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A Parent-to-Parent Program in Taiwan

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Parent-to-parent programs provide emotional and informational support to parents of children with special needs by matching trained and experienced parents with parents needing support. This study examined the implementation and effects of a Parent-to-Parent Program in Taiwan that supported 3 families of youngsters with special needs. Based on the individual family's needs and the availability of local resources, these families were supported by 2 trained and experienced mothers of children with special needs, the staff of the family-centered early intervention center as well as the self-help parent group, and a researcher. Notwithstanding the myriad of criteria considered when matching the families before the program implementation, the fitness of the match would ultimately be determined on the basis of the initial contact or subsequent interactions between families. During the program implementation, this study found the following: (1) "natural" and well-prepared initial contact facilitated subsequent relationships; (2) understanding real needs was the key; (3) "being present" was a form of support; and (4) experienced parents could help "translate" professionals' recommendations. After the program was implemented, experienced parents needed support, too. This study concludes that "localization" is the key in implementing parent-to-parent programs. Furthermore, with more people involved in the program, trained professionals will no longer exert a dominant influence and more members of the families' informal support network can be empowered. **Key words:** *action research, early intervention, family-centered, informal support, parent to parent*

FAMILY-CENTERED early intervention emphasizes family's inherent strengths, empowerment of families, partnership between professionals and parents, and integration and utilization of community resources (Bowe, 2007; Dunst, 2012; Hsu, Wang, Chang, & Chang, 2003; Krauss, 2000; Turnbull, Turnbull, Erwin, Sookak, & Shogren, 2010; Turnbull, Zuna, Turnbull, Poston, & Summers, 2007; Wang, 2013). However, many challenges lie in the path of delivering family-centered intervention as related to leadership, training, attitude, professionals' expertise in family-centered intervention, collaboration between professionals and families, family's power, resources, rules and regulations, and accountability (Bruder, 2000; Cress, 2004; Gooding et al., 2011; Halpern, 2000; Jackson, Traub, & Turnbull, 2008; King et al., 2003; Kuo et al., 2011; Perrin et al., 2007; Shannon, 2004; Sheehey, 2006; Turnbull, Summers, et al., 2007; Turnbull et al., 2010). For example, professionals need to reflect on whether or not parents remain the focal point during the process (Krauss, 2000). Turnbull et al. (2007) believe that professionals should value family's strengths and will, be willing to support families, and defer the final say to families in terms of families' real needs. However, in reality, professionals remain the ultimate decision-makers. This could be attributed to professionals' limited understanding of the families supported, as well as their lack of training and experience in cultivating rapport with different types of family and exposure to related issues experienced by families. Challenges also stem from professionals'

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lack of understanding of family's needs and knowledge about the community resources available (Harbin, McWilliam, & Gallagher, 2000). Trained professionals may overlook parents' strengths as well as the impact to their daily life from rearing a child with special needs and fail to appreciate the support networks formed among parents (Aldersey, Turnbull, & Turnbull, 2016; Turnbull et al., 2010). There is thus a clear disconnect between the trainings that these professionals receive and what they encounter in the real world—a gap between theory and practice.

Therefore, we embarked on a praxis-oriented action research to investigate the implementation of a Parent-to-Parent Program among three families of children with special needs and the effects of the services provided. The goal was to explore a new knowledge paradigm that is anchored on the relationships forged when people meet people and to understand how people react to their respective circumstances as they perceive them (Levinas, 1969, 1989).

FAMILY-CENTERED EARLY INTERVENTION

The shift of service orientation from narrowly focusing on the children with disabilities to also including their families (Bowe, 2007; Dunst, 2012; Krauss, 2000; Turnbull et al., 2010; Turnbull, Zuna, et al., 2007; Wang, 2013) resonates with Dunst's (1985) definition of early intervention (formulated on the basis of Ecological Systems Theory) in which various formal and informal social support networks and types of assistance and services ought to be provided to infants and toddlers as well as their families. Early intervention may include attentiveness of friends, recommendations of doctors, temporary childcare offered by neighbors, support parent groups, division of labor between husbands and wives, and so on. In other words, early intervention may utilize resource-based and family-centered environmental intervention that allows parents to build support networks suitable for them and their children.

The formal support of early intervention in Taiwan is predominantly delivered by health care professionals (Research Center for Humanities and Social Sciences, 2017); however, health care professionals may not always be able to provide families with the support needed in a timely manner. The study conducted by Chang and Lin (2007) revealed that, in Taiwan, the early intervention services that families received were from formal support sources more than from the informal ones, which was indicative of the strides made by the social support rendered by early intervention professionals. On the contrary, the finding also pointed to an ongoing change in the family structure locally and, as a result, it has become more difficult for families to receive support from relatives and friends. Yet, as the resources within families fluctuate with the external social environment, parents cannot always rely on these resources. The literature has shown that parents generally view their spouses as the most important source of informal support, followed by their own parents and support groups (Chen, Chih, & Su, 2004). When parents are raising children with disabilities without sufficient support from family or friends, they feel isolated. In these cases, support groups can actually provide informal support and relieve much of parents' stress (Shu & Lung, 2005; Singer, Hornby, Park, Wang, & Xu, 2012).

THE PARENT-TO-PARENT PROGRAM

Parent-to-parent programs provide emotional and informational support to parents of children with special needs by matching trained and experienced parents with parents newly referred to the program in a one-on-one relationship (Santelli, 2000; Santelli, DiVenere, Yoder, & De Carolis, 2000; Santelli, Turnbull, Marquis, & Lerner, 1995, 1997, 2000; Santelli, Turnbull, Sergeant, Lerner, & Marquis, 1996). Parents have indicated that, among all the support that they receive, the most helpful support comes from parents with similar experiences (McGill, Papachristoforou, & Cooper, 2006), which

mirrors the findings of studies conducted by Thoits (1986, 1995) among societal members. This commonality deepens supporters' empathy so that their support can better meet the needs of support seekers and prompt the latter to reach out more.

Empirical studies have demonstrated the effectiveness of parent-to-parent programs among parents of hospitalized children (Silver, Ireys, Bauman, & Stein, 1997; Winch & Christoph, 1988). Ainbinder et al. (1998) and Singer et al. (1999) also studied groups of mothers in five states and found that participating in a support network like a parent-to-parent program benefited parents by improving parents' receptiveness to their respective families and obstacles, parents' abilities to seek help for their own needs, and parents' coping capabilities. The great majority of participating parents felt recognized and understood. The importance of trained parents' company was also confirmed in studies (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Winch & Christoph, 1988). Furthermore, research has shown that both the parents supported and those providing support experience mutual positive effect through exchanges and interactions (i.e., "bidirectional feedback"; Ainbinder et al., 1998; Hartman, Radin, & McConnell, 1992; Kerr & McIntosh, 2000; Klemm & Santelli, 1999; Singer et al., 2012).

In Taiwan, parent-to-parent programs have been studied by several researchers. Hsu, Chang, and Wang (2006) conducted action research to explore the feasibility of implementing "parent-to-parent" programs among families receiving early intervention services by modeling after the "pilot parents" program in the United States. Study participants included 13 seed parents, 13 parents in need of support, one supervisor, and a team of three researchers. The interviews with five paired parents revealed that the program benefited parents chiefly by facilitating the exchange of information and experience as well as emotional connections and mutual support. Despite the unanimous acknowledgement of the positive effects of the program by parents, they also voiced concerns about issues such as cultural background, resources, willingness to serve, motivation, expectation, and outcome measurement. In particular, pilot parents became involved because of the initiation of the action research and did not share a sense of belonging to particular groups. Hence, parents were less committed to sustaining their support after the conclusion of the research. In addition, Hsu, Chan, Huang, and Cheng (2012) helped parents form small groups to participate in the early intervention administered at a preschool (the "action field") in Taiwan. The groups later morphed into parent support groups and gradually became self-sufficient as the group leadership shifted from the trained social worker to the parents. Although these parent support groups remained affiliated with the preschool, they were able to operate more or less independently. Nevertheless, the full-time involvement of trained professionals remained the key.

METHODS

Research design

In praxis-oriented action research that is anchored on a reiterative process of reflections-in-action and blurs the line traditionally separating the researcher and the study subjects, the researcher can affect actions taken during the research, study participants can change due to these actions, and the researcher can also change as a result (Schön, 2005). The knowledge sought by action research is derived from the actual meeting/encounter of people, which differs from the knowledge derived on the basis of subject-object dualism (Levinas, 1969). The moment one individual communicates deep from his or her heart to the other individual, "I understand you" or "you understand me," it marks the start of a new stream of knowledge. This knowledge is experienced, contextualized in relationships and attained through direct meetings between people, unlike the objective knowledge "about" a study subject (Levinas, 1989).

As a result of my interactions with participating parents in the action research, I became cognizant of the gap between theory and practice and struggled between staying true to myself and following the professional training and role-play that I received. I began detaching myself from my professional role, adjusting my vantage point, and searching for a new knowledge paradigm—a new kind of professional knowledge based on intersubjectivity and equity that is more liberating.

I believe that the practice of "parent-to-parent support" does empower parents. Therefore, the current action research started by identifying the challenges faced by a family-centered early intervention center in T County in Taiwan and the needs of a self-help parent group. As parents tended to their own children's rehabilitation and daily activities, especially when the children were young, the early intervention center found it particularly difficult to recruit seed parents to help newly referred families. For the self-help parent group, on the contrary, willing parents were experienced but might need more training. They mostly just phoned new parents, informing them of group activities. Thus, the Parent-to-Parent Program was initiated as a viable alternative to provide the support that new families needed.

Participants

Two experienced mothers and the vice director from the self-help parent group participated in this program. From the family-centered early intervention center, the participants were three new families and one early interventionist.

Participants from the self-help parent group

Experienced mothers: H & J

Background of H: Aged 45 years, H. was a college graduate working as a researcher at a chemical plant. She had two sons who were 5 years apart. The elder son was a senior in high school and the younger son with cerebral palsy was going to attend the middle school after summer. When the younger son was 1 year and 10 months of age, he was brought to a local health clinic for vaccination. The nursing staff noticed that he seemed behind the normal development curve. He was then brought to a general hospital for evaluation and had been undergoing rehabilitation since then. H. had been a member of the self-help parent group for 5 years.

Background of J: J. was 40 years of age and a college graduate. She was a full-time mother and occasionally engaged in businesses such as Internet auction, key-making, and seal-carving. J. had a son and a daughter who were almost 3 years apart. The son was 5 years of age. The daughter was a little older than 2 years and ready to attend the preschool after summer. The son was diagnosed with hearing impairment at the age of 3 years, soon after the birth of the daughter. J. had to juggle between taking her son to hearing rehabilitation, taking care of her daughter, and sharing the responsibility of caring for her father with cancer. Her husband had difficulty in accepting his son's hearing impairment and was contemplating divorce. Suddenly, J.'s life was turned upside down. Since J. joined the self-help parent group, she regularly participated in activities hosted and accessed resources provided by the group. J. had been a member of the self-help parent group for 2 years.

Vice director

The vice director was also a member of the self-help parent group and had been in charge of the group in T County for almost 7 years. She had a daughter with an intellectual disability who graduated from the Special Education Program of a vocational high school. The daughter had a full-time job cleaning the offices of companies.

The vice director was familiar with the personality of the experienced parents at the self-help parent group and their circumstances. She was the key information provider during the selection of experienced parents as well as the key supporter when experienced parents encountered difficulties while supporting the parents referred to the parent group.

Participants from the family-centered early intervention center

Three families of youngsters with special needs

Initially, P.P.' and Q.Q.'s families from the early intervention center participated in the Parent-to-Parent Program in this study. Two months later, Y.Y.'s family joined the study as well.

Background of P.P.'s family: P.P. was a 3-year-old girl born prematurely with delayed development. P.P.'s mother, originally from China, married P.P.'s father when she was 20 years of age. She was a stay-at-home mother. P.P.'s father was a truck driver and the sole breadwinner of the family. P.P.'s mother did not drive and needed P.P.'s father to drive her if the place she needed to get to was beyond the walking distance. Hence, she seldom left the house. She was deciding on which kindergarten P.P. should attend.

Background of Q.Q.'s family: Q.Q. was a 4-year-old boy and diagnosed with spinal muscular atrophy Type II at the age of 2 years. Q.Q.'s sister was diagnosed with spinal muscular atrophy Type III at the age of 3 years, although her symptoms had not yet manifested. She just started attending a private preschool. Q.Q.'s mother was also a stay-at-home mother and Q.Q.'s father, the sole breadwinner, worked at a trading company. Q.Q.'s mother attended many workshops on raising and caring for children with severe disabilities, so Q.Q.'s grandmother would stay with the two children to provide relief for Q.Q.'s mother. However, Q.Q.'s grandmother had been a major stressor for Q.Q.'s mother because Q.Q.'s grandmother held Q.Q.'s mother responsible for the disabilities of both children.

Q.Q.'s parents were wrestling with issues of school placement and whether to acquire a wheelchair for him. They were hoping that parents with experience in managing similar types of disability could be their guide.

Background of Y.Y.'s family: Y.Y. was an 11-month-old boy who was born prematurely and weighed 480 g at birth. Y.Y. needed to wear hearing aids as he was just diagnosed with hearing impairment. He lived with his mother in the home of his father's sister. Y.Y.'s father worked in one of the outer islands and visited Y.Y. and Y.Y.'s mother in T County every 3 weeks to a month. Y.Y.'s mother had no friends in T County.

Early interventionist

The early interventionist, a female, also served as the case manager for the three families who participated in the study. She majored in social work and had worked as an early interventionist at a privately run organization that served people with disabilities. She had worked with families of children with special needs for 3 years. She understood the needs of the families served by the center and was a key information provider when matching the families and implementing the Parent-to-Parent Program.

The researcher

My roles ranged from sharing information, consulting, and interacting with the study participants to conducting research throughout the study. During the planning stage of the Parent-to-Parent Program, I provided information and recommendations based on the literature published domestically and overseas. I discussed the content of services and how to implement them with the staff from the early intervention center and the self-help parent group. Once the content of the Parent-to-Parent Program and implementation workflow were formulated, I shared the responsibility of contacting participating families with the staff from both groups. I rolled out the program with experienced mothers and met with them regularly to assess whether the plan was implemented as scheduled and, if any problems surfaced, worked with experienced parents to diagnose the problems and make modification or adjustment if needed. I also collected and organized data throughout the process, while observing and recording participants' viewpoints and attitudes, adjustments made to the implementation strategies, and participants' reflective process.

Procedures

The implementation workflow for the Parent-to-Parent Program was developed on the basis of discussions with the vice director of the self-help parent group and key elements outlined in the manual titled *Developing and Expanding a Statewide Parent-to-Parent Program* (Santelli, 2000; Figure 1). The workflow is detailed as follows.

Recruit and train seed parents from the self-help parent group

There were 17 seed parents in the self-help parent group, including both parents from

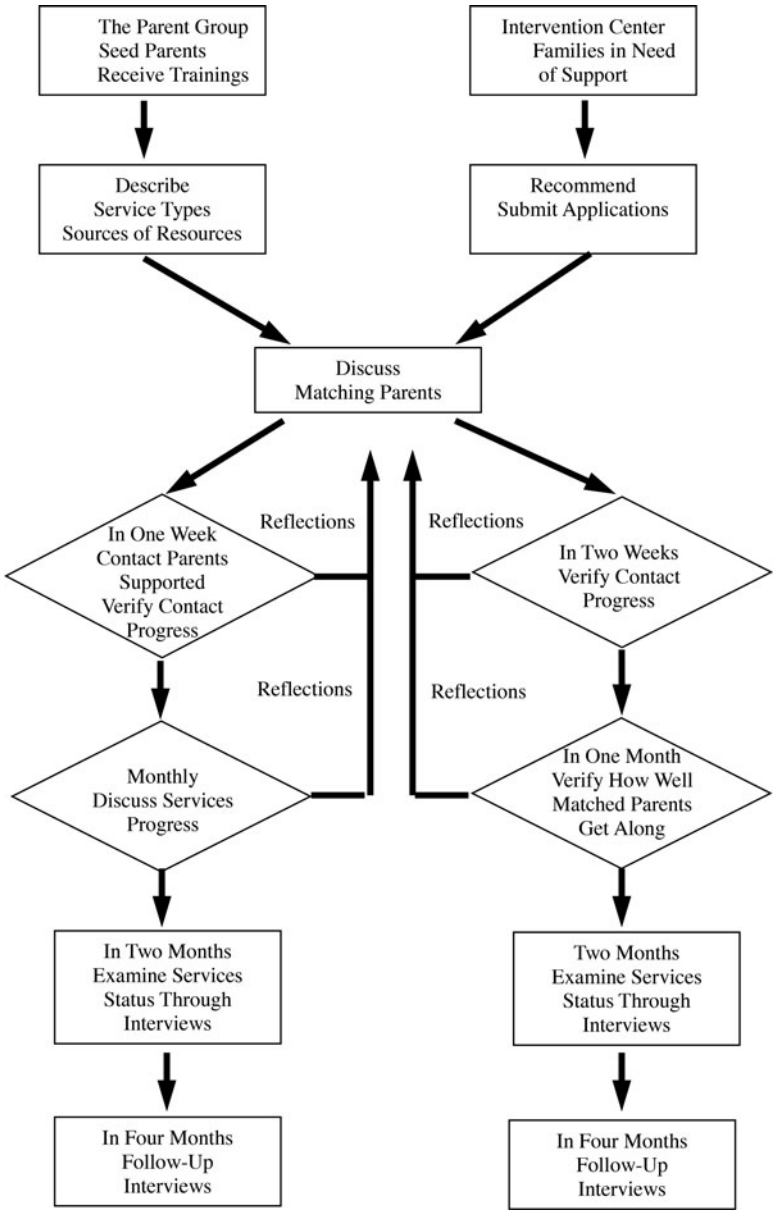

Figure 1. The workflow of the Parent-to-Parent Program.

five families and mothers from seven families (one being a single mother). Parents active in the self-help parent group for a long time and willing to serve other families were invited by the staff to become seed parents. They then received an average of two 3-hr trainings each year arranged by the parent group. The speakers at the trainings were counseling psychologists or professionals with a background related to special education.

Match seed parents with parents in need of support

During the matching process, the vice director from the parent group, the early interventionist, and I discussed which seed parents were suitable for the program and what they shared in common with the participating families from the early intervention center. The matching was conducted by considering the needs of the parents from the intervention center (e.g., what kind of seed parents they would prefer), the type and extent of the child's disability, and the location of family residence. The goal was to match parents who shared the most in common.

As a result, H. was paired with P.P.'s family (Figure 2) and Q.Q.'s family, respectively. Both P.P.'s and Q.Q.'s mothers were concerned about transitioning their child to the next learning phase, and both had been served by the center for more than a year. Two months later, J. was paired with Y.Y.'s family (Figure 3). At a talk hosted by the self-help parent group 4 months later, J. met Q.Q.'s mother and they decided to form a pair as well. Hence, both J. and H. were supporting Q.Q.'s family (Figure 4).

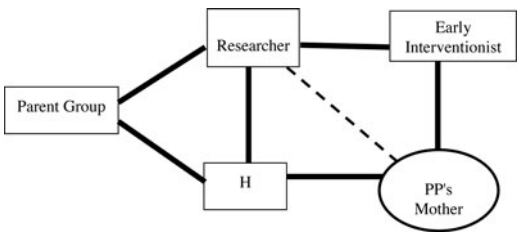

Figure 2. The support network of P.P.'s mother. Solid lines indicate direct relations and dotted lines indicate indirect relations.

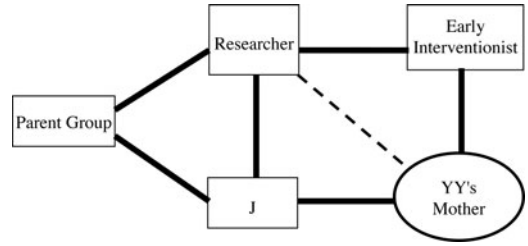

Figure 3. The support network of Y.Y.'s mother. Solid lines indicate direct relations and dotted lines indicate indirect relations.

Implement the match

Both H. and J. made the initial contact with the families they were paired with during the first week, following the workflow of the program. The subsequent support was led by the experienced mothers, while I mostly just offered opinions and suggestions.

After the initial contact, H. mostly invited P.P.'s mother and Q.Q.'s mother to activities hosted by the self-help parent group. J., on the contrary, stayed in touch with Y.Y.'s mother and Q.Q.'s mother using the social media software, LINE, and visited Y.Y.'s family three times, including one visit that she paid together with her own family. J. also provided the knowledge and information that Y.Y.'s mother might need and gave Y.Y. the extra hearing aids that she had after confirming that Y.Y. could use them. In addition, J. signed Y.Y.'s mother up for another Internet

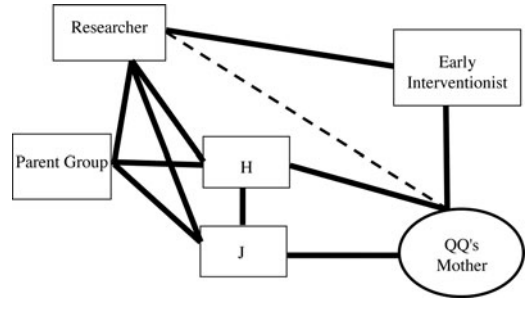

Figure 4. The support network of Q.Q.'s mother. Solid lines indicate direct relations and dotted lines indicate indirect relations.

group for parents of children with hearing impairment. As for J.'s interactions with Q.Q.'s family, despite J.'s limited knowledge about Q.Q.'s conditions, J. and Q.Q.'s mother felt as if they had known each other for a long time the moment they got acquainted. Aside from sharing through the social media information related to raising children with disabilities, J. and Q.Q.'s mother often attended workshops on spiritual development together.

Between 2 weeks and 1 month after the start of the program, I visited the three families supported, together with the early interventionist, to understand how the match had progressed and what the parents thought of the Parent-to-Parent Program.

Provide follow-up support

During the implementation of the program, I monitored through Facebook how the paired families were interacting with each other and whether parents needed any additional support. Experienced mothers and the parents whom they supported also formed a virtual community group via LINE to stay connected. Furthermore, invitations to activities hosted by the self-help parent group were extended to the families supported by the parents with whom they were paired. For example, Q.Q.'s family attended one talk on parenting, and Q.Q.'s mother and J. participated in a gathering for parents of children with autism spectrum disorder together.

Data collection

Data were collected from multiple sources to produce a holistic view of the program implementation and facilitate cross-referencing among data points. During this action research, data were collected through "interview," "participant observation," and "documentation."

Interview

At the beginning of the research, interviews were conducted with the vice director of the self-help parent group to understand the challenges faced by the group and the group's needs, member parents' willingness to participate in the program and their views about the action research, and the training courses design for seed parents. Four interviews were conducted with the vice director and each lasted from 40 min to $1\frac{1}{2}$ hr.

After the parent matching was completed, two types of interview were conducted: formal and informal. The formal, semistructured interviews were guided by an interview outline, starting by discussing with parents their firsthand experience (e.g., when they discovered the disability of their children, how they felt upon the discovery) and proceeding to the main topic of "parent-to-parent support." The formal interviews conducted with individual participants introduced the Parent-to-Parent Program to the parents supported and took place between the first and second weeks. Formal interviews with experienced mothers took place between the first and second months after the matching. The vice director of the self-help parent group was again interviewed at the parent group facility for 40 min, whereas the early interventionist was interviewed at the early intervention center for 30 min. Informal interviews were conducted in a free-form manner throughout the study, which allowed me to clarify comments voiced by study participants during the formal interview.

The goal of the interview was to capture factual information by engaging study subjects in different forms of exchange. As recommended by Merriam (1998), only one question was posed to the interviewee at a time. Efforts were also made to avoid yes–no or dominant questions and maintain an open dialogue. I only intervened to guide or steer the conversation in response to what the interviewees shared so that more questions could flow naturally.

Consent of the interviewees was obtained before the interviews were recorded electronically. Key points of the interviews as well as nonverbal cues were also recorded manually on-site. All interview recordings were later transcribed by me.

Participant observation

Two months after J. and Y.Y.'s mother were paired together, with the consent of both

of them, I, as a special education instructor, went with J.'s family to visit Y.Y.'s family and acted as "participant-as-observer" during the visit. However, the circumstances of the family visit did not lend themselves to photography or video recording for me to acquire augmentative data.

Throughout this action research, I also observed how the 2 experienced mothers interacted with other people at prayer meetings, trainings, and group activities hosted by the self-help parent group, and wrote down my on-site observations as well as personal commentary and reflections, following the recommendations of Bogdan and Biklen (2007).

Related documents

Relevant documents were also collected, which included my research notes, Facebook communications with research participants, and meeting minutes. The documents managed by the self-help parent group were also used, including intercession prayers, bimonthly periodicals, training course outlines, attendance sheets (individuals and groups), and so on. The documents managed by the early intervention center that were consulted included news clips, family service logs of the early interventionist, development assessments of children with special needs, professional teams' joint evaluation reports, and so forth. Any confidential information related to the families or the children was retrieved and viewed only at the facility of the self-help parent group or the early intervention center.

Data organization

The data collected were coded in the format of "subject/data source/date." The study subject was coded using the keyword that represented the subject's title or role: "R" for researcher, "VD" for vice director, and "EI" for early interventionist. Experienced mothers who became prominent figures during the research were coded using their pseudonyms, such as "H." and "J." As for the parents who were supported, the pseudonyms of their children were used because the children remained the focus of the study, for example, P.P.m. for P.P.'s mother, Q.Q.m. for Q.Q.'s mother, and Y.Y.m. for Y.Y.'s mother. In terms of the sources of data, they were coded as follows: "Interview" for interview data, "Meeting" for meeting records, "FB" for Facebook messages, "Note" for research notes, "Service" for service records, and so on. Dates were coded using Arabic numerals with the first two digits representing the last two digits of the year of the common era, the third and fourth digits representing the month, and the last two digits representing the day. For example, "H. Interview, 150426" referred to the interview with parent H. conducted on April 26, 2015.

Data analysis

Data were analyzed holistically. First, I "read" data, because only through "reading" the data could the event and experience together with their respective contexts be recalled. Hence, the reading of data proceeded in tandem with the collection of data, and raw data were read repeatedly. During this process, one of the first steps was to code the data according to the key topics or key words. Meanwhile, as events, processes, or experiences were recalled, special attention was paid to the characteristics, key points, and patterns of recurrent development. For example, whenever I reached P.P.'s mother by phone, she always handed the phone to P.P.'s father. What could this pattern of behavior have suggested? J. had consistently mentioned "professionalism" during parent trainings, be it related to spouses, children's learning, or seed parents. It did not become clear to me until my interview with J. that J. wished she had been equipped with more psychological training so that she could more adeptly interact with mothers with diverse backgrounds, despite their shared concern about supporting their children with disabilities. For example, mothers with depressive symptoms often phoned J. and continued their conversation late into the evening. As J. was familiar and empathetic with what these mothers were experiencing, J. could not bear to cut them

short even though these long conversations had also interfered with J.'s personal life.

Similar data were also grouped together. Both H. and J. mentioned their past and present. Hence, the category of "change" was created to capture these data. However, these categories were not fixed and could be adjusted or reconfigured as new data became available, so that complicated data could be properly captured.

Data validation

Data validation through various measures was carried out to avoid self-fulfilling prophecy so that the thoughts and behaviors of study participants could be correctly captured. To ensure "accuracy" and "credibility," efforts were made to continuously verify the research questions, collect relevant data, observe and conduct interviews on-site, and engage in regular discussions with study participants throughout the program implementation (Johnson, 2012).

Verify and augment data by participants

Electronic files of transcripts, observation records, and meeting minutes were delivered to study participants for verification to ensure that the message captured in the records accurately reflected participants' intent. Participants would then make corrections or add information where needed. Removal of any data that they would rather exclude could also be discussed.

Cross-reference multiple data points

A multitude of methods were employed to investigate each phenomenon. For example, the viewpoints of all participants—experienced mothers, parents supported, and the staff at the self-help facility and the intervention center—were cross-referenced. Data were collected through various avenues, such as interview, observation, research note, and documentation/record. Data were also collected at different time points throughout the research, including formal communications about this project at the beginning of the research, daily Facebook correspondence, interviews conducted 1 and 4 months after the start of the research, and research notes compiled on an ongoing basis.

Conduct self-reflections at multiple levels

A sound validation of action research rests on sharing personal experience in a meaningful way. Adopting the "human-as-instrument" approach (Guba & Lincoln, 1981), I engaged myself with reflexivity at two levels throughout this study:

First, the self-reflection centered around me being more cognizant of my own "spontaneous," "instinctive," or "direct" responses or reactions. For example, when the staff or families in need of support appeared less than enthusiastic about participating in the Parent-to-Parent Program, it would be more beneficial for me to examine the context and actual needs of the families first, instead of launching into a rebuttal, sounding defensive, or trying to persuade them right away.

Second, I could no longer rely on tried-and-true practices, skills, and existing knowledge to navigate through the complicated and fast-changing environment within which I was conducting this action research. I had to learn by doing, established new methodologies, and applied them to actions. This level of reflection prompted me to engage myself with continuous examination of every aspect of this action process, in particular, the multitude of my roles and my ever-evolving points of view during this research: (1) Stage I—When I first stepped into the self-help parent group, I felt like an outsider, unsure of my position relative to members of the group; (2) Stage II—Once the parent training started, I was gradually able to put myself into participants' shoes and acquire a deeper understanding of their personality and their "manner of speech." I became an "insider." I grew to empathize with the hope parents harbored and the challenges they faced; (3) Stage III—During the matching of parents, I was the key figure who bridged between the self-help parent group and the family-centered early intervention center; and

(4) Stage IV—After the rollout of the Parent-to-Parent Program, I provided knowledge, resources, and emotional support to experienced mothers as they served the parents in need of support.

RESULTS

Before implementation: Match families on the basis of multiple factors

The matching of H. and P.P.'s mother was triggered by the need of P.P.'s mother for support to transition P.P. to the next learning phase and by the fact that H. shared at a meeting her experience with school transition for her own child. The matching of H. and Q.Q.'s mother was based on the type of their child's disability as well as the preference of Q.Q.'s mother to consult with families with experience in disability rehabilitation. The matching of J. and Y.Y.'s mother was also on the basis of child's disability type, as J.'s child was hard of hearing and Y.Y. was just diagnosed of hearing impairment. However, even after multiple factors were taken into consideration when making the match, paired parents still would not know whether they were the right partner for each other until after the initial contact or even during the subsequent interactions.

During implementation

"Natural" and well-prepared initial contact facilitates subsequent relationships

H. experienced some frustration during her initial phone contact with P.P.'s mother, in contrast to the experience that she had when contacting Q.Q.'s mother via phone. H. had participated in the professional teams' joint evaluation of Q.Q. and Q.Q.'s family had also attended a talk on parenting upon H.'s invitation. In other words, there had been some interactions between H. and Q.Q.'s mother before their initial phone contact. H. believed that the unease with the initial phone contact could be alleviated if a meeting took place in a "natural" setting first, such as summer camp, day trip, or home visit with the presence of other staff members.

J. also noted that it was important to be well prepared before the first meeting. In fact, communicating via Internet before meeting face to face is a form of preparation as well. J. first helped Y.Y.'s mother join an Internet group and became friends there. Afterward, J. began sending Y.Y.'s mother messages every evening, by introducing herself first and sharing web articles, information, and relevant resources later on. J. did not mind even if Y.Y.'s mother just read the messages without responding. J. and Y.Y.'s mother gradually became comfortable with each other. J. eventually visited Y.Y.'s family, because it was inconvenient for Y.Y.'s mother to go out with Y.Y. J. visited Y.Y.'s family three times, including one visit that she paid together with her husband and two children.

Understanding real needs is the key

The needs identified by trained professionals may not necessarily be what the parents would like. Both P.P.'s and Q.Q.'s families had been served by the intervention center for more than a year. Therefore, connecting with experienced mothers by participating in the Parent-to-Parent Program just meant "an opportunity to hear other people's experiences" and the families might not necessarily need such support at that moment. On the contrary, Y.Y.'s family was just referred to the intervention center by the reporting and referral center and Y.Y.'s mother was living away from Y.Y.'s father. Thus, the family felt that seed parents' support could be "quite helpful."

These misunderstandings appear to have stemmed from the early interventionist's perception and interpretation that differed from those of the two mothers. The early interventionist recommended that P.P.'s and Q.Q.'s mothers join the Parent-to-Parent Program because she believed that the two mothers needed emotional support. Instead, the two families would prefer to focus on more immediate challenges.

Both P.P.'s mother and Q.Q.'s mother inquired about information related to "transitioning" their children to kindergarten. P.P.'s mother asked, "Which school should P.P. attend?" whereas Q.Q.'s mother asked, "I hope people could share with us their experiences with transitioning their children with physical disabilities to the next learning phase." However, what P.P.'s mother really wanted to know when asking "which school to attend" was, "We couldn't make the school we initially targeted which was spoken highly of by many people. Is the school that we are considering now good?" (P.P.'s mother, personal communication, March 19, 2015) The phrase of "physical disabilities" in the inquiry of Q.Q.'s mother also masked her real question of "what situations might QQ encounter if he rides a wheelchair on campus?" (Q.Q.'s mother, personal communication, March 26, 2015).

Understanding families' needs does not necessarily mean being able to meet those needs. Yet, simply understanding their needs would have made family members appreciate supporting families' good will and enthusiasm that can still be valuable.

"Being present" is a form of support

When J. met Q.Q.'s mother at the parent group, she decided to help, so she started researching information related to spinal muscular atrophy even before she herself figured out what the disorder was about. Maybe, Q.Q.'s mother had already known the information which J. found for her or this information might not necessarily solve the immediate problems that Q.Q. faced. Yet, J.'s "enthusiasm," "candor," and "directness" made it quite natural for the two mothers to pair themselves together. Q.Q.'s mother "was happy to know J." and felt that "it's great to have a friend like J. who I feel very comfortable to be around" (Q.Q.'s mother, personal communication, June 13, 2015). Q.Q.'s mother was more than willing to interact with J. and had joined other web communities upon J.'s recommendations.

J. always respected the families whom she interacted with even when they differed in parenting philosophies. At a group meeting, J. shared the special bond that she forged with parents with similar experiences. This bond enabled them to cherish one another because of their appreciation of one another's stories, "All I have to do is start my story, and people know exactly what I am about to say next." J. even quoted the notion of "selflessness" from the Bible to describe the attitude that supporting parents should have, that is, to "minimize the self," share experiences humbly, and, most importantly, guide the parents who they supported to see a "promising future."

Experienced parents help "translate" professionals' recommendations

Trained professionals have grown accustomed to jargon. Hence, laypeople often joke by saying, "These experts are not speaking the common language we speak!" As liaisons, experienced parents can help translate professionals' recommendations to practices that the families supported understand and go on to implement in routine activities.

For example, H. participated in the professional teams' evaluation of Q.Q. The professional team not only "breathed a sigh of relief" (researcher, personal communication, March 14, 2015) at H.'s arrival but H.'s presence and participation also offered Q.Q.'s family with valuable emotional support. More importantly, the inquiries presented by H. from the viewpoint of Q.Q.'s family prompted the professional team to adjust the number of intervention goals as well as replace the jargon of "handedness" with an expression more friendly to laypeople. H. also illustrated the professional team's explanation:

> Usually, QQ does not voluntarily use his left hand. Therefore, we need to create opportunities to encourage him to raise his left hand. For example, let's put something that QQ likes to his left and ask him to raise his left hand. First, let's have Dad try it.... What does Mom think QQ likes? (Professional evaluation team, personal communication, March 14, 2015)

In the case of Y.Y., the doctor had been suggesting removing the oxygen cylinder to let Y.Y. breathe on his own. The doctor had also recommended removing the nasogastric tube for food intake once Y.Y.'s weight was normalized. However, Y.Y.'s mother had been reluctant to do so. She was still haunted by what Y.Y. had gone through—premature birth, numerous hospitalizations, and surgeries. "What if YY couldn't breathe when the oxygen cylinder is removed?" Y.Y.'s mother asked (Y.Y.'s mother, personal communication, May 20, 2015).

J. empathized with the concerns of Y.Y.'s mother. After further discussions with the doctor, it was suggested that Y.Y. not wear the oxygen cylinder between 10 min before and 10 min after the bath, because the oxygen cylinder would not be worn during bath anyway. Depending on how Y.Y. responded, the oxygen cylinder could be put back on if he experienced difficulty breathing. However, if Y.Y. could breathe on his own when the cylinder was off, the period of not wearing the oxygen cylinder would then be gradually extended. Finally, with J.'s support, Y.Y. did not need the oxygen cylinder any more. Later, Y.Y.'s mother also tried to phase out the nasogastric tube and even tried to feed Y.Y. using syringes herself.

After implementation: Experienced parents need support, too

While J. was serving as a seed parent in the Parent-to- Parent Program and also becoming a member of the early intervention committee in T County, J.'s son was diagnosed with autism and, as J. also found out, bullied. J. was candid and direct:

> Seed parents also need support. When we and/or our children face challenges, we don't have people to turn to. Furthermore, seed parents usually work independently, without forming horizontal networks. We fail to become one another's support. (J., personal communication, April 29, 2015)

The virtual community created on Facebook by lead parents of the self-help parent group mostly just posted activities hosted by the self-help group, without truly facilitating interactions among lead parents themselves. If seed parents connect with one another and form a team, when "one seed parent's family visit falls through, another seed parent can fill in or the original seed parent can be paired with a different family" (J., personal communication, April 29, 2015).

Furthermore, although J. knew how to search for relevant information, she also believed that professional support in this regard would improve the efficiency. The professional support that J. alluded to could come from trained professionals or the acquisition of certain professional skills by the parents themselves.

Seed parents also needed emotional support, especially from their spouses. H. called her husband "a cash machine," and J. called her husband "a chauffeur." Although both H. and J. made fun of their husbands, there was no doubt in my mind that both mothers were well supported by their husbands.

DISCUSSIONS AND REFLECTIONS

Schön (2005) has argued that a person who takes actions should be a reflective practitioner. During this action research, the early interventionist, the vice director of the self-help parent group, and I embarked on the research together and we each have our reflections on the related processes and observations.

Early interventionist

The early interventionist realized that the needs identified by the trained professionals might not necessarily be the needs felt by the parents. Turnbull et al. (2010) believe that trained professionals should value family's inherent strengths and wishes, be willing to support the family, and respect the family's final say on their needs. However, in general, the bulk of decision-makings still rests with the trained professionals. The challenge may lie in professionals' lack of familiarity, experience, and training when it comes to interacting with families. The early interventionist also became

more cognizant of her judgment of family's needs predominantly from the vantage point of a trained professional. For example, in the case of P.P.'s mother who emigrated from China, the interventionist observed, "She is 20 years younger than PP's father and defers all decisions to him. She has no friends here and her social circle is limited to just the hospital and the home" (early interventionist, personal communication, June 8, 2015). In the case of Q.Q.'s mother, the interventionist observed,

> Being a young mother caring for two children with rare disabilities, QQ's mother is splitting her time between taking children to see the doctor and going to rehabilitation sessions for the children. She must have endured tremendous pressure. It should be beneficial to her to have some company. (Early interventionist, personal communication, June 8, 2015)

In fact, both P.P. and Q.Q. had been receiving services from the early intervention center for more than a year. The mothers of P.P. and Q.Q. might view the company of another parent simply as an opportunity to "learn about the experiences of other parents" who also cared for children with disabilities. Learning such experiences might not be the most pressing for the mothers of P.P. and Q.Q. at the time. For Y.Y.'s mother, however, as Y.Y. was just referred to the intervention center by the reporting and referral center and Y.Y.'s mother was living away from home at the time, she "valued deeply" the supporting parent's company.

Vice director

In parent-to-parent support, being present is a form of support. The vice director of the self-help parent group had been skeptical of the value of "being present":

> "Being present" is not easy and can take up a lot of energy. Oftentimes, professional social workers end up shouldering most of the work, while supporting parents simply making their cameo appearance or attending some activities . . . . How do we know if "being present" has really delivered value? For example, if parents get together outside of special occasions for casual chats and exchanges, does that count as "being present? "I like to think it does." (Vice director, personal communication, May 5, 2015)

"Being present" is somewhat abstract. What it entails varies with time, location, and parties involved. "Parent-to-parent support" can take place at the intensive care unit (Cescutti-Butler & Galvin, 2003; Hurst, 2006) or the rehabilitation clinic (Winch & Christoph, 1988). For the current action research, parent-to-parent support took place at locales such as people's homes, communities, schools, fast food eateries, and self-help groups. Some parents connected right away as if they had known each other for a long time and could "chat late into the evening" (J., personal communication, April 15, 2015), whereas others preferred to keep a distance "lest unnecessary pressure would be imposed on others" (H., personal communication, April 26, 2015). Therefore, there is no prescribed model for parent-to-parent support.

Although research has highlighted the ready accessibility rendered by parent-to-parent support as the most valuable and supporting parents are only one phone call away (Ainbinder et al., 1998; Kerr & McIntosh, 2000; Winch & Christoph, 1988), none of the three mothers supported in this action research proactively phoned their paired supporting mothers. It is thus critical that supporting parents proactively reach out to the parents whom they support.

Being present helps foster a relationship between supporting parents and those in need of support. This relationship is formed on the basis of similar experiences shared by parents. The vice director believes that such experience is neither good nor bad and is linked with a particular "stage" in a journey. She stresses that supporting parents shall anchor their support on respect, suggest options and choices, and leave the decision to the parent whom they support. Supporting parents shall refrain from "commanding" or cajoling others to concur by claiming that their recommendations are "for the good of the parents supported."

Researcher

Lincoln and Guba (2000) have pointed to "validity as an ethical relationship." As the action research proceeded, my relationships with the study participants have evolved through stages, so have my roles. The most instructive self-reflections I had upon the multiple roles I played throughout this action research centered around empowerment through "no actions." As elucidated by Turnbull et al. (2010), empowerment is predicated on a motivation to take actions and the possession of relevant knowledge/skills.

The two seed parents in the current study were willing to support the families in need of partners. They were fully motivated. Yet, during our discussions about what strategies to implement based on individual family's needs, seed parents suggested worthy but not necessarily optimal strategies. At that moment, I faced a dilemma. Should I interject my recommendations? Should I not interject because these parents' ideas were worth a try? Or, should I, nonetheless, present my recommendations so that a better outcome could be produced? I decided to present my recommendations, without insisting upon their adoption. So, was the power shifted from me to the parents?

In cases such as these, I find myself "not engaged in actions" in the traditional sense. However, by me "not taking actions," parents are given the opportunity to become more involved, have more choices, and feel more empowered to make decisions.

Levinas (1969) believes that truth resides in the actions and creativity from which relationships emerge rather than merely existing in written words. Meeting others is an adventure which one voluntarily engages in and to which one is open to adapting oneself. As I moved from the classroom to join the self-help parent group, I witnessed the strengths of parents—which are beyond the scope of the early intervention training that I have received—and realized that what professionals bring to the field is not only their knowledge but, more importantly, their sense of intellectual superiority. This sense of superiority blinded me from the parents' strengths and prevented me from really knowing the parents. Professionals should be cognizant of this sense of superiority and engage themselves in continuous dialogues with the professional knowledge that they possess. This reflection has firmed up my professional development goal, that is, to devote myself to uncovering knowledge about parents of special education children and to restoring the balance of power for these parents so that they can be understood and respected.

CONCLUSION

The concept of parent-to-parent program is not new. However, to implement it in Taiwan will require thoughtful "localization." As the immediate challenges faced by the early intervention center and the self-help parent group were complicated and the solutions to address these challenges needed to be contextualized, implementing a rigid protocol of parent-to-parent program would not yield the desirable results. For example, the particular seed parents recruited were in response to the particular challenges at hand. My immersion in the self-help parent group also played a key role in the implementation of the parent-to-parent program. In addition, the pairing of seed parents with parents in need of support was mediated by third-party professionals (the interventionist, the vice director, and the researcher as in the current research) based on the type of child's disability and the similarities between families, instead of participating parents forming relationships out of their own initiative. With a cultural ethos that values naturally formed connections, not all Chinese parents are open to such "artificial" partnerships and ready to follow through on their respective role-play. Hence, the early intervention center and the self-help parent group integrated their resources to host social activities so that not only could parents' social network be expanded but also more

opportunities could be provided for parents to become acquainted in natural settings and more comfortable and motivated to continue their partnerships.

Take the seed parent, H., as another example. The literature has shown that the more frequent the contact initiated by seed parents, the more satisfied the families supported (Santelli et al., 1996). However, on average, H. phoned the families whom she supported just once a month—H. did not want to "impose pressure on others." H. was also not inclined to making friends over the cloud-based network, because it was "not real." Yet, she did invite the families to attend activities hosted by the self-help parent group. She believed that attending these group activities would allow these families to meet other parents first, feel less awkward, and start receiving more support and accessing more resources. In fact, this is currently the preferred model in South Korea, especially for parents in need of support who are not comfortable with one-on-one interactions right away (Singer et al., 2012).

More people need to be involved in the program, so professionals no longer exert dominant influence and members of families' informal support network can be empowered. Patience will be needed from all collaborating parties when implementing the parent-to-parent program—waiting for the right moment, for the opportunity, and for people to be ready.

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