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Evaluation of Early Intervention Program Provided By the Right to Live Society for Children with Down Syndrome In Gaza Strip: Family Perspective

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"A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master in Community Mental Health: Rehabilitation Sciences"

2008 – 1429

بسم الله الرحمن الرحيم

﴿يَرْفَعِ اللَّهُ الَّذِينَ آمَنُوا مِنكُمْ وَالَّذِينَ أُوتُوا الْعِلْمَ دَرَجَاتٍ﴾

المجادلة - 11

"Allah will exalt in degree those of you who believe, and those who have been granted knowledge" Al-Mojadelah - 11

ABSTRACT

Researcher: Lubna Abd. Shallah

Supervisor: Dr. Sanaa Abou-Dagga & Dr. Yousef Aljeesh

Evaluation of Early Intervention Program Services provided to Down's Syndrome Children in the Right To Live Society – Gaza Strip: Family perspective

This study, to the knowledge of the researcher, is considered the first evaluation study about the field of children with Down's Syndrome (DS) in Gaza Strip, which aims to perceive families' perspectives about services in Right To Live Society **(**RTLS).

The general objective of this study is to evaluate the services provided in EIP in RTLS from families' viewpoint for their Down's Syndrome children.

The problem of the study has identified the following research questions:

☒ **Research questions:**

1. To what extent EIP services are effective from family perspective?
2. To what extent families are satisfied with EIP services in the RTLS?
3. To what extent does a family participate in implementing the rehabilitation plan for the D.S child?
4. Is there any relationship between family satisfaction with their level of participation in implementing rehabilitation plan?
5. Is there a relationship between family satisfaction with detected socio-demographic variables?
6. What is the family perspective regarding the performance of service provider in EIP in RTLS?

☒ **Method:**

- **Participants:**

  The sample was estimated 73 mothers of D.S children from total population, 55 from EIP whose children have continuous care in EIP, 18 from kindergarten whose care was ended from EIP, aged between 6 months to 72 months.

- **Baseline measures:**

  In this study, the researcher developed a structured questionnaire according to the review of previous literature which consists of 5 domains of general satisfaction, evaluation service provider, effectiveness of capabilities development, effectiveness of physiotherapy services and accessibility of services using Likert scale of 5 points (1= strongly disagree, 2= disagree, 3= uncertain, 4= agree, 5= extremely agree), in addition to open-ended questions and general information questions.

- **Statistical analysis:**

  Cross tabulation, descriptive statistics, person correlation and non parametric test "Chi-square".

☒ **Results:**

1) Family's perspective with regard to the effectiveness of EIP services was positive. This is shown to all available services.
2) The family satisfaction with regard to the services in EIP in RTLS was high (88.8%), in spite of the critical political situation we live in and the limited sources and services we have for disabled children.
3) The level of family's participation in rehabilitation plan was 85% extremely participated, 15% was participated little.
4) Results showed that there is no statistical significance relationship between family's satisfaction with the level of family participation in implementing a rehabilitation plan.
5) Results showed that there are no statistical significant relationships between family's satisfaction with selected socio-demographic variables.
6) Family's perspective about the service provider in RTLS was a positive. This result is associated with our Palestinian values and cultural traditions which are Islamic in nature.

☒ **Recommendations:**

1. Policy makers and managers of RTLS should be informed with the results of this study to take necessary steps to improve the rehabilitation services for D.S client.

2. The staff of EIP should be encouraged to increase their knowledge and skills regularly through continuous education.
3. Establish an internal system in the RTLS to evaluate regularly the services provided to clients for all the different programs.

الملخص

اسم الباحثة: لبنى عبد الله شلّح

اسم المشرف: د. سناء أبو دقة ود. يوسف الجيش

تقييم خدمات برنامج التدخل المبكر للأطفال ذوي متلازمة داون في
جمعية الحق في الحياة بغزة – وجهة نظر الأهل

تعتبر هذه الرسالة التقييمية هي الأولى في حقل الأطفال ذوي متلازمة داون في قطاع غزة التي تعنى بآراء أهالي الأطفال المنتفعين من خدمات برنامج التدخل المبكر في جمعية الحق في الحياة.

وقد كان الهدف الأساسي لهذه الدراسة هو تقييم خدمات برنامج التدخل المبكر المقدم لأطفال ذوي متلازمة داون في جمعية الحق في الحياة من وجهة نظر الأهل.

أما مشكلة الدراسة فتحددت في الأسئلة التالية:

☒ **أسئلة الدراسة:**

1) ما مستوى الاستفادة من خدمات التدخل المبكر من وجهة نظر الأهل في جمعية الحق في الحياة؟
2) ما مستوى رضى الأهل عن الخدمات المقدمة في برنامج التدخل المبكر بجمعية الحق في الحياة لأطفال ذوي متلازمة داون؟
3) ما مستوى مشاركة الأهل في تنفيذ الخطة التأهيلية لأطفال ذوي متلازمة داون في برنامج التدخل المبكر في جمعية الحق في الحياة بغزة؟
4) هل يوجد فروق جوهرية ذات دلالة إحصائية بين مستوى رضى الأهل عن خدمات التدخل المبكر ومستوى مشاركة الأهل في تنفيذ الخطة التأهيلية ببرنامج التدخل المبكر؟
5) هل يوجد فروق جوهرية ذات دلالة إحصائية بين مستوى رضى الأهل عن خدمات التدخل المبكر والعوامل الاجتماعية مثل (المستوى التعليمي – الوظيفة – عدد أفراد الأسرة)، والعوامل الديمغرافية مثل (الجنس – العمر – مكان الإقامة)؟
6) ما هي وجهة نظر الأهل بأداء مقدمي الخدمات في برنامج التدخل المبكر؟

☒ الإجراءات:

عينة الدراسة: تكونت من 73 أم لطفل ذوي متلازمة داون في برنامج التدخل المبكر تم اختيارهم بشكل مناسب. (55) من الذين لازالوا يتلقون خدمات التدخل المبكر، و(18) من الذين أنهوا خدمات التدخل المبكر والتحقوا ببرنامج الروضة في جمعية الحق في الحياة، وتراوحت أعمار الأطفال بين 6 شهور ــ 72 شهرا، أما أعمار الأمهات 20 ــ 47 سنة، وكانت أقل مدة تلقي للخدمة 6 شهور فأكثر أثناء تطبيق الدراسة.

☒ الأداة المستخدمة:

قامت الباحثة بإعداد استبانة تقييم خدمات التدخل المبكر معتمدة على الدراسات السابقة من وجهة نظر الأهل وتكونت من 5 محاور أساسية للتقييم واعتمدت مقياس ليكرت الخماسي (غير موافق بشدة ــ غير موافق ــ لا أدري ــ موافق ــ موافق بشدة)، وتكونت فقرات الاستبانة من 52 بندا، مع مجموعة من الأسئلة المفتوحة والأسئلة الوصفية.

☒ التحليل الإحصائي:

تم استخدام جداول التوافق، معامل ارتباط بيرسون، الإحصاءات الوصفية بالإضافة إلى (Chi-square).

☒ النتائج:

1. مدى الاستفادة من خدمات برنامج التدخل المبكر كانت عالية.
2. مستوى رضا الأهل عن خدمات التدخل المبكر كان عاليا بنسبة 88.8%.
3. مستوى مشاركة الأهل في تنفيذ الخطة التأهيلية كان بدرجة عالية بنسبة 85%.
4. لا توجد فروق ذات دلالة إحصائية بين مستوى رضا الأهل عن خدمات برنامج التدخل المبكر ومستوى مشاركة الأهل في تنفيذ الخطة التأهيلية.
5. لا توجد فروق ذات دلالة إحصائية بين مستوى رضا الأهل عن خدمات برنامج التدخل المبكر والعوامل الديمغرافية (الجنس ــ العمر ــ مكان الإقامة)، وكذلك العوامل الاجتماعية (المستوى التعليمي ــ الوظيفة ــ عدد أفراد الأسرة).

6. رأي الأهل في العاملين ببرنامج التدخل المبكر كان إيجابيا بالإجماع.

☒ **التوصيات:**

1) إطلاع المسئولين في جمعية الحق بالحياة عن نتائج هذه الدراسة للتغلب على أي عيوب في خدمات برامجهم.
2) تشجيع العاملين في برنامج التدخل المبكر على استكمال دراستهم لتنمية خبراتهم ومهاراتهم.
3) تشجيع المسئولين في الجمعية بإنشاء قاعدة بحثية تعتني برأي الأهل في خدمات الجمعية لتقييم عملية سير الخدمة في جمعيتهم.

DEDICATION

I dedicate this thesis to the souls of my mother and my father

To my husband

To my daughters

To my brothers and sisters

To my sweat friends and colleagues

To my best friends:

Dr. Khitam & Jehan

ACKNOWLEDGMENT

I would like to express my great thanks to all the people who contributed to the success of this work, those who are responsible for making me optimistic and think of nothing as impossible.

My great appreciation is to Dr Sanaa Abu Dagga and Dr. Yousef Aljeesh, my academic supervisors for their continuous advice, help, and friendly support.

My thanks are to the manager of the RTLS and staff of EIP for their support and encouragement during the application of the instrument in their society.

My sincere thanks are for all doctors who validated the instrument of my study.

Special thanks to my family, husband and daughters for their help and support.

I would like to offer my deepest thanks and respect to all Down Syndrome children and their families who participated in this study.

Last but not least, I would like to thank all my friends, especially my dearest friend Khitam and Jehan, and my colleagues during the study period.

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LIST OF ABBREVIATIONS:

BEEP	Brookline Early Education Project
CA	Chronological age
CG	Control groups
CHD	Congenital heart disease
CHDs	Congenital heart diseases
CSHCN	Children with special health care needs
CVA	Cerebro-vascular accident
CVS	Chroioic villous sampling
D.S	Down's Syndrome
DM	Diabetes mellitus
EI	Early intervention
EIP	Early intervention program
FCS	Family centered service
FSH	Follicle Stimulating Hormones
HTN	Hypertension
ID	Intellectual disability
IDEA	Individuals With Disabilities Education Act
IFSPs	Individualized family service plans
IP	Intervention program
ITG	Intensive training group
IVF	Invitro fertilization
MA	Mental age
MaxLU	Maximum length of utterance
MOH	Ministry of Health
NCDs	Non-communicable diseases
OADS	Oral Assessment Down Syndrome
OPVD	Obstructive pulmonary vascular disease
PPVT	Peabody Picture Vocabulary Test
PT	Physiotherapy
PUBS	Precutaneus umbilical blood sampling
QOL	The quality of life
QRS	Questionnaire on Resources and Stress
RTLS	Right to Live Society
SECDI-w&s	Swedish Early Communicative Development Inventory-words and sentences

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CHAPTER 1

Chapter 1

Introduction

Justifaction, research questions, and objectives

1.1. Introduction:

Evaluation is the systematic assessment of the worth or merit of some objects as it determines the effectiveness of program in light of the attainment of preset priorities and goals. Also, it helps document to confirm if the program accomplished its goals or not. Furthermore, it identifies program weakness and strengths, and the areas of the program that need revision (Joint Committee for evaluation, 1994). Evaluation has become increasingly a useful force in improving societies including the quality of life who live in it (Worthen et al, 1997).

Quality of life has been used as a scientific concept, but conceptualizations vary with much common domain content embraced by the term. The fact that what is important and needed varies to each person. The life domain may be categorized with six areas: physical, material, social, productive, emotional and civic well being. (Felce, 1997).

At the same time quality of life becomes the most important issue for all professional, health administrators, business or others. The child disability services are under pressure to evaluate what they provide, which encompasses both the procedures and the outcomes for the client, children and families. (McCondachie, 1999)

The quality of life (QOL) concept is now challenging some of the more traditional views and approaching to Intellectual Disability (ID), and these challenges resulting in modifications and adaptations in current services and supports along with the need to evaluate the outcomes from the application of QOL principles to a person with ID. While the family quality of life is a relatively new field of study and research, it has primarily concentrated on families of children and young adults with ID, moreover to achieve the concept of quality of life. We should emphasize on the current family and services issues that need to be addressed with relation to funding finances, staffing and the need to adapt to age related needs. (Jokinen & Brown, 2005).

(King et al, 2006) reported that raising a child with a disability can be a life changing experience that spurs families to examine their belief systems. Parents can come to gain a sense of coherence and control through changes in their world views, values and priorities that involve different ways of thinking about their child, their parenting role, and the role of the family. Although parents may grapple with lost dreams, over time positive adaptations that can occur in the form of changed world views concerning life and disability, and an appreciation of the positive contributions made by children to family members and society as a whole. Parent's experiences indicate the importance of hope and of seeing possibilities that lie ahead; this information used to provide families with an advance understanding of the changes in beliefs that might undergo and assist service providers in providing individualized and family centered services, and support the families.

In the past, quality of health care was measured principally with reference to provider established norms. More recently, increased attention has been paid to patient's views on care delivery and outcomes. However, in rehabilitation medicine, this trend has not been established provider assessed outcomes during short stays in specific settings, which are the focus of care. (Adnrew, 1997).

In the past decades, there was growing recognition of the need to involve clients in decision about the health care they receive. And in the evaluation of services offered in health services research, survey and scaling method have became important tools for research into consumer views and the perspective of people receiving health care. (Glogowska et al, 2001).

Down's syndrome (D.S.) considers the most common chromosomal abnormality of a generalized syndrome. The cause of D.S. exactly is not known. Approximately 95% of all cases of D.S are attributable to an extra chromosome 21 (trisomy 21) and the result in cell development is 47 instead of the usual 46 chromosome. This extra chromosome changes the orderly development of the body and the brain. The most risk factor for D.S is the aging of mother, especially 35 years old and more, and there is some valuable increasing in the incidence of D.S with increasing in the age of the mother. The diagnosis of D.S basically depends on the clinical manifestation and the result of chromosome test that administered shortly after birth. (Wong, 1993).

National Down's Syndrome Society reported that D.S is a common genetic variation which usually delays in physical, intellectual and language development, and it is not related to race, nationality, religion or socioeconomic status with over 50 sign and symptoms for D.S, but it is rare to find all in one person at the same time. On the other hand, even there is an advancement of the life expectancy for D.S, but it is still low for general population.

Some evidence suggested that genetic and congenital disorders are more common in Arab countries than in industrialized countries. For example, the rate of children with Down's Syndrome in some Arabic countries exceeds the 1.2 – 1.7 per 1000, and this is relatively may be related to aging of mother, up to 50% of children with D.S in Arab region which are estimated to be born to mothers aged to 35 years old or over (Al-Gazali et al, 2006).

After reviewing the records of MOH in Gaza Strip, there is not any statistical data about the incidence rate of DS in Palestine at the same time only RTLS(right to live society) which is the only non governmental institution providing rehabilitation care for DS, has estimated the number of DS 2740 –3000, incidence rate for DS was 1 in every 500 live birth each year (RTLS record, 2007).

Comparing the incidence of D.S in Arab countries; for example, Dubai, United Arab Emirates, one study surveys a total number of 63,398 newborn babies in Dubai during 5 years period of 1999-2003. Results showed that a total of 141 cases were confirmed cytogenetically as Down syndrome, and of this total case, 139 were trisomy 21 and of the remaining 2, one was a translocation and the other a mosaic. The overall incidence of Down syndrome in Dubai was 1/449 live births (2.2 per 1000), 1/319 live births (3.13 per 1000) among UAE and 1/602 live births (1.66 per 1000) among non-UAE national (Murthy et al, 2007).

Statistical information data illustrated that the incidence rate for Down's Syndrome in Saudi Arabia is estimated to be 1 per 554 live births, the estimated total number of D.S is 15,000; average rate to be 2-3 D.S baby each day (Kuwait networks clubs, Down's Syndrome 2007).

Internationally, it is recorded that in the United States, the estimated incidence rate for Down's syndrome is to be 1 in every 800-1000 live birth, of all children born in this country. Approximately there are 1/4 million families in the United States affected by Down's syndrome (National Down's Syndrome Society, 2007).

In this study, the researcher evaluated the services provided by early intervention program (EIP) through RTLS from families perspective, mainly mothers, This society is the one and only institution in Gaza Strip to provide services for D.S clients, in this society there are many service programs, the first one is the early intervention program which provides comprehensive rehabilitation services ranged from physiotherapy services to capabilities improvement, language and hearing skills and others.

Early intervention programs have grown rapidly over the last 30 years. Despite the numerous answers to the question of whether or not early intervention works, results to date have been equivocal. This answer suggests that this question must be addressed to evaluation of specific services rather than to the evaluation of early intervention as a whole to get global sense in answering this question (Caroline et al, 1992).

Locally, in our country, with relevance to Down's Syndrome children receiving rehabilitation services, through RTLS in Gaza Strip, no research studies have been found in relation to evaluating any type of services provided, so this research study is considered the first in this field that highlights the positive and negative issues in this program to decision makers in this non-governmental institution.

1.2. Justification of the study:

In Gaza Strip, RTLS is the only professional society that is providing rehabilitation services for Down's syndrome clients. At the time there is an increase in the number of DS clients recorded in RTLS. During the period from 2001 – 2006 the total number estimated was 650 DS.

Furthermore, no local studies have been conducted to evaluate and document the services provided in this society for this target group of disabled in our country, so comes this study to be the first one in Gaza Strip which is concerned with families' perspectives to improve the quality of RTLS services for DS.

Beside that, this study chose the first program provided to D.S clients in the RTLS, which aimed to beneficiate child form birth up to 4 years old, which is considered the important one, and any improvement in child development depends on the success of EIP services, that is one of the most important rationalizations of this study.

1.3. Significance of the study:

- **Theoretical significance:**

This study will guide other researchers to conduct further studies related to evaluation of services provided by EIP, rather via RTLS or other societies dealing with DS by using the instrument which the researcher constructed to measure the family perspective for such services.

- **Practical significance:**

By analyzing the study results, the researcher will provide suggestions and recommendations to improve the quality of services in EIP in RTLS for DS with concerns to family perspective.

Furthermore, the researcher will identify the most aspects that effect the family's satisfaction in order to overcome any problem issue related to this field in future.

1.4. General objective:

The overall aim of this study is to evaluate early intervention program services in the RTLS for Down's syndrome children in Gaza Strip from the family's view.

1.5. Specific objectives:

1. To assess the effectiveness level of EIP services for Down's syndrome child from the family' perspective.
2. To assess the satisfaction level of family from EIP services provided to Down's syndrome children.
3. To assess the level of the family' participation in implementing rehabilitation plan for Down's syndrome children through early intervention program.
4. To examine the relationship between family' satisfaction with their participation in rehabilitation plan.
5. To examine the relationship between family' satisfaction with detected socio-demographic characteristics.
6. To evaluate performance of service provider from family' viewpoint in EIP.

1.6. Research questions:

1.6.1. To what extent EIP services are effective from family perspective?

1.6.2. To what extent families are satisfied with EIP services in the RTLS?

1.6.3. To what extent does a family participate in implementing the rehabilitation plan for the D.S child?

1.6.4. Is there any relationship between family satisfaction with their level of participation in implementing rehabilitation plan?

1.6.5. Is there a relationship between family satisfaction with detected socio-demographic variables?

1.6.6. What is the family perspective regarding the performance of service provider in EIP in RTLS?

1.7. Operational definitions of terms:

1.7.1.Evaluation:

The researcher defined it as the process of collecting data about a specific objective to verify the achievement of the intended goals.

1.7.2.Early intervention program services (EIP):

Described rehabilitation services started from recording in this program that included physiotherapy services, capabilities development services, medical services, psychological services, social services, and hearing auditory services from 1 month up to 4 years old children.

1.7.3.Evaluation of EIP:

It is defined as the process of collecting data about the services in EIP from D.S children families using a specific research instrument developed by the researcher. It included the following domains: general satisfaction domain, performance of service provider domain, effectiveness of services domain, accessibility of services domain and some kinds of open-ended questions.

1.7.4.Right To Live Society (RTLS):

Is the non-governmental society that provides rehabilitation services for Down's Syndrome clients in Gaza Strip, which is the only society in Gaza Strip to include many programs; each one deals with specific target group of Down's Syndrome.

1.7.5.Down syndrome child:

A child that is medically diagnosed as Down's Syndrome child and admitted to the RTLS to receive early intervention services.

1.7.6.Satisfaction level:

In this study the researcher defined satisfaction according to family view about services as a whole, improvement in a child with Down's Syndrome development, accessibility of services, duration period of services, time sessions to this program, and finally toward the communication with staff in this program.

1.7.7.Family centered services:

Services that are concerned with family as well as child, other side, to which degree the family has a role in implementing the rehabilitation plan in order to become as normal as possible.

1.8. Context of the study:

1.8.1.Health context in Palestine:

- **Health situation in Palestine:**

The MOH is the main health care provider in Palestine with the other health care provider, the United Nations Relief and Works Agency (UNRWA), Medical Services for Police and General Security (MSP), health services of national and international Non Governmental Organizations (NGOs), and private health sectors for profit. The MOH is the health authority responsible for supervision, regulation, licensure and control of the whole health services. (MOH, 2004)

The health services until now are unable to meet the challenges of non-communicable diseases (NCDs) without complete knowledge about prevalence, incidence and severity of these diseases. No national data are available toward the incidence of cerebro-vascular accident (CVA), hypertension (HTN), diabetes mellitus (DM), and accidents. Beside that there is no information on disabilities that result from any chronic disease. This limitation in health situation leads to inability to estimate the cost and resources required. (MOH, 2004)

- **Primary health care services in Palestine:**

The MOH is working with the other health sectors in providing the primary health services mainly with UNRWA and NGOs sectors. At the end of

2005, there were 645 (PHC) centers in Palestine. These centers care for about 3.7 millions people, (129 centers in Gaza and 525 centers in the West Bank).

Classification of PHC according to providers show that MOH is considered the main provider with 63.6% from total PHC centers, followed by NGOs with 28.3% then UNRWA with 8.1%. (MOH, 2005)

- **MOH hospitals and categories:**

  There are 17 general hospitals with 2,163 bed (1,999 in Gaza, and 964 in WB), two psychiatrics hospitals with 319 beds (280 in WB and 39 in GS), one ophthalmic hospital in Gaza Strip with 31 beds and two major pediatric hospitals in Gaza Strip with 222 beds. (MOH, 2004)

- **Non MOH Hospitals:**

  The NGOs hospitals increased in number and beds from 24 hospitals to 31 NGOs hospitals in 2004. In Gaza Strip NGOs hospitals are 10 with total capacity of 459 beds. In West Bank the NGOs own and operate 21 hospitals with total capacity of 1,106 beds. (MOH, 2004)

- Non-governmental Organizations **(NGOs) rehabilitation hospitals:**

  Non-governmental Organizations Provided services for 2,132 inpatients during 49,800 hospitalization days. The average bed occupancy rate at four rehabilitation hospitals in Palestine was 86.9%; this is due to increase incidence of disabilities as a result of Al-Aqsa Indtifadah.

- **Child health in Palestine:**

There are 260 health clinics in MOH providing health services for children included preventative and curative services.

Immunization against infectious disease according to child immunization schedule given free to all Palestinian infants and children, also treatment is free without insurance coverage for children until the age 3 years. Only 146 cases of disabilities among children aged 1-3 years in West Bank were reported, these disabilities were form of movement, hearing and eye sight. Only 753 case of congenital disease among children aged 1-3 years were reported in Palestine.

In 2004, in Gaza Strip it was reported that Infant Mortality Rate (IMR) was 20.5 per 1,000 live birth, and the first leading cause of death for children under 5 years are the conditions of prenatal period with proportion of 39.8%, while the first leading cause of death for children aged 1-4 years, 5-19, and 20-

25 years were accidents with percentage of 22.9%, 56.1% and 29.3% form total death. Whereas, it is recorded that Infant Mortality Rate (IMR) declined over the past two decades from 150/10,000 prior to 1967 to about 22.8/1,000 live birth since 1996. (MOH, 2004)

- **Al-Aqsa Intifadah:**

No one can deny or forget the Israeli occupation crisis and crimes during September and December 2004. Number of Martyrs were 3,665 (1727 in Gaza) and (1938 in West Bank), while the total number of casualties were 42,650 (14,251 form Gaza) and (28,399 form WB).

The Israeli occupation forced even though ambulance vehicles, medical staff and facilities.

The Palestinian Ministry of Health reported that 36 death among health staff and 443 injuries in the period of September 2001 to December 2004. Moreover, 371 ambulances were attacked, 38 completely destroyed, 351 health facilities were attacked in the same period (MOH, 2005).

1.8.2.Geographical context:

Palestine constitutes the southwestern part of a huge geographical unity in the eastern part of the Arab world, which is Belad El-Sham. The entire area of Palestine is about 27,000 sq. Km.

Palestine comprises two areas separated geographically: the West Bank and Gaza Strip. The total area is 6,020 sq. Km with total population living in is 3,762,005 individuals in 2005 with capita per sq. Km 625.

43.8% of the population in West Bank and Gaza Strip is refugees according to the UNRWA statistic 2005.

Gaza Strip: is very crowded place with area 365 sq. Km and constitute 6.1% of total areas of Palestine territory land. Total population in Gaza Strip in 2005 was 1,389,789 mainly concentrated in the cities.

West Bank: is located west of the river Jordan with total area 5,655 sq. Km. it is divided into four geographical regions. The total number of population in it is 2,372,216 individuals in mid year of 2005. (MOH, 2005)

- **Parent's level of education: (Gaza Strip)**
  - ☒ About 4.9% of fathers and 3.4% of mothers reached to the level of primary school.
  - ☒ 9.3% of fathers and 10.3% of mothers reached to the level of preparatory school.
  - ☒ 64.6% of fathers and 74% of mothers reached to the level of secondary school.
  - ☒ Only 21% of fathers and 11.5% of mothers completed the first university degree.
  - ☒ Whereas, illiterate percent among fathers in 0.01% and 0.03% among mothers.

- **Parent's job: (Gaza Strip)**
  - ☒ Fathers who are workers constituted 40.9%, employees 31.2%, jobless 5.3% and 3.5% tailors.
  - ☒ On the other hand, most of mothers are housewife 95.6%, only 2% of mothers are employees and 1.2% teachers.

- **Palestinian economy:**

During the last five years, high fluctuations in Gross National production observed. It was 5,454 millions US$ in 1999 decreased to 4,169 millions US$ in 2005.

On the other hand, the number of workers in Israel decreased from 135,000 in 1999 to 36,000 in 2005. And the total unemployment rate was 32%, poverty rate was 32% in 2005. This is as result of Israeli enforced restriction on Palestinian movement, military operations, land confiscation and leveling and the construction of Barrier. In addition to other escalating activities imposed on Palestinian people. (MOH, 2005)

1.9. Research setting:

This study was conducted in the RTLS which is a non-governmental charity organization, was established in 1992 to be first and only one looking after Down's syndrome citizens of the Gaza Strip. This society was established by Mrs. Adala Abu Middain who had an experience of being a mother of child with Down's syndrome who passed away at early age of one. Since that RTLS began as kindergarten for 7 children with Down's syndrome providing special care by 3 volunteer teachers in 1993 in a rented tiny villa in Gaza, El-Remal.

After that services developed to cover 180 individuals with Down's syndrome aging from birth to 15 years old receiving comprehensive rehabilitation program by 23 professionals. In 1998 this society was constructed permanently over 9000 sq. meter in the east of Gaza, Al-Shjaeia.

By February 1st 2000, RTLS begin serving 650 individuals with Down's syndrome by 140 staff and volunteers.

The overall aim of this society is rehabilitation of individuals with Down's syndrome, to deal with this group as any other to ensure their integration into Palestinian society by giving suitable chances to become more independent in daily living

1.9.1.The programs of RTLS:

This society implements its services through the following programs:

1. Early intervention program for Down's syndrome.
2. Kindergarten program for Down's and normal child.
3. The special education school for Down's syndrome.
4. Prevocational program for Down's syndrome.
5. Vocational program for Down's syndrome.

(Right To Live Society Leaflet, 2007).

1. Early Intervention Program:

The RTLS aims at providing its comprehensive rehabilitation program for Down's syndrome children from birth up to 4 years old. The main task of this program is to educate mothers how to deal with and raise their children appropriately and work closely with the specialists in the society. This achieved by main activities included (physiotherapy, capability development, speech therapy and audiology, psychotherapy, social study and counseling). They all work as a team to serve Down's syndrome children.

2. Kindergarten program:

Children with D.S who graduate from the early intervention program aged from 4-6 years are enrolled within this program where they receive specialized services. In addition, numbers of same age normal children from local community are integrated in this program as a first step of RTLS philosophy and policy toward mainstreaming and integration.

3. School for special education:

This program provides educational services for 190 children through different program. Informal education is applied to expand and develop the educational and living skills by the use of different communication means. The program provides these services through suitable curriculum prepared upon the society's experience in this field and technical assistance from outside the society. The children have transportation to and from the center and daily healthy meal. Periodic medical care is provided for them according to their susceptibility. Health insurance is provided to all beneficiaries

4. Prevocational and vocational program:

This program aimed to create job opportunities for Down's syndrome people in Gaza Strip. The vocational training program provides practical skills for 60 children in cane work, carpentry, rug making, embroidery, knitting and other handicrafts. This program also includes other skill training such as reading, writing and simple math.

1.9.2.RTLS services and activities:

☒ **Social work services:**

These services aim to provide counseling to local community regarding D.S disability and its related problems through home visits and continuous follow-up. Social workers try to help families to overcome their social problems.

☒ **Physiotherapy services:**

This services mainly served children from birth up to 3 years old, by having 2 sessions every week. This service aimed to decrease physical problems through mother's awareness promotion. Also it provides services for those who older than 3 years by counseling and therapy within special sessions or refer to other organizations for help.

☒ **Psychotherapy services:**

Provide care for Down's syndrome child's family through psychological and mental standard measures. These services mainly targeted to some problems (sexual, shyness and stubbornness) solving with sharing social services.

☒ **Speech/language services:**

Mainly aimed to solve and detect any early problem with Down's syndrome children related to communication through family counseling. The early intervention program focused to explore any medical problems in middle ear by medical or regular check up examination, Other children rather than EIP, have periodic check up for hearing sensitivity, middle ear dysfunction and speech/ language enhancement.

☒ **Medical services:**

It offers medical check up for all referred babies with Down's syndrome from hospital or by own families to verify the case early. Mainly depends on physical and physiological characteristics of D.S. Other services provide care for pregnant women whom have history of previous D.S, referred to Al-Maqassed Hospital to verify the cause during first trimester of pregnancy. Comprehensive medical services for all beneficiaries are performed through this unit in cooperation with other medical associations.

CHAPTER 2

Chapter 2

Conceptual framework

2.1. Introduction:

In this chapter the researcher will present the conceptual framework which consists of three parts. The first concerns with evaluation [specifically program evaluation]; the second will cover early intervention program for Down's Syndrome, and the third will be about Down's Syndrome.

2.2. Evaluation:

2.2.1. Definition of evaluation:

Program evaluation is carefully collecting information about a program or some aspect of a program in order to make necessary decisions about the program. The program evaluation can include many types of evaluation and the type of evaluation you undertake to improve your programs depends on what do you want to learn about the program (Carter, 2007).

2.2.2. Types of evaluation

Some major types of evaluation regarding programs. They are follows:

1. **Goal-based evaluation:**

Which is defined as measuring the extent to which a program or intervention has attained clear and specific objectives; also the focus is on intended services and outcomes of a program goals.

By other words, goal-based evaluation is evaluating the extent to which programs are meeting predetermined goals or objectives.

2. **Goal-free evaluation:**

Goal-free evaluation is defined as gathering data on a broad array of actual effects and evaluating the importance of these effects in meeting demonstrated needs. By other words this type of evaluation concerned with the outcome of program intervention and this type of evaluation does not need to be performed with a high degree of involvement. (Patton, 1990).

3. Criteria-based evaluation:

This type of evaluation depends on criteria such as check lists or principles which are derived from one or more specific perspective theories (Nielesn, 1994).

4. Process-based evaluations:

This type is fully understanding how a program works, how does it produce that results. This type is useful in programs that long-standing and has changed over the years (Carter, 2007).

2.2.3. Steps of program evaluation:

- **Define program evaluation:** Evaluation is defined as a systematic investigation of the worth or merit of an object. This is a general definition for evaluation, but as step for program evaluation this step is defined as systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness and inform decisions about further program development. (Patton, 1997).
- **Use the framework for program evaluation:** **t**his step emphasizes the importance of constructing practical evaluation strategies that involve diverse program stakeholders, not just evaluation experts.
- **Seek cultural competence:** In program evaluation planning, implementation and use of findings, to achieve this step, program evaluation must be responsive to the cultural context by using appropriate framework and methodology to arrive the results and further findings.
- **Identify the purpose of the evaluation:** Unfortunately the purpose of program will completely differ from this; by articulating the purpose of evaluation will prevent premature decision making regarding how the evaluation should be conducted program evaluation may have at least four general purposes: gain insight, change practice, assess effects, affect participants.

  Whenever the purpose of the evaluation is being defined, the subsequent pieces of the study fall into place more easily (e.g.: allocation of resources identification of key evaluation questions selection of appropriate source of data).

- **Identify key evaluation questions:**
  Evaluation questions should be form the heart of the evaluation plan and pragmatic decision about design and data collection methods.
- **Attend to process and outcome evaluation:**
  - **Process evaluation** is the systematic collection of information to document and assess program implementation and operations (e.g.: can be used to document the allocation and use of resources, quality of the intervention and the integrity of implementation).
  - Whereas the **outcome evaluation** measures the quality of achieved goal, related also to the impact evaluation otherwise it concerned with the information about the results, benefits of programs during or after participation.
- **Maximize use of existing surveillance systems for outcome measurement:** This is a systematic collection, analysis and interpretation of outcome-specific data for use in planning, implementing and evaluating. (Patton, 1997).

2.3. Framework for program evaluation

Effective program evaluation is a systematic way to improve and account for public health actions by involving procedures that are useful, feasible, ethical, and accurate. The framework comprises six steps that must be taken in any evaluation (Milstein & Wetterhal, 1999, Worthen et al, 1997). The steps are as follows:

Step 1: Engaging stakeholders.

The evaluation cycle begins by engaging stakeholders (i.e., the persons or organizations having an investment in what will be learned from an evaluation and what will be done with the knowledge). There are three principal groups of stakeholders that are critical. They are:

- Those involved in program operations (e.g., sponsors, collaborators, coalition partners, funding officials, administrators, managers, and staff);
- Those served or affected by the program (e.g., clients, family members, neighborhood organizations, academic institutions, elected officials, advocacy

groups, professional associations, skeptics, opponents, and staff of related or competing organizations);

- Primary users of the evaluation.

Step 2: Describe the program.

Usually program descriptions convey the mission and objectives of the program being evaluated. In order program descriptions to be valuable they should be sufficiently detailed to ensure understanding of program goals and strategies. Descriptions should discuss the program's capacity to effect change, its stage of development, and how it fits into the larger organization and community.

Moreover descriptions should set the frame of reference for all subsequent decisions in an evaluation. The description enables comparisons with similar programs and facilitates attempts to connect program components to their effects

There are several aspects to include in a program description; they are need, expected effects, activities, resources, stage of development, context, and logic model.

Step 3: Focus the evaluation design.

The evaluation must be focused to assess the issues of greatest concern to stakeholders while using time and resources as efficiently as possible. There different design options are not all equally well-suited to meeting the information needs of stakeholders.

After data collection begins, changing procedures might be difficult or impossible, even if better methods become obvious. A thorough plan anticipates intended uses and creates an evaluation strategy with the greatest chance of being useful, feasible, ethical, and accurate. Among the items to consider when focusing an evaluation are purpose, users, uses, questions, methods, and agreements.

Step 4: Gather credible evidence from different sources

An evaluation should try to collect information that will convey a well-rounded picture of the program so that the information is seen as credible by the evaluation's primary users. Collected information should be perceived by stakeholders as believable and relevant for answering their questions.

Collected data to evaluate services of a program could cover different areas or dimensions such as: clients' satisfaction, accessibility to services, technical competence of providers, and interpersonal relations.

Step 5: Justify conclusions.

The evaluation conclusions are justified when they are linked to the evidence gathered and judged against agreed-upon values or standards set by the stakeholders. Stakeholders must agree that conclusions are justified before they will use the evaluation results with confidence. Justifying conclusions on the basis of evidence includes standards, analysis and synthesis, interpretation, judgment, and recommendations.

Step 6: Ensure use and share lessons learned

Lessons learned in the course of an evaluation do not automatically translate into informed decision-making and appropriate action. Deliberate effort is needed to ensure that the evaluation processes and findings are used and disseminated appropriately. Five elements are critical for ensuring use of an evaluation, including design, preparation, feedback, follow-up, and dissemination.

2.4. Evaluation of satisfaction:

As a main domain for evaluation, physicians and health administrators increasingly incorporate patients' perspectives into health-care; patient satisfaction has become a significant health care outcome. However, there is limited knowledge regarding the patient satisfaction instruments being used by leading academic medical centers. Although much attention has been focused on patient satisfaction in recent years, there is little standardization of the patient satisfaction instruments currently being used at the academic medical centers surveyed, particularly for outpatient care. This lack of standardization limits opportunities for benchmarking of patient satisfaction data among peer institutions and may limit efforts to improve care **(**Aerlyn & Dawn, 2003**)**.

Increasingly, patient satisfaction is viewed as a criterion by which the quality of healthcare services can be measured. However, most evaluations of patient satisfaction rely on self-administered written questionnaires, which may lie beyond the patient's ability to complete. Because patients with low health literacy report poorer health status and less use of preventive services3 and may face greater barriers to accessing and navigating the healthcare system, it is especially important to develop instruments that can reach this population (Janet et al, 2004).

(Richard, 2000) reported that the need for increased consumer involvement in rehabilitation services has been emphasized in professional literature. Growing empowerment among consumer groups who demand informed choice, and changes in current service intervention strategies, individually and collectively, have contributed to a heightened interest in the opinions of the persons who utilize rehabilitation services. Furthermore, as empowered consumers continue to voice opinions regarding their service needs, the effectiveness of current services will be of a greater interest to providers, consumer opinions, nonetheless, should be solicited to insure that knowledgeable consumers are more involved in the assessment of current services as well as in the development of more effective services. Finally, there is evidence that consumer involvement is supportive by many researchers. Otherwise, experts suggested that discussions continue regarding issues surrounding increased consumer involvement in service planning and in how to be more effective and satisfied.

2.5. Early intervention program (EIP):

The decade of the 1990s marks the beginning of actuationly optimistic yet critical period for the field of early intervention program. Building on 20 years of research, demonstration programs, and the efforts of advocates, we enter this decade with an unprecedented commitment to provide comprehensive, coordinated, and family focused services to children with established disabilities and their families (Guralnick, 1991).

2.5.1. Definition of early intervention program:

Early intervention applied to children of school age or younger who are discovered to have or be at risk of developing a handicapping condition or other special need that may affect their development, and this program mainly consisted of provision services to children and their families. This services can be remediate or preventive in nature may focus on child alone or the child and the family together, ranged from center-based, home-based, hospital-based, or referral services to diagnostic and direct intervention program, furthermore this program may begin at any time between birth and school age, and there is many reasons for it to begin as early as possible.

- To enhance the child's development.
- To provide support and assistance to the family
- To maximize the child's and family's benefit to society.

Furthermore, society will get maximum benefits by increase child developmental and educational gains so it decreases dependence upon social institutions, the family's increased ability to cope with exceptional child, increased child eligibility for employment, all provides economics and social benefits (U.S. department of education, 1996).

Early intervention (EI) refers to provision of services to children that significantly at risk fro developing a problem. EI, includes both educational and therapeutic components, and is conceptualized as a systematically planned method of taking action based on the child's needs during the first pivotal year of life. EI encompasses a variety of activities including, but not limited to, family centered practices, parent implemented teaching approaches, participation in natural learning opportunities, social integration intervention in inclusive settings, goal identification linked with learning strategies, professional collaboration programs, and parent education programs, and it is recorded from child developmental research that learning and development is most rapid in the preschool years and thus intervention should begin as early as possible to enhance the child's development (www.earlyinterventionCanada.com).

Early intervention is a systematic program of therapy, exercises and activities designed to address development of delays that may be experienced by children with Down's Syndrome or other disabilities. These services are mandated by a federal low called the Individuals with Disabilities Education Act (IDEA). The most common early intervention services for babies with Down's Syndrome are physical therapy, speech and language therapy and occupational therapy. (National Down's Syndrome Society, 2007).

- **Physical therapy:** Focuses on motor development, so the physical therapist can illustrate exercises that parents can do with their baby to help him or her to achieve the milestone of motor development.
- **Speech and language therapy:** It is critical component of early intervention, because Down's Syndrome baby may not say his/her first words until he or she is 2 or 3 years of age. There are many pre-speech and pre-language skills that must be acquired first by learned through games, looking at the speaker and looking at objects, listening to music and listening to speech sounds, exploring objects in the mouth, using the tongue, moving lips, and understanding object performance, cause and effect relationship.
- **Occupational therapy:** Mainly helps children develop and master independence skills, focus on developing fine motor skills for infant D.S. For child D.S, occupational therapy can help with abilities such as opening and choosing things, picking up and release toys of various size and shapes, also help child learn to feed and dress themselves and how to play and interact with other children.

Furthermore, early intervention program offers many benefits to parents including information, encouragement and support. Therapists can teach parents exercises and activities to do alone at home to meet specific needs and enhance development. Finally EI give parents the chance to share their concerns with other parents.

EIP provides specialized instruction and related services like speech therapy, physical therapy, occupational therapy, often in the context of home visiting program (Bialey et al, 1999).

Pediatrician play on important role in the identification and referral of children with disabilities to early intervention program and as participants on the multidisciplinary team that conducts developmental assessment determines goals for treatment and coordinates services. (American Academy of Pediatrics Committee on Children with Disabilities, 1999).

Early intervention services are designed to meet the needs of children from birth to 36 months of age who have delays in 1 or more areas of physical, cognitive, communication, social, emotional or adaptive development. Services are also available to children who have a diagnosed condition that has a high probability to resulting in delayed development.

The type and extent of services are determined through the development of an individualized family service plan in which family plays a lead role in the assessment of resources, priorities and concerns in conjunction with a care coordinator (Lipkin & Schertz, 2007).

Slightly more than 200,000 children are identified as having or being at risk for a disability before 36 months of age are enrolled in early intervention program internationally (Ramey. CT & Ramey. SL. 1994).

The timing of identification and entry into early intervention program spans the birth to 36 months age period (Hebbeler et al, 2004).

2.5.2. Rational for early intervention:

There is neuro-cognitive research that has demonstrated that there are optimal periods for all children during which the brain is particularly efficient at specific types of learning, well designed, timely early intervention can improve the outcome and the quality of life of young children at risk of developing cognitive, social or emotional impairment (Share, 1997).

2.5.3. The benefits of early intervention:

Systematic reviews of many literatures conclude that early intervention results in significant benefits for children (Gorey, 2001).

The effect of early intervention services is not only for children but also on the families was helpful to decrease negative effect of disabilities and learn families how to deal well with their children (Guralnick et al, 1988).

Otherwise, early intervention could help parents learn to read their child's communicative signals and interaction more developmentally facilitative ways, success of EIP services depends on the extent to which parents modified their behavior in accordance with their child's needs and whether such alterations had an effect on infant behavior or development.

Alternatively, a child's disability may be associated with significant stress for some family members, interfering with normal family routines, altering life expectation, and forcing family members to deal with challenging behavior or the frustrations inherent in trying to gaining access to comprehensive and appropriate services (Warifield, 1999).

There is growing evidence that early intervention services have a positive influence on the developmental outcome of children with established disabilities as well as those who are considered to be at risk for disabilities. (American Academy of Pediatrics, 2007)

Early intervention could help by providing support for family; building informal and formal support systems and helping families learn strategies for advocating for their children. Indicators of a successful intervention could include the extent to which family members are optimistic about the future of feel empowered as agents of change or as advocates for their children. (Dunst, 2002)

Although several studies have investigated for families, all of it suffers major limitations. To date studies have typically focused on signal domain (e.g. parent satisfaction, parent teaching skills, stress) that have not incorporated representative samples of sufficient size to warrant generalization, and typically have failed to assess family outcomes at consistent point in time (Bailey, 2004).

In reality, early intervention should respond to varying family circumstances through individualized services that are designed to support the identified needs of families in ways that are consistent with each family's values and priorities (Turnbull, 2000).

(Goodman et al, 1984) recorded that IQ intelligence rate for mental retarded children will improved more rapid with early intervention services that same mental retarded children without included in this program.

Recent developmental brain suggests the plausible biological basis for early intervention. However, specific intervention practices must be judged on their efficacy, effectiveness, and cost justification. Furthermore, EI has made important shifts in emphasizing social competence in the child and the essential role of the family and community. (Blackman, 2002)

Recent literature has revealed that these programs may be effective not only in improving some individual child cognitive outcomes but also in leading to important improvement in family function. (Guralnick, 1997)

Other study suggested that for children from birth up to 3 years, global intervention that are focused on positive family interactions generally are more effective than those that are focused on the child, but services must be individualized. Otherwise, early intervention services generally are more effective for children with milder disabilities than for those with sever disabilities.

Result of another study showed that despite the great variability of child and family function and of the types and extent of services offered, most young children in early intervention programs improved in all domains of functioning.

About early intervention services for D.S many study revealed that these services may be useful in preventing declines in the IQ of Down's Syndrome children. (Shonkoff, 2001)

(Ramey CT and Ramey SL, 1994) Demonstrated positive developmental outcome as a result of intensive early intervention of children of low income and under families intellectual development especially when these children are not provided with intensive early intervention. Fortunately, children whose mothers have low IQ respond positively to intensive-high-quality early intervention which leads to a dramatic reduction in their rates of mental retardation during the intervention program.

2.6. Family-centered services:

As a main domain for this study, the researcher is measuring this aspect in relation to early intervention program. Therefore, it is necessary to identify this aspect from literature review.

Family centered care emphasizes interpersonal aspects of care that include skills or behaviors that service providers use during interaction with families (King et al, 1996). To examine the domains of interpersonal aspect in family centered, many researchers pointed out that it is composed of three mainly domains: Information exchange, respectful and supportive care, enabling and partnership. There are in details as follows:

- ☒ **Information exchange:** Refers to the characteristic of communication between provider and parents. Where providers solicit as well as offer information to parents.
- ☒ **Respectful and supportive care:** Refers to interpersonal sensitivity on the part of the provider to ensure that parents feel respected and supported.

☒ **Enabling and partnership:** Refers to the provider practices that encourage collaboration with parents and support their roles as decision makers and advocates for their children. (Margaret et al, 2001)

Almost all parents experience challenges in learning about the family centered services, specially if they have a child or a family member with a disability, or a child who is a newborn with Down's Syndrome or a second grader with a newly diagnosed learning disability. Parents usually share a need for common set of tasks, they are as follows:

- Learning about their child's ability.
- Becoming aware of their child's educational and therapeutic needs.
- Identifying the range of services which potentially could help support them and their child.
- Gaining access to these services.

However, it appears that there is considerable variation exists in the extent to which parents are aware of use, and are satisfied with services. Many factors interact with each other to cause this variation including the following:

- **Characteristics of child** (e.g.: severity of disability, specialization of needs for services or equipment, known features of the disability).
- **Characteristics of family** (education of parents, knowledge of services, advocacy efforts).
- **Characteristics of the community** (e.g.: availability of resources, attitude of professionals, interagency collaboration) (Bailey et al, 1999).

It is known that the family plays an important role in the child's treatment, and that parent training and involvement in the services often improves the effectiveness of particular intervention or treatment. For example, mothers of children receiving early intervention services showed significantly more interaction with their child than did mothers of children not receiving services (Lessenberry, Rehfedt, 2004).

One of most important improvement in early intervention program during the past 30 years has been the shift to providing services in collaboration with parents and families. This emphasis is reflected in family centered approaches to care, direct family support, and the implementation of early intervention based on individualized family service plans (IFSPs).

On the other hand term of parent education typically refers to systematic activities implemented by profession also to assist parents in accomplishing specific goals or outcomes with their children. This definition includes the expectation that parents will acquire knowledge and skills that allow them to mediate or extend the intervention with their child, and the typical goals of parent education include teaching parents strategies to assist children in attaining developmental skills, helping parents manage children's behavior in the course of daily routines, and enhancing parent's skills in engaging their children in play and social interaction (Mahoney et al, 2001).

2.7. Down's Syndrome:

2.7.1. Definition of Down's Syndrome:

Down's Syndrome is a chromosomal disorder that usually results in delays in physical and mental development. A person with Down's Syndrome has an extra 24th chromosome, which is why Down's Syndrome is also referred to as trisomy 21. Down's Syndrome is not related to race, nationality, religion or socioeconomic status. While there is a wide variation in mental abilities, current research indicates that the majority of people with Down's Syndrome have mild to moderate impairments. (National Association for Down's Syndrome, 1991)

Down's Syndrome consider the most common chromosomal abnormality of a generalized syndrome occurring in 1 in 800 to 1000 live births, it's owes it's once common but unacceptable name "Mongolism", to the particular facial characteristics, which resemble those of the mogole race. (Whaley and Wong's, 1997)

It is investigated that chromosomal anomalies occur in 0.4% of live birth and they are an important cause of mental retardation and congenital anomalies, of these anomalies is Down's Syndrome. The most common abnormalities of chromosome number are trisomies. These occur when there are three representatives of a particular chromosome instead of the usual two. The most frequent and best known trisomy in humans is trisomy 21 or Down's Syndrome, which was first described in 1866, but it is cause was not known until 1959. (Nelson, 1996)

Down's Syndrome is relatively common birth defect caused by the presence of an extra chromosome number 21 (three instead of two number 21 chromosomes, or trisomy 21). This adversely affects both the physical and intellectual development of the individual. Down's Syndrome cause mental retardation, a characteristic facial appearance and multiple malformation. It is associated with a major risk for heart malformations, and a small but still significant risk of acute leukemia. (The National Information Center for Children and Youth with Disabilities, 2007)

Down's Syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality for some unexplained reasons. And accident in cell development results is 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down's Syndrome is made according to results from a chromosome test administered shortly after birth. (National Dissemination Center for Children with Disabilities, 2004)

Down's Syndrome is a major cause of mental retardation, congenital heart disease (CHD), and congenital anomalies of the gastrointestinal tract affecting the welfare of > 300,000 individuals and their families in the USA alone. Down's Syndrome is also associated with a characteristic set of facial and physical features, defects of the immune and endocrine systems and increased risk of leukemia, and an Alzheimer-like dementia. (Yamakawa, et al, 1998)

Where it is recorded that major risk factor for getting Down's Syndrome is the age of mother, (Sallie et al, 2000) recorded that women who reported surgical removal of all or part of an ovary or congenital absence of one ovary were significantly more likely to have delivered a child with Down's Syndrome than were women who did not report a reduced ovarian complement that cause lead to increase level of Follicle Stimulating Hormones (FSH) similar hallmark of advanced maternal age. This finding suggested that the physiological status of the ovary is a key to maternal-age effect, and that women with reduced ovarian complement should be offered prenatal diagnosis.

2.7.2. Incidence of Down's Syndrome:

- Around 1 in 800 lives birth each year. Approximately 40,000 children with Down's Syndrome are born in the USA each year. Although, parents of any age may have a child with Down's Syndrome. The incidence is higher for women over 35. Most common forms of the syndrome do not usually occur more than once in a family. (National Down's Syndrome society for children with disabilities, 2004).
- There is evidence that the incidence rate of Down's Syndrome will dramatically increase with the mother age, for example the incidence is less than 1 in 1,000 live births to women under 30 years old, whereas it increase to 1 in 400 to mothers aged 35 years old and 1 in 35 live births to mothers aged 44. (Bellenir, 1996)
- Internationally 20% of Down's Syndrome children are born to mothers more than 35 years old, whereas 80% are born to mothers less than 35 years old. (National Down's Syndrome society, 2003)
- Relevant to the incidence of Down's Syndrome, one study was conducted in County Galway Recorded that the incidence rate of Down's Syndrome between 1981 and 2000 was 26.8 in 10,000 live births for the full period. Although there were 5119 fewer births in the 1991-2000 periods the incidence was 29.8/10,000 compared to 24.1/10,000 in previous decade.
  (Dineen & Avalso, 2007)
- Locally the incidence rate for Down's Syndrome in Gaza Strip according to Right to live society statistics the incidence rate was approximately 3000 D.S client in Gaza Strip (RTLS, 2007).

2.7.3. Clinical manifestation of Down's Syndrome:

Several physical problems are associated with Down's Syndrome many of these children have congenital heart malformation, the most common being septal defects. Respiratory tract infections are very prevalent and when combined with cardiac anomalies are the chief causes of death particularly during the first year of life. Hypotonicity of chest and abdominal muscles and dysfunction of the immune system probably predispose to development of respiratory tract infection. Other physical problems include thyroid dysfunction, especially congenital hypothyroidism and increase incidence of leukemia (Whaley & Wong's, 1997).

There are over 50 clinical signs of Down's Syndrome, but it is rare to find all or even most of them in one:

- Broad feet with short toes,
- Flat bridge of nose,
- Short, low set ears,
- Short neck,
- Small head,
- Small oral cavity, and/or
- Short, high pitched cries in infancy.

Approximately one third of babies born with Down's Syndrome have heart defect. Some of them are born with gastrointestinal tract problem that can be treated surgically. Some of them may have a condition known as Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck. (National dissemination center for children with disabilities, 2004)

Infants with Down's Syndrome are known to have a high frequency of associated birth defects and some authors have suggested an association between Down's Syndrome and esophageal atresia. (Bianca & Ettore, 2000)

A number of congenital malformations are clearly associated with Down's Syndrome and generally occur with a much higher incidence than in the general population. (Kallen & Robert, 1996)

Related to clinical manifestation of spine in D.S, the major condition associated with the spine in Down's Syndrome is Atlantoaxial instability, which is the looseness between the first and second vertebra of the neck. Another condition with spine in Down's Syndrome is scoliosis which is the curvature of the spine to the side. Five to eight percent of children with D.S develop hip dislocation (sublaxation) that is hardly ever found at birth but instead is most common between the age of 3 and 13 years, and instability of the patella has been estimated to occur in close to 20% of people with Down's Syndrome, also vast majority of D.S people has been demonstrated flat foot. (Diamond, 1981)

2.7.4. Types of Down's Syndrome:

Mainly there are three types of DS described as the following:

- **Translocation Down's Syndrome:**

All individuals with Down's Syndrome have three copies of chromosome 21 about 1% of individuals are mosaic with some normal cell, 4% have a translocation involving chromosome 21.

Translocation account for 9% of children with Down's Syndrome born to mother age of 30 yrs old.

The phenotype in translocation Down's Syndrome is not distinguishable from regular trisomy 21 Down's Syndrome. (Nelson, 1996)

This type of Down's Syndrome is usually hereditary and it is not associated with advanced parental age. (Whaley & Wong's, 1993)

This type occurs when a part of the number 21 chromosome breaks off during cell division and attaches to another chromosome. Whereas the total number of chromosomes in the cells remains 46, that the extra part of the number 21 chromosome causes of the features of Down's Syndrome. (National Down's Syndrome society, 1999)

- **Mosaic Down's Syndrome:**

From 1% to 2% of the affected persons demonstrate mosaicism which refers to cell with both normal and abnormal chromosome. The degree of physical and cognitive impairment is related to the percentage of cells with the abnormal chromosome makeup. (Whaley & Wong's, 1993)

They have fewer physical problems with higher level of intellectual ability than children with the rest of other types of Down's Syndrome. (Morlow and Redding, 1988)

This type occurs only when one representative of a chromosome is present. They may be complete or partial. Complete monosomies may be the result of non-disjunction of anaphase lag. In non-disjunction during cell division, the two chromosomes in a replicating pair fail to separate; one cell ends up with only one copy (monosomic) and the other with three copies (trisomic) of the specific chromosome. (Nelson, 1996)

- **Trisomy:**

Approximately 95% of all cases of Down's Syndrome are attributable to an extra chromosome 21, although children with trisomy 21 are born to parents of all ages, there is statistically greater risk in older women, those over 35 yrs of age. (Whaley & Wong's, 1993)

This is the most common abnormalities of chromosome number occur when there are three representative of a particular chromosome instead of the usual two. It is associated with a characteristic set of congenital anomalies and mental retardation. It is also result of failure of chromosome pair to separate. (Nelson, 1996)

2.7.5. Antenatal screening for Down's Syndrome:

Many pregnant women wish to undergo antenatal testing for Down's Syndrome, unfortunately, some test are invased which may lead to loss of pregnancy in about 1% of cases. Therefore the criterion for antenatal screening program is to identify mother in whom a risk of D.S is sufficiently high to justify such an invasive test and to minimize the risk of miscarrying a healthy baby. (Alfirevic & Neilson, 2004)

The universal screening tests started with the observation that serum concentration of α fetoprotein used to screen for neural tube defects which tended to be lower when the fetus had Down's Syndrome. Other several biochemical tests were combined with age related risk to calculate an individual risk for Down's Syndrome.

Other test is Nuchal translucency (fluid filled space behind the fetal neck) and this is useful in earlier detection for fetus with Down's Syndrome, especially in the period in between 10 and 13 weeks of pregnancy. (Snijder et al, 1998)

According to (The National Down's Syndrome society, 1999) there were 3 procedures to screen Down's Syndrome child, one of these tests is amniocentesis, chroioic villous sampling (CVS) and precutaneus umbilical blood sampling (PUBS), with consideration that each of this test has risk for miscarriage on fetus.

Researchers have developed a DNA test that might allow doctors to detect Down's Syndrome in embryos during infertility treatment. This new test uses a single cell to detect Down's Syndrome during invitro fertilization (IVF) treatment before the embryo is implanted in the women uterus. In this test the researchers identified six areas on chromosome 21 that could be used as marker to detect how many copies of chromosome 21 are in a single cell. They used the test to compare cells taken from healthy people with those taken from people with Down's Syndrome, as well as with individual cells from embryos. The above new test is available only to women in high risk groups such as those aged over 35 or with a family history of the D.S condition. (Scott Gottlieb, 2001)

Screening of maternal serum to identify fetus with Down's Syndrome is now routinely offered during the second trimester of pregnancy. Parental screening by means of serum assays or ultrasonographic measurements, either alone or in combination, may also be possible in the first trimester. (Haddow et al, 1998)

2.7.6. Treatment for Down's Syndrome:

The 20th century witnessed great advanced in the diagnosis, treatment and prevention of birth defects and development disabilities and in the quality of life and life expectancy in people living with disabilities. The development of new surgical techniques and clinical management of selected birth defects, such as congenital heart disease, spina bifida and Down's Syndrome has resulted in marked increase in survival of children and adults with these conditions. (Coleen et al, 2005)

As treatment no cure exists for Down's Syndrome. On the other hand, number of therapies are advocated which deals with correction of mainly malformation, for example surgical treatment for CHD, esophageal atresia, evaluation for hearing and sight to treat ottits media to prevent auditory loss. Periodic testing for thyroid function is recommended, participating in special sports to correct atlantoxial instability which include neck pain weakness and risk for spinal cord compression. (Whaley & Wong's, 1997)

2.7.7. Prognosis of Down's Syndrome:

The prognosis for individuals with D.S varies depending on the severity of their physical and cognitive limitation. Some may be able to live independently and others may need more support throughout their life. D.S client with sever medical conditions may need to take drugs regularly or have surgeries. However, there is advanced in medicine, rendered most health problems treatable and majority of people born with D.S today have a life expectancy of approximately 55 years. For young children, parents should be encouraged to enroll their child in an infant development/early intervention program. These programs offer parents special instruction in teaching their child language, cognitive, self-help, and social skills, and specific exercises for gross and fine motor development. Finally the researchers, shown that stimulation during early developmental stages improves the child's chances of developing to his or her fullest potential. (National Down's Syndrome Society, 2007)

2.8. Islamic view on disability:

In Islam the body is seen as a gift from God and needs to be looked after and not abused. Thus keeping the body healthy is a part of one's religion. Any illness is to be received with patience and prayers and Muslims are strongly encouraged to seek treatment and care. On the other hand, Death is seen as part of a Journey to meet the creator. However, assisted suicide and euthanasia are not permitted. (Carers Muslims Women's Support Project, 2006)

The word disability can not be found within the Quran's but the concept of Muslims having inabilities or special needs and how they interacted in society can be found throughout the history of Islam, in particular is the example of Itban bin Malik a religious leader who was blind.

Disability is seen as neither a blessing nor a curse in Islam. It is the belief of Muslims that everyone was created with different abilities and disabilities with the objectives for a Muslim to focus on their abilities and show gratefulness rather than focus on the disability. According to this Islamic view Muslim has the right to improve the situation of their disability through prayer, medical, educational and advocacy resources.

Within the Islam and every Muslim regardless of their abilities or inabilities human life should be regarded as valued members of the community. Islamic history highlights many examples of people whom while having some form of disability, excelled to very high positions and prominent status in society.

Islamic community as a whole is enjoined to be accepting all people regardless of their disability and Muslims are required to support them in addressing their needs as well as creating an inclusive environment and encouraging full participation of all members of community. (Carers Muslims Women's Support Project, 2008)

Within Islamic community, caring for a family member with a disability is viewed as being highly rewarding. Generally speaking, Muslim careers prefer to remain with the care recipient at all times and prefer to have activities that involve the whole family. Respite care is often avoided unless absolutely necessary.

No one can forget that, this is shine view to Islam who respect human as a whole one, respect her/his own rights in the community and it is the right of disabled one to receive all best activities to improve their care in the community, and it is the responsibility of the service provider that Islam obligated it to provide the qualified services for disabled one.

A few studies have been conducted in order to analyze the content of the holy Quran on the subject of disability. In the Islamic teaching history we found that the concept of disability in the conventional sense, dose not exist in the Quran, rather than concentrates on the notion of disadvantages that is created by society and imposed on individuals who might not possess the social, economic, or physical attributes that people happen to value at a certain time and place.

It is seen disability as neither blessing nor a curse and clearly disability is accepted as being an inevitable part of the human condition. It is simply a fact of life which has to be addressed appropriately by the society of the day. (Mosse, 2002)

The researcher tried the best to covered most of the available literature which investigated any relationship between family satisfaction as primary determinant in evaluating early intervention program.

The researcher concluded the next model to identify that there is mainly 4 determinants that is mainly effect on the family satisfaction as major part in evaluation EIP services. Furthermore, the instrument of the research study was developed depending on these 4 parts, which the researcher chosen it according to the previous literature that investigated more than this, but the researcher emphasize on the most important parts in evaluating EIP. The first is the accessibility to the early intervention services for all disabled family members and there is strong relation between family satisfaction with availability of such services, and one of literature review that investigated this relation is, (Bailey et al, 2004).

The second determinant is the improvement in their child outcome either by development in cognitive, motor or other aspects for example study of e.g. (Mahoney et al, 2001), (Virji et al, 2006) investigated this relation.

The third determinant is the communication with service provider and it is documented that there is strong relation between family satisfaction regarding communication with service provider, e.g. (Arnkjotsdotti et al, 1993).

Finally was more investigated through literature review and there is significant relation between family satisfaction with more family centered services, e.g. (Law et al, 2003) study.

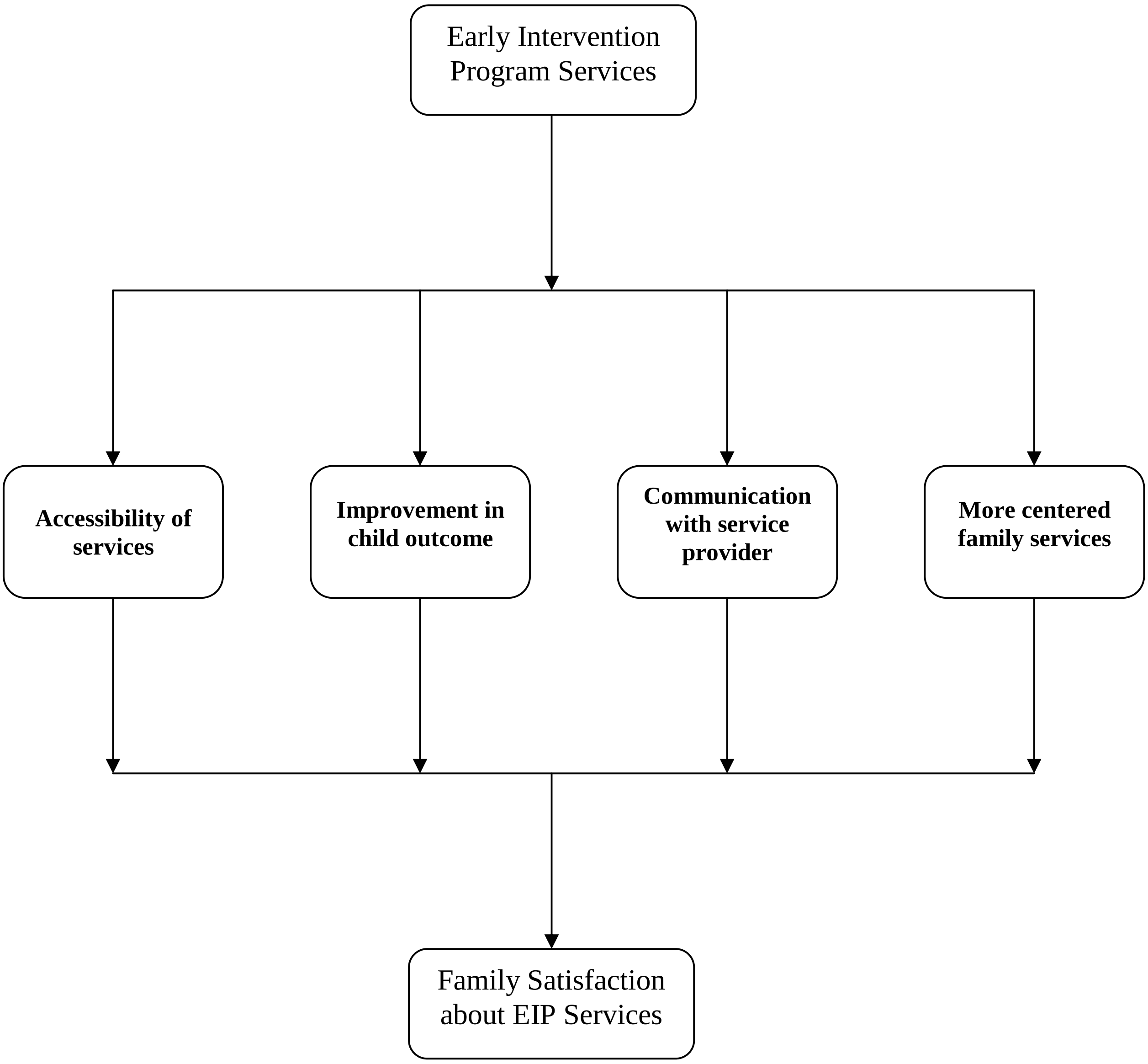


Figure (2-1): Evaluating Model for EIP services.

2.9. Commentary on conceptual framework:

The researcher came to a conclusion from the previous review that Down Syndrome is a very old syndrome in the world. It is defined to be one of the most genetic syndromes which affect mental and developmental growth. The cause of this syndrome exactly unknown, but literature shows a strong relation between mother age and the probability of getting it. No cure for this syndrome was discovered, however, there is evidence that rehabilitation management could have an effect on it by enrolling children in early intervention programs.

With regards to the EIP's, literature shows that they are designated to serve disabled children or whom at risk of having disabilities (e.g.: D.S) from birth up to pre-school age. Moreover EIP's do not only serve children but also family as a whole, either in a formal or informal way through a support system. There is evidence that the effectiveness of EIP's are increased with the involvement of family participation early in the program.

Evaluation of programs were mentioned in the literature involves collecting information that conveys a well-rounded picture of the program so that the information is seen as credible by the evaluation's primary users. Dimensions for evaluating the programs includes elements such as: clients' satisfaction, accessibility to services, technical competence of providers in addition to outcomes of the program.

Related to the evaluation of EIP is carefully collecting data about the outcome of this program, in order to highlight the strongest and weakness points in the outcome of EIP to manager of society.

Also, the researcher defined family centered service and satisfaction as main domain in evaluating EIP from family perspective.

CHAPTER 3

Chapter 3

Literature Review

3.1. Introduction:

In this chapter the researcher presents related previous studies in the field of early intervention program, studies related to Down's Syndrome, studies related to satisfaction from parent perspective and studies related to family centered services, finally the researcher will present her own comments on the all previous literature view.

3.2. Evaluative early intervention program studies:

3.2.1. Parent participation in pediatric rehabilitation treatment centers in the Netherlands: a parents' viewpoint (Siebes et al, 2007):

The aim of this study was to describe how and to what extent parents are involved in pediatric rehabilitation treatment process, to determine the level of parents' satisfaction about the services the child received, and to describe what ideas parents have to enhance their involvement in the treatment process. A random sample of 75 parents was interviewed within 4 weeks after completion of the measure of processes of care and the client satisfaction questionnaire. The result showed that average level of parent satisfaction about the services received was high according to the interviewed parents. The communication between professionals and parents' involvement in goal setting, and parents' involvement in treatment could be improved upon.

3.2.2. Children with Down syndrome improved in motor functioning and muscle tone following massage therapy (Maria et al, 2006):

This study evaluated twenty-one moderate to high functioning young children (mean age, two years) with Down syndrome receiving early intervention (physical therapy, occupational therapy and speech therapy) were randomly assigned to additionally receive two 0.5-hour massage therapy or reading sessions (control group) per week for two months. On the first and last day of the study, the children's functioning levels were assessed using the Developmental Programming for Infants and Young Children scale, and muscle tone was assessed using a new preliminary scale (the Arms, Legs and Trunk

Muscle Tone Score). Results showed that children in the massage therapy group revealed greater gains in fine and gross motor functioning and less severe limb hypo-tonicity when compared with the children in the reading/control group. These findings suggest that the addition of massage therapy to an early intervention program may enhance motor functioning and increase muscle tone for children with Down syndrome.

3.2.3. Parent's perceptions and children's experiences of early intervention – inclusive practice (Smith & Rix, 2006)

This study explored the experiences of early intervention for three families in England as case research study. The result showed that the parent's view and experiences enable a conceptualization of the implementation of policy and practice, in relation to the opportunities provided and the difficulties encountered. The tensions identified raise questions about whether parents are receiving the kinds of support they need and expect, and in particular whether suitable consideration has been given to the models being applied through early intervention programs.

3.2.4. Perceptual motor deficits in children with Down's Syndrome: implications for intervention (Virji et al, 2006):

This study aimed to evaluate the nature and extent of perceptual motor impairments presents in children with Down's Syndrome. 12 child with Down's Syndrome between the ages of 8-15 years with adaptive ages between 3-7 years and a group of 12 typically developing children between the age 4-8 years were tested on their ability to make increasingly complex perceptual discriminations of motor behaviors. The result showed that children with Down's Syndrome are able to make basic perceptual discriminations but show impairments in the perceptions of complex visual motion cues. The study recommends of the implications of these results for early intervention program services.

3.2.5. Cephalometric evaluation of children with Down syndrome after early intervention with the stimulating plate (Korbmacher et al, 2005)

The aim of stimulating plate therapy in patients with trisomy 21 is to correct orofacial dysfunctions and prevent the establishment of subsequent morphological characteristics such as protrusion of the incisors and pseudoprognathia. This study investigated the effectiveness of this type of therapy in improving skeletal traits of patients with Down syndrome. The lateral cephalograms of 22 consecutive juveniles with Down syndrome, whose orofacial dysfunctions had been successfully treated with a stimulating plate according to Castillo Morales in infancy (17 months +/- 24 months), were examined 136 months on average (minimum of 78 months, maximum of 231 months) after initiation of treatment. In 16 of the 22 patients, the anomaly-typical bialveolar protrusion of the anterior teeth was diagnosed. The cephalometric results indicated larger values of cephalometric parameters concerning cranial base and maxilla, and markedly larger mandibular cephalometric values when compared to untreated children with Down syndrome. These results show that a stimulating plate may not always be indicated in patients with Down syndrome with a skeletal Class III pattern and minor orofacial findings.

3.2.6. The Brookline Early Education Project: a 25-year follow-up study of a family-centered early health and development intervention (Palfrey et al, 2005):

The goal of this follow-up study was to test the hypotheses that Brookline Early Education Project (BEEP) participants, in comparison with their peers, would have higher levels of educational attainment, higher incomes, and more positive health behaviors, mental health, and health efficacy during the young adult period. The sample consists of young adults who were enrolled in the BEEP project from 1973 to 1978. Comparison subjects were young adults in Boston and Brookline who did not participate in BEEP but were matched to the BEEP group with respect to age, ethnicity, mother's educational level, and neighborhood (during youth). The study used a quasi-experimental causal-comparative design involving quantitative analyses of differences between the BEEP program and comparison groups, stratified according to community. Results showed that young adults from the suburban community had higher levels of educational attainment than did those in the urban group, with little difference between the suburban BEEP and comparison groups, suburban participants reported more positive health behaviors, more perceived competence, and less depression. Among the urban samples; however, participation in BEEP was associated with higher levels of health efficacy, more positive health behaviors, and less depression than their peers.

3.2.7. First Experiences With Early Intervention: A National Perspective (Bailey et al, 2004)

This study was designed to determine families' initial experiences in determining their child's eligibility, interactions with medical professionals, effort required to obtain services, participation in planning for services, satisfaction with services, and interactions with professionals. The researcher interviewed a nationally representative sample of 3338 parents of young children with or at risk for disability. All the children had recently entered an early intervention program operated under the auspices of Part C of the Individuals with Disabilities Education Act. The average age at which families reported a concern about their child was 7.4 months. A diagnosis was made, on average, 1.4 months later, the child was referred for early intervention an average of 5.2 months after the diagnosis, and the individualized family service plan was developed 1.7 months later or at an average age of 15.7 months. Result of the study showed that most families were very positive about their entry into early intervention programs. They reported discussing their concerns with a medical professional and finding that person helpful. Families reported relative ease in accessing services, felt that services were related to their perceived needs, rated positively the professionals working in early intervention, and felt that they had a role in making key decisions about child and family goals. A small percentage of families experienced significant delays in getting services, wanted more involvement in service planning, or felt that services were inadequate, and nearly 20% were unaware of the existence of a written plan for services. Minority families, families with limited income, and families with less-educated mothers were more likely to report negative experiences.

3.2.8. Orofacial development in children with Down's syndrome 12 years after early intervention with a stimulating plate (Limbrock et al, 2004)

In this study, 20 children with trisomy 21 were examined more than 12 years after starting treatment in infancy with a Castillo Morales stimulating plate. The follow-up examination showed that the improved orofacial appearance resulting from the early treatment had remained stable in most cases. Although the mechanical stimulus of the stimulating plate was absent during the follow-up period, some patients revealed a lip and tongue posture superior to that recorded at baseline.

3.2.9. Creating a family centered approach to early intervention services: Perceptions of parents and professionals (Iversen et al, 2003):

This study compared the attitudes of parents and early intervention providers concerning the effectiveness of family centered services, identified factors associated with parental satisfaction, and described providers perception of obstacles in forming collaborative relationships with families. A cross sectional design used to assess 11 providers and 18 parents perceptions of EI services. Completed questionnaire including basic demographics, service received, and perceived effectiveness in the delivery of services. Result showed that 87% of parents were satisfied with their EI programs, with lesser parental satisfaction noted in learning how to develop strategies and set goals, and available community resources. Providers overall satisfaction was 99%. Providers felt they need more development in building parent networks and helping parents value the time their child spends with children without delays.

3.2.10. Factors affecting family-centred service delivery for children with disabilities (Law et al, 2003):

The purpose of this study was to examine factors that are most important in determining parent perceptions of the family centeredness of care and parent satisfaction with service. A cross-sectional survey was completed by 494 parents, 324 service providers, and 15 cases from 16 organizations delivering children's rehabilitation services. Analyses were completed using a structural equation modeling approach. Results Survey return rates ranged from 77 to 94%. Findings indicated that the principal determinants of parent satisfaction with services are the family-centered culture at the organization and parent perceptions of FCS. Parent satisfaction with services was also influenced by the number of places where services were received and the number of health and development problems experienced by their child. Parent satisfaction with services is strongly influenced by the perception that services are more family centred, fewer places where services were received and fewer health and development problems for their child.

3.2.11. Parental perspectives on inclusion: Effects of Autism and Down's Syndrome (Kasari et al, 2002):

This study examined the effects of the child's diagnosis (autism, Down's Syndrome), age, and current educational placement on parental perspective toward inclusion for their child with disabilities. Parents of children with autism and with Down's Syndrome completed surveys regarding their opinions of their child's current educational placement, their desire for changing the current placement, and their view on inclusive education. Result showed that diagnosis, age and current placement influenced parental opinion on the ideal educational placement for their child. Parents of children with Down's Syndrome were significantly more likely endorse inclusion (full-time placement in general education) whereas parents of autism were more likely to endorse mainstreaming (consistent part-time placement with general education students).

3.2.12. Parent's perceptions of motor interventions for infants and toddlers with Down Syndrome (Sayers et al, 2002):

The purpose of this study was to analyze parents perceptions of their participation in a university, directed, parent implemented, home-based pediatric strength intervention program as (1) one approach to evaluating the effectiveness of a program conducted over 4 years period with families of infant and toddlers with Down's Syndrome and (2) a mean of deriving guidelines for future early intervention program. Participants were 22 parents from 11 families of children with Down's Syndrome where their age ranged between 6-24 months. Participatory evaluation research, semi-structured audio record home interview and qualitative content analysis were used. The result showed that parents perceived themselves as being empowered to implement the program was worth-wile. The parents' perceptions provided meaningful evaluation data that enabled the development of guidelines for future pediatric strength intervention program.

3.2.13. The effects of early motor intervention on children with Down syndrome or cerebral palsy: a field-based study (Mahoney et al, 2001)

This study reports the results of a field-based investigation of the effects of two motor intervention approaches, neuro-developmental treatment and developmental skills-on children with two different diagnoses. The sample included 50 children, of whom 27 were diagnosed as having Down syndrome and 23 as having cerebral palsy. Children had a mean chronological age of 14 months at the beginning of the study. Children's motor functioning was examined at entry into the study and after they received 1 year of motor intervention services. By using dependent Gross Motor Function Classification System for Cerebral Palsy, measures included children's general development, rate of motor development, and quality of movement. Pre-post comparisons indicated that children made significant changes in their motor development age and quality of movement over the course of intervention. However, the result of this comparison showed that there was no evidence that motor intervention accelerated development or improved quality of movement beyond what could be expected on the basis of maturation. Furthermore, no differential intervention effects were associated either with children's diagnosis or treatment model. Regression analyses indicated that the rate of motor development children attained after 1 year of intervention was highly related to their rate of development at the onset of intervention and, to a lesser degree, to the number of sessions of intervention that children received. The results are discussed in terms of the need for the field of motor intervention to develop new treatment paradigms.

3.2.14. **Longitudinal effects of an early family intervention programme on the adaptation of parents of children with a disability (Bouchard et al, 1999)**

This study assesses the longitudinal effects of an original early intervention program on the adaptation of parents of children with a disability (Down syndrome and cleft lip/palate; i.e., DS and CLP). Variations in the effects of the program according to the time of measurement, the type of disability and parent's gender are also examined. The results showed a better adaptation among parents who participated in the intervention program compared to those who did not participated in the program. These parents had lower levels of parental stress, they had more positive perceptions and attitudes concerning their child's disability and their parental situation, they were more confident in their own resources and the help they could receive from others, they had lower levels of emotional distress, anxiety and depression and they perceived more emotional support from the spouse.

3.2.15. A longitudinal study of children with Down syndrome who experienced early intervention programming (Morgan et al, 1993)

The purpose of this study was to examine long motor, cognitive and adaptive functioning of a sample of adolescents with Down Syndrome who experienced early intervention program. Sample consists of ten children with Down syndrome (7 girls, 3 boys) who had participated in an early intervention program constituted the early intervention (EI) group. An age-matched group of children with Down syndrome (6 girls, 4 boys) who had not experienced an early intervention program served as a comparison group. The EI group's motor functioning was compared with that of a normative sample used in the development of the Bruininks-Oseretsky Test of Motor Proficiency. The cognitive and adaptive skills of the EI group were compared with those of the comparison group. The children were assessed using the Stanford-Binet Intelligence Scale, the Vineland Social Maturity Scale, and the Bruininks-Oseretsky Test of Motor Proficiency. The Result of this study showed that EI group subjects fell below their chronological age levels in gross and fine motor skills; however, their mean gross motor skill levels exceeded their mean fine motor skill levels. The EI group subjects had significantly higher scores on measures of intellectual and adaptive functioning than did the children in the comparison group. The EI group subjects did not show the decline typically seen with age in adaptive functioning in individuals with Down syndrome.

3.2.16. Infants with Down syndrome: description of an early intervention approach (Louw & Kritzinger, 1991)

Children with Down syndrome are particularly at risk for language learning problems for reasons beyond the associated cognitive deficits. An early intervention program had applied on three Down syndrome infants who are aged 10 months at the initiation of the program. The subjects were individually assessed prior to the treatment program and again at the completion of it. Comparison of pre and post treatment levels of functioning indicated that all three subjects made satisfactory progress, although developmental lags were still evident. The intervention program was found to be clinically successful and verifies that the language development of Down syndrome infants can be facilitated by early intervention.

3.2.17. The school achievement of children with Down's syndrome (Irwin, 1989)

In this study the academic achievement of nine children with Down's syndrome who had participated in a systematic early intervention program between the ages of two and five years was compared with the achievement of all other children with Down's syndrome of the same age in Auckland schools (n = 12). The children were between nine years six months and eleven years six months at the time of assessment. Results showed the first group to be significantly more advanced in reading and moderately more advanced in reading and moderately more advanced in numerical skills than the others.

3.2.18. Early Intervention for Disabled Infants and their Families: A Quantitative Analysis (Shonkoff & Hauser, 1987)

This study evaluated 31 selected studies by using meta-analysis to assess the effects of early intervention services for a disabled child younger than 3 years and their families. Results indicate that early intervention is effective in promoting developmental progress in infants and toddlers with biologically based disabilities, programs that served a heterogeneous group of children, provided a structured curriculum, and targeted their efforts on parents and children together appeared to be the most effective. Results showed that definitive evaluation of the efficacy of early intervention programs is tempered by the restricted range of outcomes measured and by a paucity of information about the children and families enrolled in such programs, as well as about the specific nature of the services received. Despite their limitations, available data provide the basis for a rational pediatric approach to early intervention programs, while highlighting specific directions for further investigation.

3.2.19. Developmental profile of Down's syndrome infants receiving early intervention (Gendron et al, 1986)

The aim of this study was to follow-up thirty-two infants with Down's syndrome, who were enrolled in an early intervention program during the first 2 years of life. Progress in five developmental domains was monitored prospectively by evaluating the children at 6, 12, 18 and 24 months. The Result of this study revealed that the largest degree of retardation was consistently exhibited in the hearing and speech subscale. The loco-motor subscale experienced the most severe decline over the 24 months and was the second most retarded domain at 2 years of age. The remaining three subscales, personal-social, hand-eye and performance, demonstrated less severe declines over time as well as actual increases in developmental quotients at specified points in time. The overall performance of female infants at 18 months was significantly better than that of male infants ($P = 0.05$). The degree of retardation of Down's syndrome infants receiving early intervention services differs according to chronological age, developmental domain and sex.

3.2.20. Performance of retarded children, with and without Down syndrome, on the Bruininks Oseretsky Test of Motor Proficiency (Connolly & Michael, 1986)

The purpose of this study was to examine the gross motor and fine motor abilities of children with mental retardation using the Bruininks Oseretsky Test of Motor Proficiency. They compared the motor skills of 24 mentally retarded children, 12 with Down syndrome and 12 without Down syndrome. The children ranged in chronological age from 7.6 years to 11 years and were of comparable mental age. Within each group, there were no significant sex differences, nor were there differences between the two groups in motor performance for the male subjects. Result of comparison showed that the female subjects with Down syndrome, however, scored significantly lower than female subjects without Down syndrome on running speed, strength, visual motor ability, speed, and dexterity and fine motor composite scores. As a group, the children with Down syndrome scored significantly lower than the children without Down syndrome in the areas of running speed, balance, strength, and visual motor control. The gross motor and fine motor skill composite scores were also significantly lower for the children with Down syndrome than for the children without Down syndrome.

3.2.21. The effect of intensity of training on sensori-motor development in infants with Down's syndrome (Cunningham et al, 1986)

Twenty-four children with Down's syndrome involved in an early intervention program were divided into matched intensive training group (ITG) and control groups (CG), at a mean age of 42 weeks. Parents of children in the ITG were given exercises to be carried out daily to train object permanence, imitation and span of attention. Parents of children on the CG were given general advice. All children were assessed on checklists in the three areas and on standard developmental tests. Results showed small short-term effects in favor of the ITG during the training but no long-term effects on development.

3.2.22. Parental reactions to early intervention with their Down's syndrome infants (Arnljotsdottir et al, 1983)

Results of early intervention programs with Down's syndrome infants are well documented in terms of the effects on the infants' development, but less attention has been given to the reactions of parents who are required to carry out the programs. A small scale interview study of three groups of parents receiving different 'intensities' of intervention is described. The result of this study showed that parents' view of the intervention programs are positive, but the difficulties experienced by some parents pointed to the need for interveners to be sensitive to family situations and feelings and for programs to be flexible enough to meet these needs.

3.2.23. Early intervention for infants with Down syndrome: a controlled trial (Piper & Pless, 1980)

In this study, the mental development of 37 infants with Down syndrome, allocated either to an experimental or control group, was assessed over a six-month period by an independent evaluator. The experimental group participated in biweekly therapy sessions designed to stimulate normal development, while the control group received no intervention. The Griffiths Mental Developmental Scales were used to assess changes in the developmental status in the two groups, which were shown to be equal initially on a variety of variables. No statistically significant differences in mental development between the experimental and control groups were found. The result of this study showed that the early intervention program investigated in this study was not efficacious in altering the pattern of mental development in those Down syndrome infants participating in the program.

3.2.24. Early intervention with Down syndrome children: follow-up report (Richardson et al, 1980)

This study compared developmental milestones and current intellectual and adaptive functioning of 20 children with Down Syndrome who participated in an early intervention program with those of 53 non-institutionalized children with Down syndrome who did not experience such a program. The children in the former group generally showed earlier acquisition of motor and self-help skills and significantly higher intelligence quotients and social quotients at three to six years of age. Because of certain variables that could not be rigorously controlled in this type of program, the higher functioning cannot be clearly attributed to early intervention. Nevertheless, these findings are consistent with the hypothesis that early intervention has a beneficial effect and should provide encouragement for further studies.

3.2.25. The effect of early intervention and preschool stimulus on the development of the Down's Syndrome child (Ludlow & Allen, 1979):

This study described the effect on a group of D.S children of early and continuous parental counseling together with intensive preschool stimulation in which parents were fully involved. This group was compared with similar group who developed unaided in their own homes, with third group who were institutionalized before their second birthday. The instrument used is Griffiths developmental and Stanford-Binet scales, and the school placement at five years was studied. The result showed that the stimulated group scored higher on IQ and DQ tests and particularly on personal and speech development. School placement acts as an unbiased measurement of progress, and suggests that they are more easily integrated into the normal community.

3.2.26. Interdisciplinary early intervention program (Connolly & Russell, 1976)

This study examined the effect of early intervention program provided by interdisciplinary team on developmental characteristics of Down's Syndrome by comparison of 40 children who received this interdisciplinary of early intervention and with 40 children with Down's Syndrome who didn't receive this program. The result showed that early intervention helps the child in earlier attainment of many developmental tasks and enhances functioning of the family unit.

3.3. Studies of Down's Syndrome:

3.3.1. Study on the social adaptation of Chinese children with down syndrome (Wang et al, 2007):

The purpose of this study was to evaluate social adjustment and related factors among Chinese children with Down syndrome (DS). A structured interview and Peabody Picture Vocabulary Test (PPVT) were conducted with a group of 36 DS children with a mean age of 106.28 months, a group of 30 normally-developing children matched for mental age (MA) and a group of 40 normally-developing children matched for chronological age (CA). Mean scores of social adjustment were compared between the three groups, and partial correlations and stepwise multiple regression models were used to further explore related factors. Results showed that there was no difference between the DS group and the MA group in terms of communication skills. However, the DS group scored much better than the MA group in self-dependence, locomotion, work skills, socialization and self-management. Children in the CA group achieved significantly higher scores in all aspects of social adjustment than the DS children. Partial correlations indicate a relationship between social adjustment and the PPVT raw score and between social adjustment and age (significant ranging between 0.24 and 0.92). A stepwise linear regression analysis showed that family structure was the main predictor of social adjustment. Newborn history was also a predictor of work skills, communication, socialization and self-management. Parental education was found to account for 8% of self-dependence. Maternal education explained 6% of the variation in locomotion.

3.3.2. Congenital heart diseases and other major anomalies in patients with Down syndrome (Abbag, 2006):

The aim of this study was to determine the frequency and types of congenital heart diseases (CHDs) and other congenital anomalies among Down syndrome (DS) patients, and the short-term survival rate. By retrospective review of 98 DS patients seen in Aseer Central Hospital from July 1994 to June 2005. The clinicians' notes, echocardiography reports and operative notes were examined. The result showed that the mean follow up period was 30 +/- 40.1 months. Ninety-three patients had echocardiography; CHDs were found in 57 patients (61.3%). Ventricular septal defect (VSD) was the most common (33.3%)

followed by atrioventricular septal defect (22.8%), atrial septal defect (21.1%), patent ductus arteriosus (14%) and tetralogy of Fallot (5.3%). Three patients (5.3%) developed inoperable obstructive pulmonary vascular disease (OPVD) and 3 were deemed inoperable for other reasons. The CHD was clinically suspected in 96%. The most common non-cardiac anomalies were gastrointestinal, affecting 22 patients (22.4%): duodenal atresia 8 patients, imperforate anus 7 patients and Hirschsprung disease 4 patients. Sixteen patients (16.3%) died at a mean age of 19 months, 15 of them (93.8%) had anomalies.

3.3.3. Experiences of mothers of children with Down syndrome (Turan et al, 2006):

This qualitative study explored the experiences and lifestyles of families in Turkey with children with Down syndrome, including the impact on family members. Twelve mothers with a Down syndrome child (three from each of the age groups 1-3 years, 4-6 years, 7-12 years and 13-18 years of age) participated in the study. The data were collected during in-depth interviews and were evaluated using qualitative data analysis methods. Result of this study showed that families were affected socially, physically, economically and emotionally by having a child with Down syndrome.

3.3.4. Down's Syndrome, paternal age and education: comparison of California and the Czech Republic (Dzurova and Pikhart, 2005):

This study aimed to evaluate the epidemiological characteristics of Down's Syndrome in two culturally and socially contrasting population settings, in California and the Czech Republic by using Birth Defects Monitoring Program to observe live birth prevalence of Down's Syndrome. The result showed that a total of 516,745 (California) and 475,834 (the Czech Republic) were included in analysis. The mean maternal age of children with D.S was 32.1 years in California and 26.9 years in the Czech Republic. Children born to older mothers were at greater risk of Down's Syndrome in both population. The association between maternal education D.S was stronger in California than in the Czech Republic, but parental age influences higher occurrence of Down's Syndrome both in California and in the Czech Republic.

3.3.5. What do the Parents Think?: A Pilot Survey on the Health Service for Children With Down Syndrome in Hong Kong (Yam et al, 2005):

This survey aimed to reflect the health service for children with Down Syndrome in Hong Kong from the parents' perspective. Ninety-eight questionnaires were collected from families with children aged 0-18 years old during the Annual Meeting of the Hong Kong Down Syndrome Association in 1999. The instrument was used contain all of the following domains (medical and allied health services, educational provisions, surveillance and assessment programs were analyzed, the utilization pattern, referral time, follows up frequency and satisfaction ratings were reported, the necessity and accessibility of the services were ranked). The result of the study showed that Most parents of Down Syndrome children were satisfied with the current service provisions. Educational assistance and assessment service were regarded as highly necessary. Services provided by Physiotherapy, Occupational Therapy, Speech Therapy were perceived as necessary but difficult to access.

3.3.6. Evaluation of oral health and access to care in Senegalese children with Down syndrome: preliminary study (Faye et al, 2004):

The aims of this study are:-to evaluate the general and oral health of a Senegalese group of children with Down syndrome and their siblings the closest in age,--to assess their access to care. It was used the Oral Assessment Down Syndrome (OADS) questionnaire in 25 Senegalese children with Down syndrome living in Dakar and 17 old their siblings the closest in age. Their ages range from 4 to 20 years old in both groups. Results revealed that Senegalese children with Down syndrome have more general and oral health problems compared to their siblings, the closest in age, but they were more likely to have difficulty finding both medical and dental services. The study pointed out the need for special care services with trained people for a better management of these specific patients.

3.3.7. Cancer incidence in persons with Down's Syndrome in Israel (Boker and Merrick, 2002):

The purpose of this study was to assess the incidence rates of leukemia and other malignancies in person with Down's Syndrome in Israel. Target population of this study consisted of all persons with Down's Syndrome in the period of 1948-1995. The study population was linked to the cancer registry and cases that had been diagnosed through December 1995 were subsequently identified. The observed incidence rates were compared to expected rates in the general population. The result of analysis in the registry group showed that seven cancer cases were observed as compared to 1.5 expected all of which were leukemia cases; whereas 17 cancer cases observed in institution group with compared 12.8 expected, four cases of leukemia, other result showed increase incidence of gastric cancer in males.

3.3.8. Association of Down's Syndrome and water fluoride level: a systemiatic review of evidence (Kleijen et al, 2001):

The aim of this study was to examine the evidence for an association between water fluoride level and Down's Syndrome. By reviewing six research studies which investigated the incidence of Down's Syndrome in areas with different levels of fluoride in their water supplies. The result showed that 4 studies showed no significant associations between the incidence of Down's Syndrome and water fluoride level, whereas the two studies showed that significant ($p<0.05$) positive association (increased Down's Syndrome incidence with increased water fluoride level).

3.3.9. Children with disabilities: a longitudinal study of child development and parent well-being (Warfield et al, 2001):

This Monograph presented the results of the Early Intervention Collaborative Study, a longitudinal investigation of the cognitive and adaptive behavior development of children with developmental disabilities and the adaptation of their parents, extending from infancy through middle childhood. The study was designed to generate and test conceptual models of child and family development and contribute to the knowledge base that informs social policy and practice. The sample for the investigation consisted of 183 children with Down syndrome, motor impairment, developmental delay and their families who were recruited at the time of their enrollment in an early intervention program in Massachusetts or New Hampshire. Data were collected at five time points between entry to early intervention and the child's 10th birthday. Home visits were conducted at each time point and included child assessments, maternal interview, and questionnaires completed independently by both parents. Trajectories in children's development and parental well-being were analyzed using hierarchical linear modeling. Predictor variables were measured at age 3 years when children were exiting early intervention programs. Children's type of disability predicted trajectories of development in cognition, social skills, and daily living skills. Children's type of disability also predicted changes in maternal (but not paternal) child-related and parent-related stress. Beyond type of disability, child self-regulatory processes (notably behavior problems and mastery motivation) and one aspect of the family climate (notably mother-child interaction) were key predictors of change in both child outcomes and parent well-being.

3.3.10. Parental reports of spoken language skills in children with Down syndrome (Berglund et al, 2001):

Spoken language in children with Down syndrome and in children in a normative group was compared. Growth trends, individual variation, sex differences, and performance on vocabulary, pragmatic, and grammar scales as well as maximum length of utterance (MaxLU) were explored. Subjects were 330 children with Down syndrome (age range: 1-5 years) and 336 children in a normative group (1;4-2;4 years; months). The Swedish Early Communicative Development Inventory-words and sentences (SECDI-w&s) were employed. Performance of children with Down syndrome at ages 3;0 and 4;0 was comparable with that of children in the normative group at ages 1;4 and 1;8 respectively. In comparison with children in the normative group of similar vocabulary size; the result indicated that children with Down syndrome lagged slightly on pragmatic and grammar scales. The early development proceeded in most cases with exponential or logistic growth. This stresses the great potential of early intervention.

3.3.11. Effect of parity, gravidity, previous miscarriage, and age on risk of Down’s syndrome: population based study (Chan et al, 1998):

This study investigated whether the risk of Down's Syndrome is increased independently of maternal age by maternal parity, gravidity or previous miscarriage in South Australia for 20,000 births annually. The effects of parity, gravidity, number of previous miscarriages, and mother’s age (by single year of age) on risk of having a fetus with Down’s syndrome were modeled separately using person regression; then the effects of parity, gravidity, and previous miscarriage were modeled separately after adjustment for the effect of mother’s age. Over-dispersion was detected in all the Poisson models constructed, and an over-dispersion factor was estimated using the square root of Pearson’s $\chi 2$ divided by the number of degrees of freedom. After analysis using births and terminations of pregnancy, the result showed no significant increase in risk for increase in parity or gravidity. When only births were analyzed for 1986-95, the increased risks with increase in parity ($P<0.001$) and gravidity ($P<0.01$) were not significant after adjustment for age ($P=0.46$ and $P=0.75$ respectively); similar results were obtained for 1986-90 for increase in parity. The risk was not increased with the number of previous miscarriages, but the increase in risk with age was constant ($P<0.001$).

3.3.12. Time demands and experienced stress in Greek mothers of children with Down's syndrome (Padeliadu, 1998):

The purpose of this study was to asses the time demands placed on mothers of children with Down's syndrome, and the possible relationship between those demands and the stress which the mothers experience. The study sample consisted of 41 mothers of children with Down's syndrome living in Northern Greece and a comparison group of 41 mothers of non-disabled children. Three instruments were used for the data collection: (1) a questionnaire for biographic information; (2) a self-report form assessing the time demands placed on the mothers; and (3) an adaptation of the Clark Questionnaire on Resources and Stress (QRS) for the evaluation of the stress experienced. The results of this study revealed increased time demands on the mothers of children with Down's syndrome in comparison to the mothers of non-disabled children in terms of recreational/educational activities and total time demands. Furthermore, the mothers of children with Down's syndrome perceived the time they spend with their children less positively than the mothers of the comparison group.

3.3.13. Expressive pragmatic skills in pre-school children with and without Down's Syndrome: parental perception (Johnston, stansfield, 1997):

Parental perceptions of the pragmatic skills of six-preschool children with Down's Syndrome were compared to six-children without cognitive impairment. Children were matched for language comprehension age on the Reynell Developmental Language scale and parents were interviewed by using the pragmatic Profile of Early communication skill. Data from parents’ interview were analyzed by taking qualitative approach using content analysis. The result of this study showed that the children with and without Down's Syndrome had many similarities in reported behaviors and responses in addition five out of the six children with Down's Syndrome had some skills which were more advanced than their matched pairs. Researchers suggested that children with Down's Syndrome have a normal range of pragmatic skills and communicative intentions compared with children of similar levels of comprehension functioning at an early pre-school level.

3.3.14. **Immediate and long-term effects of developmental training in children with Down's Syndrome (Aronson & Fallstrom, 1997):**

The aim of this experimental study was to determine whether the rate of development of a group of mentally retarded children could be improved by early systematic mental training. 8 children with Down's Syndrome aged from 21-69 months, were trained systematically following a pattern of normal development, over a period of 1.5 years. The mental age of trained child compared with eight matched control group before, during and after the training period. The result showed that training had a significant effect on the mental age of the trained children. One year after the completion of training, the good effect was reduced in trained group, but still higher-over all than the control group. This finally suggested that continuous training process to achieve long-term benefit.

3.3.15. **Fathers' views of the effects on their families of children with Down syndrome (Hornby, 1995):**

This study examined fathers' views about the effects of children with Down syndrome on themselves and their families. Taped interviews were obtained from 90 fathers of children aged from 7 to 14 years. Qualitative analysis of the interview data revealed 28 categories of comments made by fathers. Result showed that the most frequent comment, made by 46% of fathers, was about the cheerful personality of their child with Down syndrome. About 42% of fathers talked about the initial trauma they experienced following the diagnosis; 43% of them bemoaned the restrictions imposed on the family, and 30% commented that the child had minimal effects on family life. The greatest concern expressed by fathers was the long-term provision for their children. More fathers commented on the positive effects on their marriage than on negative effects.

3.3.16. Parents' evaluations of pre-school services for children with Down syndrome in two Scottish regions (Rowan et al, 1993):

This study evaluates services provided for children with Down's syndrome in two Scottish regions. Two methods were used: postal questionnaires and telephone interviews. Services covered were those provided by general practitioners, hospital specialists, health visitors, speech therapists, occupational therapists, physiotherapists, educational psychologists, home teachers, social workers and voluntary organizations. The result showed that regional differences were found in provision and in parental satisfaction with currently available services, with some of these differences being dependent on child age. Overall, parents felt they were being given insufficient professional support, with contradictory advice not uncommon. Findings indicate that if limited resources are to be used to the maximum benefit of family and child, both subjective and objective measures of the relative values of different kinds of support at different ages are urgently needed.

3.3.17. Health problems in children with Down's Syndrome (Turner et al, 1990):

The aim of this study is to identify health problems of 117 children with Down's Syndrome through questionnaire to their mothers. The child age of this study school aged with mean age 2 years 2 months, range 6 to 14 years. The result of this study showed that vision and hearing problems and respiratory infectious were identified as the most common health problems, affecting a large percentage of the children.

3.3.18. Evaluation of preschool children with Down's Syndrome in Cape Town using the Griffiths scale of Mental Development (Neser et al, 1989):

This study aimed to evaluate 55 children with Down's Syndrome by using Griffiths scale of Mental Development to evaluate development milestone. The result showed a significant decrease in developmental quotient with increase age child, and the hearing and speech sub-score was lower than the other sub-scores. No significant associations were found between maternal age, sex, social class or race of the child and mental development. There was significant association between developmental quotient and the number of siblings. Finally the developmental functioning was improved with preschool stimulation when comparing children cared at home during the day.

3.3.19. Effect of maternal education on prognosis of development in children with Down's Syndrome (Sharav et al, 1985):

Longitudinal development data from 40 home-reared children with Down's Syndrome who had been enrolled in an infant stimulation program were analyzed by the level of maternal education: high, medium or low. The result showed that high level of maternal education was significantly correlated with higher mental development scores (P less than 0.001), and significantly differed from scores of those with medium and low maternal educational level (P less than 0.001). In the same study analysis of longitudinal data of a subgroup of 11 children with Down's Syndrome showed remarkable intra-subject consistency and inter-subject variability. This suggested that the intellectual functioning of the population with Down's Syndrome is not a uniform one but is subject to the same genetic and environmental influences as the rest of population.

3.3.20. Counseling about Down's Syndrome: the parents' viewpoint (Gilmore & Oates, 1977):

The aim of this study was to study the viewpoint of child Down's Syndrome parents about what sort of information they were given at the time of diagnosis and what arrangements were made for the child's future. By interviewing 50 parents of Down's Syndrome children aged ranged between 3 months and 8 years at the time of survey. The result during the first week with an increasing proportion being dissatisfied with the timing the longer the delay in telling what was wrong with children. The mother has been told first in 48% of cases, and both parents have been told together in only 20% of cases, 84% had medical follow up, community follow up, whereas 10% had no such arrangements. Parents were suggested to give chance to meet other parents of children with Down's Syndrome.

3.4. Studies of satisfaction:

3.4.1. Outpatients' satisfaction with physiotherapy services at Al-Shifa Hospital and Al-Wafa Medical Rehabilitation Hospital in Gaza (Hillis, 2008):

The aim of this study was to evaluate the level of clients' satisfaction with physiotherapy services in both major hospitals in this field, Al-Shifa and Al-Wafa Medical Rehabilitation Hospitals. The researcher used cross sectional design to select representative convenience sampling consists of 100 subjects from Al-Shifa Hospital and 51 from Al-Wafa Medical Rehabilitation Hospital. A standardized structured questionnaire was developed to cover seven domains of satisfaction (appointments registration, environment comfort and convenience, approach of care, physiotherapy staff skills and courtesy, communication and information, privacy and loyalty). The result of this study showed that the overall satisfaction with physiotherapy services in both hospitals was 88.7%, whereas it is extremely high in Al-Wafa Medical Rehabilitation Hospital 100% than 83% in Al-Shifa Hospital. On the other hand, there was no significant relationship between demographic (age, gender residency), socioeconomic variables (marital status, educational level) and the level of clients satisfaction. But there was a significant relationship between organizational variables (e.g. hospital knowledge, first experience with hospital, physiotherapy session duration, session number) and level of client satisfaction. This study recommended encouraging educational training program for physiotherapy staff, to establish monitoring system for policy makers to detect problems and solve it. Finally the manager of physiotherapy should inform about this study result in order to take action toward improvement quality of physiotherapy services which will influence clients' satisfaction.

3.4.2. Evaluation of integrated mental health counseling into primary health care from the point view of clients (Abu Seedo, 2007):

The study aimed to examine the effectiveness of integrated mental health counseling into primary health care from point view of the clients. The sample of this study consisted of 40 women who attending to psychological department of Ard El-Insan clinics (Gaza, Khanyounis). The study tools were 3, the first one is symptoms checklist 90. This scale consists of 90 mental symptoms which may women experience during her life. The second is a checklist of attitude toward mental services into primary health care which was developed by the researcher. The third one is a checklist of satisfaction with mental health services which was developed by the researcher. The result of this study showed that the level of client satisfaction about mental health services into primary health care was 87.4%. Otherwise, there were significant differences between average scores of women in pre-test and post-test on mental health symptoms. There were statistical differences between average scores of the pre-test and post-test on checklist of attitude toward mental health services into primary health care clinics. This study recommend to integrate mental health services into primary health clinics as in Ard El-Insan clinics, provide training courses to all medical team on mental health issues. Finally to encourage researcher to study subjects related to integration medical health with mental health.

3.4.3. Parental satisfaction with health services provided to children with Down's Syndrome in north west England: an ENT Perspective (Hans et al, 2007):

This study aimed to evaluate parents satisfaction with medical and allied health services provided to children with Down's Syndrome in north west England compared ENT and its services with other areas of health service provision. A questionnaire survey of parents attending a north west England Down's Syndrome association conference. Demographic data, departments visited, satisfaction with each service, waiting time for each service, service need and accessibility were recorded. The result showed that otolaryngology had been used by 50% of children with satisfaction of 2.63 (second worst score). Speech and language therapy was used by 90% of children with a satisfaction of 3.26 (the worst score). The service felt to be most needed and the most difficult to access was speech and language.

3.4.4. Parent–Therapist Communication and Satisfaction with the Services of a Child Development Center: A Comparison Between Israeli Parents—Jews and Bedouins (Carmel et al, 2006):

This study evaluates the level of general satisfaction with the services of a child development center in 2 groups of Israeli parents, Jews and Bedouins. It also assesses 3 dimensions of therapist-parent communication significantly explain general satisfaction with the center's services. A total of 193 parents of children ranging from 6 months to 6 years of age participated in the study (84% response rate). Parents' attitudes regarding their communication with the center's therapists were evaluated by 15 items that were clustered into 3 dimensions of communication: caring, collaboration, and interest. The result showed that general satisfaction with the center's services was high in both groups. Relatively high average scores were also given to the studied dimensions of communication. Jews were more satisfied with the center's services than were Bedouins and ranked caring and collaboration significantly higher than did Bedouins. Caring and collaboration best explained the variability in general satisfaction in a multivariate analysis. Being a Jew or a Bedouin parent was not found to be a significant explanatory variable of general satisfaction with the center's services. Therapists' expressions of care and collaboration with parents seem to be key factors in explaining parents' general satisfaction with rehabilitation services in the 2 different cultural groups.

3.4.5. Satisfaction with care and ease of using health care services among parents of children with special health care needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care (Ngui & Flores, 2006):

The purpose of this study was to examine whether racial/ethnic disparities exist in parental reports of satisfaction with care and ease of using health care services among children with special health care need (CSHCN) and to identify factors associated independently with satisfaction with care and ease of use of health care services among CSHCN. By analyzing data for 38,886 CSHCN <18 years of age in the National Survey of CSHCN, conducted from 2000 to 2002. Outcome variables included perceived satisfaction with care and ease of service use. Covariates included socio-demographic factors, insurance, interview language, condition severity and stability, adequacy of family-centered care measures, and having a personal doctor/nurse. The result of this study showed that the prevalence of reported dissatisfaction with care and problems with ease of using services among parents of CSHCN were 8% and 25%, respectively. Black and Hispanic parents were significantly more likely than white parents to be dissatisfied with care (13% and 16% vs. 7%) and to report problems with ease of service use (35% and 34% vs. 23%).

3.4.6. **Clients satisfaction with nursing care provided at selected hospitals in Gaza Strip (Abu Saileek, 2004):**

The aim of this study was to assess levels of clients' satisfaction with nursing care in two major governmental hospitals in south Gaza. By using cross sectional design, the researcher selected his own sample randomly from both hospitals; 159 subjects form European Gaza Hospital and 268 from Nasser Hospital, the response rate was 93.6%. Standardized structured questionnaire was developed containing six domain of satisfaction with nursing care (information and interaction, availability/ attentiveness and openness, comfort and environment, nursing skills and professionalism, organizational culture, counseling and advising). Result of this study revealed that there was significant relationship between clients' satisfaction and the service provider, the overall satisfaction was 70.1% in both hospitals, whereas satisfaction level in European Gaza Hospital was 61.7%. Finally this study showed that there was significant relationship between the level of clients' satisfaction and socio-demographics. This study recommended some information in order to improve quality of nursing services in hospitals that will influence the level of client's satisfaction.

3.4.7. **Parental satisfaction with an early family intervention program (Reidy et al, 2004):**

The objective of this study was to evaluate parental satisfaction with a family intervention program. The program provides help and support for parents with newborns who have specific health problems (e.g., cleft palate and/or lip; Down syndrome). Four-family subscales, personal (emotional and cognitive), marital, parental, and extended family and others, were examined. The Results revealed that the majority of parents were satisfied with the intervention and significant differences in satisfaction levels (depending on the sex of the parent), the child's diagnosis, and annual income. Mothers of newborns with Down syndrome were more satisfied than fathers with the personal-emotional support they received. Low-income families were more satisfied than those with higher incomes for all subscales. On the parental subscale, those whose child had a cleft lip/palate were more satisfied than those whose child had Down syndrome.

3.4.8. Parents' satisfaction with medical and social assistance provided to children with Down's Syndrome: experience in Estonia (Reimand et al, 2003):

The main aim of this study was to investigate the extent of parents' satisfaction with medical and social services in Estonia provided for the D.S individuals and their families. 59 Down's Syndrome parents from 1999 to 2001, answered questionnaires in which their satisfaction to medical and social services were assessed. The result showed that satisfaction with the quality of the information about D.S is low; most parents were not satisfied with the social and rehabilitation benefits. This study suggested that D.S families need more medical information about this syndrome. More work need to be done in the area of rehabilitation and social assistance.

3.4.9. Clients' satisfaction with radiology services in Gaza Strip (Al Hindi, 2002):

The aim of this study was to identify the clients' satisfaction from radiology services in both centers in Al-Shifa Hospital radiology department and Gaza Diagnostic Center, by using cross sectional design to select systematic randomized sampled was 410 clients from both centers. The response rate was 78.4%. A standardized structured questionnaire was developed contain seven dimensions of satisfaction (organizational culture, continuity and affordability, availability, interaction and communication, attitude and perception, comfort and privacy and approach of care). The result of this study showed that there was high level of satisfaction with radiology services 82.5%, other result showed that there was significant relationship between financial status, educational level and level of satisfaction, the number of visits, waiting time and client satisfaction. On the other hand, there was no significant relationship between age, gender, residency place, occupation and the level of satisfaction.

3.4.10. Impact of child health centre organization on parental satisfaction (Sundelin et al, 2000):

The aim of this study is to describe differences in parental satisfaction with child health services under different organizational arrangements. The study had a cross-sectional design and was based on 3 largely identical surveys, involving 60 questions, performed in 1970, 1988 and 1993. The original questionnaire was developed by one of the authors in 1970. This study analyzes responses to 5 demographic questions and 12 questions regarding the content of child health services, evaluating parental satisfaction with these services. The study population in 1970 consisted of 443 parents (93% of those invited to participate) with children 6-18 months old, 1008 (82%) in 1988 and 1071 (80%) in 1993. the result showed that parents expressed more satisfaction with child health services in 1970 and 1993 compared to 1988. The results highlighted the vital question of how child health care should be organized in order to satisfy parents.

3.4.11. How satisfied parents are of pre-school children who have special needs with the services they have received? A consumer survey (Stallared & Lenton 1992):

This survey summarizes the parents’ perceptions of 41 pre-school children with special needs to ascertain their satisfaction with the services they had received and how these could be improved. The result showed that there is an overall high level of satisfaction, although parent's felt they had not received as much information as they wanted on their child's condition (29%) available help for family recorded was (44%) of participants, (61%) were financially benefited, information about their child's future 61%, also families felt that they had not received enough family support 43%, and that professionals regularly did not understand their concerns 32%.

3.4.12. Life satisfaction and activity preferences in parents of Down's syndrome children (Bränholm & Degerman, 1992):

In this study the impact of parenting a child with Down's syndrome on life satisfaction and non-work activities was investigated in 37 couples using mailed checklists. The results were compared with those found in all 89 parents from a randomly selected population. Only for 7 of the 41 non-work activities were different between the two groups of parents. The vast majority of both groups were satisfied or very satisfied with life as a whole and with partnership relations, sexual life and family life. The 8 domains of life satisfaction formed 3 factors. In congruence with previous findings in a non-selected sample, these factors were significant classifiers for satisfaction with life as a whole, an expressive (emotion related) factor being the major classifier. The close similarities in non-work activities and life satisfaction are interpreted as a result of adequate adaptive resources within the majority of families of children with Down's syndrome.

3.5. Summary of Literature Review:

3.5.1. Early intervention program studies:

After reviewing the literatures, the researcher found that there are different studies that evaluated the early intervention program for Down's Syndrome children, most of the available studies are new studies. The researcher tends to high light on these studies in the following points:

- **Objectives of the studies:** Most of them were assessing similar goals. for example the study of (Maria et al 2006), evaluated functioning of children whom receiving early intervention program That study was similar with (Shonkoff and Hauser, 1987) study, which was to evaluate effects of early intervention servieces in disabled child less than 3 years and their families.

- **Population of studies:** Most of literature reviewed was focused on children e.g. (Richardson et al, 1980) study, some samples consisted from 50 children with Down's Syndrome e.g. (Mahoney et al, 2001) study. On the other hand, there are some studies that allocated sample that differs from that study e.g. (Donald Bailey et al, 2004) study; the sample consists of 3338 parents of young children with or of risk for having disabilities. Other studies like (Louw & Kritzinger, 1991) used 3 infants with Down's Syndrome sample for studies.

- **Instrument of studies:** Most of the studies, which evaluated the effectiveness of early intervention program on motor, cognitive, intellectual, adaptive, and social skills, showed little similarities in the instruments used, e.g. (Maria et al, 2006) study used Muscle Tone Scale; whereas (Morgan et al, 1993) study used Stanford-Binet Intelligence Scale and Bruininks-Test, although the scale used was different in each study. Literature showed that different tools were used to evaluate effectiveness of different intervention program. Instruments highlight the following dimension: satisfaction, performance of service provider, effectiveness of program services and the accessibility of services.

- **The result of the evaluative studies:** results were slightly similar to each other like (Maria, 2006) study, which showed grater gains in fine and gross motor function and less sever limb hypo-tonicity that slightly similar to (Shonkoff and Hauser, 1987) study, resulted that the early intervention program is effective in promoting developmental progress.

- On the other hand, there were few studies showed that no differences exist between D.S group who participated in early intervention program and who didn't participate like (Wang et al, 2007) study and (Piper & Pless, 1980) study. Relevant to this point these studies suggested improving the way and altering pattern of early intervention programs with development and modification. Moreover, the studies suggested and stressed out that great potential of early intervention will be achieved when facilitating early intervention program for each field.
- From the previous review of literature, the researcher came to the a conclusion that there is a need to conduct this study which aimed to evaluate the effectiveness of early intervention program for Down's Syndrome child in our community from parent's point of view. This will be considered the first step in this field in Gaza Strip.

3.5.2. Satisfaction studies on services for Down's Syndrome child:

The researcher found that all of studies were newly applied studies, for the objective of these studies was mainly to evaluate the level of parent's satisfaction with the services for a child with disabilities like (Evans 2006) study and (KL Yam 2005) study. The samples of the satisfaction studies were mainly similar as they focused on parents of a child of Down's Syndrome with little variation in total number of sample, e.g. (Evan, 2006) study was 193 parent, whereas (KL Yam, 2005) study was 98 parent.

With regard to tools that were used to evaluate level of satisfaction, researcher shows that they are many tools. One of the studies used a questionnaire, another used more than one tool, other collected data by telephone interviewed, others like (Reidy et al, 2004) study used four family subscales.

Results showed some similarities but most of them revealed that parents were generally satisfied with the services provided for their children. Little attention was paid for that have the factors effect on the satisfication level for services. (Rowan et al, 1993) study, showed that regional differences were found in provision and in parental satisfaction with currently available services with some of these differences being dependent on child age.

3.5.3.General comments:

From the previous review, the researcher considers studying satisfaction an important objective of this study, as almost all of the studies considered it to be the main domain to explore the strengths and weakness in the health services provided for Down's Syndrome.

Finally, the researcher have gained a valuable experience with regard to the topic by reviewing the literature review her knowledge about the variables of the study has increased, in addition to that, the researcher was able to develop a well design instrument to evaluate EIP services. Furthermore, review of previous studies assessed the researcher in knowing about the sampling techniques used for this kind of research and also the statistical analysis tools.

CHAPTER 4

Chapter 4

Methodology

4.1. Introduction:

In this chapter the researcher presents the study methodology which includes: study design, study population, study setting, period of study, sample size, sampling process, inclusion criteria, exclusion criteria, data collection, validity and reliability of instrument and finally limitation of study and ethical consideration.

4.2. Study design:

The design of this study is descriptive cross-sectional design that helps the researcher to have a sample once at fixed time.

4.3. Study population:

The target population of this study consists of all Down's Syndrome children and their mothers who are recorded in the early intervention program at Right to Live Society, the total number was 135 child.

4.4. Period of study:

The study was conducted in December 2007 after the researcher has an approval from the director of RTLS to apply this study. Pilot study conducted in January 2008.

Data collection started in February 2008 and continues to the end of March 2008.

Data entry, data clearing and analysis, and writing of the final report continued till the beginning of April 2008.

4.5. Study Sample:

In this study the researcher conveys all the study population 135 and finally come with 73 subjects according to inclusion criteria.

4.6. Eligibility criteria:

4.6.1. Inclusion criteria:

- All children of Down's Syndrome who were receiving early intervention services since 6 months and more, aged from 1-4 years in the RTLS: males and females; all of them were included in this study by filling the researcher questionnaire with their mothers.
- In addition to that, the researcher chose 18 cases from the cases that finished receiving the early intervention services in the RTLS, and entering another program (kindergarten).

4.6.2. Exclusion criteria:

- Mother's of a child who refuses to participate
- Children who are not related to previous criteria.

4.7. Reasons for selecting the sample:

As the researcher mentioned before that the total population was 135 cases recorded in the Right to Live Society at early intervention program during a certain period, but according to the researcher criteria 25 cases were excluded, 20 cases pilot subjects were excluded, 23 cases were recorded in program but not schedulally review the program services. The researcher tried her best to contact with this number of cases by phone, reaching their home and phone numbers via RTLS to attend the program, but it was so difficult. Finally the researcher conducted 73 subjects; 18 were newly finished from EIP and enrolled in another program (kindergarten), and 55 cases from EIP.

4.8. Sampling process:

The researcher chosed the study sample according to her inclusion criteria by covering all the study population conveniently.

4.9. Instrumentation:

The researcher used self-report structured questionnaire to collect data from 73 mothers after they receive session at EIP, timing for data collection was 10-15 minutes.

4.10. Questionnaire design:

The researcher developed her own questionnaire depending on literature review by using 5 Likert scales. The constructed questionnaire consists of mainly 3 parts (domains) (see annex 10 for more details).

The first part: consists of 19 questions which related mainly to socio-demographic data (age – sex – education – and duration of receiving services).

The second part: consists of four domains of mother satisfaction perspective, performance of services provider, effectiveness of program services and accessibility of services.

The third part: consists of five questions related to mother' perspective toward other services in EIP. Mothers were asked to use the scale of too, little, no benefit and not needed, and then elaborate more on their answers.

Finally, there are three open-ended questions about the best beneficial services, disadvantages of services available and the necessary suggestions to improve the services in this program from family perspective.

The following table shows the domains and items of the 2nd parts.

Table (4-1): Domains and numbers of items included in the 2nd part of questionnaire

No.	Domains	Total number of items	Number of items
1.	General satisfaction	9	1, 2, 3, 4, 5, 6, 7, 8, 9
2.	Services provider families perspective	18	10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27
3.	Effectiveness of early intervention services	14	28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41
4.	Accessibility to society	6	42, 43, 44, 45, 46, 47

4.11. Pilot study:

The pilot study was conducted on 20 mothers whom their children receive early intervention services in the RTLS; at least 6 months and above. Pilot study is used to examine the clarity and ambiguity, length and suitability of questions before the data collection process starts (Pilot, 2004).

4.12. Data collection:

The researcher prepared 73 questionnaires, organized and numbered serially, in addition to, a consent form attached with each questionnaire encouraging mother to participate in the study for research benefits only with complete confidentiality. The answer period for the questionnaire was estimated to be 10-15 minutes. The researcher checked all questionnaires before data entry process.

4.13. Data entry and analysis:

The researcher completed entering all 73 questionnaires using SPSS version 13 under supervision of the academic supervisors.

Steps of data entry process consist of:

1. Reviewing the filled questionnaires.
2. Coding of questionnaires.
3. Identifying data entry model.
4. Identifying variables.
5. Coding variables.
6. Cleaning data.
7. Correlation coefficients for testing validity.
8. Cornbach's Alpha for testing reliability.
9. Running frequency tables for study variables.
10. Running descriptive statistics.
11. Running Chi-quire (non parametric statistic).

4.14. Psychometric properties of the instrument:

4.14.1. Validity of the instrument:

☒ Validity: It means that the degree to which an instrument measures what is supposed to measure (Polit, 2004).

☒ Content validity: It is necessarily based on judgment, concerned with the sampling adequacy of the content area being measured (Polit, 2004). It is also defined as the extent to which a test reflects the variables it seeks to measure (Holm & Liwelly, 1986).

☒ Face validity: Refers to whether the instrument looks as though it is measuring the appropriate construct (Polit, 2004).

Content validity was conducted before pilot study and actual data collection by experts to ensure appropriateness, relevancy, clarity, and completeness of the questionnaire.

Face and content validity evidences have been gathered for the research instrument through submitting the instrument to seven experts' panel with different backgrounds (see annex 4). The researcher modified the instrument according to 85% of experts' panel recommendation. The questionnaire was then prepared in both languages: Arabic and English with a covering letter.

☒ Internal consistency validity evidence: To measure construct validity for the instrument, the researcher used the correlation coefficient for each domain of questionnaire with the total score of items in the questionnaire.

Table (4-2): Correlation coefficient between instrument domains and total score of instrument

No.	**Evaluation EIP services domains**	**Pearson correlation**	**Significant level**
1.	General satisfaction	0.80	significant at the 0.01 (**)
2.	Services provider from families perspective	0.90	significant at the 0.01 (**)
3.	Effectiveness of physiotherapy services	0.88	significant at the 0.01 (**)
4.	Effectiveness of capabilities development	0.86	significant at the 0.01 (**)
5.	Accessibility of services	0.51	significant at the 0.05 (*)

(*) Correlation is significant at 0.05 level.

(**)Correlation is significant at 0.01 level.

Table (4-2) shows the correlation coefficients between the total score for every domain and total the score of the instrument. All correlations are significant at the level 0.01, and all coefficients ranged between (0.51 – 0.90).

Table (4-3): Correlation coefficient between general satisfaction items and total score of domain

No.	Items of general satisfaction domain	Pearson correlation	Significant level
1.	You are satisfied with the services received by your child in the Society	0.92	significant at the 0.01 (**)
2.	If you have the opportunity of finding other options, you will continue your interaction with this Society	0.4	not significant
3.	You are satisfied with the way your child is treated by the crew of the Society	0.9	significant at the 0.01 (**)
4.	You are satisfied with the performance level of the service providers in the Society	0.86	significant at the 0.01 (**)
5.	You are satisfied with the period of time you wait in before receiving the service	0.86	significant at the 0.01 (**)
6.	You are satisfied with the time spent with your child during receiving the service	0.8	significant at the 0.01 (**)
7.	You feel that your child benefits from the early intervention services	0.89	significant at the 0.01 (**)
8.	You are satisfied with the number of visits for your child in the early intervention program of the Society	0.57	significant at the 0.01 (**)
9.	You are satisfied with the improvement in the development of your child since joining the Society to receive the service	0.58	significant at the 0.01 (**)

(*) Correlation is significant at 0.01 level.

Table (4-3) illustrates the correlation coefficient for each item of the general satisfaction domain with total score of the domain. All correlations are significant at 0.01 level and the correlations ranged between (0.4 – 0.92) except the item 2.

Table (4-4): Correlation coefficient between each item of service provider-family perspective domain and total score of domain

No.	Items of service provider domain	Pearson correlation	Significant level
1.	The workers present the remedial plan that suites your child	0.73	significant at the 0.01 (**)
2.	All workers explain the plan's therapeutic options clearly	0.73	significant at the 0.01 (**)
3.	The workers discuss with you all the potential expectations of the state of your child	0.58	significant at the 0.01 (**)
4.	Workers are keep that the capabilities of your child will be known to all	0.58	significant at the 0.01 (**)
5.	Workers receive you and your child with respect	0.80	significant at the 0.01 (**)
6.	Workers answer your questions truthfully	0.75	significant at the 0.01 (**)
7.	The workers tell you about the reason for selecting specific plan for your child	0.83	significant at the 0.01 (**)
8.	Employees encourage you to ask questions about everything you do not understand of the plan	0.81	significant at the 0.01 (**)
9.	The workers give you the opportunity at the appropriate time and place to receive information	0.81	significant at the 0.01 (**)
10.	The workers ask about your point of view of the service provided	0.57	significant at the 0.01 (**)
11.	The workers provide the right atmosphere for you and your child during receiving the service	0.89	significant at the 0.01 (**)
12.	Workers are keen to meet the needs of your child as he/she progress in age	0.41	not significant
13.	You Do not feel the confidentiality during the work with your child	0.31	not significant
14.	Workers take strict confidentiality in dealing with your child	0.23	not significant
15.	Respect your own feeling and your child	0.50	significant at the 0.05 (*)
16.	You feel that the workers respect you and your child	0.65	significant at the 0.01 (**)
17.	You feel that you suffer hardship in order to obtain the services required for your child	-.07	not significant
18.	All workers present all their efforts in helping you to obtain a service	0.63	significant at the 0.01 (**)
19.	Workers are keen to participate in the implementation of the rehabilitative plan for your child	0.68	significant at the 0.01 (**)

(*) Correlation is significant at 0.05 level

(**)Correlation is significant at 0.01 level.

Table (4-4) shows the correlation coefficient for each item of service provider domain and total score of domain. Correlations are significant at the level of 0.01 and 0.05. The correlations ranged between (-0.07 – 0.89), except items no. 12, 13, 14, 17.

Table (4-5): Correlation coefficients between each item of effectiveness of physiotherapy services domain with the total score of domain

No.	**Items of effectiveness of physiotherapy services domain**	**Pearson correlation**	**Significant level**
1.	Physiotherapy is suitable for your child	0.73	significant at the 0.01 (**)
2.	Your child is in continuous improvement with the physiotherapy provided	0.84	significant at the 0.01 (**)
3.	You have an understanding of the therapeutic exercises for your child	0.86	significant at the 0.01 (**)
4.	The physiotherapy Specialist is keen to assess the status of your child from time to time	0.84	significant at the 0.01 (**)
5.	The time of the physiotherapy session is appropriate for your child.	0.83	significant at the 0.01 (**)
6.	The duration of the therapeutic meeting is sufficient	0.83	significant at the 0.01 (**)
7.	You feel that your child benefits from exercises that he/she has at home	0.69	significant at the 0.01 (**)
8.	You feel that the meeting place is comfortable for you and your child	0.74	significant at the 0.01 (**)

(**)Correlation is significant at 0.01 level.

Table (4-5) shows the correlations coefficient for each item of effectiveness of physiotherapy services and total score of the domain. Correlations are significant at the level of 0.01. All correlations ranged between (0.6 – 0.8).

Table (4-6): Correlation coefficients between each item of effectiveness of capabilities development domain and total score of domain

No.	**Items of effectiveness capabilities development domain**	**Pearson correlation**	**Significant level**
1.	You are able to solve the educational and behavioral problems of your child's	0.88	significant at the 0.01 (**)
2.	You feel that the service of capacity development is basic to the success in the rehabilitation plan for your child	0.92	significant at the 0.01 (**)
3.	The specialist explained in detail the status of your child	0.71	significant at the 0.01 (**)
4.	The specialist tells you the rehabilitative plan to be implemented with your child	0.79	significant at the 0.01 (**)
5.	You participate in the rehabilitation plan for your child	0.66	significant at the 0.01 (**)
6.	The specialist follows the implementation of instructions that she/he gives you with your child	0.76	significant at the 0.01 (**)

(**)Correlation is significant at 0.01 level.

Table (4-6) illustrates the correlation coefficients for each item of effectiveness of capabilities development and total score of the domain. Correlations are significant at level of 0.01. The correlations ranged between (0.6 – 0.9.

Table (4-7): Correlation coefficients between each item of accessibility of services domain and total score of domain

No.	**Items of accessibility of services domain**	**Pearson correlation**	**Significant level**
1.	You access to the Society easily	0.98	significant at the 0.01 (**)
2.	The working hours in the Society allow you to visit appropriately	0.52	significant at the 0.05 (*)

(*) Correlation is significant at 0.05 level.

(**)Correlation is significant at 0.01 level.

Table (4-7) illustrates the correlation coefficients for each item of accessibility of services and total score of domain. Correlations are significant at the level of 0.05 and 0.01. Correlation ranged between (0.5 – 0.9).

4.14.2. Reliability:

The reliability of an instrument is the degree of consistency with which the instrument measures the attribute. The less variation an instrument produces in repeated measurements of an attribute, the higher is its reliability (Polit, 2004).

Another way to define reliability is in terms of accuracy; an instrument is reliable to the extent that errors of measurement are absent from obtained scores, that maximize true score and minimize error component.

Researchers generally used reliability coefficient which is numeric value of how reliable the instrument is. It is ranged from a low of 0.00 to a high of 1.00. The higher the value, the more reliable is the instrument for this study. The researcher used Cornbachs' Alpha coefficient, and it was 0.83 that is the higher degree of reliability of instrument.

The following table shows Cronbach's Alpha value for instrument domains.

Table (4-8): Cronbach's Alpha for instrument domains

No.	**Domains**	**Total number of items**	**Cronbach's Alpha α**
1.	General satisfaction	9	0.77
2.	Services provider families perspective	19	0.74
3.	Effectiveness of physiotherapy services	8	0.78
4.	Effectiveness of capabilities development	6	0.79
5.	Accessibility of services	2	0.80
Total		44	0.83

From the above evidences for validity and reliability, the researcher concluded that, the developed instrument has been high degree of reliability and validity.

4.15. Ethical consideration and procedures:

For completing this study smoothly, the researcher has conducted three ethical approvals letters. The first one is to the director of the RTLS to get agreement to conduct this study in their society mainly EIP (See Annex 3).

The second letter was the explanatory letter for the mother of a child to explain for her the purpose and objective of the study.

The third letter was for maintaining participants rights, also respects their anonymity and confidentiality which will be maintained by a consent form for each participant, and it explains that withdrawal at any stage of the study is discretionary (see Annex 8).

4.16. Difficulties that faced the researcher:

☒ Very bad weather condition was a big obstacle for the researcher during data collection period because D.S children are so sensitive to cold conditions.

☒ Hard and unstable political situation was a major limitation during data collection, especially with the geographical place of the RTLS.

☒ The lack of references related to the effectiveness of early intervention program in developing countries, especially family perspective.

CHAPTER 5

Chapter 5

Results and Discussion

5.1. Introduction:

In this chapter the researcher presented and discussed the results of statistical analysis of the data, including a descriptive analysis for demographic variables including: socio-economic, service duration, knowledge about services, and child arrangement. In addition to that, the relationship between family satisfaction with socio-demographic variables, and the differences between overall satisfaction with family centered services were presented and discussed. Finally the researcher discussed the results in the light of study literature review.

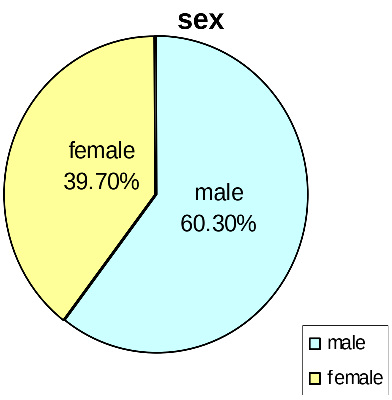
5.2. Descriptive analysis for the study variables:

5.2.1.Demographic characteristics:

The following graphics describe the main socioeconomic and demographic characteristics of the study participants which consisted from 73 subjects. The variables include: gender – governorate – age child – rank of the child – service duration – mother education level – mother employment status– number of household family members – father job.

5.2.1.1. Gender of child:

Figure (5-1) shows that the highest percentage of Down's Syndrome children in this study was male with percent 60.3%, while female percentage 39.7%.



. Figure (5-1): Distribution of the study population by gender

5.2.1.2. Governorate:

Figure (5-2) shows that most of the study participants were from Gaza with percentage of 38.3%, then Mid-zone and North with percentage of 23.3%, whereas the little percentage was from Kanyounis & Rafah areas with percentage of 5.5% & 9.6%.

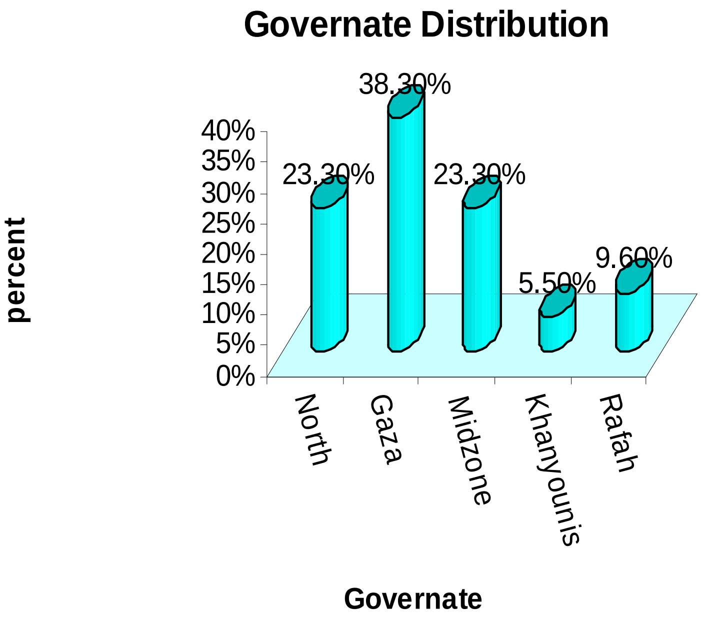


Figure (5-2): Distribution of the study population by governorate

5.2.1.3. Mother's age:

Figure (5-3) shows that the high percentage of mother age was in group of 31-40 years old with percentage of 52.1%, then age group of 20-30 with percentage of 27.4%, while the lowest percentage was for the group aged 41-48 years old with percentage of 20.5%.

This result is goes with the reviewed literature and the conceptual framework that shows that the risk for giving Down's Syndrome to children is increasing when the mother's age is 35 years old and above.

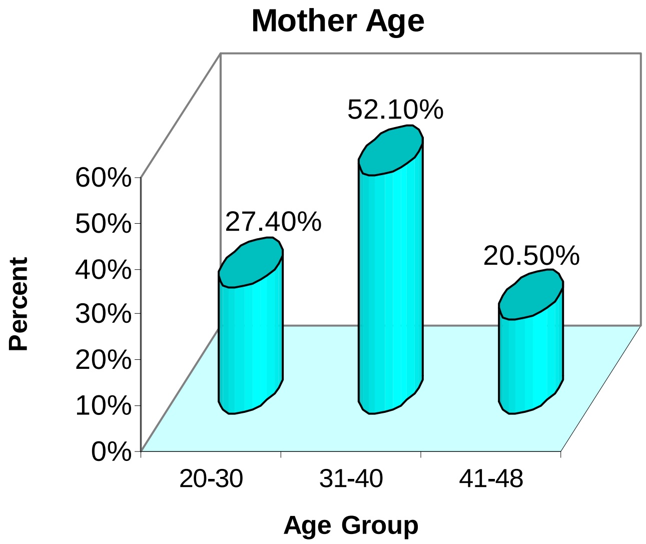


Figure (5-3): Distribution of the study population by age

5.2.1.4. Mother's education level:

With regard to child's mother education level, results showed that most of children's mothers were at the secondary level (39.7%), then come those with preparatory education (23.3%), while the lowest percentages were for those who had a diploma certificate or illiterate as in figure (5-4).

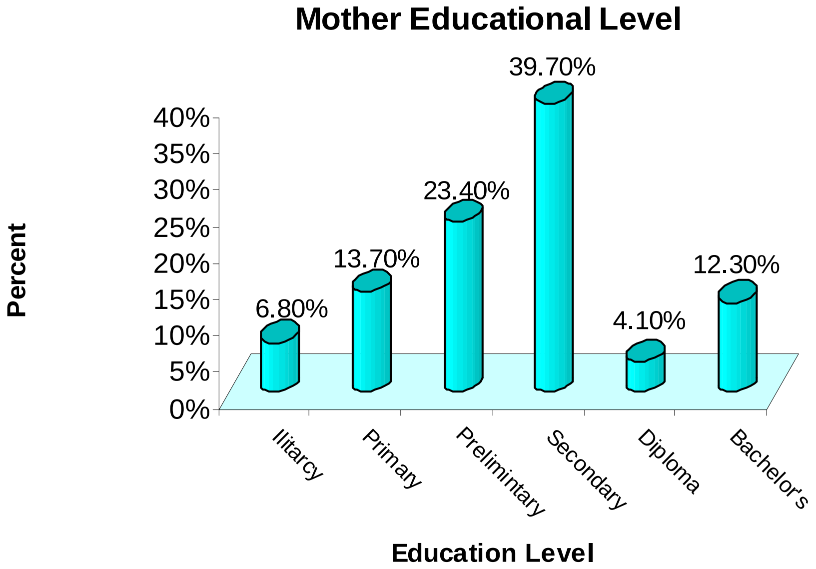


Figure (5-4): Distribution of the study population by mother education level

5.2.1.5. Mother's employment:

According to figure (5-5), the highest percentage with regard to mother employment status showed that mothers were not employed. This result is in the Palestinian culture and tradition where most of women are housewives.

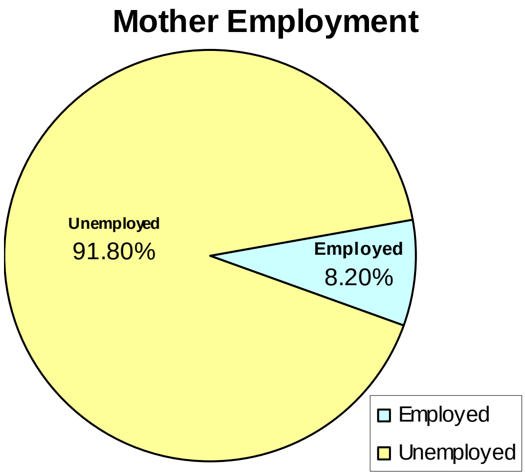


Figure (5-5): Distribution of the study population by mother employment status

5.2.1.6. Father's employment status:

As shown in figure (5-6), more than half of the fathers of the D.S children were shown to be employed. This result is connected with the instable difficult political Palestinian situation that increased the unemployment ratio.

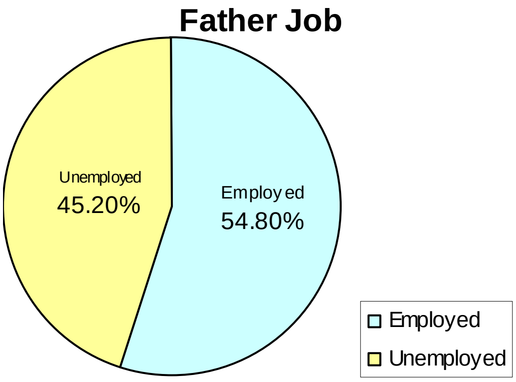


Figure (5-6): Distribution of the study population by father's employment status

5.2.1.7. Other disabilities:

When mothers were asked the following question: "Is there any other disabled child in your home?" Result showed that most families with Down's Syndrome children in RTLS did not have another disabled child in their home. See figure (5-7) for more details.

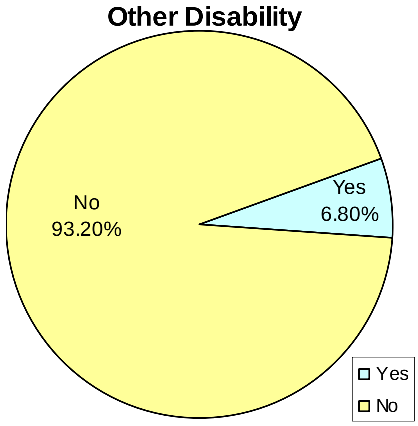


Figure (5-7): Distribution of the study population by another disabled child with Down’s Syndrom at home

5.2.1.8. Other rehabilitative institution:

Relevant to the question: "Do you have to attend another rehabilitative institution rather than RTLS society?". Results showed that the RTLS society is considered by most of the participants to be the only institution caring for Down's Syndrome in Gaza. Those who seem to attend other institutions were about (14%) as shown in figure (5-8).

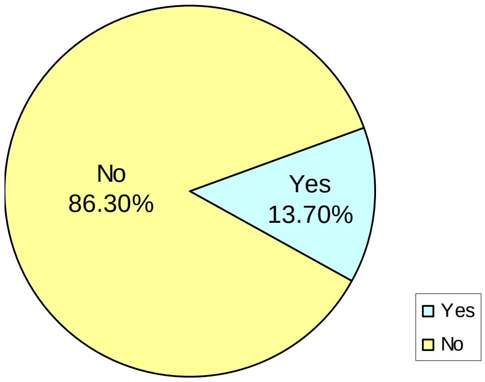


Figure (5-8): Distribution of the study population by “attending other rehabilitative institution”

5.2.1.9. Admitted to hospital:

To answer the question: "During receiving the early intervention services in the RTLS society, have you admitted your child to a hospital?". During the data collection period, results showed that about (61%) of children were admitted to hospital as in figure (5-9).

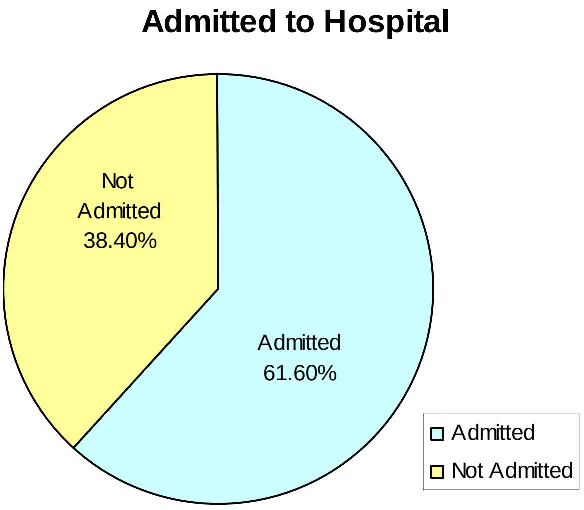


Figure (5-9): Distribution by admittion to hospital

From the total subjects who were admitted to a hospital, about (60%) reported that the cause for admitting a hospital was due to respiratory tract infection, whereas (27%) reported that the cause was due to congenital heart malformation, (13%) reported that was due to other diseases like (flue and gastrointestinal infection). This result is consistent with (Turner et al, 1990) study that concluded respiratory infection affecting large percent of Down's Syndrome children then congenital heart disease.

5.2.1.10. Knowing about the RTLS:

Concerning the question: "How do you know about the RTLS?". Results showed that the highest percentage was for those with referral from medical doctors; whereas the lowest percentage was for those with previous experience with RTLS; whilst (18%) reported knowing about the RTLS from the internet and web page. See figure (5-10) for more details.

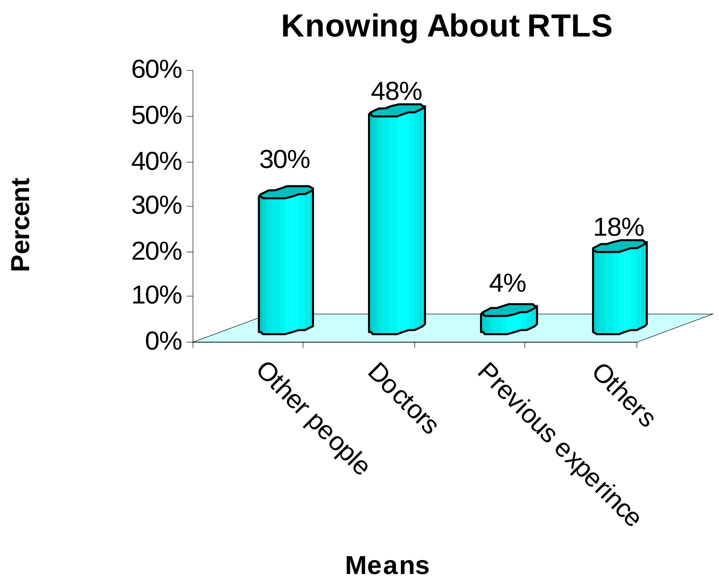


Figure (5-10): Distribution of the study population by knowing about the RTLS

5.2.1.11. Getting any help from RTLS:

As shown in Figure (5-11), 92% reported receiving help from RTLS in the forms of (milk package, medical insurance and transportation). RTLS is a non-governmental charity and had been supported from foreign volunteers to provide help for Down's Syndrome children.

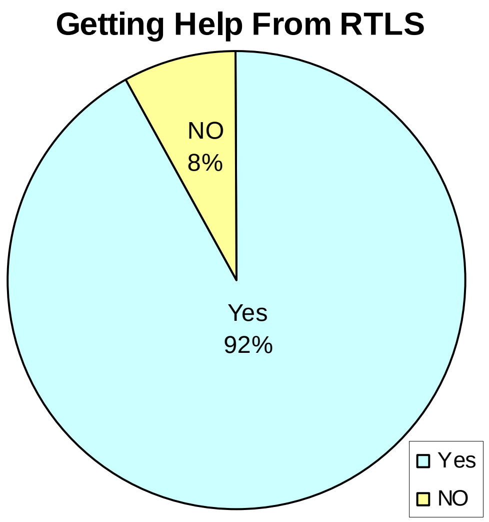


Figure (5-11): Distribution of the study population by getting any help from RTLS

5.2.1.12. Advised others to be admitted to RTLS:

In Gaza Strip there is only one institution caring for Down's Syndrome clients which is RTLS, so the result of the study showed that the all study participants (100%) reported advising others with Down's Syndrome child to get care from RTLS. This is congruous with the result of general satisfaction for participants of this study.

5.2.1.13. Child age, duration service, child rank, number of family household:

The following table shows the mean, standard deviation for duration of service, in addition to socio-demographic variables (child age, child rank and number of family household).

Table (5-1): Distribution of the study population by child age, child rank and number of family household

Variable	Minimum	Maximum	Mean	Std. deviation
Duration of service	6 months	70 months	28.19	16.96
Child age	9 months	81 months	37.09	18.19
Child rank	1 First	13.00	6.63	3.09
Number of family household	5.00	15.00	8.57	2.72

For service duration, the minimum period was 6 months whereas the maximum was 70 months (about 5 years). While the mean was 28 months (about 2.5 years) with std. (16.96). This means that most of the selected subjects received at least 6 months to 2.5 years, while little percentage received more than 2.5 years.

For child age, the minimum age of a child was 9 months with mean 3 years old and std. (18.188), which means most of all selected children were aged 9 months – 3 years, while little percentage was for those who are more than 3 years.

For child rank only one was the first for his/her family, while the mean was the sixth one for family up to thirteen one with std. (3.088).

For the variable of "the number of family household", results showed that the lowest numbers was (5) while the highest was (15) with mean of (8) and std. of (2.72). Results are meaningful in the Palestinian culture and community.

5.3. Results and interpretations:

5.3.1.1. Result of the first research question:

First question: To what extent EIP services are effective from family perspective? To answer this question the researcher studied each service in EIP and measured the family benefits of it by using descriptive statistics and frequency distributions as followed in the following tables:

- **The effectiveness of capabilities development:**

Table (5-2): Result of the effectiveness of capability development in early intervention program

Item	Min.	Max.	Mean	Std. deviation
Having abilities to solve child behavioral problems	2	5	4.14	0.484
Capabilities Development. Services is the reason for child improvement	3	5	4.26	0.472
Capabilities staff explain child condition	3	5	4.14	0.384
Staff told the rehabilitation Plan for you	2	5	4.11	0.427
Sharing in implementation the rehabilitation Plan	4	5	4.21	0.407
Staff evaluate the implementation for plan	4	5	4.21	0.407

Weighted mean (overall mean) = Σ mean/6 = 4.18

This domain was measured by 6 items starting with the item "having ability to solve your child behavioral problems" up to the item "did the staff evaluate the implementation of rehabilitative plan". Results showed the families benefited highly in all aspects of this domain with a mean score of 4 and Std between (0.38-0.48).

5.3.1.2. Interpretation the result of the first question:

☒ **Interpretation of the result of effectiveness of capabilities development:**

As a general to this domain of first question there was a high percent of families who benefited from this type of service in EIP. Furthermore, the qualitative open questions assured this result when most of the participant said about capability development is one of the best services received during service duration.

Congruous with study result of (Connolley & Russell, 1976) that examined the effectiveness of early intervention program on developmental tasks performed by 40 Down's Syndrome children when compared with 40 D.S children who didn't receive this program. The result of their study was congruous with the result of the researcher study by showing earlier attainment of many developmental tasks and enhances functioning of the family.

On the other hand, the study of (Richdardson et al, 1980) compared the developmental milestones and current intellectual and adaptive functioning of 20 children with D.S who participated in EIP with 53 children with D.S who did not experience such EIP explained that the improvement in the first group with EIP in intelligence and social adaptation was not exactly related to the services of EIP in the aspect.

At the same field, another study of (Piper and Pless, 1980) was assessed developmental status of D.S infant group who received biweekly therapy sessions designed to stimulate normal development. Follow up over six-month period, they found no statistical significant differences in mental development. This result showed that EI in this study was not efficacious in altering pattern of mental development status of D.S infant participation in EIP services.

For this research study, the result showed that EIP services were the main cause of D.S child improvement in all services.

- **<u>The effectiveness of physiotherapy services</u>:**

Results showed that most of all participants in the research study benefited from physiotherapy services provided by RTLS. There average score was (4) and more out of (5) for all items.

Table (5-3): Result of the effectiveness of physiotherapy services in early intervention program

Item	Min	Max	Mean	Std. d.
Physiotherapy services were satisfied	4	5	4.31	0.468
Continuous improvement with PT services	4	5	4.44	0.500
Doing physiotherapy exercises in home well	4	5	4.14	0.352
PT staff concerned to evaluate child prognosis	4	5	4.09	0.282
PT session schedule satisfied for you	2	5	4.00	0.341
PT session duration satisfied	2	5	4.03	0.380
Feeling child more improvement with home exercises	4	5	4.23	0.423
Place for PT session is comfortable	3	5	4.11	0.363

Weighted mean (overall mean) = Σ mean/8 = 4.17

☒ **Interpretation of the result of effectiveness of PT services:**

To measure the effectiveness of physiotherapy services in EIP for D.S from the family point of view, the researcher developed 8 items: (satisfied with PT services, there was a continuous improvement in child condition with PT services, following up exercise in home for child, PT staff concerned to evaluate child condition periodically, sessions of PT services duration of PT session, feeling your child improved more with PT exercise home, place and sitting of session comfortable).

Results showed that participants of this study highly benefited from PT services as items' means were more than 4 with std. ranged from (0.25-0.50). This result is completely in agreement with the result of the following qualitative open-ended question "which is the best services you received in EIP". Most of the participants responded to the question saying: PT and capabilities development.

This result is in agreement with the finding of (Hernandez et al, 2006), who evaluated 21 young D.S children receiving physical therapy in EIP, after 1/2 hour massage therapy per week for two months. (Hernandez et al, 2006) results showed that children in massage therapy revealed greater gain in fine and gross motor functioning and less sever limb hypotonicity, when compared with control children group. Moreover, it is founded that families benefited from PT services, and it is illustrated by high mean with improvement in their child's condition with PT services. Concerning satisfaction about PT services, the total participants were highly satisfied with mean 4.3 with std. 0.468. On the other hand, participants were little satisfied with PT services schedules and sessions mean 4.00 with std. 0.341.

Other study of (Connolly & Michael, 1986) that examined the gross motor and fine motor abilities of D.S compared with group of children without D.S. Result showed that female subjects with D.S scored significantly lower than female subjects without D.S. As a group of children with D.S scored significantly lower than the children without D.S in area of running, speed, balance, strength and visual motor control. Also, gross motor and fine motor skill were significant lower for children with Down's Syndrome.

On the other hand, the study of Mahoney et al, 2001 on the effect of early motor intervention on children with Down's Syndrome and children having cerebral palsy. The children's motor functioning was examined at entry into study and after they received 1 year of motor intervention services. The result showed that there was no evidence that motor intervention accelerated development or improved quality of movement beyond what could be expected on the basis of maturation. Furthermore, no differential intervention effects were associated with children's diagnosis or treatment model.

Consistent with Mahoney study, there was another study Morgan et al, 1998 that examined long motor cognitive, and adaptive functioning of a sample of adolescents with D.S who experienced early intervention program. The result of this study showed that EI group subjects fell below their chronological age levels in gross and fine motor skills, while the EI group subjects had significantly higher scores on measures of intellectual and adaptive functioning than did the children in the control group, that is incongruous with researcher study result.

- **<u>Effectiveness of medical services in EIP</u>: (item. Q 48)**

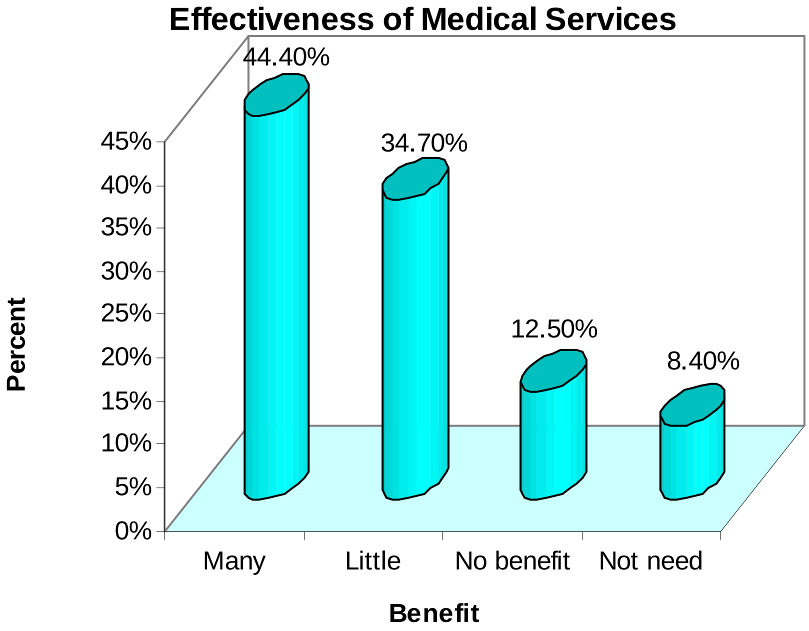


Figure (5-12): Distribution of the study population by effectiveness of medical services

This type of service is not a scheduled service for children in early intervention program, by other words, when the staff confirmed that the child is in-need for a medical consultant in RTLS, then he/she was transferred to medical services. The researcher used 4- likert scale to measure the extent of effectiveness. Results showed that (44%) of the participants benefited from it, while 35% benefited little or got no benefit. Fifty six of the total subjects recommended finding specialist doctors in Down's Syndrome, 41% suggested having treatment in the society when her/his child needs with payment, 3% suggested that one medical doctor was not enough for all society programs.

☒ **Interpretation of the result of medical services effectiveness:**

The researcher interpreted this result consistent with the result of qualitative open questions when families were asked about their suggestions to improve the quality of service provided in RTLS mainly in the EIP, most of study subjects agreed with necessity of availability of a medical doctor in RTLS to take care in consultation for their child. Furthermore, mostly it suggested the need of specialists with health problems commonly with Down's Syndrome. Otherwise, the bad political and social situation in our country Palestine, we could only be found with extremely difficulties who are specialists in the field of congenital or genetic health problem. According to the researcher knowledge, there is only one Dr. who could be consultant for genetic disease in Gaza "Mohamood Dulla".

On the other hand, the researcher couldn't find separated studies consistent with effectiveness of medical services of early intervention program through literature review. Most of previous studies were focused on physiotherapy, intellectual, adaptive, developmental improvement and school achievement.

Otherwise, most of available literatures measured the families' satisfaction with medical services provided for D.S children, like (Hans et al, 2007) study, the result showed that otolaryngology had been used by 50% of children with satisfaction of 2.63% (second worst score) (in north-west England).

- **<u>Effectiveness of social services</u>:**

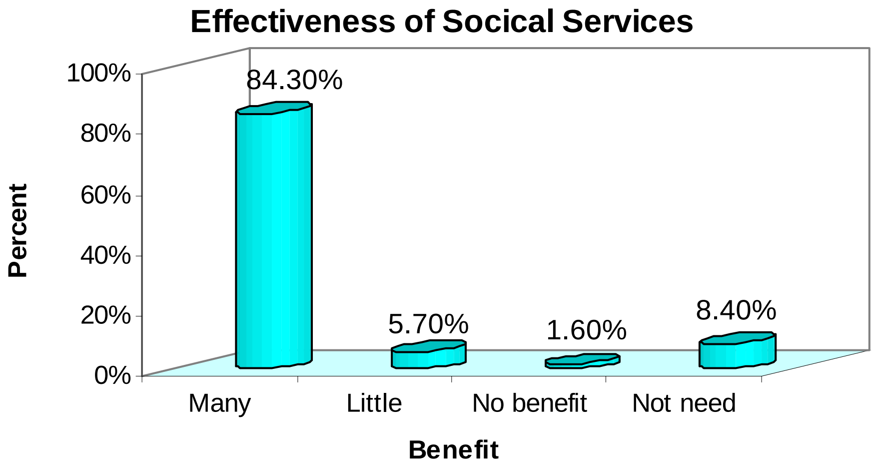


Figure (5-13): Distribution of the study population by effectiveness of social services

With regard to effectiveness of social services program, results showed that most of participants benefited from it, while little of them did not benefit form it, on the other hand, about 8% reported that they did not need these services.

☒ Interpretation of the result of effectiveness of social services:

Relevant to social services which available in RTLS included counseling and meeting with families, workshops, provide some helps from other volunteered institution, and get papers or formal record from RTLS needs by own families of D.S children to another governmental institution.

The researcher found that most of families were benefit form this service, especially when child of D.S newly record to EIP, with some recommendation of some families there was a need to encourage sharing and exchange experiences of other's families to get best benefit from meeting workshop or counseling conferences.

Throughout literature view which consistent with the effectiveness of early intervention program by social services. The researcher found that study of (Reimand et al, 2003) about families' satisfaction with medical and social services provided to children with D.S in Estonia, the result was D.S families were not satisfied with social rehabilitation services whereas most of D.S families were highly satisfied with medical health services but low level of quality services recorded with medical services.

- **Effectiveness of psychotherapy services:**

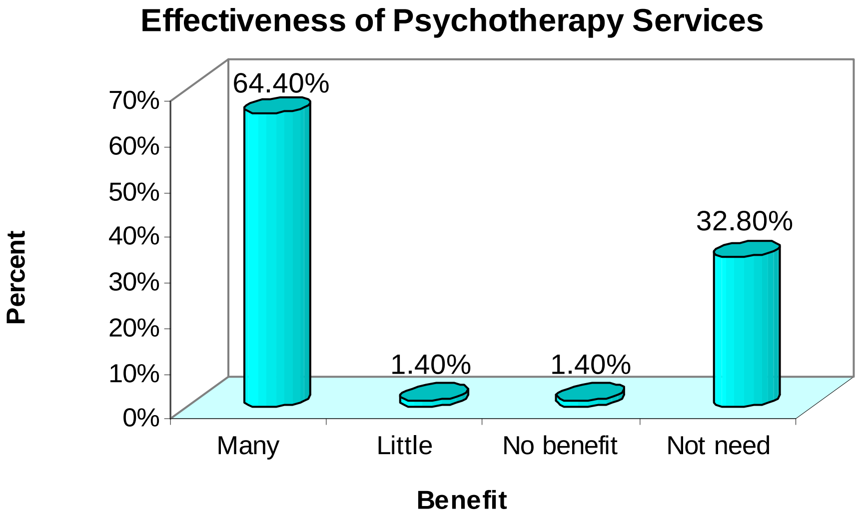


Figure (5-14): Distribution of the study population by effectiveness of psychotherapy services

Almost two thirds of all participants (64.4%) reported being benefited from psychological support services and family support program; on the other hand, about (33%) of the participants reported not needing these services. The researcher attributes this result to the fact that child age plays an important role in this variation as it's logically accepted that child aged less than 2 years old do not need the service.

On the other hand, the longitudinal study of (Bouchard et al, 1999) about the effects of an early family intervention program on the adaptation of families of children with a disability, showed better social adaptation among families who participated in early intervention program when compared to those who did not participate in the program. These groups of families had lower levels of familial stress, they had more positive perceptions and attitudes concerning their child disability and their familial situation; they had lower levels of emotional distress, anxiety and depression; and they perceived more emotional support from their spouse.

- **<u>Effectiveness of hearing and speech services</u>:**

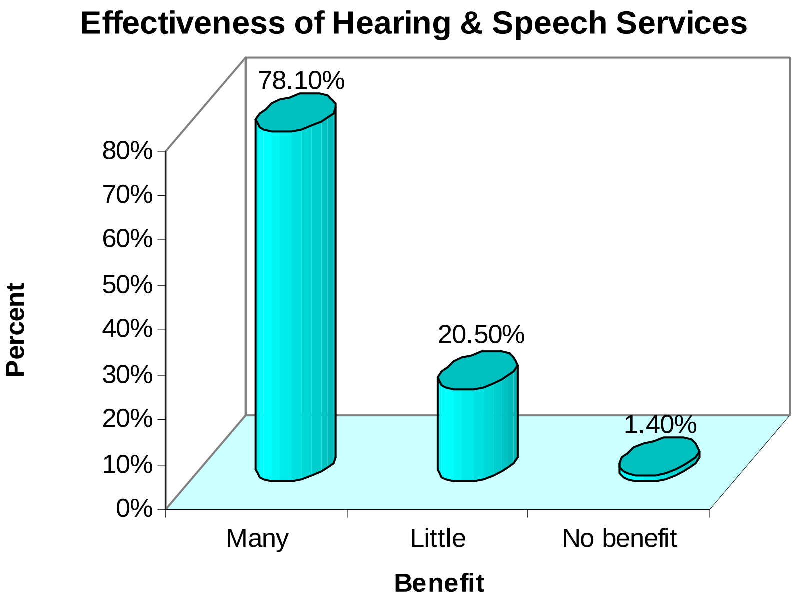


Figure (5-15): Distribution of the study population by effectiveness of hearing and speech services

Concerning getting the benefits of hearing and speech services, results showed (78%) of the participants reported getting the benefits , while (20.5%)

reported that the benefits were little. The explains why (76%) of all participants suggested having a specialized doctor for hearing and auditory diseases to facilitate services that are needed.

☒ Interpretation of the result of effectiveness of hearing and speech services:

This result is in agreement with the results of the qualitative open ended question, which reflected that most of D.S families benefited from the hearing services **and to be best service**. Most of study participants suggested getting specialists for hearing problems "audiologist" to minimize difficulties that might occur when the D.S child is transferred to a governmental hospital to get treatment or investigation.

Throughout the literature review that dealt with effectiveness of EIP services to improve speech hearing and spelling service, the researcher found that study of (Berglund et al, 2001) about familial reports of spoken language skills in children with Down's Syndrome. The study suggested that there were necessary needs and great potential for early intervention because D.S children were lagged slightly on pragmatic, and grammar scales, and the early development proceeded in most cases with exponential or logistic growth.

Johnston and stansfield, 1997 study found that children with D.S and without D.S had similarities in reported behavior and response. In addition, five out of six children with D.S had some skills which were more advanced than their matched group.

Study of Louw & Kritzinger, 1991, which described an early intervention approach for application on 3 D.S infant aged 10 months at the initiation of the program, then reassessment was made after the completion of this program. The result found satisfactory progress in the level of functioning with language development.

On the other hand, the study of Gendron et al, 1986 on the developmental profile of Down's Syndrome infant receiving early intervention, when following up 32 infants with D.S, who were enrolled in an early intervention program during the first 2 years of life, the result of this study reveled that the largest degree of retardation was consistently exhibited in the hearing and speech subscale.

5.3.2.1. Result of the second research question:

Second question: To what extent families are satisfied with EIP services in the RTLS?

The researcher divided this domain to mainly two aspects; the first was general satisfaction about services as a whole, second was satisfaction about accessibility to services.

Table (5-4): Result to second question

First aspect: General satisfaction

Min.	Max.	Mean	Std. deviation
28	**45**	**37.06**	**2.61581**

Relative weight = (37/45)*100% = 82.2%

Second aspect: Satisfaction with accessibility

Min.	Max.	Mean	Std. deviation
10	**24**	**18.8**	**2.40694**

Relative weight = (19/24)*100% = 79%

For both aspects: General satisfaction fro both domains

Min.	Max.	Mean	Std. deviation
46	**63**	**55.9**	**3.37243**

Relative weight = (56/63)*100% = 88.8% ≈ 89%

From the above table, results shows that general satisfaction with regard to EIP services was (82.2%), compared with satisfaction about accessibility to service was (79%). Whereas the total level of satisfaction about EIP was (88.8%).

5.3.2.2. Interpretation of the result of second question:

From the previous table, it was showed that highly percent of family satisfaction with EIP services was reported during the application of this study.

This result was consistent with the result of qualitative data as they said in their own words: "we extremely appreciate this program which is the only one to look after our children" and "absolutely, we can't take care of our children without this program. Moreover, if there is another program that deals with D.S clients, we will not leave this Society".

Throughout literature review this result is consisted with the result of (Abo Sedio, 2007) study while evaluating integration of mental health care in primary care form clients' viewpoints; the result showed that client satisfaction of integration of this program was 87%.

Another study which is congruous with the result of the study was (Hills, 2008) when she measured outpatients satisfaction with physiotherapy services in two major hospitals "Al-Shifa & Al-Wafa Medical Rehabilitation Hospital", the result showed the satisfaction was 88.7%.

The study of (Al-Hindi, 2002) measured client satisfaction with radiology services in Al-Shifa Hospital and Gaza Diagnostic Center, the result revealed high level of client satisfaction 82.5%. This result is consistent with the result of the research.

Relevant to the satisfaction with EIP services the study of (Iversen et al, 2003) is consistent with the researcher study that showed 87% of families were satisfied with EI programs, while less familial satisfaction was noted in learning how to develop strategies and set goals, whereas provider satisfaction was 99% with EIP services.

On the other hand, the result of the study of (Abu Hashem, 2007) disagrees with the research result. His result revealed the client satisfaction from the services that offered by Abroad Unit of MOH was 52.9% satisfied with medical doctors performance at local hospital.

5.3.3. Result of the third research question:

Third question: To what extent does a family participate in implementing the rehabilitation plan for the D.S child?

Figure (5-16) shows that most of all participants (85%) participated in a rehabilitation plan through the early intervention program. This percent is really high.

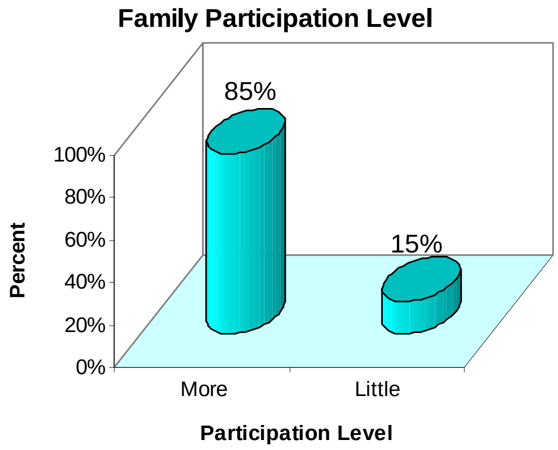


Figure (5-16): Distribution of the study population by family participation level

5.3.4.1. Result of the fourth research question:

Fourth question: Is there any relationship between family satisfactions with level of family participation in implementing rehabilitation plan?

To answer this question, the researcher used Chi-square Test to examine if there is a significant relationship between the two variables. Results showed that there is association between the level of participation and satisfaction, many participate have higher level (62.9%) then little satisfied (54.5%). This association did not reach statistical significant level. See Table (5-5) for more details.

Table (5-5): Chi-Square for the relation between family participation with general family satisfaction level

Family participation	**Satisfaction group**		**Total**
	Low satisfaction	**High satisfaction**	
Many participate	23	39	62
	37.1%	62.9%	100.0%
Little	5	6	11
	45.5%	54.5%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = .276, P value = .599

5.3.4.2. Interpretation of the result of third and fourth questions:

The researcher interpretative this result of both question with consistent of literature review which mainly reported that family-centered services is one of most determinate of families satisfaction, while the researcher found that there is no statistical significant relationship between the level of families' satisfaction about EIP services and the level of families' participation in rehabilitation plan for their children.

Otherwise, the result of qualitative open question reveled that most of when the families "family" participated in a rehabilitation plan for their children, the succeed in their child's rehabilitation was higher, according to families viewpoint.

This result of the researcher study differed from the result of Law et al, 2003 study, who were concerned to examine the factors affecting family-centered services delivery for children with disabilities, found that the principle determinants of family satisfaction was family-centered culture at the organization and families perceptions of family centered service (FCS), and the families satisfaction was strongly influenced by the perception that services are more family centered, fewer places where services were received and fewer health and development problems for their child.

Concerning the relationship between families' satisfaction with families' participation in rehabilitation plan. The researcher interpreted that by: first, this is the only institution that provides rehabilitation services for D.S children. Second, the level of general satisfaction about EIP services was high 88.8%, consistent with this result the researcher found no statistical significant relation between satisfaction and participation from families view, especially in our bad political and social situation in Gaza.

Furthermore, qualitative data were extremely congruous with this result when most of families were "disagree when they were asked if there is another rehabilitation society for D.S, did you left RTLS and go to another one, mostly were say NO".

5.3.5. Results and interpretations of the fifth research question:

Fifth question: Is there a relationship between family satisfaction with socio-demographic variables?

The socio-demographic characteristics include the following variables (age – gender – governorate – duration services – mother educational level – child rank – mother employment status – father employment status – number of household family members).

1. **Relationship between general satisfaction and child age:**

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-6): Chi-Square for the relation between general satisfaction and child age

Baby age group	Satisfaction group		Total
	Low satisfaction	High satisfaction	
Less or equal 3 years	14	24	38
	36.8%	63.2%	100.0%
More than 3 years	14	21	35
	40.0%	60.0%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = 0.077, P value = 0.782

Table (5-6) illustrated the relationship between child age and mother satisfaction. It showed that there was association between the age of child and satisfaction. Those ages where less than 3 years were highly satisfied (63.2%), while those more than 3 years were little satisfied (60%). But this association did not reach statistical significant level..

5.3.5.1. Interpretation of the result of relation between general satisfaction and child age:

The researcher interpreted this result according to her own knowledge that this program was the only one providing care for D.S in Gaza Strip, from early age after birth up to 4 years old. The qualitative collected data by the researcher by interviewing some participants of whom their child aged more than 1 year showed that participants wanted this service. They said: "We wish if we knew about this program earlier than attending its services; we didn't know that there was a program like this dealing with D.S children from earlier stage".

Literature focused on the relation between the effects of early intervention program with entry age. The study of (Shondoff and Penny, 1987) showed no significant differences relationship between the outcome and the age of enrollment. Whereas, results showed that there was a significant relationship between the degree of disability and the outcomes of enrollment to EIP.

2. **The Relationship between general satisfaction and child Gender:**

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-7): Chi-Square for the relation between general satisfaction and child Gender

Sex	**Satisfaction group**		**Total**
	Low satisfaction	**High satisfaction**	
Male	18	26	44
	40.9%	59.1%	100.0%
Female	10	19	29
	34.5%	65.5%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = .305, P value = .581

Table (5-7) revealed that there is no statistical significant relationship exists between mother satisfaction about EIP services with the gender of their children, except whom child female were highly satisfied (65.5%), while whom child male were little satisfied (59%).

5.3.5.2. Interpretation the result of relation between general satisfaction and child Gender:

Regarding to the relation between family's satisfaction with the gender of D.S child, the researcher interpreted that according to our Islamic culture in Palestinian community were parents dealing same with their children either male or female, otherwise, Palestinian families don’t discriminate between male or female especially when they are disabled, and throughout the literature review there was no available study to investigate the relation between satisfaction with EIP services and gender of D.S child. On the other hand, the available study examined the relation of family gender with satisfaction about early intervention program services. The study of (Reid et al, 2004) showed that the majority of families were satisfied with the intervention and significant differences in satisfaction levels depending on the sex of family. Mothers of newborns with Down's Syndrome were more satisfied than fathers with the personal-emotional support they received, and low-income families were more satisfied than those with higher income for all subscales.

3. The Relationship between general satisfaction and governorate:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-8): Chi-Square for the relation between general satisfaction and governorate

Governorate	Satisfaction group		Total
	Low satisfaction	**High satisfaction**	
South area	1	10	11
	9.1%	90.9%	100.0%
Mid-zone	7	8	15
	46.7%	53.3%	100.0%
Gaza & North	20	27	47
	42.6%	57.4%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = 4.77, P value = .09

Table (5-8) showed that there is no statistical significant relationship between governorate and mother satisfaction about EIP services, except those mothers from south area were highly satisfied (90.9%), where as whom from the mid-zone area were the lowest level of satisfaction (53.3%).

5.3.5.3. Interpretation of the result of relation between general satisfaction and governorate:

There is no statistical significant between family satisfaction and governorate, the researcher interpreted that we are living in small area Gaza Strip and approximately there is similarity in thinking whenever we live in any governorate.

Also the outcome of the interview which conducted with mothers during data collection, especially for mothers from South and North areas. By their own words they said: "we feel that the service provider is extremely polite and better than our sisters, and family", that means families perceived services provider as much as possible with a positive attitude.

Through the literature review, the researcher's result differed with most of the available local study; for example the study of (Al-Hindi, 2002) and the study for (Hillis, 2008), both reported that there was no significant statistical relationship between client satisfaction and place (governorate), and no statistical relationship between satisfaction and residency.

4. Relationship between general satisfaction and duration services:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-9): Chi-Square for the relation between general satisfaction and duration services

Service duration group	**Satisfaction group**		**Total**
	Low satisfaction	**High satisfaction**	
Less than 2 years	14	24	38
	36.8%	63.2%	100.0%
2-4 years	9	14	23
	39.1%	60.9%	100.0%
More than 4 years	5	7	12
	41.7%	58.3%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = .098, P value = .952

Table (5-9) illustrated the relationship between mother satisfaction with duration of services in the EIP. It showed that there is no significant statistical relationship between service duration and mother satisfaction, even though, there is association between the two variables, the group whom receiving services less than 2 years were highly satisfied (63.2%), then the lowest group whom receiving services more than 4 years were little satisfied (58.3%) .

5.3.5.4. Interpretation of the result of relation between general satisfaction and duration services:

With regarding to the relation between satisfaction and duration of services, the researcher concluded that, this is the only society caring for D.S children, at the time, the satisfaction level was very high both are explained the negative relation between the family satisfaction and duration services, and through the literature review which mainly concerned with availability of services it self rather than the duration of service, for example, study of (Yam et al, 2005) who made a survey for families of children with Down's Syndrome, revealed that accessibility of the service were ranked with positive satisfaction relationship of families.

Whereas (Hillis, 2008) study found that there is significant relationship between client satisfaction and duration of session.

Otherwise, some of literature review of early intervention program found that there is a significant relation between services of early intervention program and the intensity of the services.

5. Relationship between general satisfaction and child rank:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-10): Chi-Square for the relation between general satisfaction and child rank

Rank group	Satisfaction group		Total
	Low satisfaction	High satisfaction	
1-6	18	22	40
	45.0%	55.0%	100.0%
More than 6	10	23	33
	30.3%	69.7%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = 1.652, P value = .199

Table (5-10) showed the percentage of high satisfaction and low satisfaction with EIP services according to the rank of D.S child in their family.

There is no statistical relationship between child D.S rank and mother satisfaction about early intervention program services, except the child rank more than 6, their family were highly satisfied (69.7%), then whom in between 1-6 were little satisfied (55%).

5.3.5.5. Interpretation the result of relation between general satisfaction and child rank:

The researcher interpreted this result which is consistent with qualitative data obtained throughout researcher interview with mother of D.S child. When the child rank was the first of the thirteen, mother perceptions was: "he/she is a lovely child in the family, we want to provide all things to our child but we can not find resources. This society is the only one that provides rehabilitation care for D.S; if we know another one even though in another country we will go and take care of our child".

On the other hand, no available relevant literature was found to interpret the researcher's result, all of the available studies examined other socio-demographic variables and it's relation with client satisfaction rather than child rank or family member household.

6. Relationship between general satisfaction and mother's age:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-11): Chi-Square for the relation between general satisfaction and mother's age

Mother age group	Satisfaction group		Total
	Low satisfaction	High satisfaction	
24-34	12	11	23
	52.2%	47.8%	100.0%
35-45	13	28	41
	31.7%	68.3%	100.0%
More than 45	3	6	9
	33.3%	66.7%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = 2.720, P value = .257

Table (5-11) demonstrated the relationship between mother's age and mother satisfaction with EIP services.

It showed that there is no significant statistical relationship between age of mother and her satisfaction with EIP services rather than mother aged group 35 – 45 years old were more highly satisfied (68.3%) rather than age group 24 – 34 years old little satisfied (47.8%).

5.3.5.6. Interpretation of the result of relation between general satisfaction and mother age:

The researcher's result is consistent with result of research study for both (Al-Hindi, 2002) and (Hillis, 2008), both reported that there was no significant relationship between age of client and satisfaction level. Whereas the result of (Abu Saileak, 2004) study was incongruent with the researcher result, Abu-Saileak founded that there was a significant relationship between satisfaction and age of client and other socio-demographic variables.

7. Relationship between general satisfaction and mother educational level:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-12): Chi-Square for the relation between general satisfaction and mother educational level

Mother education group	**Satisfaction group**		**Total**
	Low satisfaction	**High satisfaction**	
less than or equal 6 (illiterate and primary)	5	10	15
	33.3%	66.7%	100.0%
7-12 (preparatory)	16	30	46
	34.8%	65.2%	100.0%
More than 12 (secondary and above)	7	5	12
	58.3%	41.7%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = 2.434, P value = .296

Table (5-12) explained the relationship between mother's educational level and level of satisfaction about EIP services.

It is showed that there is no significant statistical relationship between educational level of mother and the level of satisfaction rather than mother educated primary or illiteracy highly satisfied (66.7%), then the little satisfied mothers where whom high level educated (41.7%).

5.3.5.7. Interpretation of the result of relation between general satisfaction and mother's educational level:

This result does not agree with the results of (Al-Hindi, 2002) study that showed there was a significant statistical relationship between level of education and level of satisfaction. However, the research result was consistent with (Hillis, 2008) study that showed that there was no significant statistical relationship between level of education of mothers and satisfaction level.

These results could be attributed in relation with the existing context. Most of study participants are educated mothers finished either primary or preparatory schooling levels. Usually, people with lower levels of education get easily satisfied with regard to services as their knowledge is limited compared to people with higher levels of education. The availability of the services to them is by itself is something that they value.

8. Relationship between general satisfaction and mother employment status:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-13): Chi-Square for the relation between general satisfaction and mother's employment status

Mother job	**Satisfaction group**		**Total**
	Low satisfaction	**High satisfaction**	
Housewife	26	41	67
	38.8%	61.2%	100.0%
Employee	2	4	6
	33.3%	66.7%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = .070, P value = .792

9. Relationship between general satisfaction and father employment status:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-14): Chi-Square for the relation between general satisfaction and father's employment status

Father job	**Satisfaction group**		**Total**
	Low satisfaction	**High satisfaction**	
Employed	19	21	40
	47.5%	52.5%	100.0%
Unemployed	9	24	33
	27.3%	72.7%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = 3.129, P value = .077

Table (5-13) and table (5-14) demonstrated the relationship between the mother employment, father employment and the level of satisfaction. Both showed that there is no significant statistical relationship, except whom their father where unemployed were highly satisfied (72.7%), while those mothers housewife were little satisfied (61.2%).

Otherwise, the researcher found foreign studies which examined the relationship between level of income with satisfaction rather than mother's or father's job.

(Study from Reidy et al, 2004) showed that low-income families were more satisfied than those with higher income.

Whereas, local studies of client satisfaction found that there was a significant relationship between financial status and level of satisfaction like (Al-Hindi, 2002) study, which is incongruent with researcher study result.

5.3.5.8. **Interpretation of the result of relation between general satisfaction and mother's & father's employment status:**

The researcher interpreted this result with framework of the results collected from the interviews with mothers of D.S children, whose their partners were unemployed, were significantly satisfied more than those who are employed. At the time we live in very critical political situation that increasing unemployment ratio and decreasing level of family income for most of Palestinian families due to siege.

10. Relationship between general satisfaction and the number of family household members:

To answer this question the researcher used Chi-square test to examine the relationship between the variables.

Table (5-15): Chi-Square for the relation between general satisfaction and the number of family household members

Family number group	Satisfaction group		Total
	Low satisfaction	High satisfaction	
Less than or equal 8	18	23	41
	43.9%	56.1%	100.0%
More than 8	10	22	32
	31.3%	68.8%	100.0%
Total	28	45	73
	38.4%	61.6%	100.0%

Chi-Square = 1.21, P value = .27

Table (5-15) illustrated the relationship between family member household and mother satisfaction level. It showed that, there is no statistical relationship between the number of family household members and the level of satisfaction of mothers, except those families having more than 8 members were highly satisfied (68.8%), whereas whom having less 8 members were little satisfied (56.1%).

5.3.5.9. Interpretation of the result of relation between general satisfaction and the number of family household members:

With regarding to the relation between family satisfaction and number of family household member, result showed that no statistical significant relationship and the researcher interpret this throughout ordinary Palestinian family household members which in nature is highly and the parents love their kids and providing all facilities and services needed especially when they are handicapped or disabled. Otherwise, no local or foreign studies examined this variable in relationship with the level of satisfaction. And it could be interpreted to; that is consistent with the relation between level of income and level of satisfaction in our culture. To the researcher, it is an accepted distribution that when there is a family with a big number of members, they need higher income, and require more responsibilities, and so on, which is logical to see this group highly satisfied with our bad political situation in Gaza Strip.

5.3.6.1. The result of the sixth research question:

Sixth question: What is the family perspective regarding the service provider in EIP in RTLS?

To answer this question the researcher calculated some descriptive statistics including means and standard deviations for all related items.

Table (5-16): Family perspective regarding the service provider in EIP in RTLS

No.	Item	Min.	Max.	Mean	Std. Deviation
1.	The workers present the remedial plan that suites your child	4	5	4.10	0.296
2.	All workers explain the plan's therapeutic options clearly	3	5	4.04	0.260
3.	The workers discuss with you all the potential expectations of the state of your child	2	5	3.75	0.727
4.	Workers are keep that the capabilities of your child will be known to all	2	5	4.06	0.371
5.	Workers receive you and your child with respect	4	5	4.53	0.502
6.	Workers answer your questions truthfully	3	5	4.15	0.430
7.	The workers tell you about the reason for selecting specific plan for your child	3	5	4.04	0.311
8.	Employees encourage you to ask questions about everything you do not understand of the plan	2	5	4.01	0.456
9.	The workers give you the opportunity at the appropriate time and place to receive information	3	5	4.08	0.323
10.	The workers ask about your point of view of the service provided	2	5	4.16	0.472
11.	The workers provide the right atmosphere for you and your child during receiving the service	4	5	4.12	0.331
12.	Workers are keen to meet the needs of your child as he/she progress in age	3	5	4.10	0.379
13.	You Do not feel the confidentiality during the work with your child	3	5	4.72	0.587
14.	Workers take strict confidentiality in dealing with your child	3	5	4.22	0.562
15.	You feel that the workers respect you and your child	4	5	4.19	0.396
16.	You feel that you suffer hardship in order to obtain the services required for your child	3	5	4.29	0.485
17.	All workers present all their efforts in helping you to obtain a service	4	5	4.18	0.385
18.	Workers are keen to participate in the implementation of the rehabilitative plan for your child	4	5	4.26	0.442

Weighted mean (overall mean) = Σ mean/18 = 4.17

Table (5-4) shows that most of the participants have positive views with regard to service provider performance, especially with relevance to confirming privacy while dealing with mother child, and acceptance with humidity. Little acceptance was shown towards encouragement of child's mother to ask and talk about future expectations of their child condition.

5.3.6.2. Interpretation of the result of the sixth research question:

The researcher interpreted the result of this question focusing in the Palestinian context and which is Islamic in general. All provided services were sincerely dealing with all family members approximately in the same way. Furthermore, this result agrees with the result of the results of the qualitative open question, where most of the participants were extremely satisfied about communication with service provider who deals with them. Some participants reflected their experience with the service provider saying, "We feel them as a family unit, our sisters and brothers".

This result is consistent with the results of (Bailey et al, 2004) study which found that most of families, who were into early intervention programs, rated positively the professionals working in early intervention and medical professionals.

On the other hand, the study of (Arnkjotsdottir et al, 1993) reported that families' view of the intervention programs are positive, but the difficulties experienced by some families pointed to the need for interveners to be sensitive to family situations and feelings, and for programs to be flexible enough to meet these needs.

5.4. Commentary on the research study results:

To the knowledge of the researcher, this study is considered the first evaluation rehabilitation study in Gaza Strip; therefore it is important to inform the decision makers [RTLS manger, mangers in the governmental health sector and non-governmental organizations] with the results of the study in order to make the required actions. Results could be summarized as follows:

First, the family satisfaction with regard to the services in EIP in RTLS was high, in spite of the critical political situation we live in and the limited sources and services we have for disabled children.

Second, family's perspective with regard to the effectiveness of EIP services was positive. This is shown to all available services.

Third, family's perspective about the service provider in RTLS was a positive. This result is associated with our Palestinian values and cultural traditions which are Islamic in nature.

Fourth, results showed that there are no statistical significant relationships between family's satisfaction with selected socio-demographic variables.

Finally, results showed that there no statistical significance relationship between family's satisfaction with the level of family participation in implementing a rehabilitation plan.

Results were interpreted within the research theoretical framework and the reviewed literature.

CHAPTER 6

Chapter 6

Recommendations and Suggestions

6.1. Introduction:

In this chapter, the researcher recommends and suggests some recommendations that could help the policy maker and service provider to improve services for D.S children in the RTLS to reach qualified level of services as following:

6.2. Recommendations:

After analyzing the result of this study, the researcher recommended some points to the manager of RTLS in order to provide the best qualified service, another recommendation is to the manager of health sectors in order to take care of this category of disabled group in Gaza Strip; at the same time, there is a success story in non-governmental institution which in the RTLS.

First – Recommendations to RTLS:

1. Policy maker of RTLS should be informed with the result of this study to make decisions regarding the negative aspects that need more development to improve services.
2. Service provider should be integrated with highly graduated external training skills program to improve their abilities and to keep updating with new challenges and skills.
3. To work hard in order to open another centers for RTLS; more than one center in Gaza, and in South and Middle zone area to minimize transportation difficulties.
4. According to study result, most of families with Down's Syndrome children were satisfied with all services provided by RTLS because it is the only one to take care for D.S children, with some exception that could be overcome by availability of specialist doctors, mainly for D.S.
5. Try to motivate social and psychological workers role in the programs of RTLS, by working seriously as a team in all service provider, even though the child may not need it.

6. Try to get specialists for auditory and hearing problems doctor, to minimize difficulties when the child needs transfer to audiologist in Al-Shifa hospital or other hospitals.
7. Relevant to medical service, the need for availability of medication even with payment was very important recommendation from D.S families.
8. Knowing about EIP in the RTLS, from local community still below than expected that need to motivate the role of local media with cooperation of social workers in RTLS to increase the knowledge of families about the availability of this programs in RTLS or the society as a whole.
9. This society is the only one to provide researcher with statistics about D.S clients in Gaza Strip, so it is recommended to increase cooperation with MOH organization, centers, clinics and other governmental institution to build up a data base for D.S client incidence in Gaza Strip.
10. To be the best society for D.S, it is recommended to make a club or a park and a nursery for D.S whom their parents are employed. Moreover, the availability of a special school for D.S. children should be in the Center of Gaza.

Second – Recommendations to Managers of Health Sector:

1. The researcher recommends to the manager of Health Sector to study and discus the availability of other institution caring for D.S in Gaza Strip like the RTLS institution.
2. The researcher recommends increasing the cooperation between governmental and non-governmental organization to highlight the quality for caring D.S children.
3. The researcher recommends increasing the awareness of people toward these services in this institution.

6.3. Suggestions:

The researcher found this category of disability needs to make more suggested research study as following:

1. The researcher suggests conducting a comparative study between a D.S child who integrated in the EIP in RTLS with control group who did not receive these services.
2. The researcher suggests conducting a research study for other programs to provide services for D.S clients in RTLS.
3. The researcher suggests conducting a study to evaluate the effectiveness of integration of a normal child with a D.S child in the kindergarten in the RTLS.
4. The researcher suggests conducting a study to evaluate D.S clients who integrated in governmental schools in Gaza.
5. The researcher suggests conducting a study to perceive service provider perceptions about the services of programs in RTLS.
6. The researcher suggests conducting a study to measure the satisfaction of service provider and it's effectiveness on the quality of services provided to D.S client.
7. The researcher suggests conducting a survey to identify the exact incidence number of D.S in our country.
8. The researcher suggests conducting a study to describe the relation between risk factors of getting D.S and prevalence of D.S in our country.
9. Follow up longitudinal study for each service in the EIP in RTLS.
10. The researcher advises conducting a satisfaction study about the RTLS service after conducting the result of the research study.
11. The researcher suggested conducting a study about family perspective with rehabilitation services in stable political situation in our country, to get the differences.
12. The researcher suggested conducting evaluative study for EIP by using larger and probability random sample among Downs' Syndrome Children who have completed this program for at least one year.

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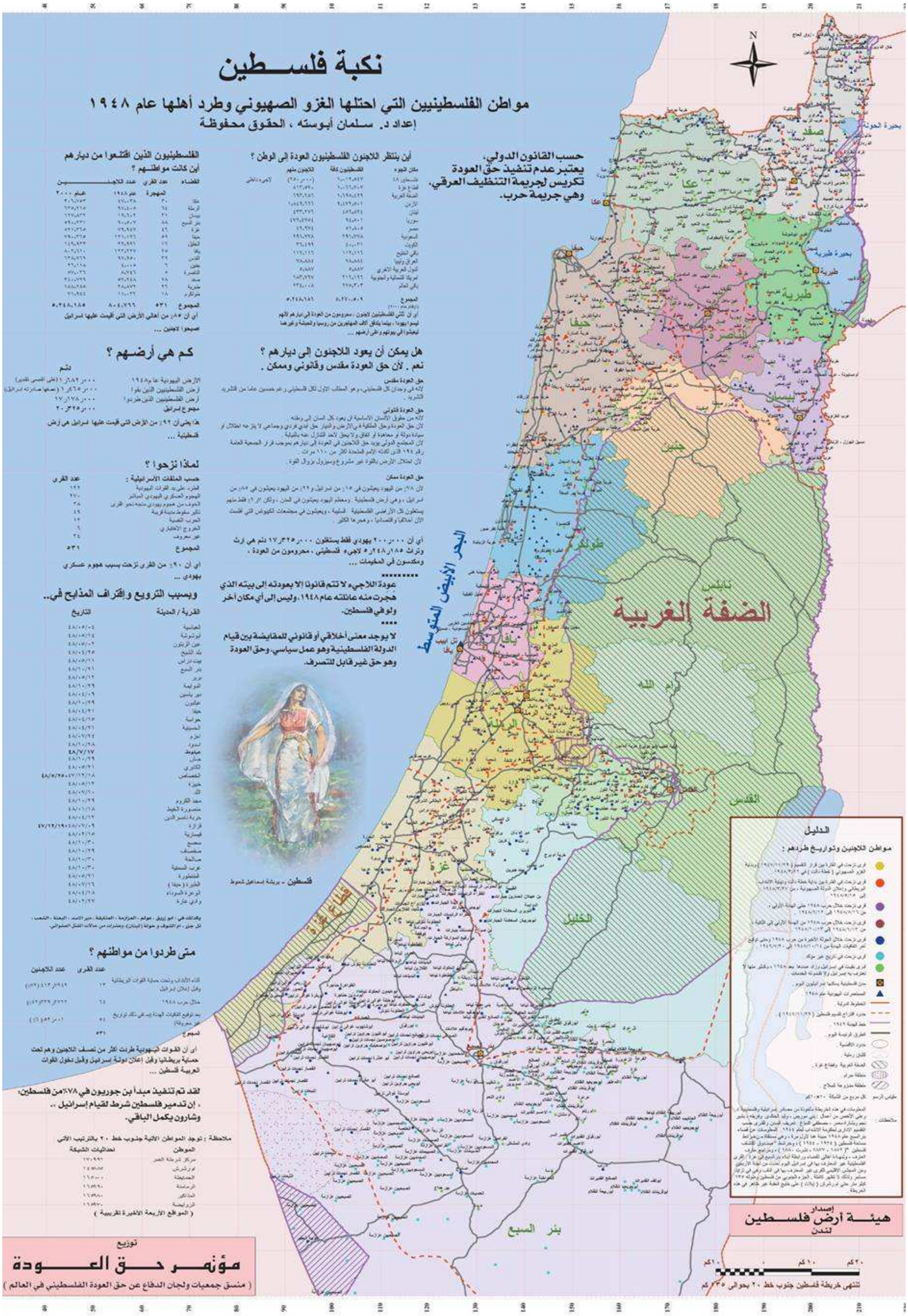
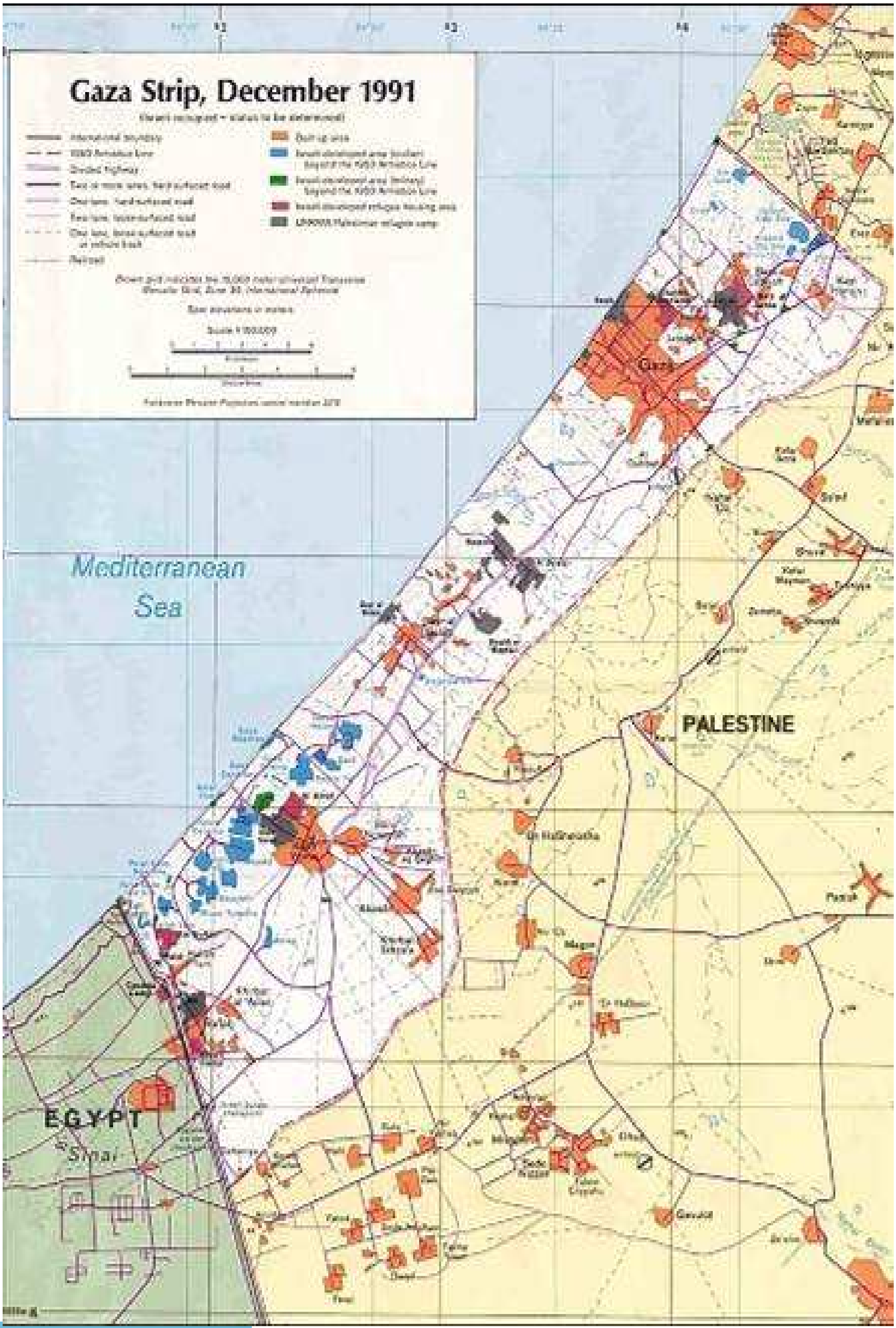
Anexes

Annex 1


نكبة فلسطين
مواطن الفلسطينيين التي احتلها الغزو الصهيوني وطرد أهلها عام ١٩٤٨
إعداد د. سلمان أبوسته ، الحقوق محفوظة
حسب القانون الدولي، يعتبر عدم تنفيذ حق العودة تكريس لجريمة التنظيف العرقي، وهي جريمة حرب.
الفلسطينيون الذين اقتلعوا من ديارهم أين كانت مواطنهم ؟
أين ينتظر اللاجئون الفلسطينيون العودة إلى الوطن ؟
كم هي أرضهم ؟
هل يمكن أن يعود اللاجئون إلى ديارهم ؟
لماذا نزحوا ؟
وبسبب الترويع وإقتراف المذابح في..
متى طردوا من مواطنهم ؟
N
صفد
عكا
حيفا
طبريا
الناصرة
بيسان
جنين
طولكرم
نابلس
الضفة الغربية
يافا
الرملة
رام الله
القدس
الخليل
غزة
قطاع غزة
بئر السبع
البحر الأبيض المتوسط
الدليل
هيئة أرض فلسطين
لندن
إصدار
مؤتمر حق العودة
(منسق جمعيات ولجان الدفاع عن حق العودة الفلسطيني في العالم)
توزيع

Annex 2


Gaza Strip, December 1991
Mediterranean Sea
Gaza
PALESTINE
EGYPT
Sinai

Annex 3

الجامعة الإسلامية - غزة
The Islamic University - Gaza

هاتف داخلي: 1150

عمادة الدراسات العليا

Ref ج س غ/35/
Date 2008/01/06

الأخوة الأفاضل/ جمعية الحق في الحياة حفظهم الله،

السلام عليكم ورحمة الله وبركاته،

الموضوع/ تسهيل مهمة طالب ماجستير

تهديكم عمادة الدراسات العليا أعطر تحياتها، وترجو من سيادتكم التكرم بتسهيل مهمة الطالبة/ **لبنى عبد الله محمد شلّح** برقم جامعي **2004/5739** المسجلة في برنامج الماجستير بكلية التربية تخصص **الصحة النفسية المجتمعية/ علوم التأهيل**، وذلك بهدف تطبيق أداة دراستها والحصول على المعلومات التي تساعدها في إعدادها والمعنونة بـــ:

"Evaluation of Early Intervention - Program Provided by the Right to Live Society for Children with Down Syndrome in Gaza Strip: Family perspective"

والله ولي التوفيق،،،

عميـــد الدراسات العليا

د. مازن إسماعيل هنية

صورة إلى:-
❖ الملف.

Annex 4

Panel Committee Names

No.	Member	Collogue	University
1.	Atef El-Agha	Education/ Psychology	Islamic University
2.	Jamil Al-Tahrawi	Education/ Psychology	Islamic University
3.	Fuaad Alagez	Education/ Psychology	Islamic University
4.	Ashraf Al-Jedia	Nursing	Islamic University
5.	Hesham Gurab	Academic Department	Community Collage Of Applied Science And Technology
6.	Bassam Abu Hamad	Public Health	Al Quds University
7.	Aalyan Al-Huwly	Education	Islamic University

Annex 5

فقرات استبانة تقييم برنامج التدخل المبكر للأطفال المنغوليين من وجهة نظر الأهل في جمعية الحق في الحياة في غزة في صورتها الأولية:

بسم الله الرحمن الرحيم

السيد الدكتور/ة ________________________ يحفظه/ــا الله

السلام عليكم ورحمة الله وبركاته،،،

الموضوع/ استبانة تقييم برنامج التدخل المبكر للأطفال المنغوليين من وجهة نظر الأهل في جمعية الحق في الحياة بغزة

أرجو الله تعالى أن تكونوا بخير وعافية وبعد،،،

الإشارة إلى الموضوع أعلاه، فإنني أتشرف أن أضع بين أيديكم استبانة بعنوان: "**تقييم برنامج التدخل المبكر للأطفال المنغوليين من وجهة نظر الأهل في جمعية الحق في الحياة بغزة**".

الاستبانة المذكورة ــ والمرفقة مع هذه الرسالة ــ هي الأداة التي ستستخدمها الباحثة في إعداد بحث لنيل درجة الماجستير في (علوم التأهيل) من قسم الصحة النفسية المجتمعية في كلية التربية بالجامعة الإسلامية والذي يحمل عنوان "**تقييم برنامج التدخل المبكر للأطفال المنغوليين من وجهة نظر الأهل في جمعية الحق في الحياة بغزة**"، تحت إشراف الأستاذ المشارك في قسم علم النفس بالجامعة الإسلامية / د. سناء أبو دقة.

إن الباحثة قامت بإعداد هذه الاستبانة لتقوم بتطبيقها على عينة من المستفيدين من خدمات التأهيل المقدمة للأطفال المنغوليين في جمعية الحق في الحياة بغزة

لذا أرجو تكرمكم بإبداء رأيكم وتوجيهاتكم في الاستبانة المرفقة من حيث ملائمة العبارات والفقرات، وسلامتها اللغوية في تقييم خدمات برنامج التدخل المبكر للأطفال المنغوليين والقيام بتعديل أو حذف بعض العبارات أو الفقرات التي ترون أنها بحاجة إلى تعديل أو حذف.

أثمن لكم عاليا حسن اهتمامكم، وكلي أمل أن أتلقى ردكم في القريب العاجل، سائلةً المولى عز وجل أن يجعل ذلك في موازين حسناتكم، وجزاكم الله خيرا.

شاكرةً لكم حسن تعاونكم وكريم جهدكم

وتفضلوا بقبول فائق الاحترام والتقدير

الباحثة/ لبنى عبد الله شلّح

رقم مسلسل: ....

استبانة

تقييم برنامج التدخل المبكر للأطفال المنغوليين في جمعية الحق في الحياة بغزة

1. اسم الطفل (اختياري):	
2. الجنس:	☐ ذكر ☐ أنثى
3. المحافظة:	☐ رفح ☐ خانيونس ☐ الوسطى ☐ غزة ☐ الشمال
4. مكان السكن:	☐ مدينة ☐ مخيم ☐ قرية أو ريف
5. عنوان السكن:	
6. هاتف السكن (اختياري):	
7. عمر الطفل (بتاريخ اليوم) بالشهر:	
8. عمر الطفل عند بداية التحاقه بالجمعية:	
9. ترتيب الطفل في الأسرة:	
10. عمر الأم:	
11. المستوى التعليمي للأم:	☐ أمية ☐ ابتدائي ☐ إعدادي ☐ ثانوي ☐ معهد/ دبلوم متوسط ☐ جامعي ☐ فما فوق
12. عمل الأم:	☐ تعمل ☐ ربة بيت
13. عدد أفراد الأسرة ويشمل الوالدين:	______________ فردا
14. عمل الأب:	☐ عاطل عن العمل ☐ عمل غير منتظم ☐ يعمل بانتظام
15. سبب مجيء الطفل أول مرة للجمعية (شكوى الأم): ____ ____	
16. هل يوجد أطفال آخرين لديهم إعاقات في الأسرة؟ ☐ نعم ☐ لا	
إذا كانت الإجابة بنعم، فحدد نوع الإعاقة ____ ____	
17. هل سبق وأن أُدخل طفلك أي جمعية أخرى قبل المتابعة مع جمعية الحق في الحياة؟ ☐ نعم ☐ لا	
إذا كانت الإجابة بنعم، فلماذا ؟	
18. هل سبق وأن أُدخل طفلك للمستشفى خلال المتابعة مع جمعية الحق في الحياة؟ ☐ نعم ☐ لا	
إذا كانت الإجابة بنعم، فلماذا ؟	
19. لماذا اخترت جمعية الحق في الحياة لمتابعة طفلك؟ ☐ لأنها أقرب لمنزلي ☐ لأن الآخرين نصحوني بها ☐ تحويلة من طبيب ☐ معرفة سابقة أسباب أخرى، حددي: ____ ____	
20. هل تحصلين على مساعدات من هذه الجمعية؟ ☐ نعم ☐ لا	
21. إذا كانت الإجابة نعم في (س20)، حددي نوع المساعدة: ________________________________ ____	

البيان	مدى انتماء الفقرة للمحور				
	بدرجة كبيرة	بدرجة متوسطة	لا تنتمي	الملائمة اللغوية	التعديلات
أولا ــ الرضا العام:					
22. بصورة عامة أنا راضية عن الخدمات التي يتلقاها طفلي في الجمعية					
23. إذا احتاج طفلي لأي خدمات تأهيلية في المستقبل، سأعود إلى الجمعية ثانية					
24. لو أتيحت لي الفرصة بخيارات أخرى سأواصل تعاملي مع هذه الجمعية					
25. أنا راضية عن الطريقة التي يتعامل بها طاقم الجمعية مع طفلي					
26. أنا راضية عن مستوى الخبرة التي يتمتع بها مقدمو الخدمات التأهيلية في الجمعية					
27. أنا راضية عن الفترة الزمنية التي أنتظرها قبل أن أتلقي الخدمة					
28. أنا راضية عن الوقت الذي أقضيه مع طفلي خلال تلقيه الخدمة					
29. أشعر بأن طفلي يستفيد من خدمات التدخل المبكر مقارنة مع غيره من الأطفال					
30. أنا راضية عن عدد زيارات طفلي لبرنامج التدخل المبكر					
31. أنا راضية عن التحسن في وضع طفلي مع الخدمة المقدمة له					
32. أنا راضية عن الوقت الذي يقضيه مقدم الخدمة مع طفلي					
ثانيا ــ أداء العاملين في البرنامج:					
33. يقترح العاملون الخطة العلاجية التي تلبي رغبات العائلة					
34. يشرح العاملون بإسهاب كل خيارات الخطة العلاجية الموجودة بالطريقة التي أفهمها					
35. يناقش العاملون معي كل التوقعات المحتملة لحالة طفلي					

البيان	مدى انتماء الفقرة للمحور				
	بدرجة كبيرة	بدرجة متوسطة	لا تنتمي	الملائمة اللغوية	التعديلات
36. يتأكد العاملون من أن قدرات طفلي معروفة تماما لكل العاملين معه في البرنامج					
37. يتقبلني العاملون أنا وعائلتي بصورتي الحالية					
38. يعطيني العاملون إجابة منطقية لكل تساؤلاتي					
39. يخبرني العاملون عن السبب في حال اختياره خطة علاج معينة					
40. يعرض العاملون دائما تغذية رجعية إيجابية ويشجعني					
41. يتأكد العاملون من تواصل الفريق معي بشكل دائم					
42. يعطيني العاملون الفرصة في الوقت والمكان المناسب لتلقي المعلومات					
43. يسألني العاملون عن وجهة نظري في الخدمة المقدمة					
44. يراعي العاملون توفير الجو المناسب لي ولطفلي					
45. يحرص العاملون على تلبية حاجات طفلي كلما تقدم في السن					
46. يتعامل العاملون معي ومع طفلي كإنسان أكثر من كونه حالة					
47. يتأكد العاملون من وجود طاقم على درجة عالية من الذوق والعطف للتعامل معي					
48. لا أشعر بسرية أثناء عملي مع الفريق					
49. يتوفر لدى العاملون المعلومات الكافية عن حالة طفلي الحالية والمستقبلية					
50. يراعي العاملون مشاعر العائلة لوجود طفل معاق عندها					
51. أشعر باحترام مقدم الخدمات لي					
52. أشعر بالاهتمام لي ولطفلي من قبل طاقم الجمعية					
53. أشعر بأن الطاقم يبدي اهتمامه التام للاستماع لي					
54. أشعر بأنني أعاني المشقة في سبيل الحصول على الخدمات المطلوبة لطفلي					
55. الطاقم يبدي كل جهوده في مساعدتي للحصول على					

البيان	مدى انتماء الفقرة للمحور				
	بدرجة كبيرة	بدرجة متوسطة	لا تنتمي	الملائمة اللغوية	التعديلات
الخدمة					
56. أشعر بأن لي دور في تنفيذ الخطة التأهيلية لطفلي					
57. أنا راضية عن مدى مشاركتي في ذلك					
ثالثا ــ مدى الاستفادة من الخدمات الطبية:					
58. أنا راضية عن الخدمات الطبية التي تتم لطفلي في الجمعية					
59. أملك القدرة الكافية على التعامل مع طفلي في المنزل لتحديد وضعه الصحي					
60. أصبحت قادرة على التعامل مع بعض المشاكل الصحية لطفلي					
61. لو احتاج طفلي علاج أو مشورة خارج الجمعية، أنا راضية عما تقدمه الجمعية في تلك الحالة					
62. الخدمات الطبية الموجودة في الجمعية تغني عن توجهي لأي مستشفى					
63. الطاقم الموجود يحرص على عمل فحوصات طبية دورية لطفلي					
64. إذا احتاج طفلي لتحويل لأي مستشفى لا أجد صعوبة في ذلك					
65. أشعر أن مشاكل طفلي الصحية تزداد منذ بداية التحاقه للجمعية					
66. لو احتاج طفلي أي أدوية أو فحوصات طبية فهي متوفرة في الجمعية					
رابعا ــ مدى الاستفادة من الخدمة الاجتماعية:					
67. أنا راضية عن عدد زيارات فريق العمل لطفلي في المنزل للتواصل معه					
68. فعليا أنا مستفيدة من الاستشارة المقدمة من فريق الخدمة الاجتماعية في كيفية التعامل مع طفلي لو تعرض لأي مشكلة نفسية أو اجتماعية					
69. أنا راضية عن المساعدات المقدمة من الجمعية سواء كانت مساعدات عينية أو نقدية أو غيره					

البيان	مدى انتماء الفقرة للمحور				
	بدرجة كبيرة	بدرجة متوسطة	لا تنتمي	الملائمة اللغوية	التعديلات
70. أنا راضية عن الندوات والورشات التي يعقدها الفريق لتوعية الأسرة والمجتمع					
71. أشعر بأن الندوات والورشات ساهمت في تقبل إعاقة طفلي بشكل كبير					
72. الأخصائي الاجتماعي يحرص على عمل زيارة ميدانية في البيت لتقييم وضع منزلي					
73. لو تعرض طفلي لأي مشكلة فإن فريق الخدمة الاجتماعية هو أول من يبادر بزيارته في البيت					
خامسا ـ مدى الاستفادة من خدمة التوجيه والإرشاد النفسي:					
74. أرى بأن الطاقم في الجمعية يقدم لي كل الخدمات المتعلقة بطفلي بصراحة					
75. أرى بأن الطاقم يحثني على الاستفسار والسؤال عن طفلي					
76. أرى بأن التثقيف والإرشاد الأسري كافي للتعامل مع طفلي بأمانة					
77. أشعر بأن طفلي يتحسن كلما ازداد الدعم النفسي المقدم له من الأخصائي النفسي					
78. خدمة التوجيه والإرشاد النفسي لها بالغ الأثر في تخفيف حدة التوتر عندي					
79. أشعر بأن خدمة الإرشاد النفسي ساعدتني في التكيف مع إعاقة طفلي بشكل كبير					
سادسا ـ مدى الاستفادة من خدمة العلاج الطبيعي:					
80. أنا راضية عن العلاج الطبيعي المقدم لطفلي					
81. أشعر بأن طفلي يستفيد فعليا من جلسات العلاج الطبيعي					
82. أنا مستفيدة من التمارين العلاجية المطلوبة لطفلي في تنمية مهارة الحركة عنده					
83. أخصائي العلاج الطبيعي يحرص على عمل تقييم لحالة طفلي الحركية بين فترة وأخرى					

البيان	مدى انتماء الفقرة للمحور			الملائمة اللغوية	التعديلات
	بدرجة كبيرة	بدرجة متوسطة	لا تنتمي		
84. أنا راضية عن موعد جلسة العلاج الطبيعي لطفلي					
85. أنا راضية عن مدة الجلسة العلاجية					
86. أخصائي العلاج الطبيعي يحرص على تدريبي على بعض التمارين التي يجب اتباعها في البيت مع طفلي					
87. أشعر بأن مكان الجلسة مريح لي ولطفلي					
سابعا ــ مدى الاستفادة من خدمة تنمية القدرات:					
88. أصبحت لدي القدرة لحل مشاكل طفلي التربوية والسلوكية					
89. أشعر بأن خدمة تنمية القدرات أساس النجاح في الخطة التأهيلية لطفلي					
90. الأخصائية تتعامل مع طفلي بسرية تامة					
91. الأخصائية تقوم بشرح حالة طفلي بالتفصيل					
92. تقوم الأخصائية بإطلاعي على الخطة التأهيلية المنوي تنفيذها					
93. يوجد لي دور في الخطة العلاجية					
94. أنا راضية عن متابعة الأخصائية للتعليمات التي تعطيها لي مع طفلي					
ثامنا ــ مدى الاستفادة من خدمة التخاطب والسمعيات:					
95. أنا راضية عن الخدمة المقدمة لطفلي إذا احتاج لجلسات في السمعيات					
96. أنا مستفيدة من النصائح التي يدليها لي الأخصائي في التعامل مع طفلي لتطوير مستوى النطق لديه					
97. أشعر بأن طفلي يستفيد من العمل كفريق واحد بين وحدة السمعيات وباقي الخدمات الأخرى في برنامج التدخل المبكر					
تاسعا ــ إمكانية الوصول للخدمة:					
98. مكان الجمعية ملائم (المواصلات العامة والمسافة)					

البيان	مدى انتماء الفقرة للمحور				
	بدرجة كبيرة	بدرجة متوسطة	لا تنتمي	الملائمة اللغوية	التعديلات
99. ساعات الدوام في الجمعية ملائمة لي لزيارتها					
100. أعتقد بأن المواعيد التي يحددها مقدمو الخدمات لي للمراجعة والاستفسار ملائمة					
101. أنا راضية عن سهولة المواصلات للجمعية (باصات خاصة)					

102. ما أفضل نوع خدمة تلقيته في الفترة الماضية؟ ____________________________

____

____

103. ما هي الاقتراحات التي ترى بضرورة تنفيذها لتحسين نوع الخدمة؟ ______________

____

____

104. ما هي السلبيات التي واجهتها في تلقي الخدمة ؟ __________________________

____

____

Annex 6

فقرات استبانة تقييم برنامج التدخل المبكر للأطفال المنغوليين من وجهة نظر الأهل في جمعية الحق في الحياة في غزة في صورتها النهائية:

استبانة

1. **عمر الطفل (بتاريخ اليوم) بالشهر:.........**
2. **الجنس:** ☐ ذكر ☐ أنثى
3. **المحافظة:** ☐ رفح ☐ خانيونس ☐ الوسطى ☐ غزة ☐ الشمال
4. **مدة تلقي الخدمة:..........**
5. **ترتيب الطفل في الأسرة:.......**
6. **عمر الأم عند إنجاب الطفل:.......**
7. **عمر الأم الحالى:.......**
8. **المستوى التعليمى للأم:**☐ أمية ☐ابتدائى ☐اعدادى☐ثانوى ☐ دبلوم متوسط ☐بكالوريوس ☐ما فوق
9. **عمل الأم:** ☐ ربة بيت ☐ تعمل، حددي نوع العمل: ____________________
10. **عدد أفراد الأسرة ويشمل الوالدين:** ____________ فردا.
11. **عمل الأب:** ☐ **يعمل** ☐ **لا يعمل، حدد نوع العمل** __________________________
12. **سبب مجيء الطفل أول مرة للجمعية (شكوى الأم):** __________________________
13. **هل يوجد أطفال آخرين لديهم إعاقات في الأسرة؟ ☐ نعم ☐ لا**
    إذا كانت الإجابة بنعم، فحدد نوع الإعاقة ________________________________
14. **هل سبق أن أُدخل طفلك أي جمعية أخرى قبل المتابعة مع جمعية الحق في الحياة؟☐نعم ☐لا**
    إذا كانت الإجابة بنعم، فلماذا تركها؟ _____________________________________
15. **هل سبق أن أُدخل طفلك للمستشفى خلال المتابعة مع جمعية الحق في الحياة؟ ☐ نعم ☐ لا**
    إذا كانت الإجابة بنعم، فلماذا ؟ ____
16. **كيف عرفت عن جمعية الحق في الحياة؟**
    ☐ الآخرين نصحوني بها ☐تحويلة من طبيب ☐معرفة سابقة ☐ أخرى
17. **هل تنصحين معارفك بالاستفادة منها؟ ☐ نعم ☐لا**
18. **هل تحصلين على مساعدات من هذه الجمعية؟ ☐ نعم ☐لا**
    إذا كانت الإجابة بنعم، حددي نوع المساعدة: _________________________________

البيـــــــان	غير موافق بشدة	غير موافق	لا أدري	موافق	موافق بشدة
<u>أولا ــ الرضا العام:</u>					
19.أنت راضية عن الخدمات التي يتلقاها طفلك في الجمعية					
20.لو أتيحت لك الفرصة بخيارات أخرى، ستواصلى تعاملك مع هذه الجمعية					
21.أنت راضية عن الطريقة التي يتعامل بها طاقم الجمعية مع طفلك					
22.أنت راضية عن مستوى الأداء التي يتمتع بها مقدمو الخدمات في الجمعية					
23.أنت راضية عن الفترة الزمنية التي تنتظريها قبل أن تتلقي الخدمة					
24.أنت راضية عن الوقت الذي تقضيه مع طفلك خلال تلقيه الخدمة					
25.تشعري بأن طفلك يستفيد من خدمات التدخل المبكر					
26.أنت راضية عن عدد زيارات طفلك لبرنامج التدخل المبكر في الجمعية					
27.أنت راضية عن التحسن في وضع طفلك منذ التحاقه بالجمعية لتلقي الخدمة					
<u>ثانيا ــ تقييم أداء مقدم الخدمة في البرنامج:</u>					
28.يعرض العاملون الخطة العلاجية التي تناسب طفلك					
29.يشرح العاملون كل خيارات الخطة العلاجية بطريقة واضحة					
30.يناقش العاملون معك كل التوقعات المحتملة لحالة طفلك					
31.يحرص العاملون على أن قدرات طفلك معروفة للجميع					
32.يتقبلك العاملون أنت وطفلك باحترام					
33.يجيب العاملون على كل أسئلتك بصدق					
34.يخبركِ العاملون عن سبب اختيار خطة معينة لطفلك					

البيـــــــان	غير موافق بشدة	غير موافق	لا أدري	موافق	موافق بشدة
35.يشجعك العاملون على السؤال عن كل شيء لم تفهميه من الخطة					
36.يعطيك العاملون الفرصة في الوقت والمكان المناسب لتلقي المعلومات					
37. يسألك العاملون عن وجهة نظرك في الخدمة المقدمة					
38.يوفر العاملون الجو المناسب لك ولطفلك أثناء تلقيه الخدمة					
39.يحرص العاملون على تلبية حاجات طفلك كلما تقدم في السن					
40.لا تشعرى بسرية أثناء عمل الفريق مع طفلك					
41.يراعي العاملون السرية التامة في التعامل مع طفلك					
42.تشعري بأن العاملين يحترموك أنت وطفلك					
43.تشعري بأنك تعاني المشقة في سبيل الحصول على الخدمات المطلوبة لطفلك					
44.يبدي العاملون كل جهودهم في مساعدتك للحصول على الخدمة					
45.يحرص العاملون على مشاركتك في تنفيذ الخطة التأهيلية لطفلك					
<u>ثالثاً ــ مدى الاستفادة من خدمات برنامج التدخل المبكر</u> <u>أ- خدمة تنمية القدرات:</u>					
46.أصبحت لديك القدرة على حل مشاكل طفلك التربوية والسلوكية					
47.تشعرى بأن خدمة تنمية القدرات أساس النجاح في الخطة التأهيلية لطفلك					
48.الأخصائية تقوم بشرح حالة طفلك بالتفصيل					
49.تقوم الأخصائية بإطلاعك على الخطة التأهيلية المراد تنفيذها					
50.تشاركى في الخطة التأهيلية لطفلك					
51.تتابع الأخصائية التعليمات التي تعطيها لك مع طفلك					

البيـــــــان	غير موافق بشدة	غير موافق	لا أدري	موافق	موافق بشدة
ب ــ خدمة العلاج الطبيعي:					
52.العلاج الطبيعي المقدم لطفلك مناسب					
53.طفلك في تحسن مستمر مع جلسات العلاج الطبيعي					
54.تفهم التمارين العلاجية لطفلك جيدا					
55.أخصائية العلاج الطبيعي تحرص على تقييم حالة طفلك بين الحين والآخر					
56.موعد جلسة العلاج الطبيعي لطفلك مناسبة					
57.مدة الجلسة العلاجية كافية					
58.تشعري بأن طفلك مستفيد من تطبيق التمارين له في البيت					
59.تشعري بأن مكان الجلسة مريح لك ولطفلك					
رابعاً ــ إمكانية الوصول للخدمة:					
60.تصلى إلى الجمعية بسهولة					
61.ساعات الدوام في الجمعية تسمح لك بزيارتها بشكل مناسب					
62.وجود فرع واحد للجمعية صَعَب عليك الوصول للخدمة					
63.مكان الجمعية يسمح لك بتلقى الخدمة فى كل وقت					
64.صعوبة المواصلات من أهم معوقات الوصول للجمعية					
65.مكان الجمعية بعيداً وشاق الوصول					

66. هل طفلك مستفيد من الخدمات الطبية الموجودة في الجمعية: □ كثيرا □ قليلا □ غير مستفيد

إذا كانت إجابتك قليلا أو غير مستفيد، ما هي اقتراحاتك لتحسين الخدمة:____________________________

____

67. هل طفلك مستفيد من الخدمة الاجتماعية الموجودة في الجمعية: □ كثيرا □ قليلا □ غير مستفيد

إذا كانت إجابتك قليلا أو غير مستفيد، ما هي اقتراحاتك لتحسين الخدمة:____________________________

____

68. هل طفلك مستفيد من خدمة الإرشاد والتوجيه النفسى: □ كثيرا □ قليلا □ غير مستفيد

إذا كانت إجابتك قليلا أو غير مستفيد، ما هي اقتراحاتك لتحسين الخدمة:____________________________

____

69. هل طفلك مستفيد من خدمة التخاطب والسمعيات؟ □ كثيرا □ قليلا □ غير مستفيد

إذا كانت إجابتك قليلا أو غير مستفيد، ما هي اقتراحاتك لتحسين الخدمة:________________________

70. هل تشاركي في تنفيذ الخطة التأهيلية لطفلك؟ كثيرا ☐ ☐ قليلا ☐ غير مشاركة

إذا كانت إجابتك قليلا أو غير مشاركة، ما هي الأسباب:________________________

71. ما أفضل نوع خدمة تلقاها طفلك في الفترة الماضية؟

72. ما السلبيات التي واجهتك في تلقي الخدمة في الفترة الماضية؟

73. ما الاقتراحات التي ترين ضرورة تنفيذها لتحسين نوع الخدمة؟

وشكرا لتعاونكم

Annex 7

استمارة وصف الاستبانة للمشاركات في الدراسة

عزيزتي الأم/ ....

السلام عليكم ورحمة الله وبركاته، وبعد . . .

إنني أثمن مشاركتك الصادقة والأمينة في تعبئة هذه الاستبانة التي تمثل جزءًا من مشروع دراسة ماجستير علوم التأهيل بالجامعة الإسلامية ـ بغزة، إذ إن الهدف الرئيس من هذه الدراسة هو تقييم خدمات برنامج التدخل المبكر المقدمة لأطفال ذوي متلازمة داون في جمعية الحق في الحياة بغزة.

فمشاركتك في هذه الدراسة سيكون لها دور قيم في معرفة مدى فاعلية هذا البرنامج، وكذلك في وضع السياسات والخطط المستقبلية في برامج هذه الجمعية، وسيكون لها بالغ الأثر والتأثير؛ مع العلم بأن المشاركة اختيارية، مع حرصنا وتأكيدنا لك على سرية المعلومات التي تقدمينها في الاستبانة وأن الإجابة لن تؤثر على تلقيك الخدمة.

الباحثة/ لبنى عبد الله شلّح

Annex 8

Dear Dr. / ______________________________

May God's peace and mercy be upon you,,,

Subject: The questionnaire of the evaluation of the program of early intervention for children with Down syndrome from the perspective of the families in the Right to Live Society in Gaza

Referring to the above subject, I am glad to put in your hands the questionnaire entitled:
"Evaluation of the program of early intervention for children with Down syndrome from the perspective of the families in the Right to Live Society in Gaza."

The mentioned questionnaire, which is attached to this letter, is the tool used by the researcher in the preparation for the Master's degree research in (the Rehabilitation Science) of the Department of Community Mental Health in the Islamic University /College of Education, which is entitled: "Evaluation of the program of early intervention for children with Down syndrome from the perspective of the families in the Right to Live Society in Gaza", under the supervision of Associate Professor in the Department of Psychology in the Islamic University, Dr. Sana'a Abu Dakka.

The researcher prepared this questionnaire to be applied to a sample of the beneficiaries of the rehabilitation services provided to children with Down syndrome in the Right to Live Society in Gaza.

Thus, I ask you kindly to give your opinion and guidance about this questionnaire regarding: the phrases and paragraphs, language, and making all the suitable amendments, or deleting certain words or paragraphs, which you believe need to be modified or deleted.

I highly appreciate your cooperation, and hope to hear from you soon.

With my best regards.
Yours sincerely,
Researcher: Lubna Shallah

Annex 9

Dear Mother,

May God's peace and mercy be upon you...

I highly appreciate your sincere and honest participation in filling this questionnaire, which is part of the study for obtaining a Master Degree in Rehabilitation Science form the Islamic University-Gaza.

The objective of this study is to assess the early intervention services provided to children with Down syndrome in the Right to Live Society in Gaza. Your participation in this study will have a valuable role to learn the effectiveness of this program, as well as, in the development of policies and programs in the future plans of this Society, noting that the participation in filling this questionnaire is optional.

It is noteworthy that the information in this questionnaire is confidential and will not affect the service you receive from the society.

Researcher / Lubna Abdullah Shallah

A Questionnaire for the Evaluation of the Program of Early Intervention for Children with Down Syndrome from the Perspective of Families in the Right to Live Society in Gaza." – Final Version

1. The child's age (dated today) by month :.........
2. Sex: ☐ male ☐ female
3. Governorate: ☐ Rafah, ☐ Khan Younis ☐ Central Governorates ☐ Gaza City ☐Northern Gaza
4. Period of receiving the service:..........
5. Order of the child in the family:......
6. Mother's age when giving birth to the child:.......
7. Mother's current age:.......
8. Educational level of the mother: ☐ illiterate ☐ Elementary education ☐ Preparatory Education ☐ Secondary Education ☐ Bachelor Degree ☐ above
9. Mother's work: ☐ housewife ☐working
   Identify the type of work:_____________________
10. The number of family members, including families: ____________ .
11. Father's work: ☐ works ☐ unemployed.
    Mention the type of work__________________________
12. Why did the Child come to the Society for the first time (the complaint)?
    ____
13. Are there any other children with disability in the family? ☐ Yes ☐ No.
    If yes, select the type of disability ________________________________
14. Has your child gone to any other society before following up with the Right to Live Society? ☐ Yes ☐ No
    If yes, why did he/she left?____
15. Has your child been admitted to a hospital during the follow-up with the Right to Live Society? ☐ Yes☐ No.
    If yes, why? ____
16. How do you know about the Right to Live Society?
    ☐ people's advice ☐ a doctor's transfer ☐ prior knowledge ☐ Other
17. Would you recommend your acquaintances of this society? ☐ Yes ☐ No
18. Do you get help from this Society? ☐ Yes ☐ No
    If yes, identify the type of assistance: _____________________________________

Statement	Strongly disagree	disagree	Don't know	agree	Strongly agree
First: General Satisfaction:					
19. You are satisfied with the services received by your child in the Society.					
20. If you have the opportunity of finding other options, you will continue your interaction with this Society.					
21. You are satisfied with the way your child is treated by the crew of the Society.					
22. You are satisfied with the performance level of the service providers in the Society.					
23. You are satisfied with the period of time you wait in before receiving the service.					
24. You are satisfied with the time spent with your child during receiving the service					
25. You feel that your child benefits from the early intervention services					
26. You are satisfied with the number of visits for your child in the early intervention program of the Society.					
27. You are satisfied with the improvement in the development of your child since joining the Society to receive the service.					
Second: Assessing the performance of the service providers in the program:					
28. The workers present the remedial plan that suites your child.					
29. All workers explain the plan's therapeutic options					

clearly					
30. The workers discuss with you all the potential expectations of the state of your child.					
31. Workers are keeping that the capabilities of your child will be known to all.					
32. Workers receive you and your child with respect.					
33. Workers answer your questions truthfully.					
34. The workers tell you about the reason for selecting specific plan for your child.					
35. Employees encourage you to ask questions about everything you do not understand of the plan.					
36. The workers give you the opportunity at the appropriate time and place to receive information.					
37. The workers ask about your point of view of the service provided.					
38. The workers provide the right atmosphere for you and your child during receiving the service.					
39. Workers are keen to meet the needs of your child as he/she progress in age.					
40. You do not feel the confidentiality during the work with your child.					
41. Workers take strict confidentiality in dealing with your child.					
42. You feel that the workers respect you and your child.					
43. You feel that you suffer hardship in order to obtain the services required for your child.					

44. All workers present all their efforts in helping you to obtain a service.					
45. Workers are keen to participate in the implementation of the rehabilitative plan for your child.					
Third: the use of the services of early intervention: A – The service of capability development:					
46. You are able to solve the educational and behavioral problems of your child's.					
47. You feel that the service of capacity development is basic to the success in the rehabilitation plan for your child.					
48. The specialist explained in detail the status of your child.					
49. The specialist tells you the rehabilitative plan to be implemented with your child.					
50. You participate in the rehabilitation plan for your child.					
51. The Specialist follows the implementation of instructions that she/he gives you with your child.					
B. The physiotherapy service:					
52. Physiotherapy is suitable for your child.					
53. Your child is in continuous improvement with the physiotherapy provided.					
54. You have an understanding of the therapeutic exercises for your child.					
55. The physiotherapy Specialist is keen to assess the status of your child from time to time.					

56. The time of the physiotherapy session is appropriate for your child.					
57. The duration of the therapeutic meeting is sufficient.					
58. You feel that your child benefits from exercises that he/she has at home.					
59. You feel that the meeting place is comfortable for you and your child.					
Forth: The access for the service:					
60. You access to the Society easily.					
61. The working hours in the Society allow you to visit appropriately.					
62. The presence of one branch of the Society makes it difficult to access for its service.					
63. The location of the Society allows you to receive the service at all times.					
64. Transportation difficulty is the most difficult obstacle to access to the Society.					
65. The place of the Society is far away and difficult to access to.					

66. Does your child benefit from the medical services in the Society?
☐ a lot ☐ very little ☐ not benefiting ☐ not needed
If your answer is slightly or not benefiting, what are your suggestions for improving the service?
____
____

67. Does your child benefit from the social service in the Society?
☐ a lot ☐ very little ☐ not benefiting ☐ not needed
If your answer is slightly or not the benefiting, what are your suggestions for improving the service?
____
____

68. Does your child benefit from the service of psychological counseling and guidance?
☐ a lot ☐ very little ☐ not benefiting ☐ not needed

If your answer is slightly or not benefiting, what are your suggestions for improving the service?

____

____

69. Does your child benefit from the services of audio services and communication?
☐ a lot ☐ very little ☐ not benefiting
If your answer is slightly or not benefiting, what are your suggestions for improving the service?

____

____

70. Do you participate in implementing the rehabilitation plan for your child?
☐ a lot ☐ very little
If your answer is slightly or not participating, what are the reasons?

____

____

71. What is the best type of service received by your child in the past?

____

____

72. What are the negatives that you have encountered of the services provided in the last period?

____

____

73. What suggestions do you think need to be implemented in order to improve the type of service?

____

____