



**THE DEVELOPMENT OF COMMUNITY-BASED SERVICES FOR
HIGHLY VULNERABLE CHILDREN**

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***The development of community-based services for
highly vulnerable children:
Stakeholder perspectives in Zhengzhou, Henan, China***

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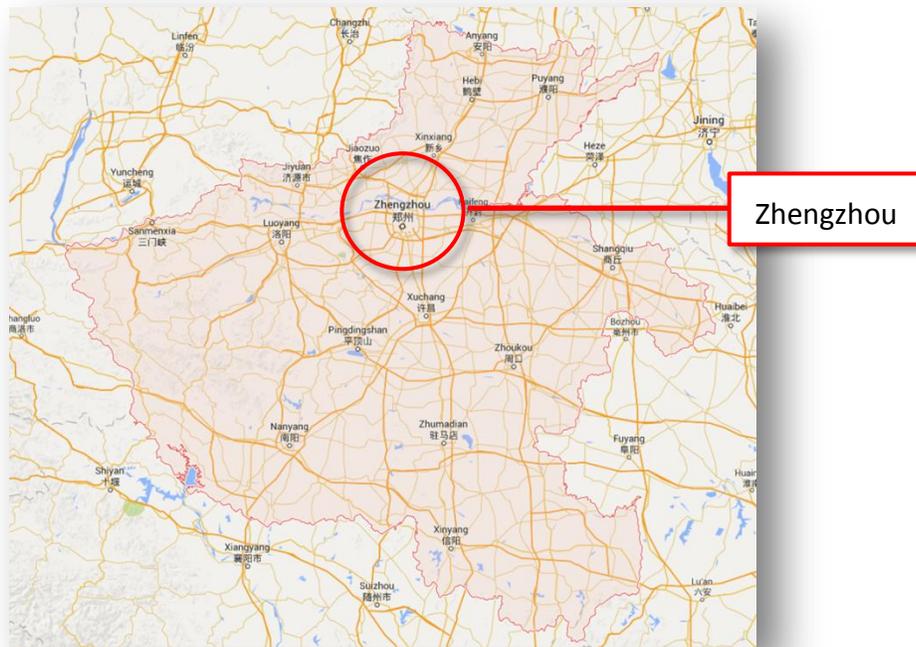
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Context

China's economic growth and development over the last 30 years can best be described as explosive. One way that China showed its leadership abilities was by being the first nation to ratify the United Nations Convention on the Rights of the Child. Yet, with a population of 1.3 billion people, China faces a unique challenge in protecting its children, who number in the hundreds of millions. As China's society continues to change (and change rapidly), the risk of its more vulnerable populations falling through the cracks of the already overstressed social welfare network is increasing dramatically. Those who are at the greatest risk of harm with this new social dynamic are orphaned and otherwise vulnerable children, many of whom are served in the current "protection" system: under-resourced institutions. Some of these institutions receive help from a small number of non-governmental organizations (NGOs) whose work is often sporadic and uncoordinated; the rest have no supports at all (Meng and Kai, 2009). Precisely identifying the actual number of orphaned children in China is challenging for a number of reasons (discussed in detail below), but one of the more reliable sources, the United Nations Children's Fund in Hong Kong (UNICEF-HK, 2009), estimates as many as 17,000,000 orphaned children in China.

The target area of the current situation analysis and needs assessment is the city of Zhengzhou, which is the capital city of Henan province. Henan is characteristic of many of China's predominately rural inland provinces, having large, impoverished populations that work primarily in the agricultural sector. According to the 2010 census, Henan had a population of 94,029,939 while Zhengzhou had a population of 8,627,089 (from National Bureau of Statistics, China, Henan Statistics as reported in <http://www.geohive.com/cntry/cn-41.aspx>).





An immediate factor affecting child protection in China is one of accurate information regarding numbers of vulnerable children. Aside from other vulnerable and at-risk groups, the fundamental question of the number of orphans in China is problematic for a number of reasons, not the least of which is agreement on the definition of "orphan". In China itself, there is a dual use of the category by government agencies, which under one definition is "children under 14, whose both [sic] parents are dead" ("actual orphans"); while a second use includes the above and "those unsupported by others" ("form orphans"). When "orphan" is used by international organizations, there are yet other definitions, such as UNICEF's: "a child under 18 who has lost one or both parents, lives in a household with an adult death in the past 12 months, or who lives outside family care". These varying definitions also go a long way toward explaining the wide variance when it comes to counting China's orphan population (Meng and Kai, 2009). Because of the potential for confusion, this proposal will use the term "vulnerable and at-risk children" to indicate not only the children in the different orphan categories, but also to include children who are at-risk of being abandoned, abused, neglected, exploited, or whose safety, health, development, and/or well-being may be compromised.

The first grouping of vulnerable children has its origins in China's One Child Policy. In 1979, this policy was able to dramatically slow population growth in China, but there were a number of additional consequences. Perhaps the most disturbing of these is the reduction of the number of females in China (the so-called "Missing Girls" of China). Data indicate that the "standard" expected sex ratio at birth world-wide is 105 or 106 boys per 100 girls (Arnold and Liu, 1986; Johansson and Nygren (1991); and Wu, Viisainen and Hemminki (2006)). Arnold and Liu (1986) found that "The overall sex ratio for children is reported to be 108.4 males per 100 females,

considerably higher than the sex ratio in most other countries (p. 240)". More recent studies noted similar findings. When applied to the actual number of births, the difference between the expected ratio (106:100) and the actual ratios (108 - 114 depending on the year) produce the number of "missing girls". All sources concur that these ratios depart from the international norm in the years after 1979, when the One Child Policy was introduced. Explanations for these higher than expected ratios that have been found across a variety of studies include "under-reporting of female births (including children given away for adoption whose births were not reported), antenatal sex determination and selective abortion of female fetuses, and excess early female neonatal mortality" (Wu, Viisainen, and Hemminki (2006), p. 172,). With regard to the first category, Johansson and Nygren (1991) found that "adding the adopted children to live births reduces the number of missing girls by about half" (p. 46). There is significant evidence to indicate the prevalence of the practice of aborting female fetuses following sex determination by ultrasound (Arnold and Liu, 1986; Currier, 2008; Greenhalgh, 2003; Johansson and Nygren, 1991; Wu, Viisainen, and Hemminki, 2006). Finally, data on registered *pregnancies* in Anhui province provide information on the mortality rates for newborns:

Most early neonatal deaths (82%) happened within 24 hours after birth, and during that time, girls were almost three times more likely to die than boys... The death rate of females on the day of birth increased much more sharply with parity than that of males. Girls born from second pregnancies were almost seven times more likely to die on their day of birth than boys, while there was no significant difference in the death rates of first-born girls and boys. At 1-6 days after birth, the death rates of girls and boys did not differ in first or in second pregnancies (Wu, Viisainen, and Hemminki, 2006, p. 175).

While there is some evidence to indicate that this dynamic is changing in parts of China (particularly in the more developed cities/regions) (Dodge and Suter, 2008), it is still regrettably common throughout many of the more rural areas of the country (which comprise fully 57% of China's general population's living environment) (Central Intelligence Agency, 2009). The majority of the country is still in the process of development, particularly the predominately rural, impoverished, and geographically mobile segment. This is the segment most likely to abandon healthy female children as a result of parental gender preference (Wu, Viisainen and Hemminki, 2006).

The second category of vulnerable children is a result of similar patterns of abandonment in many other cultures and societies: children who have been abandoned as a result of physical deformations or developmental disabilities (Feaster, 2010; Meng and Kai, 2009; Save the Children, 2004). In many countries around the world, these children represent a burden on resources for economically marginalized families and/or can be seen as culturally stigmatizing. Consequently, many are "strategically abandoned" in order to bring them into contact with care

providers perceived as better able to provide the level of care needed. The reality of the situation in rural China is much the same as in other developing countries -although strategic abandonment is seen by families as a means of securing resources, caregivers of orphans in China are themselves often struggling with limited financial, material, and medical resources, so survival for these children in orphan care is by no means assured (Save the Children, 2004).

The challenge of adequate service provision to children with disabilities is compounded by pervasive social stigma associated with having a disability in China (UNICEF-EAPOR, 2012; Hu and Szente, 2009). A rural case study by Shang, Saldov, and Fisher (2010) discussed the discrimination faced by families of children with disabilities regarding four different aspects—right to care and protection, economic security, developmental support and social participation. Parents and caregivers of children with disabilities in China have trouble finding a formal support system and must deal with the cultural barrier of a loss of face, resulting in strong stigma (Chiu, et. al, 2013). This culture of stigma surrounding persons with disabilities in China has been pierced in small, yet significant ways. Wang, et. al (2011) found that parents of children with Autism experienced higher levels of stress than any other parents. After discussing the extreme responsibilities placed on these parents (including managing behavior of their children and educating their children) it was proposed that a successful way for Chinese parents to cope with these stresses is through parent training programs that address typical development of children with specific disabilities, strategies for teaching these children and techniques for control of problem behaviors (Wang, et. al, 2011). It is in this context that two key organizations emerge in Zhengzhou – Qisehua and GIFT, both of which represent different but complimentary methods of addressing the needs of children with disabilities in their birth families in the community.

The *Qisehua* (“Seven-Colored Flowers”) Kindergarten, began in 1995 by an early childhood educator named Cai Lei as an inclusive early childhood education program for children with disabilities in Zhengzhou. This school is a “kindergarten”, a term used in China to denote a three-year early childhood program, including two years of pre-school and one year of kindergarten. This particular school has sought opportunities to develop the capacity to provide their program to children with disabilities alongside their typically developing peers, with a ratio of one child with a disability to seven of their typically developing peers. Each classroom also has a teacher and two assistants. This type of disability-inclusive program is very much an outlier in this community, as well as in much of the rest of China. In the twenty years since Ms. Cai started the program, Qisehua has become a regional resource as other community organizations and schools turn to the leadership and staff for information, resources, and training on working with children with disabilities.

The second organization is the Gift Special Needs Children's Parents' Organization ("GIFT"). This organization began as an ancillary program at the Qisehua kindergarten when a volunteer named Xu Bing noticed that many of the parents of children with disabilities seemed to be in chronic distress and had no support systems. GIFT started as a way for parents of children with disabilities to get to know other families that also had disabled children as a means of providing mutual support. Xu Bing, the architect of the GIFT program is a Chinese "house church" Christian, which informs how she went about starting and developing the program. In fact, "GIFT" actually comes from the organization's first name – "Special Needs Children are a Gift from God Parents' Support Group". The founder of this organization, Xu Bing, found her inspiration in John 9: 1 – 3, which she used as the primary reconstruction of what it means to parent a child with disabilities in China's unique social context.

Since its beginning in 2008, GIFT has become an independent registered nongovernmental organization (NGO) that is registered and recognized as a social service organization by Chinese governmental authorities. It now serves over 400 families in Zhengzhou and in Henan province. GIFT is unique among the all-too-rare community-based service providers in that GIFT works primarily with parents and families of children with disabilities as a way to create organic and sustained growth, support, and stability for children with disabilities, functioning as one element of preventing children from entering orphan care. GIFT has four primary program divisions: direct service provision to children and families; family networking and training; community outreach; and awareness raising and advocacy. It is this last component which has produced some of the most promising (and surprising) developments in the last two years. Beginning in 2012, GIFT family group leaders have organized themselves (with GIFT's support) and have petitioned the Zhengzhou Municipal Government for significant policy change, specifically to allow their children with disabilities to access local public primary education. As of 2014, the government listened and has responded positively by not only changing the policy, but also implementing it (the implementation is a greater surprise than the simple change in policy in this context). The following organizational profile was provided by GIFT:

GIFT Agency Description (Provided by GIFT)

The "GIFT Special Needs Children's Parent Club" was established in October, 2008. GIFT is a domestic Chinese faith-based (Christian) social service organization that is registered with the Government of China as a charitable organization (the Chinese equivalent of a not-for-profit organization). The initial funding for GIFT was donated by an individual, and the supervision was carried out by the Hui District You Hua Health Welfare Center (NPO). During the first two years of its existence, the club was located in the Henan Hui District at the Seven-Colored Flower Welfare Kindergarten. In March, 2011, GIFT moved to its new location, which is called Gift Parent Resource Center. Since its inception, the club has provided services for nearly 400

families with special needs children in Zhengzhou and elsewhere in Henan province. The club is a non-profit association and parents pay a small annual fee (100 RMB, or approximately \$15.73 USD) to participate. This fee is waived for families who cannot afford it. The vast majority (90%) of GIFT's operating budget is provided through donations from the Christian community in Zhengzhou and the surrounding area.

GIFT was established because of the specialized needs of the families of children with disabilities in Zhengzhou and Henan:

1. The proportion of children in Zhengzhou with special needs is high.
2. Parents with special needs children often cannot access support from government programs, and private "rehab" organizations charge parents high fees for services. Thus there is a heavy burden upon the parents, both financially and psychologically.
3. Children with disabilities are discriminated against and do not have equal rights when it comes to education and work etc.
4. Related to this, parents of disabled children often have a negative attitude towards their children and are often ashamed of them.
5. People in society have little knowledge and awareness of the existence and rights of children with special needs.

GIFT's vision: Healthy families and social environment in which special needs children are highly valued demonstrating God's love.

GIFT's mission: To care and help disabled children's families through providing practical, professional, and psychological resources and support.

GIFT's main objectives and strategies for reaching objectives:

1. Bring God's Truth to parents of special needs children so that the parents will change their attitude towards their children and toward life in general.
 - a. Set up more Bible study groups for parents to know the truth of God's word;
 - b. Maintain regular contact with the local churches;
 - c. Get the churches to support the center financially and / or prayerfully;
 - d. Get more brothers and sisters involved in out-door or in-door activities, so that they have more chances to share gospel with parents during activities.
2. Providing emotional support for parents coming to know God, opportunities for sharing their experience and promoting mutual aid among parents to help each other problems solve.

- a. Hold meetings with the parents to provide an opportunity for parents to share about their experiences of parenting children with special needs, to express their emotional anguish and to talk about the achievements which they have made, and to get the parents to take more responsibility in the assistance of other parents who have similar experiences;
 - b. Some parents receive some counseling training to help with other parents;
 - c. Provide marriage and personal counseling;
 - d. Do follow-up with parents by visiting them in their homes;
 - e. Establish QQ group, so that parents discuss deeper issues through internet;
 - f. When parents drop in the center, their children will be taken care of by volunteers so that they will have a break to reduce their stress.
3. Providing professional training for parents and opportunity to practice and improve parenting skills through interactive activities.
- a. Invite foreign and domestic specialists to give lectures to the parents on subjects like; special education, physical therapy and speech pathology, with the aim of helping the parents solve the problems which confront them in their daily lives;
 - b. Organize in-door and out-door interactive activities to help parents learn how to interact with their children
 - c. Provide parents training about day to day life skills and demonstrate how to teach children
 - d. Specialists will provide some suggestions on the problems faced by parents
 - e. Volunteers majored in special education will provide respite service for disabled children during their spare time at children's home.
 - f. Some courses on art or music will be designed for disabled children.
4. Providing resources relating to special needs children and parenting.
- a. Set up a database, including medical information, schooling, toys, training, law and regulations concerning the rights of children with special needs and welfare, etc.;
 - b. Providing information and resources about the services in the local area for special needs children;
 - c. Provide parents books on disabled children's parents' stories, disabilities information, educating, parenting marriage, etc.;
 - d. Hold exchanging market for parents to exchange their books or children's toys with each other every month

5. Through club activities the community's attitudes towards children with special needs will change to be more accepting. Besides, advocating for the rights and welfare of special needs children.
 - a. Organize big-scale activities on Down's Syndrome Day, Autism Day, Disabled People's Day, Volunteer's Day and Children's Day to publicize the center, to attract more parents , to advocate for the rights of children with special needs and to make people aware of the needs and rights of the children;
 - b. Through the Media, report the activities of the club with the aim of increasing the center's impact;
 - c. Edit and print a biannual newsletter which gives wide publicity for the club and increases peoples' knowledge and awareness of children with special needs;
 - d. Establish a website for the club, so that the latest news of the club can be easily disseminated;
 - e. Visit some special needs schools, hospitals and other organizations in order to publicize the aims and services of the club and build relationships with them, and;
 - f. Contact local government to get more support and increase the impact of the club.

GIFT provides the primary point of intersection and access to intact families of children with disabilities in 2014 and 2015. As part of the situation analysis process, two needs assessments were conducted.

The first, in July, 2014, involved interviews of parents of children with disabilities who were participating in a GIFT summer activity with their children. These parents were asked about their perceptions of the strengths, needs, opportunities, and challenges experienced by themselves and their children. Individual and couples interviews and focus groups were conducted to gather data.

The second occurred in June, 2015, and a similar process of interviews and focus groups was undertaken to secure the perspectives of GIFT staff and volunteers, relative to strengths, need, opportunities, and barriers. These investigations are described in the subsequent two sections.

Methods

The research was a two-part qualitative, exploratory investigation of the strengths, needs, opportunities, and barriers experienced by children, families, and stakeholders in Zhengzhou, Henan, PRC. For each portion of the study, the researcher traveled to Zhengzhou to collect data, utilizing a translator/interpreter in the interviews and associated event activities. As a result, responses are recorded in the third person, to indicate the presence/role of interpreter.

Data Collection

Family Perspectives: Part one of the study (July, 2014) involved a convenience sample of families who participated in a week-long activity, recreation, and training event led by GIFT. This event was designed to provide families of children with disabilities with the opportunity to have a mini-vacation with their children with individualized support for children and families provided by a cadre of volunteers. The interviewer worked with

The investigation included parent interviews and focus group sessions. The sample was selected by a snowball sampling of families participating in the GIFT summer program. A total of 13 individual interviews were conducted and input from an additional 24 families was collected in focus groups sessions. A translator/interpreter was used to facilitate interviews and discussions, which were recorded by means of a handheld digital audio recorder.

The researcher used interview guides to gather information related to individuals' perceptions of the family's experiences, their perceived strengths, needs, opportunities, and barriers, desired outcomes, and existing services and support networks. The interview guide helped to ensure that the same broad sets of questions were covered in all interviews, although there was also room to explore issues or comments that arose from particular respondents, too. Interviews typically lasted from 30 to 60 minutes each.

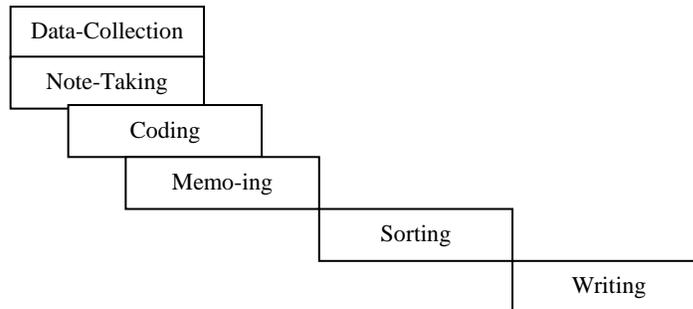
Worker Perspectives: Part two of the study (June, 2015) involved a convenience sample of staff and volunteers from two organizations that provide community-based services to children with disabilities and their families: GIFT and Qisehua. The GIFT portion of the study included ten interviews with 11 participants and focus groups with 24 participants. As in the 2014 portion of the study, the researcher used interview guides to gather information related to individuals' perceptions of their perceived strengths, needs, opportunities, and barriers, desired outcomes, and service and support functions of their organization. The interview guide helped to ensure that the same broad sets of questions were covered in all interviews, although there was also room to explore issues or comments that arose from particular respondents, too. Interviews typically lasted from 30 to 120 minutes each.

Data Analysis

Both the family and worker portions of the study utilized the same data analysis process, which occurred for both parts as follows:

Qualitative Theme Analysis:

The data derived from this process, including field notes and interview transcripts, were then analyzed by means of an open and axial coding process as depicted in the following stages (Dick, 2005):



Following the researcher's return to the US, the process of transcribing interviews began. The data analysis team transcribed the interviews and focus groups. Once the initial transcription drafts were generated, an iterative data cleaning and "chunking" process was necessary to format the transcript into sections, denote speakers, etc. A final cleaning process then occurred in which sections of the transcript that were unclear were manually revised via listening to the original recordings and process notes.

After the final transcript draft was finished for all interviews, members of the data analysis team individually read and coded each interview. This open coding process allowed for each coder to review each transcript, thus allowing for the first round of triangulated codes to be generated. The researchers then met to participate in a face-to-face coding and sorting process that, in the case of the family interviews, was organized by spatial categories, which were the residential proximity of the respondent to Zhengzhou (i.e. a master set of codes was identified from all codes in each of the spatial categories). The worker interviews were grouped by organization.

Once codes and categories were identified from the spatial/organizational categories, another round of sorting and axial coding was undertaken by the researchers which created the final set of codes for the combined data set, identifying the codes and categories that were common across all interviews, as well as identifying differences between interviews. Note: the axial coding for the 2015 worker study has occurred only across GIFT cases (Qisehua will be completed by the end of 2015).

Grounded Theory Identification: Because of the rich and varied experiences of the participants and out of respect for their perspectives and unique "voices", the research utilized a grounded

theory approach so as to ensure the accurate reflection of their perspectives as much as possible. Both studies included this additional inductive process designed to identify the implicit theory of stigma-driven family experiences and the implicit intervention theory derived from workers. For both datasets, once the axial codes and themes were identified, the cross-cutting patterns that emerged from the coding process were further sorted using a methodology derived from grounded theory. This approach uses *a posteriori* strategies that emerge from collected data rather than beginning from a particular set of *a priori* presuppositions (Patton, 2002; Blumer, 1978; Glaser and Strauss, 1967), so as to discover the theory implicit in the data (Glaser, 1992). The subsequent analysis of this data used grounded theory coding procedures to "help to provide some standardization and rigor" to the analytical process (Strauss and Corbin, 1998, p.13).

Limitations

Both the qualitative methods and the use of convenience sampling necessarily mitigate against generalizing beyond the participants and organizations themselves. It may be the case that the implicit theories identified as a result of the grounded theory process may be able to reconnect to the existing theory-base, but this is an additional step that needs to occur before discussion beyond the current scope is possible. Also, all participants were engaged with and benefitted from GIFT. This is a significant potential source of bias that needs to be considered at all parts of the findings.

Findings: Part One, 2014 GIFT Parent Interviews

Themes from Family Interviews		
Organizing Theme	Cross-Cutting Theme	Information Seeking and Sharing: Parents developing and leveraging social networks (formal and informal) to identify and evaluate information related to resources, services, “cures”, supports, etc.
	Primary Themes	Secondary Themes
(Stigma/Anti-Stigma)	Family Context	Parent Characteristics (Geographic Setting, Education, Occupation, Family Resources, etc.)
		Child Characteristics (age, diagnosis, functional level, diagnostic process)
		Extended Family (grandparents, aunts/uncles/cousins, fictive kin; also, lack thereof)
	Challenges	“No Supports”: Lack of understanding, lack of acceptance, lack of opportunity (esp. family and community)
		Lack of Resources (incl. information, funding, services)
		Cure Seeking (understanding of disability includes ability to cure/undo condition; “extreme” putative cure interventions; costs)
		Mental Health (Stressors and effects on parents, child; challenging behaviors)
	Hopes	Improved Child Situation (increased cognitive functioning, survival skills, social skills, developed/maintained relationships, “happy”/improved mental health)
		Social Change (more acceptance, less judgment, educational opportunities, vocational opportunities, residential opportunities, more understanding by society)
		More Resources (information, funding, services)
	Programs and Services	“Rehab” for children (functioning improvements, awareness of other families, sharing of information, peer support network access)
		GIFT (support, no cost to parents, affective components, high quality information sharing, connection to foreign experts, advocacy, access to more services)
		Qiseha (support, no cost to parents, affective components, high quality information sharing, connection to foreign experts, advocacy, access to more services)
		Other Community-Based Services (TCM hospitals and clinics, Kangda, programs in other cities – Beijing, Shanghai, HK; Desired services)

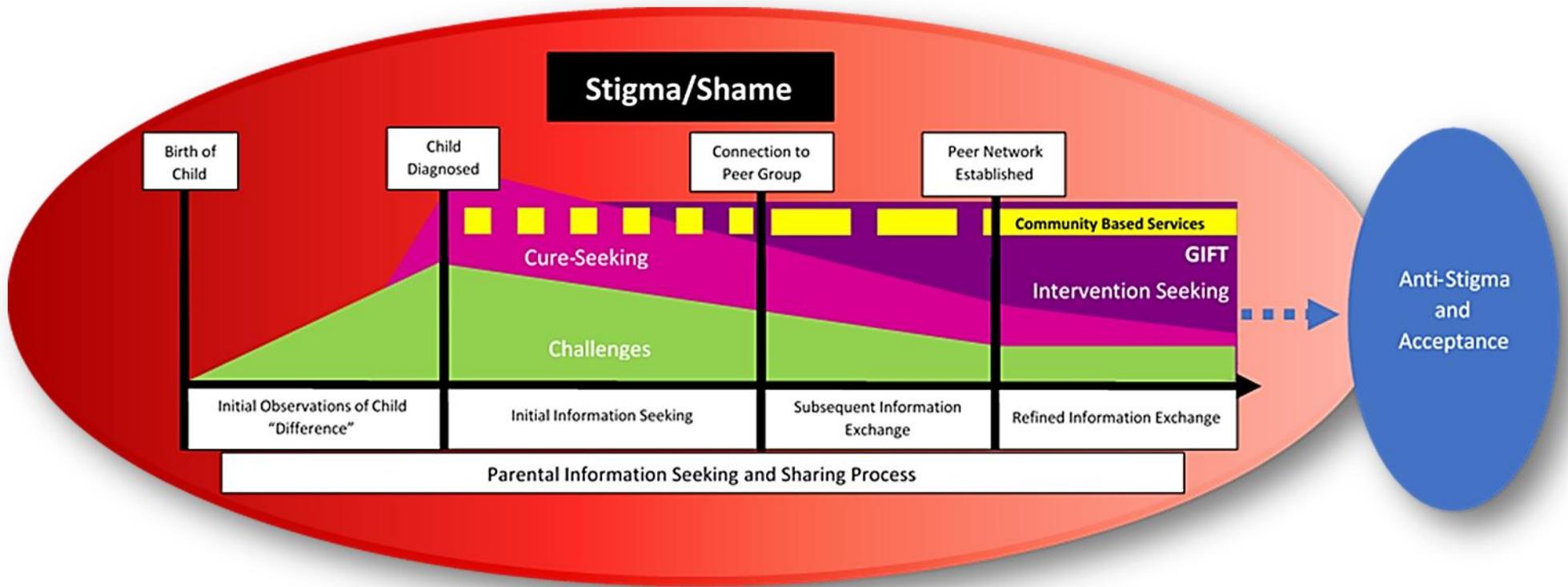
Organizing Theme: Stigma/Shame and Acceptance

The phenomenon of stigma/shame shapes every part of the respondents' lives. This is obviously clear when parents discussed the broad array of **Challenges** they face, but stigma also shapes their expressed **Hopes** and dreams. These latter are essentially the polar opposites of the stigmatization experienced by children and their families). Thus the hopes and dreams expressed by parents for their children essentially represent the "undoing" (or deconstruction) of stigma both for their individual child as well as for society at large. Nearly all of the parents interviewed also expressed a desire for a "cure" for their child's diagnosis, and many spent large sums of money and invested years of their lives in the quest for an individualized "undoing" of their child's stigmatizing condition. Stigma/shame also permeates the parent responses more subtly (and sometimes overtly), with regard to the primary themes of **Family Context** (e.g. family stressors, geographic moves, divorce/separation, etc.) and **Programs & Services** (e.g. information and advocacy for both macro- and micro- level reconstruction).

A number of discussions with several of my interlocutors in Zhengzhou highlighted the experiences of isolation and shame that many persons with disabilities and their families experience. My primary interlocutor, who leads an organization that explicitly focuses on supporting parents of children with disabilities, has related a number of stories of shame and patterns of stigma told to her by the parents she serves. Indeed, the relating of these patterns spurred the current efforts to explore the experiences of these families. The discussion about the sociocultural context and the relating social construction(s) of disability in central China provided by a number of these interlocutors is summarized in the following section.

A graphic representation of the conceptualized model of family experiences and strategy organized via the dimension of time follows:

Grounded Theoretical Model of Family Experiences



Cultural Context of Stigma/Shame

Social constructions of disability and popular understandings of etiology of developmental disabilities intersect to create a sociocultural context in which persons with disabilities are significantly devalued.

This lack of value has functional dimensions. Persons with disabilities, are viewed as being a drain on family and social systems, doomed to consume more resources than they contribute (this is especially true for children with intellectual disabilities).

There are existential dimensions to this phenomenon as well. Multiple interlocutors describe the intersection of various types of traditional cultural thought with regard to persons with (congenital) disabilities. Although the Peoples' Republic of China is officially an atheistic State, many traditional ideas and understandings of social phenomena (including disabilities) are still present. For instance, both Buddhism and Daoism include reincarnation in the corpus of their belief systems; Sayadaw (2015) provides one explanation from a Buddhist perspective on this phenomenon:

Karma is the law of moral causation. The theory of Karma is a fundamental doctrine in Buddhism.... What is the cause of the inequality that exists among mankind?

Why should one person be brought up in the lap of luxury, endowed with fine mental, moral and physical qualities, and another in absolute poverty, steeped in misery?

Why should one person be a mental prodigy, and another an idiot?

Why should one person be born with saintly characteristics and another with criminal tendencies?

Why should some be linguistic, artistic, mathematically inclined, or musical from the very cradle?

Why should others be congenitally blind, deaf, or deformed?

Why should some be blessed, and others cursed from their births?

... **In this world nothing happens to a person that he does not for some reason or other deserve.** Usually, men of ordinary intellect cannot comprehend the actual reason or reasons. The definite invisible cause or causes of the visible effect is not necessarily confined to the present life, **they may be traced to a proximate or remote past birth.** (Sayadaw, 2015, Paragraphs 1 – 4, emphasis added).

When a child is born with a disability, one understanding is that this disability is evidence of a karmic burden that is evident in the condition of the child at birth. This burden requires expiation in the present round of existence in order to make future existential progress. It also places the moral responsibility for this expiation upon the person with the disability.

In some cases, the source of the karmic debt may not be just the child, but the parents as well (i.e. the parents' karmic burden is associated with having a child with a disability). In this case the child is evidence of the parents' existential short-comings, which leads to another layer of stigma, this one related to Confucian ideals which interact with the ideas of karma:

The practice of filial piety within Confucianism still influences a vast amount of people today...Filial piety (xiao shun) is the primary duty to one's parents - a fundamental virtue for the Chinese way of life... In classical Confucianism filial piety was commonly understood to consist of three key moral obligations; respect for one's parents, **honouring (or not disgracing) them**, and supporting them financially... From the Confucian point of view, familial relations... are more important than the ruler-minister or friend-friend relation. The latter may end voluntarily, but familial relationships can never be deliberately forsaken. (Slayford, 2009, paragraphs 1 – 4, emphasis added).

Thus the fact that a child with a congenital disability exists, and that existence may be evidence of parental karmic debt (i.e. moral failing), itself conflicts with the "key moral obligation" of not disgracing one's parents. In this case, the child herself is a stigma, a mark of shame, on the face of the family.

The more typical outcomes of this modern experience of stigma related to having a child with a disability include isolation or entry into orphan care. Many families and other informants describe children with disabilities remaining in the family's living space and kept apart from interactions with those not in the immediate family. Other children, especially very young children, may enter the orphan care system (i.e. Children's Welfare Institutes) through a process of "strategic abandonment". Because of these two strategies used by families of children with disabilities to manage stigma and other challenges (e.g. economic), it can be very difficult to identify intact families of children with disabilities in many Chinese cities, towns, and villages.

It should be noted that the social construction of congenital disability as a punishment or consequence of sin or karmic debt is not uniquely Chinese. Indeed, it seems to be a very common phenomenon in many traditional cultures (e.g. John 9: 1-2, Martin Luther and the "changeling" in Dessau (Cone, 1968), etc.). Similarly, the outcomes of isolation or abandonment are also present in other cultures, as well.

Respondent Descriptions of Experience of Stigma/Acceptance

Parents expressed the lived experience of stigma and its corresponding shame in a number of ways throughout their interviews. These expressions fell into two broad categories: personal/familial and social. In the former, parents spoke of their individual biases and/or that of their family as related to their disabled child, while “social” relates to broader societal attitudes either explicit (as by neighbors) or implicit (as by lack of policies and opportunities for persons with disabilities to engage more broadly in their communities). Representative quotes of these categories include:

Personal/Familial

- The challenge they have is, well the challenge is her husband {*the child's father*}, he doesn't seem to accept this child, yeah, this girl.
- One of the challenge he faced, was when he first know his child has disabilities, he has to adjust the way he thinks, his emotions, and that was the biggest challenge to him.
- She said she haven't received any support from either family, [not] even her husband... and nothing from the community or her neighbors.
- She's a full-time mom and she divorced with her husband... when they found out her child is CP [*cerebral palsy*].
- She got divorced with her husband in 2007... that's the time they found out her child has autism.

Social

- And when they go out with the child, the neighbors will point at them, they will say something like... they will say a lot of stuff behind your back...
- Whenever they go out [the neighbors] say, “Your child is grown up” [*but you have to care for her like a baby*] or they feel like the neighbors have some they look down on her.
- The doctors and hospitals in Zhengzhou and Henan... they don't, all they do is they threaten the parents like they, yeah they tell them, ‘Your children have no hope’.
- The reason why she sent her daughter to that English school is she had no choice because it's really, really hard for them to find a school that will accept her.
- His mom, she doesn't like people ask her how old is your child? She doesn't like her neighbors to ask [about him] and sometimes the neighbors will treat him differently because they think this child got some problem cause he's, his intellectual is lower than the other children so their neighbors will see him in different ways so.

As mentioned previously, the idea of stigma/shame is present either overtly or covertly throughout respondents' narratives. Even parents' hopes and dreams represent the absence or undoing of stigma (conceptualized as a sort of “**acceptance**” or anti-stigma, typically indicated by the Mandarin term 接纳 or *jiēna*), as seen in the following representative quotes:

- They're working on the society to accept, to understand the children with disabilities.
- She works with other parents to fight for their rights, to have some job opportunities for children with disabilities when they grow up.
- Their hope is that one day maybe their community can gather all the people with disabilities children and have a gather[ing]... [they want some] type of gathering or meeting that the parents, their community [can] form [together].
- She doesn't have a very specific plan or hope for her child's future, she just hope that her son can graduate from the Kindergarten and [go] to an Elementary school that will [accept him]. And also he could take care of himself when he grows up—not necessarily to earn a lot of money, but maybe to find a job that could [allow him] to live.

Finally, the following quote includes all of these categories:

He hopes that the community can understand and accept and have compassion with the children with disabilities and for his child as well. (Be)cause it's really hard for the communities to understand and to accept the children with disabilities. Even his own parents don't understand and they don't want to know about [Autism Spectrum Disorder]... he want[s] his son to grow up and to live with dignity.

Cross Cutting Theme: Information Seeking and Sharing

A significant pattern of information seeking and sharing as described by respondents was noted throughout the analysis process. In fact, this was initially conceptualized as the organizing theme, until the deeper context of stigma/anti-stigma was discerned by the analysis team. The relationship of stigma/anti-stigma is seen as being closely related, as information seeking is seen both as a response to stigmatizing ideas and behaviors as well as a means of pursuing anti-stigmatic goals.

Because the process of information seeking and sharing was prominently communicated across respondents, it is identified here as a “cross-cutting theme”, as it is present to some extent in the other primary themes. There are a number of different phases or “flavors” of information seeking and sharing identified from responses. The focus of the information seeking and sharing process tends to evolve over time with regard to the families' experience with the child's diagnosis.

The pattern that was most prominent involved the following stages:

1. Pre-diagnosis and diagnosis
2. Initial information seeking (especially related to post-diagnosis cure-seeking)
3. Subsequent information exchange
4. Refined information exchange

In the identified pattern, the first identified stage typically began when someone (often a preschool teacher or relative) identified a difference in a child's development or behavior. Once this difference was communicated to parents, then a formal diagnosis was sought, typically from a physician. Once a formal diagnosis was rendered, the parent or parents then pursued information related to curing the child's condition. Most often the curative processes pursued were different therapeutic modalities available through traditional Chinese medicine (TCM), some of which were reputedly quite esoteric. The vast majority of the parents interviewed expressed disappointment with the treatments, and failure to secure the desired outcome (i.e. the alleviation of the diagnosed condition; it should be noted that one parent identified satisfaction related to improvement in their child's hearing, attributed to TCM). Many parents reported a period of time during which they "mixed" treatments, drawing upon TCM interventions, while also pursuing strategies from Western medical models. These Western strategies typically involved some combination of physical therapy (PT) and occupational therapy (OT), with most respondents reporting an emphasis on PT. A few respondents also described limited speech therapy, as well. The umbrella term used by respondents to include both TCM and Western medical interventions was "rehab", although this term was also used specifically of the PT elements as well.

During the rehab process, the parents typically take their child to a hospital that provides the desired services (in Zhengzhou, there are one or two hospitals that specialize in rehab for children with disabilities), where they wait with other families in a general waiting area while their children participate in therapies with hospital staff in an adjacent room or rooms. During this waiting process, the parents had time to talk together and to begin to develop relationships, which were strengthened by the fact that all of the parents had a child with some type of disability that carried at least some social stigma.

Respondents reported that this opportunity to be around others who share their experience was powerful, and were often the beginning of what would become deeper, more mutually supporting relationships. Initially, though, parents describe how information was shared between families about different types of "cures" or other treatments, as well as information about the perceived efficacy, cost, accessibility, etc. Families reported leveraging this information to pursue another opportunity to seek a cure. Over time, families describe being

exposed to a wide range of opinions and experiences related to treatment options in this informal process. Many families reported feelings of discouragement and even regret when reflecting on the pursuit of curative treatments for their children.

Through this process of networking and direct experience of treatment outcomes, families describe eventually moving away from curative treatments to pursuing more habilitative interventions as well as becoming introduced to community-based organizations that provide support to children and families (e.g. GIFT and Qisehua). Families similarly describe their experience with these types of interventions and supportive groups as providing more observable favorable outcomes than other avenues they'd previously pursued or which they'd heard about other families pursuing. This refined process allowed families to become more structured, organized, and coordinated in their efforts, to the point that several hundred families engaged in advocacy efforts that targeted local government in Zhengzhou to allow children with disabilities to access public primary schools. This three year advocacy effort was successful, and the government both mandated and implemented this change in policy in 2013. Parents now report that their advocacy efforts are directed at securing the resources necessary to allow their children to be successful in their new educational placements.

It was also noted that although the pattern was the same for both older children (12 – 15) and younger children (2 – 5), there was a difference in the amount of time spent at each stage for both groups. Informants report significantly less information and fewer resources related to disabilities in the community a decade ago, so families of older children seemed to spend more time in the first two stages. Similarly, families of younger children seemed to get to the latter stages more quickly as the amount and quality of information shared increases. Representative quotes related to information seeking and sharing include the following:

- After they went to the hospital they, she started to know the people, the families who have the children with Autism... So that's how they made connections with each other and how they can share their resources and... most common thing they'll talk about is where to go to find the best therapist and which hospitals to go and which Chinese doctor to see and yeah, things like that.
- After she went to the hospital and confirmed that her child has the Autism... the doctors and the hospital, like the people in the hospital told her about all the organizations it's like available for her and also the parents there were like the parents she knew would share information with each other... They would talk like while the children were doing the training. And also the parents in Qisehua will tell her which place to go and who has the best therapies, yeah... {*crying*}... She said she really appreciate the parents, and all the things they shared.

- Whenever she goes out, whatever the places, whenever she sees like children with disabilities she will tell their parents about GIFT and Qisehua because she saw the improvement on her daughter so she will recommend go to Qisehua.
- So one thing is he will find other organizations and like, the place where provide therapist... he will go there and like, go study with his son for about one month and he knew all the stuff that they were doing so they can practice at home... also, GIFT has really helped him because the older parents, the more experienced parents will tell him what to do at his age, what they're doing or what do you need to pay attention to.

Primary and Secondary Themes

1. Family Context

The primary theme of family context emerged from the responses as a way to represent the descriptions that families provided about their strengths, challenges, and basic demographic information. This primary theme was identified as having three secondary themes as described below.

Parent Characteristics: The content of this secondary thematic category includes information relating to the family's geographic setting (including changes/moves relating to the child's diagnosis), family members' educational status, parents' occupations, and descriptions of family resources (including economic, technical, and social dimensions). Representative quotes include:

- She's a single mom. When they had [their daughter] before they got married so after the doctor confirmed that she has Down syndrome the father left. He never come back until like five years later, so she was the one who always raised her.
- She's full-time Mom. So she graduated from middle school and yeah, that's her education and they live in Shanghai and because her child needs to do some like training in Shanghai... They were in Zhengzhou in 2012 for almost one year then they moved back to Shanghai because yeah their family is at Shanghai.
- She lives in Zhengzhou. She used to work in a big company and yeah. And also her, she graduated from college, yeah undergraduate college... she said about last year, she started a company but it is getting... things are getting too complex.... so she sold the company. Yeah and so for now she doesn't have a plan yet but yeah but her main focus is her child... Her son is 9 and 8 months old and she got divorced with her husband in 2007. Yeah that's the time they found out her child has Autism.

Child Characteristics: This secondary theme includes information related to the child’s age (both presently and at key points in time), the child’s diagnostic label, the child’s interests, personality, and functional abilities, and information related to the diagnostic process.

Representative quotes include:

- Her daughter is eight years old and nine months old, yeah eight years and nine months and she is intellectual disability... She said her daughter doesn’t have a good memory... and her cognitive ability is, capacity is very low and also sometimes she is really hard to comprehend something... [Her daughter] likes to interact with people, she likes to play, she likes to read, she likes to sing or dance...She said her daughter is very joyful. She’s willing to share with people and she’s really happy.
- Yeah he said his son 2 years old and 4 months with the time when he was ready to go to Kindergarten and the teacher told him I think there’s something wrong with your child, you better go to the hospital and do a check-up. They went to the hospital and confirmed that he has ASD. They used to think that because, he starts to speak like really late so he thought maybe child is just like him so they didn’t pay attention to it.
- She has a three years old and ten months son and he has Autism. Yeah and she said in the beginning he couldn’t talk but now he, he could sort of talk, he started talking.

Extended Family: This category includes any information related to family structures and relationships beyond the child and parents (or the lack thereof), including grandparents, aunts, uncles, cousins, and fictive kin. Representative quotes include:

- She said she got a lot of financial support from her family and also the family member, like her sister and her brother really support them, sometimes they encourage her.
- After she gave birth to her son, um her child’s grandpa and grandma moved to her house to help them to take care of her son.
- Even his own {*the responding father’s*} parents don’t understand, and they don’t want to know about [his son’s autism]... They are really tough.

2. Challenges

The primary theme of challenges was identified as families described the difficulties they encountered in the process of coming to terms with their child’s disability as well as in seeking help for their child and themselves. Four secondary themes within the Challenge Theme were also identified, and are described in the following entries.

“No Supports”: This secondary theme became immediately evident in the interview process, as parents addressed the question of, “Can you describe the supports that your family receives from your community?” Parents invariably responded with 没有 (“*mei you*” or “none/don’t

have [any]”). Not only was the content telling, but the speed of the response was universally quick and definite. Dimensions of the “no supports” secondary theme include indications of lack of understanding, lack of acceptance, and lack of opportunity with regard to the community (and in many cases from the family, too). Representative quotes include:

- She said she hasn’t received any support from either family, even her husband and like, and nothing from the community or her neighbors... So um she said she didn’t receive any formal or informal support from... yeah and sometimes the neighbors give her a lot of negative influences, yeah so she has to find the, she has to like bring her son for a therapist different places and without telling them.
- She said her son doesn’t get along with the other children in the community really well so... she doesn’t talk to other people about her son a lot so... she doesn’t have like a lot of relationships with, between, with the neighbors.
- She didn’t get much support from the community because they live in an old community. Yeah, so, it’s not a very fully developed community.

Lack of Resources: This dimension of the Challenges theme include barriers that parents experienced with regard to information (both quantity and quality), material and financial resources, and services related to disabilities and identified child/family needs. Representative quotes include:

- They have very, very little income and there is one parents, her family only has two-hundred yuan like for the whole family—four people. Yeah so they have a lot of stress. They could only buy some [very basic food] and her friends will give them some rice and yeah, flour.
- She said that she went to the, like the, she went to find the people who are in charge of the community before and she ask them... Do you have any service like, we can take a break. Her and her mom can take a break from taking care of the child... like someone, a volunteer would like anything or any person can... who knows about Autism and that is willing to take care of him for one day or half a day. Like once in a while. And the people there said sorry we don’t have this service.
- They just knew that their son is Down syndrome they had no idea how to, how to train him or what can they do, whatever they can do to help them like, yeah. They don’t have enough information online [or] books, no information in the books.

Cure Seeking: This secondary theme relates to difficulties and barriers associated with the local understanding/construction of developmental disabilities, including the possibility of curing or otherwise “undoing” a developmental disability, the use of “extreme” putative cure interventions, and the costs associated with these measures. Representative quotes include:

- After they knew about her child is Autism, they went to Zhengzhou and they went to the hospital they come from and her child has disabilities, then they, then they went to Beijing for almost one year to have a parent's training and to have like a health recovering center to help her child, like to help her child.
- Yeah she says two years ago she, her dream [was] different... two years ago she think her son will be recovered one day and he'll act like normal people. He'd have a happy life and a healthy life.
- She said um, because she always hope that her son can fully recover from CP [*cerebral palsy*]. When he was three years old, they went to the [TCM] hospital. The doctors there have some like, special therapists. Yeah, cause he was only two years old so... the doctor will use the needle and start from the head and all to the way to the bottom, all the way to your feet... every part of your body except for the stomach part [describes a type of intense total body acupuncture with subcutaneous medicine, for a total of seven complete times]. Yeah and she says she doesn't, she doesn't know what she was thinking. Yeah she just, she thought that was so cruel... Yeah she said and she thought she was really brave to face that but now when she look back she thinks, "{I can't believe} we had that done". Yeah and she said because she saw other examples like the children have CP and they did the therapies... they did the healing [and] think it recovered. So that's what motivates her to keep doing it for seven times. And yeah and she said that didn't help at all but make it worse.

Mental Health: This secondary theme includes information related to psychosocial stressors (typically related to the child's diagnosis/functioning) and their effects on parents and children, as well as challenging or maladaptive behaviors engaged in by children with disabilities.

Representative quotes include:

- And also she said she's felt kind of like killing herself before, and there's like 2 or 3 [months] she never went out of the house - she just stay at home.
- When they first knew her son has PKU, her whole family shut down. They felt a lot of stress for about two years.
- So one thing they faced is they think they need a psychologist to sort of help her child cause her child is, like he shuts down sometimes. But sometimes when he's in a good mood he'll talk, he'll like be happy. But most of the time he's afraid that he's scared to interact with people because he thinks he's not normal... And she said other families have that concern too cause like their children are a little bit shut down, yeah due to their sickness.
- Her son started to like, to like fight with her... Whenever she say something he'll do the opposite... she felt like her son is like kind of being impatient with her cause well cause now whenever she calls him, he'll say, "Evil one, go away from me", something like that, something like that will hurt her and she's like, she felt like, 'Oh I raised you for so many

years and have been through a lot of struggles and difficulties... but and now my payback is your anger and you're hurting me now'.

3. Hopes

Families described their hopes and dreams for their children and themselves in a variety of ways, which, collectively, were identified as the primary theme of Hopes. For every respondent, the hopes that were expressed involved some inversion or undoing of a stigmatizing condition. Thus, *Hopes* were seen as being closely related to *Stigma*, albeit in the obverse. Three secondary themes were identified within the Hope theme, discussed below.

Improved Child Situation: Parents universally expressed a desire for improvements or increases in a number of dimensions for their children, including increased cognitive functioning, improvements in survival and social skills, developed/maintained relationships, and "happy"/improved outlooks and mood. Representative quotes include:

- She hope that after she graduates from elementary school and middle school even... they will make an organization or an institution to teach them like some skills like to be a worker.
- So her hope for her son is that he could take care of himself. Yeah, he has the ability to feed himself and to even to find a job in the future.
- So her hope is very simple. She hopes that her son has a good life, like a happy. He'll be good mood every day and he'll be healthy situation, and her hope for her family is that her family will stay healthy as well with her son so they can have more time to be with him on the earth.... She thinks her son, even though her son may not be as normal as the other children that she hope that her son could live a life like other people. Like he'll have dignity, he's happy, he can take care of himself... that's her hope.
- Her hope is [her daughter] could take care of herself and with all her help and maybe it's possible she could find her job.

Social Change: Parents voiced a desire to see significant change occur across the community (as well as actual evidence of this change), and at all levels of society. Parents reflected these desired changes through expressions related to less negative judgment, improved educational, vocational, and residential opportunities, and in general, more understanding/acceptance by society. Representative quotes include:

- So then they start to advocate and they convince the government to pass on some law or policy for these families. So they have a policy now for the PKU family that children with (translation), yeah only for PKU families um children within three years old, the government has the responsibility to get them some milk powder (formula) four jars...So that's the policy, after all the hard work they did, yeah.

- She'll work with other parents to like, to fight for their rights, to have some job opportunities for children with disabilities when they grow up. she's very worried about her son going out to make friends with other people... yeah so yeah she hope that the children including the adults in the community will try to understand them like whenever her son does something strange they will like understand him... And also like to inform all the citizens in the community about Autism and yeah. To share some information with them.
- She said the best help we can get from the community is to, it'd be to tell the people who live in the community don't look down on children who have disabilities or to like teach them about some kind of the, various situation and about the disabilities... like to tell them like to... don't tease them, don't discriminate.

More Resources: Parents expressed the hope that they and other families would have access to more information, funding, and services that would support them and their children in the process of securing a safe, healthy, and happy life. Representative quotes include:

- Parents who have children with disabilities have to have an open-hearted, and open-minded, be open-minded... She said uh, the most important thing for them is a difference on when to talk to an organization or like a teacher. The parents who have children with disabilities, yeah that's the most important thing.
- Maybe all the organizations could negotiate with the government to find a place for the children to provide them something to do, not necessarily a job, not necessarily a job, just something to do that they could live happily in that place, a safe place... her hope is that there will be a safe place... maybe a farm I think, like they'll provide the education for the early intervention and as the time goes, when the children grow up they have a place to work at... to help with and yeah it's like a community for the children with disabilities.
- They face many challenges and struggles... they really want someone to help them... like they start with the basic to [reach out] to more people and influence more people to get involved.

4. Programs and Services

Families discussed a number of programs and services specifically for children with disabilities and/or their families in their communities. These ranged from different types of medical care to organizations that helped to organize and resource families. Four sub-themes were identified in parent responses, and these are discussed below.

“Rehab” for Children: Most of the interventions and services that are available to families of children with disabilities in and around Zhengzhou are focused on improving the child's functioning. The particular focus is on “rehab” services which are mostly PT-type exercises,

massage, as well as some traditional Chinese medicinal elements. In some cases, interventions may also include some derivative of Applied Behavior Analysis methodology, with the goal of improving cognitive functioning (change in target behaviors seems to be recognized as a secondary concern as expressed by respondents). Representative quotes include:

- “There is a hospital in Zhengzhou... [that] helps the disabilities children to heal, like a training hospital... Yeah so they have received... cognitive training. Before [the training] [their son] couldn’t go into an elevator cause the movement, he could not take it. After the training and the healing, that helped him. Also the teacher taught him how to put on his pants or yeah, how to put on clothes and how to use spoon and chopstick.”
- “Her son started to have the training and service start form 4 years old...Yeah and then they went to different hospitals. The first one they went has helped them to have some therapists about the sensory disorder.... after so many years she found like it didn’t work very well and she said before 4 years old her son like act really normally it’s just like language delay but when he was around 5, 5 and a half, he started to speak to himself and he, she felt like the training like made it worse.”
- “They got in touch with the families through the hospital and when, cause some families have financial problem when they want to give up, when they want to stop the healing, the therapists, the hospital will [put them in touch with other] families who have PKU...”

GIFT: This relates to parent responses that describe the services provided by GIFT and accessed by children and families. Because the sample frame included only families that attended a support program from GIFT, the sub-theme of GIFT was universally recognized and appreciated among the respondents. It is assumed that this is a limitation of the current study (see Limitations section). Representative

- Whenever she’s struggling she’ll go find GIFT and they’ll always help her and give her some solution or ideas to help her overcome the struggles. And one thing is like, Xu Bing like, Xu Bing talked to the parents and told the parents “you guys have to be like really strong about sending your children to go to school” and now [her daughter] is attending an elementary school.
- She said her friend introduced GIFT to her... This is her first time to get involved with GIFT, like this is her first time to come to the camp at GIFT. Yeah she heard about GIFT long time ago but she never like get involved with GIFT... She said because she heard that there will be a lot of children with disabilities here and she want her son to interact with people more

so... and she knew there will be some volunteers here to help her so, that's the reason why she wants to come... She said um, she felt that the volunteers here are very loving, they are very kind. And she think GIFT is very good. And she's willing to share with other families who have children with disabilities to come to GIFT... Yeah, to pass it on.

- She said she goes to GIFT regularly for the study group and yeah. She think it's really good... she said many people know about GIFT like the public organizations know about GIFT and hospitals, yeah. And she says she would like to tell other parents about GIFT you can go to GIFT for the study group and training, the parent's training and also whenever you have some problems with your children you can go find GIFT and yeah there are some experts there that can help you... she said that the study groups are formed by a bunch of parents who have children with disabilities and normally they would talk about their concerns and problems or issues like discuss together and find some solutions or like some people have ideas. And also [volunteers] will be there to help them to solve, like to answer some of the questions.

Qisehua: *Qisehua* ("The Seven Color Flower") began as an inclusive early childhood education program where children with disabilities and their non-disabled peers learn together in the same classroom. *Qisehua* by all accounts was really the first provider of community-based services for children with disabilities, and all of the subsequent growth and development of services for children with disabilities in the Zhengzhou area can be traced back to this organization and its founder, Cai Lei. Ms. Cai is frequently called upon to provide training and support to other organizations who are interested in beginning to provide services to children with disabilities, including programs in other provinces. GIFT started as a parent support group within *Qisehua* before spinning off into its own entity, but both organizations work cooperatively with each other, and many families access one as a result of working with the other. Representative quotes related to *Qisehua* include:

- They [heard] about *Qisehua* on the TV, yeah and their sister helped her to get in touch with *Qisehua* and her daughter went to *Qisehua* for one month... She felt a little bit better after she talked to Xu Bing [when she volunteered at *Qisehua*] and all the other staff and *Qisehua* ... she felt positive.
- She said one thing that is really rewarding is the *Qisehua* training. Sometimes they'll have the meeting, and the meeting with the professor from Taiwan. She found out how to find out her child's strength. Yeah that's really rewarding.
- Whenever she goes out, whatever the places, whenever she sees like children with disabilities she will tell their parents about GIFT and *Qisehua* because she saw the improvement on her daughter so she will recommend go to *Qisehua*.

- She went to *Qisehua* and she felt like she was really lucky to find such a good place and yeah and she felt like *Qisehua* is really helpful.
- For one year, like her son doesn't, her son couldn't recognize the colors like, and her son doesn't know how to um, bounce the ball, and how to throw the ball. And he learned all these basic skills in *Qisehua*.

Other community-based services: Parents also provided some information about other services and providers either in Zhengzhou or in other parts of China. Representative quotes include:

- [Her daughter] is like getting OT in Shanghai and yeah. And she went to kindergarten in the countryside [outside of Shanghai], yeah for one year, for one and a half years... Her mom thinks that she doesn't have to build into study in regular elementary school yet.
- Last year like December they went to [*Shanto*], it's an organization to help her son to develop. I guess it's the PT, OT thing so um, so she said the language and the speech part improved a lot but the problem is that, that training was about four months. They stayed there for almost five months and they come back in this April. Not, not April, May, May. So the problem is that her son started to like, to like fight with her... [The training was] ABA... She said they do a lot of things like one person to one person and it's like, on music, drawing and like a very detailed like computer and sports, volleyball and they do like cognitive anything... Um so yeah she said because she was with him while the training, in the training and whenever he doesn't want to do it she'll force him to do it.
- They went to *Kangda* because if you go to *Kangda* it's like a whole day training. You have to attend like 6 lessons or 5 lessons for each day. But because her son is studying the Kindergarten so he doesn't have the time so they'll go there on the weekends, on Saturday. It's like six lessons training for whole day... Also she felt like maybe the training helped just a little bit but it didn't work that well. It wasn't really effective.

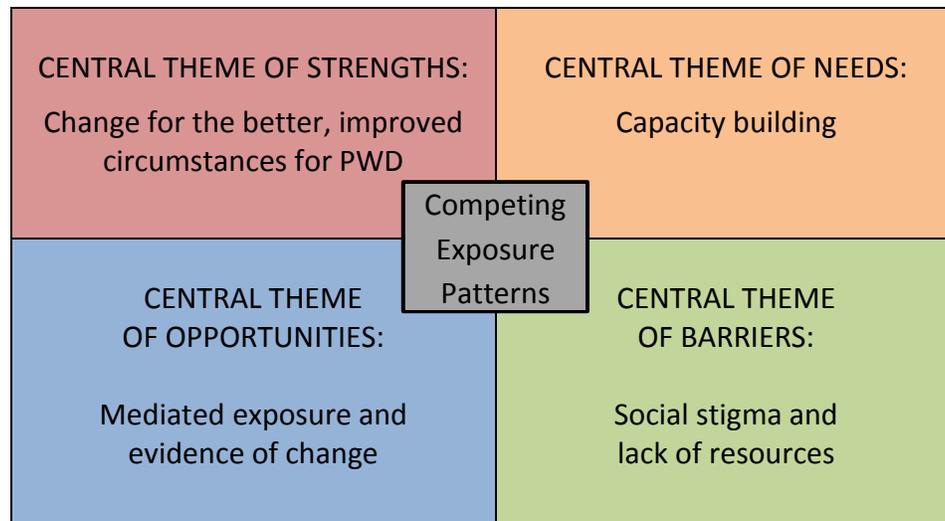
2015 Preliminary Findings: GIFT Worker Interviews

The full worker dataset is still in the analysis process, and is not scheduled to be completed until December, 2015. The GIFT portion of the dataset has been completed, though, and so the preliminary findings are included here.

The set of axial themes derived from the GIFT worker interviews and focus groups explicitly involved discussion of strengths, needs, opportunities, and barriers from the perspective of GIFT staff and volunteers. Workers provided information based upon their individual observations and perspectives relative to themselves (“**Worker**”), the “**Organization**” for which they work, the families they work with (“**Parents**”), and to their broader “**Community**”.

	WORKER	ORGANIZATION	PARENTS	COMMUNITY
STRENGTHS	“Heart”, skills, and supports to work with PWD	Systems orientation to PWD in China; mediation	Coordinating, advocating for PWD	Visible changes occurring; increased hope
NEEDS	Professional development; clearly defined roles	Capacity building; increased resources	Opportunities; access to well-trained professionals	Increased positive exposure to PWD
OPPORTUNITIES	Micro level mediated exposure to others in the community	Expand existing networks; develop new networks	Connect with one another; organize as a unit	Increased social awareness; evidence of positive change
BARRIERS	Lack of scaffolding; skills related to PWD	Trying to meet too many needs with too few resources	Stigma; discrimination surrounding PWD	Dominant culture pattern; lack of community based systems for helping PWD

The final set of distilled axial codes of the strengths, needs, opportunities, and barriers across each division is included here:

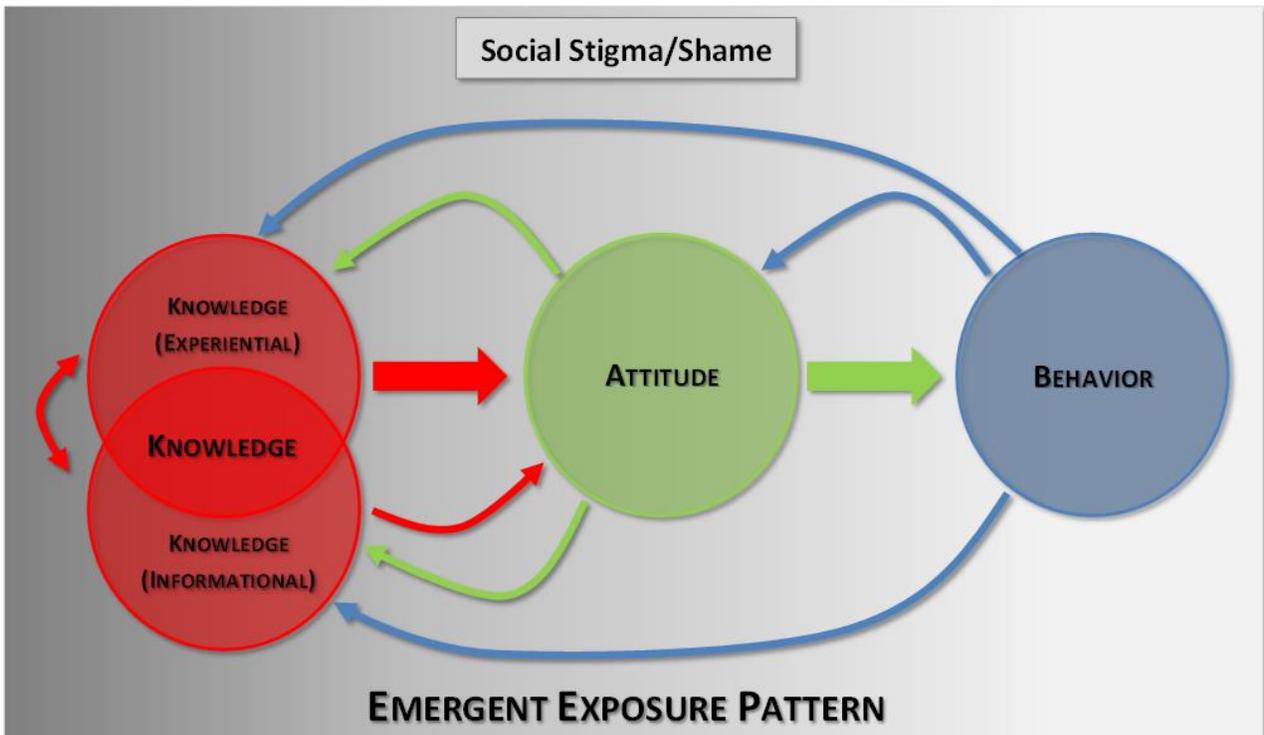
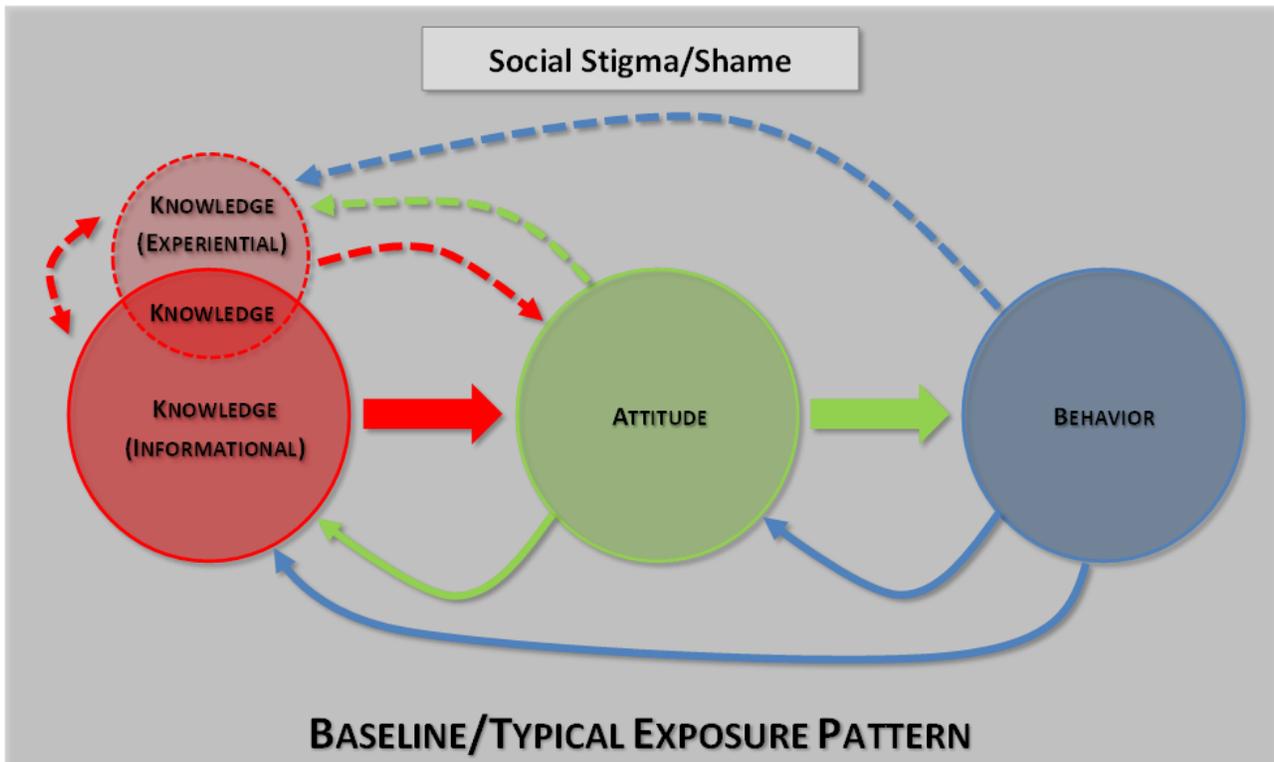


Representative quotes by quadrant include:

- **Strengths:** “[Through her work] she sees changes... that give her hope. Changes in families, changes in policies, changes in society...It’s faster now... in the last two years,, she sees really big changes.”
- **Needs:** “The challenge is [they] need more professional skills, trainings, techniques. Also more [direct] practice field training...”; “most supports they get is from overseas, because China doesn’t have much {of this kind} of professional resources.”
- **Opportunities:** “I think the awareness of the parents [is growing]... they begin to stand out, to speak, to advocate for their rights. They give some pressure on the government [to change policy]... Now the government is willing to do this, to help the disabled people.”
- **Barriers:** “The two biggest problems – the first one starts from understanding. [The community] doesn’t understand disabled people. They know nothing about them...There is still cultural discrimination... We need to fight for their future for people with disabilities. They have less opportunities.”

Competing Exposure Patterns: This pattern emerged from the grounded theory process, and articulates the workers’ understanding of how attitudes and behaviors are shaped by exposure (or lack thereof) to persons with disabilities. Two competing models were identified – a baseline model that produces stigmatizing and discriminating patterns, and an emerging model

that provides “mediated” exposure by one or more persons who have an accepting attitude and who demonstrate supporting behaviors.



- **Representative Quotes:**

- **Typical Exposure Patterns:** “I didn’t have any relationship with disabled people and I wasn’t aware of them. It just seems they are very far away from my life. I didn’t have a chance to meet them, so they never appear in my life, my world, so I never think about that.”; “There was a person in the extended family that has some mental disability, his intelligence is not very high. The other people call him like, stupid or idiot... at that time, I didn’t think a lot about it.”
- **Emerging Exposure Pattern:** “Before I knew nothing about [disabilities]. But [a special education teacher from England] taught me a lot. She is such a nice lady; she just loves the kids and their parents so much, and the way that she showed to the parents that she loves them, that really touched my heart... [now] I do feel I have a burden for the kids. I do worry about them, their future – I do worry about that.”

Discussion and Recommendations

The full discussion and recommendations will be developed following completion of the analysis of the 2015 dataset. However, the areas of overlap between the expressed reality of parents of children with disabilities and the initial worker needs evaluation dataset align well in GIFT’s organizational assessment of the context (restated here):

1. The proportion of children in Zhengzhou with special needs is high.
2. Parents with special needs children often cannot access support from government programs, and private “rehab” organizations charge parents high fees for services. Thus there is a heavy burden upon the parents, both financially and psychologically.
3. Children with disabilities are discriminated against and do not have equal rights when it comes to education and work etc.
4. Related to this, parents of disabled children often have a negative attitude towards their children and are often ashamed of them.
5. People in society have little knowledge and awareness of the existence and rights of children with special needs.

In response to these, GIFT’s approach that addresses identified needs regarding technical capacity building, leveraging of current positive changes and improved situations for children with disabilities to offset pervasive social stigma would seem to hold together well.

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