

The National Insurance Institute
Funds for Service Development – Demonstration Projects

“Shemesh” Complete Family Rehabilitation
For Families of Children with Special Needs

by:

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Executive Summary

Raising a child with special needs is a lifetime reality which dictates, to the child and to the family, an unfamiliar lifestyle for which they usually were not prepared. This reality requires appropriate adaptations in all spheres of life.

“Shemesh” began as the initiative of two mothers of children with special needs, Debby Alnatan and Miri Weiss. The Program was developed and funded by the National Israeli Insurance Institute, JDC-Israel “Ashalim” and the Israeli Ministry of Social Affairs and Social Services, and “Keshet” organization. The program was developed by national and local steering committees and managed by “Keshet” through employment of a national and regional coordinators. “Shemesh” was piloted in 2011 in Rosh HaAyin, Ashkelon, and Baqa Al-Gharbiya, and in November 2012 expanded by “Keshet” to Rehovot with the support of the Harry and Jeanette Weinberg Foundation from the United States. This report focuses on the evaluation of “Shemesh” in two sites, Rosh HaAyin and Ashkelon.

“Shemesh” was a program of and for parents of children with special needs, which focused on empowering the parents and the family as a unit. Its aim was to support families of children with special needs in finding a healthy and suitable balance for the child and the family. Due to recognition of the central role of the parents, “Shemesh” created opportunities for them to share their experiences, give and receive support, to be informed of useful knowledge and aware of effective coping strategies. In order to reach as many families as possible, the program helped in establishing a cohesive community of families of children with special needs with a firm sense of belonging and mutual responsibility. Parent leadership groups were trained and supported in order to identify unmet needs and stimulate social change. Improvement of working relationships between parents and professionals, and building collaborations with community organizations were attempted in order to create a social safety network for families of children with special needs.

The programs’ unique components included an accompanying course and process, special designed workshops and lectures, parents and professional dialogue workshops, support for parent leadership groups, and organization of a range of special events in collaboration with a wide range of community organizations.

Evaluative research accompanied the program a year after its initiation for almost three years, from 2012 to 2014. The evaluation included both formative and summative

evaluations focused on performance and results. A literature review was conducted with emphasizes on relevant programs that were developed and evaluated. The study population included all parents who took part in the accompany component, and gave their consent for participation, and a sample of parents who participated in other "Shemesh" activities. A variety of evaluation tools were used to gather information about the wide array of activities offered by "Shemesh", with emphasis on the participants' experiences and outcomes. The evaluators followed the program's development by participating and documenting all national and part of the local steering committees. Data was collected by personal face-to-face and telephone interviews, focus group discussions, written feedback, and research questionnaires measuring changes in attitudes as the results of participation in the program. Interviews with the program's staff and professionals in complementary services provided understanding of the unique relations with parents, as well as success in creating partnerships and mutual community-building experiences.

Evaluation Findings

In this section, we will examine the extent to which goals set for the program were achieved within the family, group, and community domains.

Family domain activities included an accompanying model through the development of a 'parent to parent' relationship between two parents raising a child with special needs. The accompanying training course developed by "Shemesh", consisted of 15 weekly three hour meetings. The expectation of offering an annual accompanying course was materialized in Ashkelon, where three courses were completed by 35 parents, but not achieved in Rosh HaAyin, where only one course was completed by 13 parents, due to insufficient candidates for accompanying. Course participants reported a high level of satisfaction and a good ability to implement the learned material. During all accompanying courses, the parents formed support groups that generated a sense of belonging, validated their unique experiences as parents of children with special needs and created friendships that continued beyond the course.

The program expected each accompanying parent to work with three parents, an expectation that was achieved in Ashkelon but not in Rosh HaAyin. A pre-request for fulfilling this expectation were a sufficient number of referrals. In Rosh HaAyin, 13 parents accompanied 21 parents (an average of 1.62 parents per parent). A total of 47% of the relationships were concluded during the first month; the rest continued for a period of up to one year. In Ashkelon, 35 parents accompanied 86 parents (an average of 2.46 parents per parent). A total of 22 % of the accompanying processes were

concluded over the course of the first month, 43% continued up to one year, and 35% continued for up to three years. Most parents accompanied one or two parents. However, an unexpected finding was having one third of the parents (32 parents) accompanied by only five parents, a ratio of five to eight accompanied parents each. This finding may be also related to the fact that in Ashkelon, in contrast to Rosh HaAyin, accompany parents were financially rewarded.

Quantitative analysis of parents' attitudes showed that parents of children with special needs agree with the positive contribution that raising a child with special needs has for them and their family. As a result of their participation in the accompanied course and process, the parents reported a significant increase in their sense of understanding their life's goal, and accompanying parents also felt a significant rise in their ability to be happy and fulfilled in their relationship with their child. Although from the beginning, the parents did not agree with making social comparisons regarding their child's situation, and their parental and family functioning, this tendency was significantly lower at the end of the accompanying process. These findings support the incorporation of "Shemesh" principles that emphasize that the uniqueness of each human being should be met with acceptance and lack of judgement.

Qualitative analysis of the accompanying process provides evidence for its unique nature. When a continuous, open, and trusting relationship was established, the accompanied parents indicated they felt contained, accepted and understood. They talked about having an opportunity for emotional expression, a sense of mutual cooperation, which enabled them to raise future concerns. They also benefited from sharing experiences with other parents and receiving useful information regarding access to relevant services. Barriers to establishing the relationship were related to differences in communication styles, contradictory agenda, and unequal expectations for commitment. Professionals familiar with the accompanied families perceived the accompanying relationship as a positive contribution emphasizing the value of an intimate relationship and the opportunity for sharing experiential knowledge.

Group domain activities included lectures and workshops on subjects relevant to parents of children with special needs and additional workshops based on "Shemesh" developed principles. In Rosh HaAyin, 140 parents participated in five workshops and four lectures; in Ashkelon 158 parents participated in eight workshops and four lectures. The frequent number of participants in each activity was 14 parents. The parents reported acquiring relevant and useful knowledge for families of children with special needs, and felt they learned useful and effective coping strategies. The workshops offered empathic and secure environments in which parents were able to share emotional concerns and gradually become attentive and aware toward their child's needs.

A close relationship was found between participation in the accompany process and attendance in "Shemesh" lectures and workshops. Most of the parents who attended lectures and workshops were also involved in an accompany process. Accompany parents formed the permanent core among workshop participants, and were also the driving force behind participation of accompanied parents in lectures and workshops. In Rosh HaAyin, half of the parents who participated in the workshops were accompanied parents and in Ashkelon they were three quarters of the total participants. It seems that the intensive participation of parents in workshops and lectures in Rosh HaAyin were a result of the vacuum created by the early termination of the accompany processes, while in Ashkelon the participation in these activities was smaller and occurred mostly due to encouragement from the accompany parent.

Supporting a partnership between professionals and parents of children with special needs was made possible due to dialogue workshops. One workshop was held in Rosh HaAyin, with 14 participants, six parents and eight professionals, and one in Ashkelon, with 15 participants, eight parents and seven professionals, most of them social workers. The workshop included three preparatory meetings, in which each group met separately, to express their feelings and attitudes about the other group, to discuss their expectations and to identify obstacles to effective communication. This was followed by four joint meetings which began with personal introductions and acquaintance, and invited sharing diverse points of view. Parents expressed their need for empathy and human relating, recognition of their expert experiential knowledge and abilities as parents, along with an expectation for professional treatment. Professionals related to the importance of mutual learning, based on parents' knowledge about their children. Professional also shared their emotional difficulties in working with a parent of a child with special needs, as a result of identification with the parents' difficulty, as well as a general sense of work-related burden.

Discussing communication obstacles allowed members of both groups to clarify the conditions needed for creating a positive working relationship based on trust, understanding, and empathy. At the end of the workshop, some parents reported improvements in relationships between themselves and the professionals. Professionals reported being surprised to hear the parents' images of them and experiences of their relationships, a realization that assisted them in modifying their attentiveness to the parent's need for being recognized, validated and included. During follow-up interviews, some parents reported a change in their behavior towards increased openness and empowerment as a result of taking mutual responsibility for the relationship. Professionals recognized parents' expectation from them to be more active in securing their rights and willing to share knowledge about their children.

Community domain activities played an important role in exposing the Program to the relevant populations, and in creating and maintaining meaningful connections among parents. In Rosh HaAyin, the Program created forums that supported the Program's development and introduced it to residents. Partnerships were formed with the Welfare Department, such as, inclusion of four mothers from "Shemesh" in a parent leadership group. This group conducted a survey that examined the unmet needs of parents of children with special needs, and suggested useful solutions. However, differences in perceptions of goals, mutual roles and developmental pace were barriers to creating a positive working relationship between "Shemesh" and the Welfare department, which eventually led to the program's premature termination.

In Ashkelon, the support and wealth of community services and activities for families of children with special needs welcomed "Shemesh". A productive partnership among the various organizations empowered the parent leadership group facilitated by the community welfare department, to create a strong community impetus. Together with other organizations, community events attended by as many as 400 parents, were offered during holidays and the observance of Persons with Disabilities Day. During the difficult time of operation "Protective Edge", "Shemesh" with the support of government and philanthropic organizations, distributed games to children in shelters and invited families to participate in respite enjoyable activities outside the combat zone. During the program, the parent leadership group was officially recognized as a non-profit association that was accessible and connected to families of children with special needs by an active internet website and a Facebook page.

Key Recommendations

The evaluation process included assessing the extent to which "Shemesh" fulfilled the goals determined by its developers in the different domains, as well as suggesting possible explanations, conclusions and recommendations. The following are the key recommendations for activities in each domain:

Family domain

- Due to the fact that most accompanying parents did not fulfill the expectation for three accompany relations, the expectation should be limited to two, and when accepting candidates to the course, the interviewer should assure they have sufficient time to fulfill the necessary commitment.
- The accompanying course proved its efficacy in preparing the parents for accompanying, as well as achieving additional personal and group goals that were significant for the participants. It is therefore recommended to prepare additional facilitators for future courses.

- In addition, in light of findings showing that the training course has an added value beyond training for accompany, there is room to propose that some of the contents of the course given to parents of children with special needs be used outside the accompany training framework.
- Success in engaging parents in being accompanied requires at times coping with concerns, fears, shame, stress, lack of knowledge, and hesitation in receiving help. Mutual work with recruiting agencies should be initiated in order to actively engage them in encouraging parents' and families' participation in events and activities in the program, including in being accompanied .
- Since a good fit between the diagnosis and age of the children with special needs was a supportive factor in establishing an accompanying relationship, it is recommended to strive for maximal match.
- The designated accompanying working model outlined goals, frequency, means of communication and duration. However, changes were made and supported in line with the parents' wishes and situation. We believe the program needs to rethink and redefine the essential characteristics of the model as well as define its flexible components.

Group domain

- In light of the active participation and positive feedback received from parents who participated in unique workshops and lectures offered to parents of children with special needs, they should continue to be offered in consultation with the parents regarding priorities of subjects and approach.
- The load of caring for a child with special needs leaves little room for leisure activities. In order to remove barriers to parents' participation in group activities, it is necessary to present an annual plan, and to offer support in supervising the children or involving them in another activity.
- Our findings show that those parents who were involved in the accompanying process or in a parent leadership group participated more in lectures and workshops. This finding is an indication that being involved in one activity is a motivator for greater social participation .
- Mutual workshops for professionals and parents create opportunities for sincere, respectful, personal meetings and conversations, which should be encouraged. Due to instability in attendance, a workshop should include 20 members, with a similar number of parents and professionals. Involvement of professionals from diverse field of practice and services is recommended.

- The group facilitator needs to have skills and knowledge regarding the tensed emotions and attitudes involved in these workshops. Facilitation by a professional with group work experience who is also a parent of a child with special needs can be an advantage.
- The satisfaction and small changes noted by parents and professional as a result of attending the dialogue workshop emphasize its potential. However, a longer period of work is needed in order to achieve changes necessary to develop a collaborative working relationship between parents and professionals

Community domain

- When introducing "Shemesh" program in a new location, it is important to map the community infrastructure related to families of children with special needs, as a foundation for collaboration and pooling of resources.
- Before the program starts operating, there is a need for a thorough process of acquaintance with the potential partners, in order to familiarize them with "Shemesh's" world view and its approach, as well as clarification and coordinating of mutual expectations.
- In order to sustain community activities, it is important to establish, encourage, train, and guide a parent leadership group that can promote its interests in the local and national arenas. Doing this requires employing a professional facilitator.
- The steering committees, which are a vital mechanism for the development and adaptation of the program to local needs, should meet continuously according to the programs' developmental pace and requirements.
- The local steering committees should insist on just representation of service users and service providers.

Assimilation of "Shemesh" should be viewed as part of the network of services provided for families raising a child with special needs. "Shemesh's" success depends on recognizing its true nature as a program led by and for parents of children with special needs, based on recognition of parental experiential knowledge and expertise, whose goal is to support parents in fulfilling their central role as parents. Parents and professionals, working side by side to link responses to unmet needs, is "Shemesh's" vision. Assimilation of the program is contingent on the following conditions:

- Due to the strong connection between family, group and community activities, it is essential to assimilate "Shemesh" as a "whole package".

- "Shemesh" needs to be recognized as a complementary and connecting resource to other responses and formal services that exist for families of children with special needs in the community or locale.
- While assimilating the program, it is vital to allocate resources for an integrating source that will regulate the tasks, examine the work force and available resources, in the role of a coordinator for the "Shemesh" program.
- A connection between parent leadership groups in different settlements should be encouraged in order to pool together resources for promoting policy changes within the central government.
- The mutual inspiration and improvement created by comparing similar and different experiences learned during the pilot stage in all locations (Rosh HaAyin, Ashkelon, Baqa Al-Gharbiya and Rehovot) should continue.

The success of "Shemesh" program is a result of initiatives and actions by parents of children with special needs and national and local coordinators, along with all those who worked tediously for developing the program through professional guidance and allocation of resources. Continued development of the program requires extending the program in order to continue to draw conclusions from the current evaluation and assimilate them as part of the network of municipal services provided for families of children with special needs.