Giovanni, parent
- Rochelle and Thomas Turan, University of Minnesota Youth and Family Summit
- Beth Fondell, Arc GTC
- Bonnie Marshall, Arc GTC
- Fatmata Barrie, Arc GTC
- Kelsie Oyango, Arc GTC
- Pat Mellenthin, The Arc of Minnesota
- Mary Kay Kennedy, Advocating Change Together
- Scott Schifsky, Arc GTC
- Bette Rosse, founding Arc member
- Gail Dorn Beddor, parent and advocate

- Pam Huston Neuenfeldt, sign language teacher and special friend
- Hunter Sargent, self- advocate
- Lisette Schlosser, CFO, Arc
- Ellen Hatfield, Arc GTC
- Val Spencer, parent/community volunteer/ donor
- Keith Wolfstelle, Opportunity Partners
- Jon Thompson, Opportunity Partners
- Wendy Waldner, Opportunity Partners
- Tim Dickie and Brian Pederson
- Traci Laliberte, Center for Child Welfare Studies, University of Minnesota
- Ronna Linroth, Gillette Lifetime Specialty Healthcare

## Instructional resources and materials provided

ICI compiled reading packets for the Zambian team that included the following —

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## Zambian disability leadership team members

- Sr. Adrophine "Agnes" Daka, Cheshire Homes
- Mikela Mukongolwa, Bauleni Street Kids
- Alice Kaunda, parent of a child with a disability, Parent Partnership Association, Hidden Voice School
- Grace Banda, Ministry of Education
- Sr. Joyce Phiri, Franciscan Missionary Sisters of Assisi
- Sr. Namangolwa Lamunga, Sisters of Charity
- Fr. Deodatius Mbebe, Zambia Special Needs Advocacy Team
- Fr. Patrick Chisanga, The Conventual Franciscan Friars of the Proto-Martyr
- Br. Joseph Ntumblia, The Conventual Franciscan Friars of the Proto-Martyr

#### Host families in the Twin Cities

- Beth and Chuck Fondell
- Kim Keprios and John Everett
- Amy Hewitt and Brad Perry
- Jan and Paul Anderson
- Steve and Maureen Hayes
- Bonnie Marshall
- Beth and Gary Metzler
- Mary Meuwissen and Clare Fischer

#### Host families in Colorado

- Tina and Tom Vessels
- Liz Fuselier
- Sandy Beddor